

**Investing
in the mental
wellbeing and
resilience of informal
carers and long-term
care workers**

**through
the
identification,
evaluation and
promotion of good
practices across
Europe**

Well Care

**Final report on
40 good practices in
5 European countries
November 2025**



**Funded by
the European Union**

WELL CARE has received funding from the European Union's Horizon Europe research and innovation programme under grant agreement No 101137468

Final report on 40 good practices in 5 European countries

November 2025

Project details

Project acronym	WELL CARE	Start / Duration	1 January 2024 / 48 Months
Project number	101137468	Topic	HORIZON-HLTH-2023-CARE-04-02
Type of Action	RIA	Coordinator	Linnaeus University (Sweden)
Contact persons	Principal investigator: Elizabeth Hanson, elizabeth.hanson@lnu.se Project manager: Francesco Barbabella, francesco.barbabella@lnu.se		

Deliverable details

Title	Final report on 40 good practices in 5 European countries		
Project number	D2.1	Work Package	Review, analysis and report of good practices
Dissemination level	PU - Public	Type	Report
Due date (month)	31 August 2025 (M20)	Submission date (M)	29 August 2025 (M20)
Deliverable responsible	IRCCS INRCA (Italy)	Contact person	Marco Socci, m.socci@inrca.it

Deliverable Contributors

	Name	Organisation	Role	E-mail
Deliverable leader	Marco Socci	IRCCS INRCA	WP2 leader	m.socci@inrca.it
Contributing Author(s)	Maria Gabriella Melchiorre	IRCCS INRCA	WP2 contributor	g.melchiorre@inrca.it
	Gabriele Morettini	IRCCS INRCA	WP2 contributor	g.morettini@inrca.it
	Beatrice Ietto	IRCCS INRCA	WP2 contributor	b.ietto@inrca.it
	Sabrina Quattrini	IRCCS INRCA	WP2 contributor	s.quattrini@inrca.it
	Elizabeth Hanson	Linnaeus University	Principal investigator	elizabeth.hanson@lnu.se
Reviewer(s)	Andreas Hoff	Zittau-Goerlitz University of Applied Sciences	WP7 contributor	A.Hoff@hszg.de
	Katja Knauthe	Zittau-Goerlitz University of Applied Sciences	WP7 contributor	katja.knauthe@hszg.de
Final review and quality approval	Elizabeth Hanson	Linnaeus University	Principal investigator	elizabeth.hanson@lnu.se
	Francesco Barbabella	Linnaeus University	Project manager	francesco.barbabella@lnu.se

Document History

Release	1.0
Date	29 August 2025
Changes to previous version	
Status	Submitted

Acknowledgements

We would like to thank Andreas Hoff and Katja Knauthe, who kindly acted as internal reviewers in the process of finalising this document.

We acknowledge all project partners within the WELL CARE consortium, for their contributions to the work activities carried out in Tasks 2.1-2.3 of WP2, the results of which are included in this Report: Elin-Sofie Forsgårde, Maria Nilsson, Francesco Barbabella (Linnaeus University-LNU); Lennart Magnusson, Linnéa Aldman Sennemark (Region Kalmar-NKA); Ludo Glimmerveen, Henk Nies, Chantal Hillebregt, Karin Kee (Free University Amsterdam-VUA); Jan Smelik, Esmee Beldman (Nederland Zorgt Voor Elkaar-NLZVE); Giovanni Lamura, Davide Lucantoni (IRCCS INRCA - National Institute of Health and Science on Ageing-INRCA); Licia Boccaletti, Giusy Trogu (Anziani e Non Solo-ANS); Andreas Hoff, Katja Knauthe (Zittau-Görlitz University of Applied Sciences-HSZG); Franziska Jentsch, Sebastian Fisher, Notburga Ott (Wir Pflegen-WiPf); Valentina Hlebec, Tatjana Rakar, Miriam Hurtado Monarres (University of Ljubljana-UL); Ana Ramovš, Alen Sejt, Tjaša Potočnik (Anton Trstenjak Institute of Gerontology and Intergenerational Relations-ATI); Elizabeth Olson (University of North Carolina at Chapel Hill-UNC-CH); Camille Roux, Elena Bokshi, Francesca Centola (Mental Health Europe-MHE); Claire Champeix, Olivier Jacquemain, Stecy Yghemonos (Eurocarers-EuCa); Karel Vostrý, Vojtěch Měříčka (European Ageing Network-EAN); Kallianne Farren, Miguel Buitrago, Irene Bertana (European Association of Service Providers for Persons with Disabilities-EASPD).

We also acknowledge members from the five national Blended Learning Networks (BLNs), for their inputs during the process to define agreed criteria to select good practices (Task 2.2), as well as for their suggestions and feedback to WP2 results and activities. We also acknowledge the contributions of all the interview participants across the five project partner countries (Germany, Italy, The Netherlands, Slovenia and Sweden) who gave of their time and shared their expertise with us (Task 2.3). We also acknowledge the contributions of members of the project's External Advisory Board, who validated the MS2 Internal Report of the completed systematic literature review (the results of which are reported in Section I of this Report) at their November 2024 online meeting.

Disclaimer

Funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Health and Digital Executive Agency (HADEA). Neither the European Union nor the Granting Authority can be held responsible for them.



**Funded by
the European Union**

Table of contents

Executive summary	11
Introduction	13
Section I - Task 2.1: Systematic review of scientific and grey literature	15
1.1. Introduction	15
1.2. Methodology	15
1.3. Results	19
1.3.1. Scientific literature review: overview of main findings	19
1.3.2. Grey literature review: overview of main findings	23
1.4. Summary remarks	27
Section II - Task 2.2: Methodology for selection criteria and data reporting tools	28
2.1. Introduction	28
2.2. Methodology	28
2.3. Results	29
2.3.1. Agreed criteria to select good practices	29
2.3.2. Agreed template to report findings of selected good practices	32
Section III - Task 2.3: Selection, analysis and report of good practices, evidence, and data	33
3.1. Introduction	33
3.2. Expert interviews	33
3.2.1. Introduction	33
3.2.2. Methodology	33
3.2.3. Results	35
3.2.4. Summary remarks	41
3.3. Reporting good practices	42
3.3.1. Introduction	42
3.3.2. Methodology	42

3.3.3. Results	46
3.3.4. Summary remarks	68
Section IV: Next steps	70
Conclusions	71
References	74
Annex A: Additional tables and figures of SLR and GLR	76
Annex B: Summary of the main findings from the BLN members' discussions about the criteria	88
Annex C: Criteria and sub-criteria included in the EC document and the ones selected for the WELL CARE project purposes	92
Annex D: Template to collect information on potential/promising good practices (GLR) in Task 2.1	98
Annex E: Template to report good practices	102
SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE	102
DESCRIPTION OF THE GOOD PRACTICE	104
Annex F: Expert interviews: the coding process	107
Annex G: Templates reporting findings of the 40 selected good practices	108
GOOD PRACTICES	
Culturally informed psychoeducational course for Charedi Orthodox Jewish Community (Charedi OJC)	110
Early Positive Approaches to Support (E-PAtS) for Families of Young Children with Intellectual Disability	117
Family Carers Training	122
Carers' Alert Thermometer for Stroke Family Caregivers (CAT-S)	127
Augmentative and Alternative Communication Intervention (AAC)	132
LIVIND - A lifestyle monitoring system to support (in)formal caregivers of people with dementia	138
E – Qalin – Quality Management Model	144
REACT-NOR – Norwegian version of the Relatives Education and Coping Toolkit	150
Digital support for quality assurance in 24-hour caregiving at home	161

pflegen-und-leben.de (care and live)	166
Assertive Community Treatment (ACT) Teams	170
Supporting Families Living with Dementia in Rural Areas	175
Rosetta: a web-based e-learning platform for informal carers of people with dementia	185
Care at home	194
Mobile Technology for Personalised Reminiscence for People Living with Dementia and their Carers	198
Video Conferencing Peer Support and Rarer Forms of Dementia	202
Partner In Balance (PIB)	207
Psychoeducation program for patients with bipolar disorder and their caregivers	213
Open Dialogues	219
Act Belong Commit	226
Staff Training Programme and Family Liaison Service	233
Inclusive Culture Program	238
Meeting Centres Support Programme (MCSP)	245
Care Companion Web-Based Information Resource for Supporting Informal Carers of Older People	251
Carer Supporter Programme	255
Carers Outcome Agreement Tool (COAT)	264
Web-based mindfulness intervention for families living with mental health problems	270
Colourful Unburdening	274
Rehabilitation Enablement in Chronic Heart Failure (REACH-HF)	279
The Renaissance of Workforce Models in France's Mental Healthcare	284
Meeting centres support program (MCSP)	290
Community Care Dongen	300
Community Houses	309
Integrated care intervention for the frail elderly on informal caregivers	313
The Wulverhorst	321
MOST project – Integrated care in Krško Municipality	330
Cognitive-behavioural intervention for Dementia caregivers' coping with pre-death grief	335

The conversation with (caring) relatives	340
The online training with app for LTC workers (RESIST)	345
Training informal caregivers to care for older people after stroke (InCARE program)	349

Executive summary

- This report, namely “D2.1: Final report on 40 good practices in 5 European countries”, is a public deliverable of the WELL CARE project, developed within “WP2: Review, selection and analysis of good practices”, and produced at month 20 (August 2025). The overall aim of this final report is to report findings of at least 40 good practices in Europe, implemented in informal care contexts and/or in public long-term care (LTC) organisations of different settings and preferably covering different groups of LTC workers and informal carers (e.g. LTC workers who are also informal carers, those having a migration background and/or with low education levels).
- Population ageing across Europe is driving a significant rise in demand for long-term care (LTC). By 2070, the share of people with LTC needs in the population over 50 years old in the European Union (EU) is expected to increase from 11.6% (2020) to 14.1%. In response, the European Commission launched the European Care Strategy (2022) to enhance the quality, accessibility, and sustainability of care services, and to improve working conditions for both formal and informal carers. The LTC workforce (predominantly female) is exposed to high levels of emotional stress, long shifts, and adverse social behaviours, increasing their risk of mental health issues such as, anxiety and burnout. Informal carers, who provide around 80% of care in the EU, also face challenges to their mental wellbeing, particularly women providing high-intensity care to a family member or significant other over a prolonged period of time. The COVID-19 pandemic further worsened their mental wellbeing.
- Against this backdrop, the EU Horizon Europe funded WELL CARE project seeks to strengthen the supports available for both formal and informal carers, by identifying and promoting good practices across Europe that enhance carers’ mental wellbeing and resilience. The project also aims to address and foster care partnerships (i.e. the coordination, integration, and mutual recognition of care and caring activities performed by LTC workers and informal carers, in a vision of integrated LTC) in order to reduce the care burden, mitigate or prevent risks affecting carers’ mental health, and improve the overall quality of care across Europe.
- This report presents the findings of WP2 “Review, selection and analysis of good practices” of the WELL CARE project. The research activities conducted so far under WP2 encompass three main tasks. Task 2.1 involved a systematic scientific literature review (SLR) and a grey literature review (GLR), analysing a wide array of recent scientific publications and interventions designed to improve mental wellbeing among both formal and informal carers. The search spanned eight scientific databases and numerous websites, including the EU Public Health Best Practice Portal, ensuring multidisciplinary perspectives on the topic. Key insights revealed that most interventions target informal carers, with LTC workers receiving less focus. Care recipients are predominantly older adults, often with cognitive or mental health issues, and many practices are delivered outside traditional healthcare settings, including clients’ own homes and online environments. Notably, several identified practices show potential to foster care partnerships between formal and informal carers. The comprehensive approach adopted by this literature review study addresses dimensions that previously were rarely examined together (inclusion of several countries, different types of practices, of carers and recipients, and diverse intervention settings), thus providing a holistic view of the topic.
- Task 2.2 focused on selecting good practices from the collected dataset in Task 2.1, by applying a rigorous set of 12 selection/inclusion criteria and 20 sub-criteria adapted from those used to select practices for the [EU Public Health Best Practice Portal](#) (see Section II for more details) and defined taking into consideration inputs from the project’s five-country Blended Learning Networks (BLNs; WP5). A template to report on the findings of the good practices responding to the criteria was also developed.
- Task 2.3 comprised two key activities: i) expert interviews and ii) the reporting of good practices. Twenty-three experts representing diverse sectors/stakeholders (academia, policy, LTC employers, and non-governmental organisations) were interviewed to gather qualitative insights into the topic. The expert participants generally endorsed the findings of Task 2.1 and highlighted 14 additional promising practices (even focused on fostering care partnerships), seven of which were later evaluated as good practices. A thematic analysis of the interviews revealed that the grey literature captures more innovative and implementable practices compared to the scientific literature which was constrained by more rigid methodological approaches. Experts highlighted that good practices should be understood as context-dependent rather than universally transferable, requiring tailoring to local institutional and legal frameworks, with common barriers including resource constraints and structural resistance, while enabling factors included formal policy recognition and continuous training. These insights shall be taken into consideration in the subsequent phases of the project.
- With regards to the reporting of good practices, an innovative methodology was developed to evaluate and rank the

collected practices, ensuring objectivity, inclusivity, consistency with project aims, reproducibility, and operational simplicity. The multi-step selection process involved country partners' evaluations of collected practices against the 20 sub-criteria (based on those used for selecting practices for the EU Public Health Best Practice Portal), threshold-based filtering and classification aimed to select the 40 highest ranked good practices, and standardisation to mitigate subjective assessment bias.

- This rigorous evaluation identified 170 good practices, predominantly from the five partner countries (57.6%), confirming both the effectiveness of the research carried out and the availability of a broad repertoire of good practices. From this pool, the top 40 highest-ranked good practices were selected, which exhibited a balanced distribution between SLR and GLR sources and various typologies, even though the majority of the such good practices belong to two main types of good practices outlined in our earlier conceptual framework that formed the basis for the systematic literature review work in Task 2.1 (i.e. interventions or programmes dealing with organisational models and management approaches, or aimed at mental health/wellbeing and resilience promotion and training initiatives). Most interventions were implemented at home, online, or in local communities, primarily targeting informal carers and, to a lesser degree, LTC workers. Care recipients were mainly older adults with cognitive or psychological/mental issues. Importantly, 85% of these top practices (34 out of 40) have the potential (with different gradients and characteristics) to foster care partnerships, reinforcing previous findings (Task 2.1).
- These selected good practices and their evidence (see Annex G, reporting the templates containing the key information to describe the top 40 good practices) will serve as the foundation for subsequent solution prototype development in WP3. The extensive selection provides partners with suitable flexibility to choose from the top ranked practices or others within the broader set of good practices, ensuring an inclusive, reproducible, and context-sensitive approach grounded in EU-adopted criteria.
- Beyond project activities, the findings have significant implications for advancing knowledge on mental health and care provision in both informal and formal LTC, particularly for older people and those with disabilities or chronic illnesses. They emphasize the need for sustainable, scalable, and transferable strategies that account for economic, organisational, and contextual factors. Policymakers and stakeholders are encouraged to identify the most promising practices, assess their transferability, and adapt them to new settings, avoiding ineffective “one-size fits all” strategies.
- In this regard, the WELL CARE project has made a valuable contribution by collecting and evaluating 170 local good practices, creating a useful database for sharing and adapting successful approaches. Spreading knowledge of these practices encourages innovation through discussion and transfer across regions. The majority of the top 40 practices highlight that care partnerships play a crucial role in enhancing the mental wellbeing and resilience of informal carers and LTC workers.
- The findings included in this report also highlight the crucial role of informal carers, who can no longer be overlooked or viewed separately from LTC workers.
- Indeed, informal carers and LTC workers have often been viewed as two disparate groups with differing needs and situations, rather than as being inter-connected. The European Care Strategy (2022) recognised that the wellbeing of both these groups and of care recipients with LTC needs is determined by the capacities of both professional and informal carers to provide good care. In this context, care partnership practices involving informal and formal carers should be promoted, to reduce care burden and improve mental wellbeing of both groups, while enhancing care quality of people with long-term health and/or care needs. In summary, this report contributes with evidence to inform LTC policy and practice across Europe with regard to good practices that support improved mental health and resilience among carers and some of which also help to strengthen care partnerships between carers and care recipients.

Introduction

Due to population ageing trends, both the number of older people and the share of older age groups within the total population are projected to increase, and these phenomena will lead to a growing demand for long-term care (LTC). According to the Ageing Report (European Commission, 2021a), the number of people in the European Union (EU) in need of LTC is projected to increase from 30.8 million in 2019 to 38.1 million in 2050. Moreover, research conducted by Belmonte and colleagues (2023), estimated that in the EU the number of people with LTC needs in the population over 50 years old will rise from 11.6% in 2020 to 14.1% in 2070, representing an increase of 21% in 2070 compared to 2020. Such a context is boosting the demand for accessible LTC services and policies for improving both the quality, working conditions and attractiveness of the LTC sector (Belmonte and Nedee, 2024).

The European Commission launched the European Care Strategy (European Commission, 2022a) aimed at ensuring high-quality, affordable and accessible care services across the EU. This strategy also aimed to improve the conditions of both formal and informal carers and care receivers, through the promotion of work-life balance and better working conditions in the care sector for the former, by also tackling the gender issue on care. This promising policy environment underlines how the LTC sector, informal carers and LTC workers, are crucial key priorities of the policy agenda at EU-level and within the Member States. This is also due to the impact of the Covid-19 pandemic which particularly affected the LTC sector, as well as the health, working conditions, and personal circumstances of LTC workers and informal carers (Socci et al., 2024).

In the EU, the LTC workforce has grown rapidly, from 4.7 million in 2009 to 6.3 million in 2019, i.e. from 2.5% of the EU's workforce in 2009 to 3.2% in 2019 (Eurofound, 2020). However, the share of LTC workers within the total workforce shows large country differences, ranging from below 1% in Romania, Cyprus and Greece to over 5% in Finland, Belgium, Netherlands and Sweden (Eurofound, 2020). LTC workers are mainly women (88%), who provide formal care and are employed by LTC providers or directly by care recipients/family, mainly in residential LTC settings. Despite 75% of LTC workers perceiving that they are doing useful work, the highest proportion of strained jobs is among LTC workers (42%) (Eurofound, 2023), due to various factors (e.g. complex tasks, longer working hours, shift work, heavy workload and a high exposure to adverse social behaviours) (Eurofound, 2023; OECD 2020). This situation, and especially the emotional demands of their working tasks and exposure to adverse social behaviour at work, represent a high risk for LTC workers to develop mental health problems (e.g. anxiety, depression, burnout) which was also exacerbated by the Covid-19 outbreak (Eurofound, 2020; Eurofound, 2023; Boamah et al., 2022). The deterioration of working conditions reduces both the recruitment and retention of carers, thus endangering the long-term sustainability of the care sector in Europe (Florek, 2021).

Moreover, it is also estimated that informal carers account for nearly 80% of the care providers across the EU, where 52 million people, i.e. 14.4% of the adult population aged 18-74, provide informal care on a weekly basis, and two thirds of all informal care is carried out by women (European Commission, 2021b). Informal caregiving can lead to positive outcomes (e.g. meaningful experiences, increasing positive psychological appraisal and occasionally better wellbeing) (Kim et al., 2019), but also a sustained burden is often reported (Cattaneo et al., 2025; Chan et al., 2023; Or and Kartal, 2029). Informal carers, especially those providing high-intensity care over a prolonged period - mainly women (Eurofound, 2025) - experience worse physical and mental health conditions, including depression, anxiety and burnout (Li and Song, 2019). Furthermore, the Covid-19 pandemic also led to an increase in informal carers' psychological distress, strain and overall health deterioration (Eurocarers/IRCCS-INRCA, 2021; Socci et al., 2024).

Set against this contextual backdrop, it seems crucial to strengthen the supports available to both LTC workers and informal carers, in order to improve their mental wellbeing and resilience, thus tackling the possible negative mental health conditions they risk experiencing in relation to providing care to older, frail and/or disabled people, as highlighted by the above research in the field.

The EU Horizon Europe funded [WELL CARE project](#) addresses such issues, as it is indeed aimed at improving supports available across Europe for LTC workers and informal carers to increase their resilience and mental wellbeing, by contributing to the identification of good practices and the improvement/adaptation and implementation of innovative solutions on a wide scale that, in particular, address and foster care partnerships. As for the latter, in the context of the project, we mean the coordination, integration, and mutual recognition of care and caring activities performed by LTC workers and informal carers, in a vision of integrated LTC. Both formal and informal carers are often considered by policy and research as separate and diverse groups with different needs and conditions, whereas in practice they are often

interconnected. Thus, their collaboration should be promoted (European Commission, 2022a; McPherson et al., 2014), with the aim of alleviating the care burden and mental health problems of both groups, and to improve the quality of care provided.

Therefore, one of the specific aims of the project is to investigate what are the good practices that directly improve LTC workers and informal carers' mental health, as well as those which prevent or mitigate the occupational risks (e.g. heavy workload, stressful working conditions, precariousness, ethical stress) and non-occupational risks (based on factors such as gender, age, migration background, socio-economic status, and the quality of the care partnership) affecting their mental health.

This Report presents the results (at month 20; August 2025) of the Work Package (WP) 2 ("Review, selection and analysis of good practices") of the WELL CARE project, specifically aimed to report good practices of innovative solutions supporting LTC workers' and/or informal carers' resilience and mental wellbeing in European countries, by using, as a starting point, a conceptual framework offering a classification of types of practices (see Chapter 1.2 for details), developed by INRCA and in collaboration with project partners, through available evidence in the literature.

Section I provides an overview of the Task 2.1 results ("Systematic review of scientific and grey literature" - M1-9; January-September 2024), aimed at performing a systematic literature review of scientific publications and grey literature to identify practices (still active/long-standing or finished for 1-3 years), implemented and in the five European partner countries (Germany, Italy, the Netherlands, Slovenia, and Sweden) and in international contexts to support LTC workers and/or informal carers' resilience and mental wellbeing, with a special focus on those developed and/or adapted after the Covid-19 outbreak.

Section II focuses on the insights from the Task 2.2 ("Methodology for selection criteria and data reporting tools" - M10-12; October-December 2024), aimed at developing the methodology for the fieldwork to be carried out in Task 2.3 "Selection, analysis and report of good practices, evidence, and data" - M13-24; January-December 2025). On the one hand, the work carried out in Task 2.2 involved identifying and defining shared and agreed inclusion/selection criteria to be used to assess whether a practice implemented in LTC organisations/settings to promote LTC workers and/or informal carers' resilience and mental wellbeing can be considered to be a good practice. The practices to which the shared and agreed criteria were applied by project country partners are those collected in Task 2.1, supplemented by additional practices highlighted by Expert interviews in Task 2.3 and by members of national Blended Learning Networks (BLNs) in WP5 ("Blended learning networks (BLNs) with long-term care workers, informal carers and stakeholders" - M1-48; January 2024-December 2027) (see Sections II and III for more details). On the other hand, a common template was developed by partners in Task 2.2 and subsequently used in all five partner countries to report findings on the selected good practices responding to the criteria in a comparable way.

Section III presents the results of the Task 2.3 ("Selection, analysis and report of good practices, evidence, and data" - M13-24) involving three main activities: 1) expert interviews (M13-15; January-March 2025); 2) reporting good practices (M16-20; April-August 2025); and 3) case studies (M21-24; September-December 2025). For the purposes of this Report, the main insights from the above first two activities (which are completed at M20) are presented.

After providing some information on the next steps of WP2 activities, the final section provides several conclusions based on the overview of the main results reported.

Following the main Report itself, several Annexes are also included, to provide additional materials/documents, including the templates containing the key information to describe the selected 40 good practices to support informal carers and/or LTC workers' resilience and wellbeing implemented throughout Europe.

To summarise, D2.1: "Final report on 40 good practices in 5 European countries" is a public deliverable of the WELL CARE project, developed within WP2 at month 20 (August 2025). The work to search, review, select and report at least 40 good practices was carried out by the project Consortium by applying a broad geographical perspective, to strive to secure as up to date and comprehensive evidence as possible on the available good practices to support informal carers and/or LTC workers' resilience and wellbeing (as well as with the potential to foster care partnerships). This means that some of the reported good practices are implemented in the five partner countries, and some of them are implemented in other European countries (i.e. other EU-27 Member States, the United Kingdom, and EFTA countries).

Section I - Task 2.1:

Systematic review of scientific and grey literature

1.1. Introduction

This section presents the results of a systematic literature review of scientific publications and of the grey literature (e.g. by also analysing existing relevant databases) of potential good practices recently implemented in international contexts (e.g. EU-27, United Kingdom, EFTA countries) to support LTC workers' and/or informal carers' resilience and mental wellbeing. The purpose was to address these issues in a holistic way, e.g. with an integrated vision aimed to bridge informal and formal care.

This systematic review was carried out between January and September 2024 as part of Task 2.1, and its results represented Milestone 2 of the project (approved by the External Advisory Board in December 2025), demonstrating the completion of the literature review activity.

The activities related to Task 2.1 were coordinated by INRCA (WP2 leader) in close collaboration with the Coordinator (LNU), with the contribution of all project partners. Specifically, research partners (HSZG, INRCA, LNU, UL, UNC-CH, VUA) led the review of the scientific literature review (SLR) and advocacy partners carried out the grey literature review (GLR) in collaboration with research partners, both at European level (EAN, EASPD, EuCA, MHE) and at national level (ANS, ATI, NKA, NLZVE, WiPf).

Following this introduction, Chapter 1.2 provides methodological information on how the reviews were carried out, specifying the inclusion criteria for the search, the tools used, the phases of the reviews and details on data analysis. Methodological details of the scientific literature review (SLR) and grey literature review (GLR) are provided separately. Chapter 1.3 presents the results of the reviews. More specifically, Paragraph 1.3.1 provides the main insights from the SLR, while Paragraph 1.3.2 highlights the results of the GLR. Chapter 1.4 proposes some summary remarks of the systematic review.

1.2. Methodology

Scientific literature review (SLR)

Concerning the SLR, we referred to the earlier definition provided by Booth and colleagues, a *"systematic, explicit, and reproducible method for identifying, evaluating, and synthesising the existing body of completed and recorded work made by researchers, scholars, and practitioners, in a chosen field"* (Booth, Papaioannou and Sutton, 2012).

The first methodological steps were as follows: i) to define the string for making the search; ii) to select the scientific databases for making the search; iii) to define the inclusion criteria for the search phase.

The string to be used for making the search, included terms/keywords highly related to the contents and aim of the project, and by using a combination of Boolean operators, was as follows:

- ("LTC professional*" OR "care professional*" OR "care worker*" OR "LTC worker*" OR "nurse*" OR "caregiver*" OR "carer*" OR "family care*" OR "informal care*")
- AND ("practice*" OR "solution*" OR "innovation*" OR "approach*" OR "initiative*" OR "program*" OR "support*" OR "intervention*" OR "caring communit*" OR "community care" OR "training" OR "partnership*" OR "integrated care" OR "health promotion")
- AND ("resilience" OR "mental wellbeing" OR "mental well-being" OR "mental health" OR "psychological wellbeing" OR

"psychological well-being" OR "psychological health" OR "quality of life")

- *AND ("Austria" OR "Belgium" OR "Bulgaria" OR "Croatia" OR "Cyprus" OR "Czechia" OR "Czech Republic" OR "Denmark" OR "Estonia" OR "Finland" OR "France" OR "Germany" OR "Greece" OR "Hungary" OR "Ireland" OR "Italy" OR "Latvia" OR "Lithuania" OR "Luxembourg" OR "Malta" OR "Netherlands" OR "Poland" OR "Portugal" OR "Romania" OR "Slovakia" OR "Slovenia" OR "Spain" OR "Sweden" OR "Iceland" OR "Liechtenstein" OR "Norway" OR "Switzerland" OR "United Kingdom" OR "UK" OR "England" OR "Northern Ireland" OR "Scotland" OR "Wales" OR "EU" OR "European Union" OR "EU-27" OR "European countries" OR "Europe").*

The string focused on Europe due to the potential operational challenges of obtaining information on practices (described in retrieved papers) from countries outside Europe and due to the practices being implemented in highly different health, care and LTC systems compared to Europe.

The following eight scientific databases were selected to be used for the search phase: PubMed; Web of Science; Scopus; PsycINFO; CINAHL Complete – EBSCOHost; Applied Social Sciences Index & Abstracts (ASSIA); Global Health (EBSCO); ProQuest Health Care Administration. These databases are focused on different topics/disciplines and therefore their use was designed to enable the possibility to search for literature assuring a multidisciplinary approach (e.g. psychological, social, behavioral and health sciences, arts and humanities, technology, biomedical literature) and thus the potential selection of papers meeting the inclusion criteria from a variety of academic disciplines.

The inclusion criteria for carrying out the search on the selected scientific databases were as follows:

- Language: English
- Data range: 2013-2024 (31 March)
- Type of document: only scientific articles/reviews (i.e. excluding research reports, textbooks, etc.)
- Availability: full-text available; literature with author (plus some other limitations/filters as appropriate, e.g. open access, selecting categories)
- Topic: good practices, innovative solutions supporting LTC workers' and/or informal carers' resilience and mental wellbeing, with attention to care partnerships
- Geographic coverage: EU-27 Member States, United Kingdom, EFTA countries, i.e. Norway, Switzerland, Iceland, and Liechtenstein.

Concerning the topic, a more detailed point of reference was a conceptual framework, developed by INRCA, in collaboration with the Coordinator (LNU), in which the following set of possible types of interventions (based on the broader scientific literature in the area) was referred to for making the search:

- primary, secondary and tertiary prevention interventions (e.g. early detection and early treatment programs/measures, rehabilitation, relapse prevention, providing access to support services) (type 1)
- interventions or programmes dealing with organisational models and management approaches and/or targeted at the individual level (e.g. age-management policies, HR policies changes, organisational practices for care relief, re-organisation of care work practices/routines aimed at reducing the workload, innovative digital solutions/initiatives, psychological support, occupational health programs, group/peer support activities) (type 2)
- interventions aimed at mental health/wellbeing and resilience promotion and training initiatives (e.g. psychotherapeutic or psychosocial interventions, psychoeducational programs on resilience and mental wellbeing for LTC workers and/or informal carers, training programs for health and care providers/managers on how to support informal carers and/or LTC workers in the care environments) (type 3)
- integrated approaches and strategies for fostering partnerships for care collaboration and integration between LTC workers and informal carers, in order to favour the sharing of both caring responsibilities and workload, leading to a reduction of care burden (type 4)
- interventions and programmes targeted at LTC workers and/or informal carers with pre-existing mental health conditions, or for favouring work-life balance for LTC workers who are also informal carers (i.e. working carers) (type 5)
- community-based initiatives/measures supporting informal carers' mental health (e.g. voluntary work initiatives providing respite care, support and stress relief) (type 6).

- International or national strategies and initiatives launched/implemented by various institutions (type 7).

The search phase in the scientific databases was carried out by all research partners, and performed through block searching, by means of the following steps: i) the four blocks of the string were first searched separately with “OR” between each of the synonyms; ii) then the four blocks were searched together with “AND” between them; iii) the limitations/filters (e.g. English language, full-text, data range, geographic coverage) were then added, and the final search results were retrieved.

The records retrieved after the search underwent the following prior steps: i) a deduplication process; ii) the screening (phase 1) of title and abstracts; iii) the screening (phase 2) of full texts of included records. Both screening phases were carried out by country research partners according to the inclusion criteria outlined above, and thus motivating the exclusion of full-texts when they presented, e.g. inapplicable outcome, population group, publication type and study design and/or intervention. Also, the publication was excluded when the full-text was not available via open access.

Finally, country research partners extracted some relevant key information on selected papers after full-text screening (e.g. authors, title, year of the publication, journal, type of study, research methods, geographic coverage, country/ies involved, research questions/aim of the study, target groups, sample size, type of practice/intervention, measurement/evaluation issues, outcomes/main findings, aspects fostering care partnership, etc.). Further methodological details about the extracted variables is available from the first author upon request.

PRISMA flow diagram of SLR

The PRISMA flowchart reported below (Moher et al., 2009; Page et al., 2021) highlights that after the search phase in the eight selected databases, 16,357 records were identified, and after the deduplication process 9,172 records were screened.

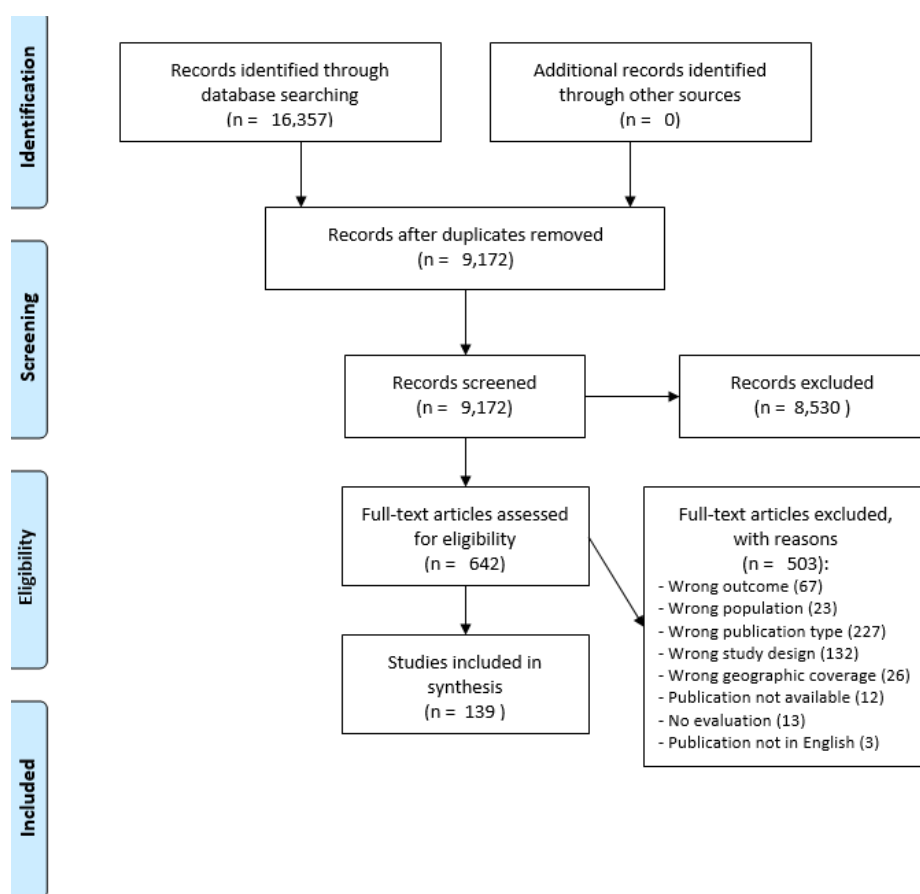


Figure 1. The PRISMA flowchart reporting the SLR screening process

The screening of titles and abstracts led to 642 papers to be assessed for eligibility which subsequently, after their full-

text screening, resulted in a total of 139 included studies. A total of 503 papers were excluded after full-text screening for the following main reasons: inapplicable/wrong type of publication (227), study design (132), outcome (67), and/or geographic coverage (26), publications without evaluation (13), not available (12) or not in English (3).

Data analysis of SLR

Data analysis was performed by INRCA on information collected from the 139 articles selected after the completion of the full-text screening phase. The key information was divided into the following blocks:

- closed multiple-choice and quantifiable questions;
- closed multiple-response questions and quantifiable questions;
- open-ended questions (free text).

We mainly focused on the first and second blocks, which provide quantifiable and therefore more easily summarised information from the included articles. With regards to the open-ended questions, only the topic of measurement/evaluation has been examined.

Unreliable and unspecified information was considered as missing data. The results of the analysis are presented in figures and tables, with either absolute or percentage values. In some figures, the sums of the latter may not perfectly match to 100% because of rounding. In other cases, the sums of the absolute and percentage values do not correspond to a total of 139 records or 100% (or 103 practices for GLR), due to multiple response questions.

Grey literature review (GLR)

In order to complement the findings of the scientific literature review, a search was also carried out by collecting the available grey literature (including those in the national languages of the five partner countries) to identify existing databases of good practices, evidence, and data in the field, by using the overall same inclusion criteria applied in the SLR, with some adaptations. Both the Google search engine (i.e. Google Scholar) and websites/databases of relevant institutions and organisations were also consulted. In more detail, the grey literature search was articulated into three main blocks of activities:

- Research partners made a search in Google Scholar in their national languages, by using and adapting in a flexible way (i.e. according to national/contextual specificities) the search string and the related terms/keywords used for the SLR but limited and focused to the five partner countries.
- EU and national advocacy partners, as well as research partners, highlighted practices implemented directly, or identified via their own networks (e.g. calls, email communications and survey among members, newsletters, etc.)
- EU and national advocacy partners also highlighted and consulted several existing databases, websites and repositories¹ (both in English and in partner national languages) of potential good practices, including the [EU Public Health Best Practices Portal](#) (the latter analysed also by INRCA).

The inclusion criteria for making the search of the grey literature were the following:

- Language: English and languages of national partner countries
- Data range: 2013-2024 (31 March); also possible to report documents published prior to 2013, if considered by partners as key for their contexts
- Type of document: reports, textbooks, government publications, policy briefs, newsletters, practice/initiative description sheets, etc.
- Availability: full-text available; literature with author/source
- Topic: good practices, innovative solutions supporting LTC workers' and/or informal carers' resilience and mental

¹ Websites, databases and repositories consulted are not listed in the Report, but they are available in a separate document upon request.

wellbeing, with due attention given to care partnerships

- Geographic coverage: EU-27 Member States, United Kingdom, EFTA countries, however with a systematic focus on the five partner countries (Germany, Italy, The Netherlands, Slovenia and Sweden).

Concerning the topic, as for the SLR, a more detailed point of reference for making the search of the GLR was the set of possible types of interventions previously outlined in Paragraph 1.2 above.

Since the search in Google Scholar did not provide valuable results (e.g. papers/books were not available in full text, often they overlapped with publications retrieved by means of the SLR, and also often publications were out of the topic scope), the GLR solely focused on the searches in databases, websites and repositories known to the partners and/or within their respective networks. In addition, partners' members organisations directly provided information on practices/interventions they or their members put in place. In total, 103 practices were collected.

Similarly to the SLR, some relevant key information on selected GLR practices were extracted (e.g., name and goals of the practice, geographic coverage, country/ies involved, target groups, type of practice/intervention, measurement/evaluation issues, outcomes/main findings, aspects fostering care partnership, etc.) by research and advocacy partners, at both EU and national level. Further methodological information on the extracted variables is available upon request.

Data analysis of GLR

The data analysis, carried out by INRCA, was based on data collected from the 103 selected practices. The information was divided into four blocks:

- questions that cannot be quantified or with unreliable information (e.g. total budget);
- closed multiple-choice and quantifiable questions;
- closed multiple-response questions and quantifiable questions;
- open-ended questions (free text).

The last three blocks have been examined. Incomplete information that was not possible to retrieve was considered as missing data. Regarding free text questions, some have been analysed by means of selected categories, which have then been subsequently quantified. The results of the analysis, as for the SLR, are presented in figures and tables, with either absolute or percentage values. In Chapter 1.3 some tables and figures are included, whilst others providing detailed results for both the SLR and GLR are reported in Annex A2.

1.3. Results

1.3.1. Scientific literature review: overview of main findings

Multiple choice questions

The literature we examined is relatively recent, as almost half of the sample consists of publications published within the last four years (Fig. 2).

2 As discussed above, the search strategy applied by the Consortium for both the SLR and GLR aimed to cover a broad geographical perspective and to use several scientific databases (SLR) as well as to consult existing websites, databases and repositories, and to gather additional practices implemented directly by project partners, or identified via their own networks (GLR), in order to collect up-to-date and comprehensive evidence as possible on good practices to support carers' resilience and wellbeing (and having the potential to foster care partnerships). Despite this, some possible biases and limitations in collecting other potential good practices in the field could have emerged (e.g. not retrieving: papers not in English, practices implemented before 2013, or included in other non-consulted databases, even in diverse languages. Moreover, the SLR mainly included quantitative research, thus it did not identify a higher number of qualitative studies).

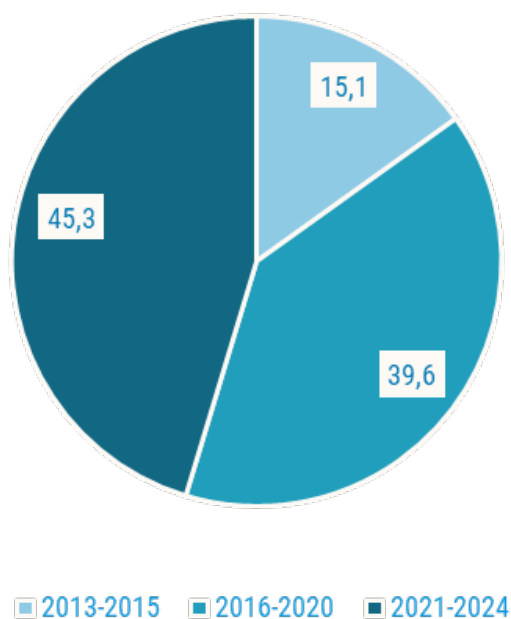


Figure 2. Papers by year of publication (%)

The retrieved literature was published in 79 different scientific journals, but in 26.6% of the cases papers can be attributed to 5 scientific journals, which have each published 5 or more of the retrieved articles (Fig. A1.1)³.

The selected papers can be traced back to 16 countries and in three cases to international contexts, which include more than one country. However, a significant concentration of papers emerges in six countries (UK, Germany, Spain, Netherlands, Sweden, Italy), which account for 77.7% of the sample (Fig. A1.2).

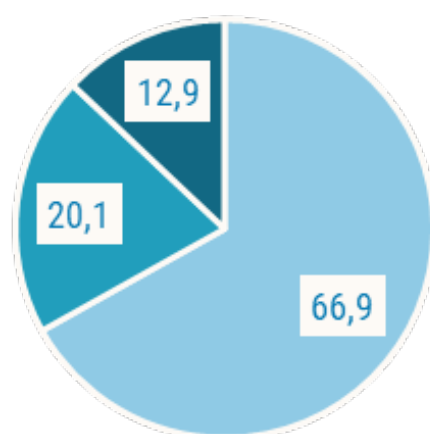
The geographic coverage of the practices described in the retrieved papers is mainly national and local/regional, whereas interventions addressing the international or European contexts are almost absent (Fig. A1.3). This represents an added value of the review, which systematically collected and pooled good practices implemented at local/national level and therefore likely to be less well known at European level.

The literature we examined is almost exclusively composed of (mainly) trials and research articles (Fig. A1.4) and predominantly adopts quantitative methodologies, and to a lesser extent mixed-methods. Articles using purely qualitative methods represent a minority share of the sample (Fig. A1.5).

Multiple response questions

For the most part, selected papers mainly solely refer to a specific target group (Tab. A1.1). The latter generally is represented by informal carers (which in some cases are also working carers, namely informal carers who combine paid work with providing care to a family member/significant other). The most common target group among LTC workers are nurses (i.e. both qualified and assistant nurses), while few papers address personal/private care workers/assistants (Fig. A1.6). Only a small number of papers target both informal carers and LTC workers (Fig. 3).

³ Tables A1.1-A1.2 and Figures A1.1-A1.14 in Annex A show detailed results for the SLR.



■ Informal/working carers ■ LTC workers ■ Both informal carers and LTC workers

Figure 3. Papers by main target group (%)

The selected papers address target groups of different ages. Informal carers are the most common target group in each age group, but they become almost the entire target group at older ages (over 65). Between the ages of 18 and 64 we also find a discrete presence of nurses and other LTC workers (Fig. A1.7).

The gender of the target group is not among the distinguishing features of the examined papers, which are indifferently addressed to both males and females. A minority share of the papers is aimed at female target groups, while none is exclusively directed at male target groups (Fig. A1.8).

Regarding the sample size, the studies we reviewed mainly involved between 101-500 participants (Fig. A1.9). Informal carers are almost always the category most represented in the studies. The only exception concerns the high-numbered samples, which consist mainly of the group of other LTC workers (Fig. A1.10). Nurses are particularly represented in the small samples (1-10 units), whereas care recipients are not mentioned.

The selected papers focus predominantly on care recipients with cognitive and psychological problems (Fig. A1.11). This also confirms the results from the GLR (see Paragraph 3.2.2) and highlights how the mental health problems of care recipients could heavily reverberate on the mental resilience of caregivers.

The study sample mainly focuses on practices aimed at older care recipients, aged 65 years and over, and adult people of working age (18-64 years). Studies aimed at youths and adolescents are less common, but still present (Fig. 4).

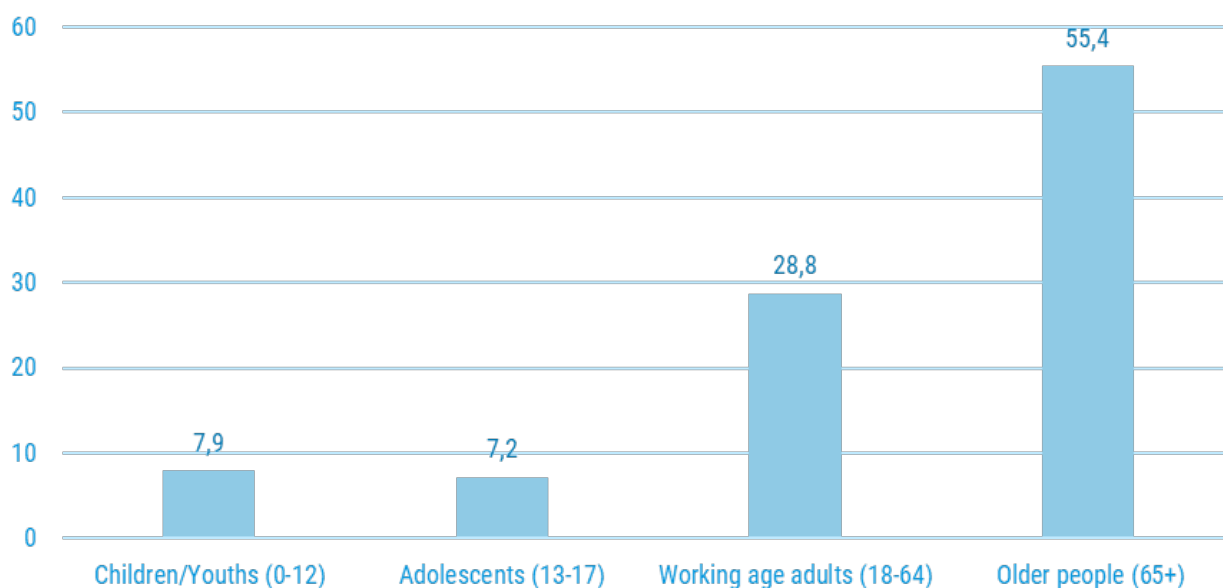


Figure 4. Papers by age profile of the care recipient (%)

A greater part of the reviewed papers refers to a single setting where the described practices/interventions are implemented (Tab. A1.2). However, widespread heterogeneity emerges in the settings considered, with (especially) home and online settings playing a crucial role (Fig. A1.12). The focus is thus mainly on out-of-hospital settings, where caregivers' support needs arise.

Regarding the type of practices, the majority focuses on interventions aimed at improving mental wellbeing and resilience and training of the target groups of informal carers/LTC workers (Fig. 5). A much smaller sample deals with prevention interventions and programmes dedicated to organisational models and management approaches. Only 2 practices emerged as integrated approaches and strategies.

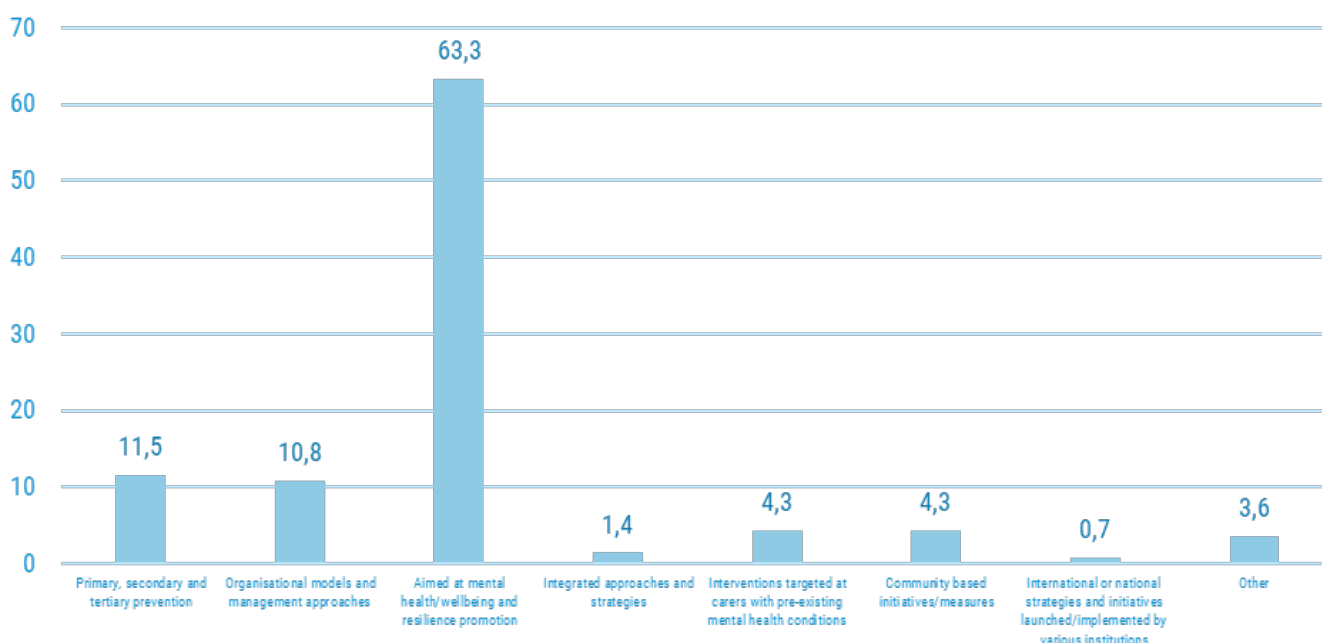


Figure 5. Papers by type of practice (%)

From the analysis of potential aspects fostering care partnerships, 28 papers emerged, which can be traced back to various countries but with a marked presence in the UK and in the Netherlands respectively (Fig. A1.13). The articles with potential for fostering care partnerships are mainly focused on interventions aimed at mental health/wellbeing and resilience promotion. However, there are also community-based initiatives, integrated approaches and prevention, which affect a smaller share of the study sample (Fig. A14).

Free-text questions

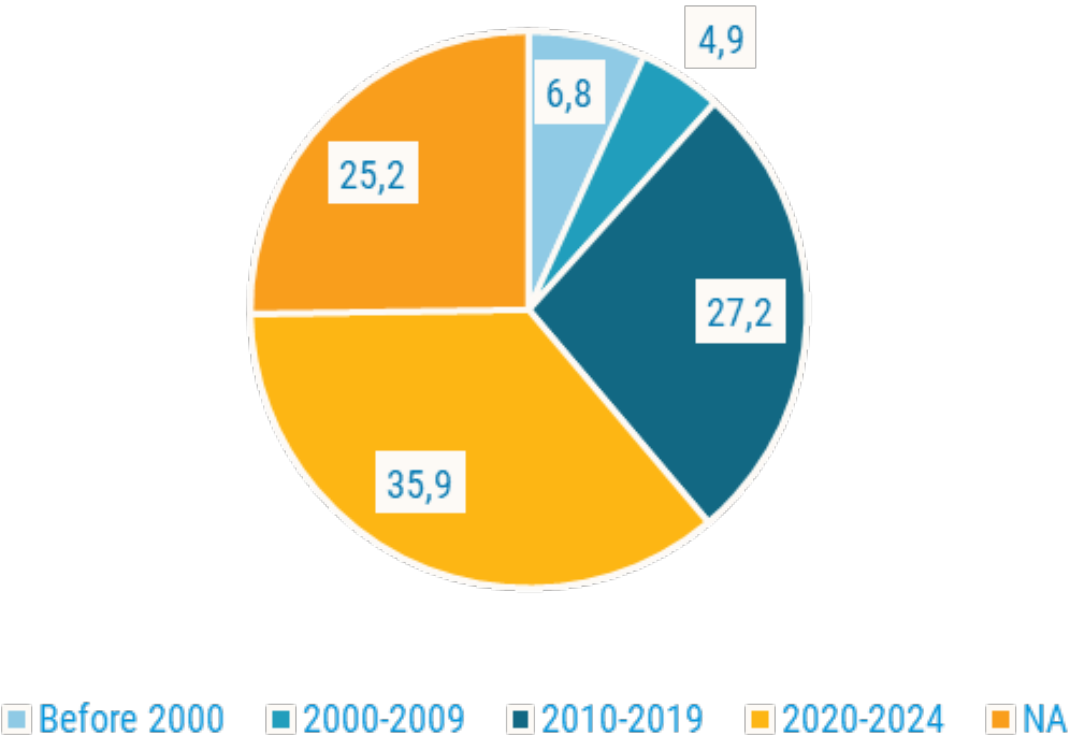
Overall, 104 out of 139 practices (74.8%) present at least one aspect that could be related to the evaluation of the intervention that is described in the paper (e.g., analysis of: efficacy/effectiveness; pre-post design/follow up; acceptability/acceptance; usefulness/usability/user-friendly/ease of use; appreciation/satisfaction/perceived benefits; treatment effect/impact perception). However, among these, only 52 out of 104 (50%) explicitly mention the term “evaluation” (or synonyms, e.g. assessment, estimation) of the intervention. The other practices (35 out of 139) more generally present an overall assessment of the results, however with implications on caregivers’ burden/stress/anxiety/ wellbeing/self-efficacy/capacity to act or similar dimensions.

1.3.2. Grey literature review: overview of main findings

Multiple choice questions

The 103 selected practices in the GRL are implemented in 20 countries, but a significant concentration emerges in six countries (Italy, Netherlands, Slovenia, Germany, UK, Sweden), which account for 75% of the sample (Fig. A2.1).

The selected grey literature includes recent (Fig. 6) and still ongoing or recently completed practices (Tab. A2.1)4.



4 Tables A2.1-A2.4 and Figures A2.1-A2.13 in Annex B show detailed results for the GLR.

Figure 6. Practices by start date (%)

Regarding the gender composition of the target group(s), most practices are generally aimed at both males and females. There are no practices that are addressed solely to males and a small proportion of practices are addressed mainly to women (Fig. A2.2).

Multiple response questions

The mapped practices have a heterogeneous geographical coverage. They are in fact implemented in various areas, mainly local, but also at the national level and regional scale, and less at the international or European level (Fig. A2.3).

Overall, most practices are targeted at a specific context, usually 1 or 2 geographical levels (Tab. A2.2), e.g. local, regional). This is indicative of the difficulty of implementing practices on a large scale, often for economic reasons and/or difficulties to adapt them to different geographical, economic and/or cultural contexts.

The high fragmentation of the places of delivery is in turn further evidence of the variety of practices selected in the grey literature (Fig. A2.4). In this respect, we note that the sample includes a significant number of practices performed outside healthcare facilities, to which only 45 out of 103 responses can be attributed. The item “Other” concerns 20 practices and constitutes a heterogeneous group with several multiple answers.

Most of the practices are addressed to 2 or more target groups. In 19 cases the practice addresses as many as 6 target groups (Tab. A2.3)⁵. The practices involve mainly informal carers (and informal carers who also combine paid work with care of a relative/friend, i.e. working carers), and to a lesser extent nurses and personal/private care workers/assistants (Fig. 7). This corroborates the findings that also emerged from the SLR about the share of informal carers involved, while all the other target groups are more overrepresented in the GLR.

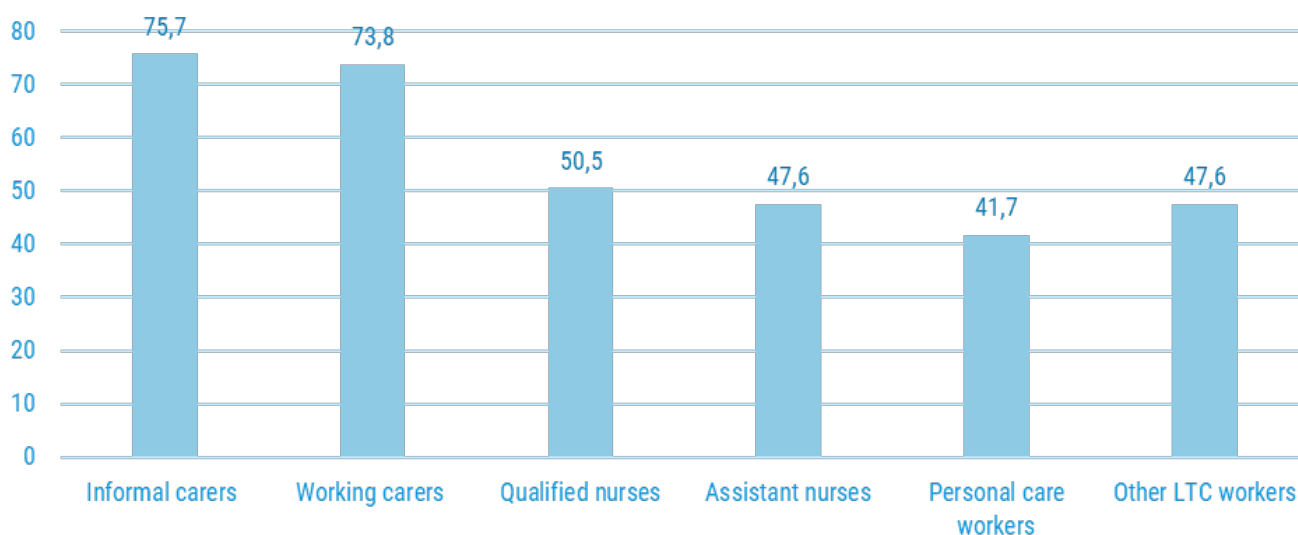


Figure 7. Practices by target groups (% on total)

The 35-64 age group constitutes a target group for almost all practices (Fig. A2.5), and 78.6% of the total of 103 practices are directed at young people aged 18-34 years. Practices targeted at older people are however also highly represented, with 76.9% for older people aged 65-74 years and 70.9% for those aged 75 and over.

The study sample is predominantly focused on care recipients with cognitive or psychological/mental wellbeing problems. Those with physical or chronic illnesses represent a smaller, albeit significant, portion of the total (Fig. A2.6). The fact

⁵ Target groups considered in the reviews and which could be included in selected practices are the following: informal carers, working carers, qualified/registered nurses, assistant nurses, personal care workers, other LTC workers/health-social care professionals.

that the mapped practices involve care recipients with cognitive/psychological problems may also imply that caring for persons with such problems challenges the mental resilience of caregivers. Almost all practices are addressed to older care recipients or (to a significant but lesser extent) to working age adults, while children and adolescents account for slightly less than half of the care recipients (Fig. 8).

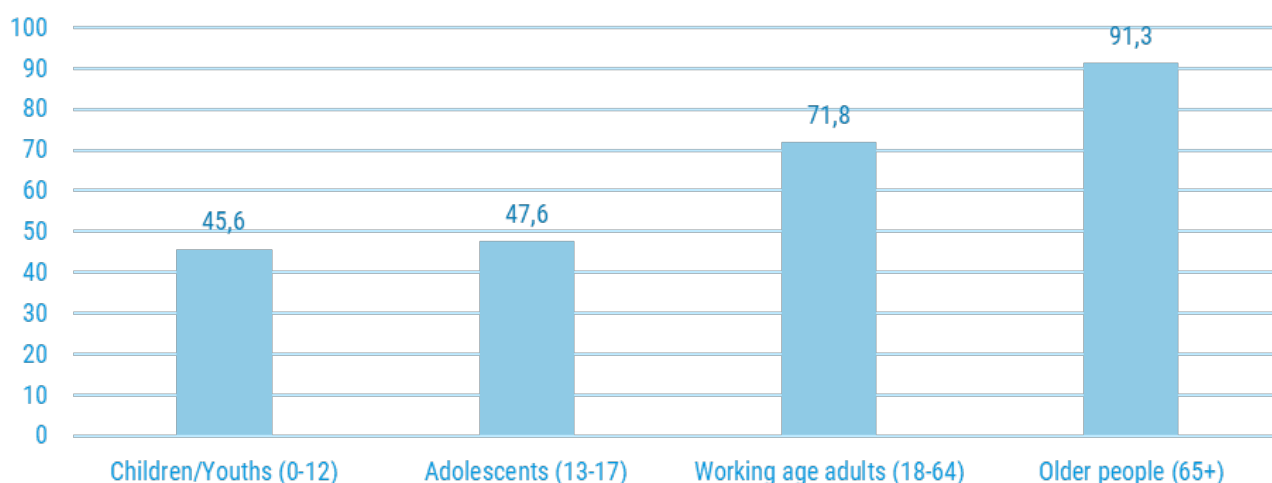


Figure 8. Practices by age of the care recipients (%)

Regarding outcomes, the mapped practices produced multiple results: in 69 cases, the achievement of 3-5 different types of outcomes is even reported (Tab. A2.4). The high average number of outcomes obtained is also related to the nature of the needs to be addressed, which are often multiple and interrelated. In fact, the options offered have numerous points of contact: for example, “improving mental wellbeing” often implies a “reduction of negative aspects” and an “increase in satisfaction” of care work. Almost all practices succeed in improving the mental wellbeing and resilience of the target group (Fig. 9). The majority of practices also succeed in both reducing negative aspects and increasing satisfactions of caring. Further, 50.5% (n=52) of the collected practices have the potential of fostering care partnerships between informal carers and LTC workers. The item “Other” includes multiple and varied answers, sometimes generic (e.g. “Create an inclusive society”) or highly specific (“Reduction of absenteeism”). In some cases, the expected outcome concerns the care recipients rather than the caregivers (e.g. “Allowing older people to live at home”).

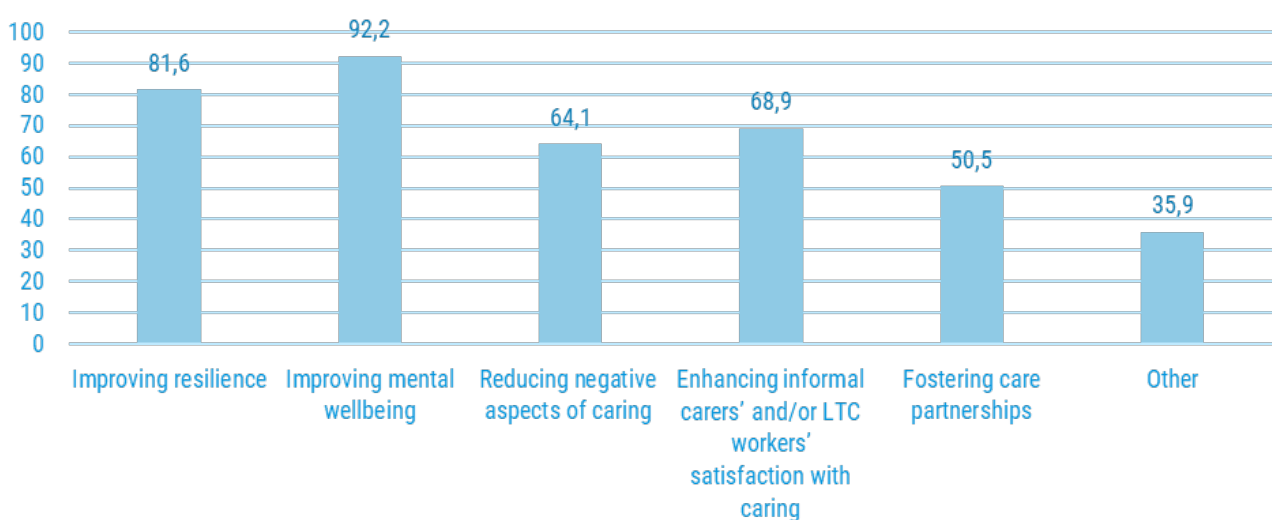


Figure 9. Practices by main outcomes (%)

The collected data also highlights the marked fragmentation of funding sources, which mainly come from national sources

or from statutory LTC/healthcare financing systems (Fig. A2.7). The heterogeneity of funding sources on the one hand reduces the risk of the sudden ending of available funds, but on the other hand hampers the opportunities for expanding projects on a larger scale.

Free-text questions

Responses to the free-text questions reveal that the implementation of the selected practices requires confronting a wide range of challenges, first and foremost the availability of funds and the management of technical-organisational aspects (Fig. A2.8).

A strong complexity also characterises the measurement/evaluation of the various practices. The sample shows heterogeneous responses in this respect (evaluations on the financial aspects, user satisfaction, health results, etc.), and also a diversity with regards to the assessment tools used (ranging from very simple evaluations to accurate analyses with numerous indicators). However, the methods used are predominantly mixed and quantitative (Fig. A2.9).

When other dimensions⁶ with free-text questions are considered/compared with measurement/evaluation, this represents the most reported topic (around 80% of the total), rather than other topics such as sustainability (around 44%), scalability (34%), and transferability (39%) (see Fig. 10).

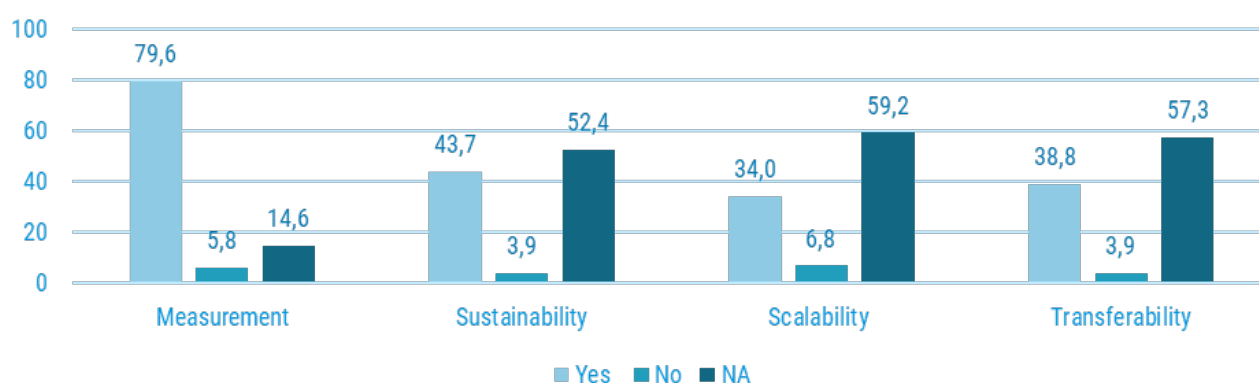


Figure 10. Practices by main characteristics (%)

Figure 10 shows noticeable data gaps for certain characteristics mainly due to lack of information in primary sources. However, according to available information forty-three percent of practices are sustainable, very few are not explicitly so, whilst with regard to others there is still uncertainty or a lack of information (Fig. A2.10). Nine potential determinants of sustainability are mentioned, which mainly focus on availability of funding, political support and of adequately trained professionals and volunteers (Fig. A2.11). The focus on funding shows how sustainability is declined substantially in economic terms, although there is no lack of other broader meanings (“environmental and organisational”). Political support is a transversal theme that could represent almost a precondition for activating the other “levers”. In any case, the distinguishing factor is to be able to continue implementing the practice, and it is often the economic aspect that makes the difference in this respect.

Concerning the responses regarding scalability and transferability of practices, respective values are rather similar (Fig. A2.12). Only a minority (17.5%) of the mapped practices are both scalable and transferable, 38.8% have only one of the two potentials and 43.7% do not possess either of these properties (Fig. A2.13).

Requirements for ensuring the scalability of practices include the availability of funds, political support and the ability to adapt the practice to different contexts. The transferability of the practice, on the other hand, is influenced by the complexity of the needs, the availability of funds, political support and the ability to coordinate with other stakeholders.

⁶ Sustainability, scalability, and transferability are addressed in the GLR results but not analysed in the SLR section, due to difficulty/complexity to retrieve information on such dimensions in scientific papers.

1.4. Summary remarks

Both the scientific literature review (SLR) and grey literature review (GLR) resulted in the collection of a significant and representative sample of mostly recent (and still ongoing) practices aimed at improving the mental wellbeing and resilience of informal carers and LTC workers in European countries.

Overall, both reviews highlight the following aspects: practices involve mainly informal carers and to a lesser extent registered nurses, personal/private care workers/assistants, and other LTC workers; they mainly target both genders; care recipients are mostly older people aged 65 years and over, who often present with cognitive or psychological/mental health problems which heavily impact on the mental resilience of caregivers. Moreover, among the various settings of delivery of the practices, a significant number of them are performed outside healthcare facilities, with home and online however playing a crucial role and with increasing societal relevance (especially during the Covid-19 pandemic).

With regards to the SLR, the articles (139) were published in a wide set of scientific journals and often concern practices implemented at local/national scale, therefore less well-known at European level. Also, papers retrieved used mainly quantitative methodologies, which provide verifiable and monitorable results. The majority of selected papers refer/describe interventions aimed to improve mental wellbeing and resilience of the target groups, and, to a lesser extent but however important to consider, practices dealing with organisational models, management approaches, and prevention interventions. Interestingly, the SLR also identified a number of practices (28) with the potential for fostering care partnerships between informal and formal caregivers.

With regards to the GLR (103 practices), concerns emerged about their sustainability, scalability and transferability. The difficulty of implementing practices on a large scale was often due to financial reasons and difficulties with adaptation to both different economic and cultural contexts. Sustainability, scalability and transferability of practices indeed firstly require adequate availability of funds, but also political support and efficient and flexible organisations. It is worth noting that half of the collected GLR practices (52) have the potential to foster care partnerships between informal carers and LTC workers. The higher number of practices with the potential of fostering care partnerships than in the SLR (52 vs 28) could be related to the different respective methods for collecting data/information (i.e., for the SLR by means of a string with keywords that “approximately” endeavored to detect papers focusing on this issue, and for the GLR asking partners/referents implementing the practices, to provide information on them, devoting particular attention to finding interventions with potential in terms of integrated approaches/fostering care partnerships).

Section II - Task 2.2:

Methodology for selection criteria and data reporting tools

2.1. Introduction

This section presents the main insights from Task 2.2 “Methodology for selection criteria and data reporting tools” (M10-12; October-December 2024), the aim of which was to develop the methodology for the fieldwork to be carried out in Task 2.3. “Selection, analysis and report of good practices, evidence, and data” (M13-24; January-December 2025).

This section is structured as follows:

Chapter 2.2 reports information on the specific methodological process employed by the Consortium to: i) reach an agreement on the set of criteria to be applied by country partners to all the practices collected via the SLR and GLR to select good practices; ii) to develop a common template to be used in all five countries to report findings on the selected good practices responding to the criteria in a comparable way.

Chapter 2.3 presents the set of established and agreed criteria and a summary of the structure and contents of the common template developed by partners.

Annexes B-E provide the following documentation: i) a table with a summary of the main findings from the cross-country BLN session 3 and session 4 discussions about the criteria; ii) a table comparing criteria and sub-criteria included in an [European Commission document](#) (European Commission, 2022b; see Chapter 2.2 for more details) and the ones selected/adapted in Task 2.2 for the project purposes; iii) the template to collect information on potential/promising (GLR) good practices used in Task 2.1 (on which the following mentioned template was partly based); iv) the template to report information/findings concerning the selected good practices;

2.2. Methodology

Selection criteria

The work carried out in Task 2.2 involved identifying and defining shared and agreed inclusion/selection criteria to be used to assess whether a practice implemented in LTC organisations/settings to promote LTC workers and/or informal carers’ resilience and mental wellbeing can be considered to be a good practice. As a starting point, the criteria to select practices for the [EU Public Health Best Practice Portal](#) (European Commission, 2022b; Stepien et al., 2022) - included in a [European Commission \(EC\) document](#) (European Commission, 2022b) - were used and adapted to suit the purpose and issues to be addressed in WP2 of the WELL CARE project.

Subsequently, in close collaboration between WP2 and WP5 (“Blended learning networks-BLNs with long-term care workers, informal carers and stakeholders” - M1-48) leaders (INRCA and NKA) and country BLN facilitators, two national BLN sessions (sessions 3 and 4, October 2024 and December 2024) were organised in each of the five partner countries (Germany, Italy, the Netherlands, Slovenia, and Sweden), with all relevant BLN members (including project target groups and stakeholders), to discuss, gather feedback, and inputs on criteria for selecting good practices. After an analysis of such discussions by using a deductive content analysis carried out by WP5 leader (NKA), the results of all five countries’ BLN sessions were presented in a table (see Annex B), which provides a summary synthesis of the cross-country BLN 3 and 4 discussions about the criteria. Based on the summary BLN findings, the INRCA team subsequently reviewed these findings with close reference to the criteria included in the EC document, and proposed a set of criteria, that were initially shared and discussed with the Coordinator (LNU) and agreed on prior to then sharing and reaching agreement with the

country partners (see Section 3.3.2.2. Evaluation tool for more details, as well as Annex C, where, for the sake of clarity, it is specified which of the criteria and sub-criteria listed in the EC document were included or not among the ones agreed for the project purposes). The agreed criteria were subsequently applied by country partners to allocated practices collected via the SLR and GLR carried out in Task 2.1 and integrated by some additional practices highlighted by BLN members (by December 2024) as well as by Experts interviewed in Task 2.3 ("Expert interviews-M13-15"- January-March 2025).

Template to report findings of selected good practices

The template to be used in all five country partners to report and compare findings on the selected good practices responding to the selected criteria, was designed by INRCA in collaboration with the Coordinator and subsequently with the partners, taking into consideration and adapting to the purposes of the project, the one used to report information and describe the best practices included in the EU Public Health Best Practice Portal. It was also developed by considering the types of information/variables collected through the template (see Annex D) used in the GLR carried out in Task 2.1 of the project, to gather information on potential/promising good practices to support LTC workers and/or informal carers' resilience and mental wellbeing. INRCA provided a first draft template to the Coordinator (LNU), and after the feedback of the latter, INRCA team further refined the contents of the document, leading to a bilateral agreement, prior to sharing the draft template and reaching agreement with the partners. The final version of the template was subsequently used by country partners to report information on selected good practices in Task 2.3 (in particular in the activity "Reporting good practices" -M16-20- June-August 2025).

2.3. Results

2.3.1. Agreed criteria to select good practices

In detail, in relation to the contents of the EC document, the methodological process described above (see Chapter 2.2) resulted in maintaining: a) the main blocks of criteria: namely, Exclusion - but renamed for our project purposes as General⁷ - Core and Qualifier criteria; and b) all the specific criteria within these three main blocks of criteria. Concerning the sub-criteria included in the EC document, it was decided: a) to maintain/include some of them that are more focused on the topic of the project (and in several cases proposing a rephrasing of the text and/or several integrations, to align with the project aims/vocabulary and also for taking on board the inputs received from BLNs); b) to exclude others, mainly due to the difficulty to apply such sub-criteria in the context of the project, as well as because they were considered to be too specific and therefore more directly relevant concerning practices for the EU Public Health Best Practice Portal. Moreover, following overall BLN members' inputs, two additional Qualifier criteria were included, i.e. Care partnerships and Innovation.

At the end of the process, in total, 20 sub-criteria were proposed and agreed on (out of a total of 48 included in the [EC document](#)) (see also Annex C).

Table 1 lists the agreed set of criteria and sub-criteria defined within Task 2.2, to select good practices in Task 2.3.

⁷ According to the EC document (European Commission, 2020b), if all the Exclusion criteria (Relevance, Intervention characteristics, Evidence and theory based, Ethical aspects) are not fulfilled, other criteria have not to be checked and assessed. For the purposes of the project activities, it was decided that the Relevance criteria was only considered as "mandatory" to be met. Thus, only if this criterion was not fulfilled, the other criteria were not assessed. This adaptation/choice was made for allowing a wide and more inclusive approach in assessing the collected practices.

Table 1. Agreed set of criteria and sub-criteria to select good practices

Criteria	Sub-criteria (in brackets are reported the code we assigned to sub-criteria)
GENERAL CRITERIA	
Relevance	The practice is aimed at increasing mental wellbeing and/or resilience of informal carers and/or LTC workers, and/or to foster care partnerships (at community local/regional level, national level or European level) (G1)
Intervention characteristics	The target population is clearly described (e.g. informal carers, working carers, qualified/assistant nurses, personal care workers, other LTC workers/health-social care professionals, etc.) (G2) Objectives are defined and actions to take to reach them are clearly specified (G3)
Evidence-informed and theory based	The practice is built on a well-founded theory and/or is well-documented, and is evidence-informed (G4)
Ethical aspects	The expected benefits are superseding the potential harms (G5)
CORE CRITERIA	
Effectiveness and efficiency	Process evaluation: The practice has been evaluated, or an evaluation is planned (taking into account, if feasible, individual, social and/or economic aspects from both the target population - e.g. LTC workers and informal carers - and the perspectives of relevant other stakeholders concerned - e.g. professionals/representatives of LTC, health and social care, civil society, public institutions, policy, academia/research, LTC workers' employer organisations, trade unions, mental health and/or carers' associations, home, community and residential care settings) (C1) Outcome evaluation: The evaluation outcomes demonstrated beneficial impact (e.g. the practice is successful/ effective to improve the mental wellbeing and/or resilience of the target groups, fostering care partnerships or elements thereof, etc.) and (if applicable) in various settings (C2)

Equity	The relevant dimensions of equity are adequately and actively considered throughout the process of implementing the practice (e.g. age, gender, socioeconomic status, rural and/or urban area, vulnerable groups, as e.g. people with hearing and/or visual/impairments, chronic illnesses, multimorbidity, without family support, with language barriers, etc.) (C3)
QUALIFIER CRITERIA	
Transferability	The practice uses instruments (e.g. a guide/manual/materials - even online - with a detailed activity description) that allow for repetition/transfer (Q1) The practice has already been successfully transferred/repeated (if applicable) (Q2) The practice is adequately defined, showing potential adaptability, flexibility, and user-friendliness/acceptance that allow for repetition/transfer to different contexts (e.g. different countries/regions, different/larger population) and/or settings (e.g. home, community, residential care settings) (Q3)
Sustainability	The practice has institutional support, and/or an organisational and/or technological structure and dedicated human resources, paying also attention (if applicable) to environmental sustainability (Q4) The practice presents information which discloses the sources of financing (which potentially can allow continuity as financial sustainability - if applicable) (Q5) The continuation of the practice could be ensured through the involvement of relevant stakeholders and/or (caring) communities in the planning/implementation of the practice (Q6) The practice provides training of staff (e.g. in terms of knowledge, techniques and approaches) in order to sustain it (Q7)
Collaboration	Several sectors and related stakeholders (e.g. LTC, health and social care, civil society, public institutions, policy, academia/research, LTC workers' employer organisations, trade unions, mental health and/or carers' associations, home, community and residential care settings, etc. - and their representatives) collaborate to carry out the practice (Q8)
Care partnerships	The practice promotes or has the potential to promote/foster care partnerships/alliances between informal carers and LTC workers (i.e. the project target population) and/or other relevant stakeholders from several sectors (e.g. LTC, health and social care, civil society, public institutions, policy, academia/research, LTC workers' employer organisations, trade unions, mental health and/or carers' associations, home, community and residential care settings, etc.) (Q9)
Participation	The structure, organisation and content (also evaluation outcomes and monitoring, if applicable) of the practice is defined and established together with one or more of the following: informal carers, families, LTC workers, other relevant stakeholders (e.g. professionals/representatives of LTC, health and social care, civil society, public institutions, policy, academia/research, LTC workers' employer organisations, trade unions, mental health and/or carers' associations, home, community and residential care settings, etc.) (Q10)
Innovation	The practice entails social innovation* (Q11) The practice entails technology innovation** (Q12)

- * Social innovations are new ideas (products, services and models) that simultaneously meet social needs (more effectively than alternatives) and create new social relationships or collaborations.
- ** Technology innovation is defined as the creation and application of new or improved technologies, tools, systems, and processes that bring about significant advancements or breakthroughs in various fields. It involves harnessing knowledge, expertise, and resources to develop innovative solutions that solve problems, improve efficiency, drive progress, and deliver value.

2.3.2. Agreed template to report findings of selected good practices

The final agreed template was articulated in two main blocks. The first/initial part is aimed at providing a summary of the main details of the selected good practice (e.g., type, name, country, stage, funding, summary, etc.), whilst the second part entails a detailed description of the good practice, with a set of 17 variables/key information to be reported (including e.g., observed outcomes/impacts, potential to foster care partnerships between LTC workers and informal carers, potential of sustainability, scalability, transferability, adaptability, implementability of the practice, etc.). The agreed template, with contents and details related to information to be collected to describe the selected good practices⁸ is presented in its entirety in Annex E.

⁸ It is however to be clarified that as information from practices collected via the SLR and the GLR do not fully share the exact same characteristics due to different sources of information/literature, the template has been designed with the endeavor to seek a “compromise” among these different data sources. It also means that in the template, some details could be reported in a slightly different way, e.g., for practices described in papers (SLR), if the name of the practice is not available, it was possible to report the title of the paper.

Section III - Task 2.3:

Selection, analysis and report of good practices, evidence, and data

3.1. Introduction

This section provides an overview of the results of Task 2.3 ("Selection, analysis and report of good practices, evidence, and data" - M13-24), and in particular of the following activities: i) expert interviews (M13-15; for details, see Chapter 3.2); ii) reporting good practices (M16-20; for details, see Chapter 3.3).

Interviews were carried out with experts in the five partner countries (Germany, Italy, The Netherlands, Slovenia and Sweden), to complement and extend the findings that emerged from the SLR and GLR carried out in Task 2.1, and to provide inputs useful for the following WP2 activities, as well as for the links with other WPs (e.g. to underpin the development of prototypes in WP3 and in due course, of evidence-based and action-oriented recommendations for policy makers and stakeholders in WP4).

As for the second activity, by using the criteria defined and agreed by key stakeholders in Task 2.2, and based on the literature review, BLN members' inputs, expert interviews and desk research and analysis, partners worked to select/identify and report findings, evidence and data of good practices (using the common template created in Task 2.2). The overall aim was to report findings of at least 40 good, effective/innovative practices in Europe by M20 (August 2025), for the purposes of this D2.1 (see Chapter 3.3 and Annex G).

3.2. Expert interviews

3.2.1. Introduction

The specific aim of conducting expert interviews was to integrate the findings from the literature review, and to gather opinions, insights and knowledge mainly concerning:

- a) other existing (potential) good practices implemented at the LTC organisational/employer level and/or in informal care settings, focusing on practices having the potential to foster/promote care partnerships;
- b) drivers and barriers, suggestions and recommendations on how to better design, adapt, tailor, develop/implement good practices to support informal carers and/or LTC workers' resilience and mental wellbeing and to foster care partnerships in different care settings.

3.2.2. Methodology

Recruitment, data collection and interviews characteristics

A purposive sampling strategy was employed to identify 4-5 experts in each of the five participating countries (Italy, Germany, Netherlands, Slovenia and Sweden). Experts were selected by country partners based on potential expert participants' experience, expertise and knowledge relevant to WP2 and overall project objectives (e.g. formal and informal caregiving, mental wellbeing, resilience, LTC). The sample aimed to include (as far as possible) representatives belonging to various sectors, namely:

- Academia and research institutions;
- Policy;
- LTC workers' employer organisations;
- Mental health or caregiver associations.

This multi-stakeholder approach ensured comprehensive perspectives on the complex dynamics of good practices and care partnerships in LTC settings to promote the mental wellbeing and resilience of the project target groups of informal carers and LTC workers.

In order to guarantee consistency across the countries while still allowing a degree of flexibility for exploring emerging themes (McCracken, 1988), a common topic guide was developed by INRCA in collaboration with the Coordinator (LNU) and country partners for carrying out semi-structured interviews with experts, which consisted of the following four key sections.

- Section A: opinions on main results of the SLR and GLR, including feedback on two examples of potential good practices retrieved in Task 2.1;
- Section B: opinions on definitions of good practices and care partnerships;
- Section C: insights on other existing innovative good practices not captured in the literature review, aimed at supporting LTC workers and/or informal carers' mental health and resilience, with particular attention to those fostering care partnerships;
- Section D: suggestions and recommendations regarding main drivers (facilitating factors) and barriers (hindering factors) for designing, implementing and transferring good practices and which could help foster care partnerships in different settings.

Interviews were conducted between months 13-15 of the project (January-March 2025). Two weeks before the interview, the experts received the following documentation:

- Invitation letter with study information;
- Informed consent form (where anonymisation measures, deletion policies and data protection procedures were described);
- PowerPoint slides summarising key findings from the literature review;
- Two examples of identified potential good practices;
- Interview topic guide.

The interviews were conducted in-person or online in experts' native languages and were audio-recorded with consent of the participant experts. A standardised protocol ensured consistency across national levels for transcription and translation. Audio recordings were transcribed verbatim in original languages, with careful editing to enhance clarity while preserving intended meaning through removal of excessive verbal fillers, clarification of acronyms, and readability improvements. Transcripts were then translated into English, prioritising contextual meaning over literal translation.

Data Analysis

The 23 translated expert interviews were analysed using NVivo (Release 1 2020) through a systematic four-stage coding process that combined deductive and inductive approaches (Charmaz, 2006; Saldaña, 2016). Annex F - Tab. F.1 exemplifies the full open coding process which follows Gioia et al.'s (2013) approach.

The analysis was conducted separately for each country before being aggregated across all five countries into seven broad categories covering opinions on the literature review, good practice examples, visions of good practices and care partnerships, enablers and barriers, potential stakeholders, and emerging practices. This comparative cross-country approach enabled theoretical synthesis through cross-case analysis (Yin, 2014), developing both common elements and country-specific insights.

It is to be noted that in the below Results chapter (Paragraph 3.2.3.2) some quotations of the experts are reported to

corroborate findings, indicating the country (i.e. Germany=DE; Italy=IT; the Netherlands=NL; Slovenia=SI; Sweden=SE) of the expert (EXP) and the number of interviews (e.g. 1-5).

3.2.3. Results

3.2.3.1. Sample description

In total, 23 experts participated in the interview study, representing diverse geographical and professional perspectives across Germany (4 experts), Italy (5 experts), the Netherlands (5 experts), Slovenia (4 experts) and Sweden (5 experts) respectively. The gender distribution showed a slight female majority at 60.9%, reflecting the predominantly female composition of the care sector (OECD, 2020).

The age distribution revealed a mature expert sample, with 35% aged 50 or older, including 22% in the 50-59 years age range and 13% aged 60+. 26% were between 30-49 years old, while 39% did not report their age.

The educational profile of the experts was high, with 39.1% having a doctoral qualification and 13% possessing master's degrees, followed by 27.7% having a bachelor's/university degree and 26.1% with other qualifications (e.g. secondary school degree), indicating a strong research and academic foundation among participants.

From a stakeholder representation perspective, the sample achieved good diversity across sectors. Research representatives comprised the largest group at 32%, followed by academic representatives⁹ at 28% and policy representatives, employers of LTC workers and mental health or caregiver associations, which contributed 12-16% of the sample each (Fig. 1).

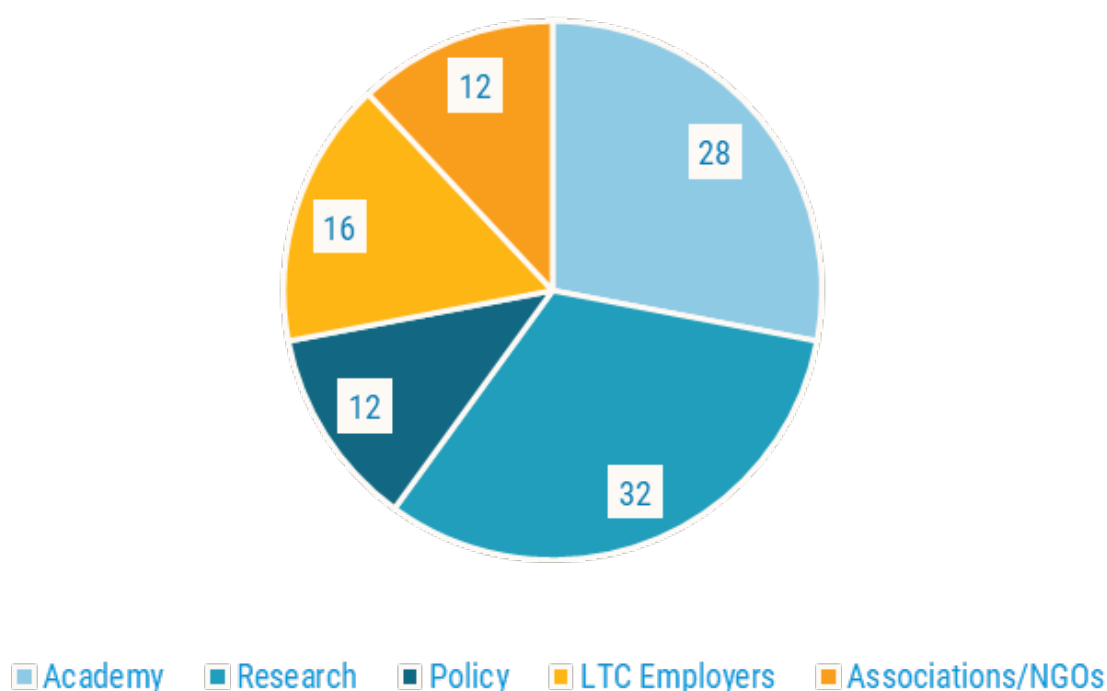


Figure 1: Stakeholders' representation (%)

Finally, all the experts showed substantial experience, with participants averaging 16.8 years in their current profession or organisation, and 21.3 years working with LTC populations.

⁹ The profiles of academics and researchers have been listed separately for the following reasons: an academic primarily refers to the environment in which someone works, such as a university or college, and often involves teaching alongside research and service. A researcher refers to a person who conducts research to generate new knowledge, which can be done in various settings, including academia, government, or industry.

3.2.3.2. Thematic analysis

Opinions about SLR and GLR

Overall, the experts provided several insights into the SLR and GLR findings from Task 2.1 (see Section I). First, the exponential growth in publications on caregiver wellbeing in recent years was noted by EXP-DE-1 as “quite remarkable”, indicating increasing recognition of this topic as a crucial issue.

A key observation was that the GLR appeared to capture more innovative practices with greater implementation potential and offered better balance across different care settings, compared to the SLR. Experts noted that the SLR seemed constrained by too many methodological restrictions, potentially missing important real-world innovations that don't fit traditional research publication formats.

“There is almost more potential in the GLR examples than in the scientific ones because... Science becomes... It pushes it too much; it inhibits too much” (EXP-SE-2);

“There is a lot of knowledge in the grey literature that we do not take into account when we only look at what can be published in scientific journals” (EXP-SE-4).

The identified papers were criticized for rarely addressing integration between formal and informal care. Instead, they focused predominantly on individual-level interventions such as mindfulness, stress management, and psychological support, rather than addressing structural issues or prevention strategies.

“So it does ask of the organisation that you actually find it as a kind of logical first step. If you have a kind of chain reasoning, we first have contact and ask: what are you doing yourself? Then we look at what we are going to do with informal care. Then it's a natural part of the overall chain. Then it goes well by itself. But most start at the first care request, the first indication. And I think that's why many organisations see it as separate” (EXP-NL-3).

EXP-IT-5 also highlighted a disconnection between research and practice: “A lot of good practices are not published, they are there, but they are not published” (EXP-IT-5).

Several experts highlighted the underrepresentation of certain regions and care contexts: Eastern European research was notably absent, creating a bias toward Western European and Anglo-Saxon approaches. Additionally, palliative care was largely missing from the SLR, despite being a crucial area where care partnerships are particularly important: “Very little knowledge in terms of formal caregivers about palliative care and probably also... not only probably, also actually in home informal caregivers” (EXP-SI-4).

The predominance of pilot projects raised concerns about the sustainability and scalability of reported interventions: “45% of the articles presented findings from a pilot project” (EXP-DE-2).

Finally, many experts noted that while individual studies might show promising results, the transition from research to established practice remained poorly addressed in the SLR.

Opinions on two examples of potential good practices

Two potential promising good practices were presented to experts for their consideration: the [Austerlitz Zorgt](#) community support model from the Netherlands (from the GLR) and the [CAT-S](#) tool for assessing caregiver stress (from the SLR).

Overall, the Austerlitz Zorgt model received considerable appreciation by the experts for its community-embedded approach and the fact that it enabled care recipients to remain in their home environment. Experts appreciated the personal, face-to-face contact that formed the foundation of the intervention, viewing this as far more effective than digital solutions.

By contrast, the CAT-S assessment tool generated more mixed responses. Whilst experts acknowledged its potential value as a screening instrument for identifying caregiver stress and burden, many questioned what would happen after assessment.

Vision and key elements of good practices

Experts were presented with the WELL CARE definition of good practice¹⁰ and asked to comment on it.

According to experts, although this definition captured essential elements, good practices must be understood as context-dependent rather than universally transferable. Instead of seeking practices that work everywhere, experts suggested understanding why practices work in specific contexts and how those mechanisms might be adapted elsewhere.

“If it’s a good practice in a context where the local context is incredibly important, the result and the way of working can be as good as you like, but if it doesn’t work outside that context, then it won’t be a good practice anymore, but it will be a bad example” (EXP-SE-4).

This quote highlights an intrinsic contradiction which lies at the heart of the definition of good practice, as they should ideally be solid enough to transfer across contexts but also flexible enough to adapt to local contexts. In other words, according to experts, a good practice should have solid underlying principles and mechanisms but also be adaptable to be implemented in different socio-cultural and institutional contexts.

Important key elements for all experts included: context-specific adaptation capabilities, user-centered design that values stakeholder involvement throughout its development, systematic evidence-based evaluation processes and sustainability mechanisms that extend beyond initial funding periods.

Vision and key elements of care partnerships

Experts were asked to provide their considerations about the definition of care partnerships provided by the WELL CARE project¹¹ and asked to comment on it.

Overall, they showed a complex and nuanced understanding of what care partnerships mean, as well as a certain heterogeneity in how good practices aimed at fostering care partnerships should be implemented across different national contexts.

At an overarching level, experts across countries had a similar vision on some key principles for effective care partnerships practices, including the importance of mutual recognition, mutual valorisation and trust among formal and informal caregivers, with each of them respecting and valuing the knowledge and contributions brought by the other. Experts also emphasised the importance of shared vision and objectives, especially regarding understanding the care recipient’s needs, genuine passion from all parties, and a true willingness to engage:

“The common element that I see, at least in these good practices that I know in Rome and Orbetello is that they arise from a common need of all the actors of care, that is the willingness to engage in this care partnership. In one of them, the idea comes from a nurse, in the other one, it comes from parents and relatives. So, I see that in all these actors of care this desire to ally” (EXP-IT-3).

However, at an organisational/structural level, each country had a different vision on which aspect of a good practice could serve to foster care partnerships.

For example, Swedish experts highlighted the importance of “documented care agreements” that ensures systematic coordination of care responsibilities and supports the formalisation of care partnerships through the creation of a shared planning document between patients and families.

“Her husband has severe heart failure and then they have received such a documented care agreement, a care contract that we have talked about for a long time... It has become so safe because we read it together at the kitchen table we

¹⁰ The WELL CARE project defines good practice as: *“a set of strategies, approaches and/or activities that have been shown through research and evaluation to be effective, efficient, sustainable and/or transferable and to reliably lead to a desired result”*.

¹¹ The WELL CARE project defines care partnerships as *“the coordination, integration (i.e. working together) and mutual recognition of care and caring activities performed by LTC workers and informal carers, in a vision of integrated LTC strengthening the mental wellbeing and resilience of both”*.

can see what is next and we can plan... It has given her greater resilience” (EXP-SE-1).

Italian experts instead believed that good practices which can foster care partnerships should facilitate knowledge exchange between formal and informal caregivers through mediated processes. They recognise that mediation is fundamental for successful care partnerships as leaving collaboration to the goodwill of two subjects is not sufficient. Such mediation role could be covered, for example, by volunteers as in the good practice described by EXP-IT-5:

“In the meeting centres or the (Alzheimer) cafés, what has surprised us is that people feel the volunteer as a figure who helps them to interact with professionals”.

By contrast, for Dutch experts a “real sharing” that goes beyond information exchange to a genuine collaboration between formal and informal caregivers is fundamental to foster care partnerships. Ideally such collaboration should be a bottom-up process emerging from community connections and passion rather than being imposed through formal structures. As EXP-NL-2 describes:

“When my mom was doing really poorly, we used a PGB (Persoonsgebonden budget - personal care budget) [...] it allowed us to arrange an army of professional care workers around my mother to get her up in the morning and put her to bed at night. During the day, my dad and we, the kids, took over”.

Similarly to Netherlands’ vision, Slovenian experts argued that good practices which can foster care partnerships require a highly integrated “team-based” approach where the health, social and psychological spheres work together in a holistic way.

“Here we are talking about some really integrated care, in which we are talking about this holistic care” (EXP-SI-4).

Overall, Slovenian experts strongly support a comprehensive care approach which, however, they believe to be quite unattainable in practice, given their health care system situation.

Finally, German experts held a more skeptical vision about whether good practices which can truly foster care partnerships currently exist in practice:

“I do not think this concept is already being put into practice, at least not here in Germany... You cannot promote something that does not yet exist” (EXP-DE-4).

Enablers of and barriers for care partnership practices

Overall, experts identified a number of factors that can either facilitate or hinder the development of effective good practices aimed at fostering care partnerships within LTC settings. In terms of enablers (Tab. 1), formal recognition through policy and legislation emerged as a fundamental prerequisite. As one Slovenian expert noted, recognising caregivers’ importance at the societal level is crucial:

“Maybe from the point of view of society, these are people who are also very important, that their work is extremely important. Because it seems to me that society itself also looks down on these people” (EXP-SI-4).

Experts also emphasised that structural support from established institutions is essential for sustainability, as well as a broader cultural shift at the societal level that restores values of solidarity and respect for older adults and recognised caregiving as essential, valuable work. Training and education were identified as crucial enablers, as long as they are continuous and tailored to different stakeholder needs:

“Another very important aspect is training (including joint training) for social and health workers and caregivers. Of course, training can be of different types, depending on whether it is for all these three groups or for individual carers. Some trainings can be common, but other trainings need to be different” (EXP-IT-4).

Table 1: Enablers of care partnership practices according to expert interview participants

Factor	Description
Formal recognition	Policy and legislative recognition of care partnerships and their actors
Structural support	Support from established institutions
Cultural shift	Societal transformation toward more solidarity, respect for older adults and people with long-standing care needs, recognition of caregiving as valuable work
Training and education	Continuous and tailored education for different stakeholder needs. Must be ongoing and adapted to specific roles and contexts

In terms of barriers (Tab. 2), resource constraints - financial, human and temporal - were universally acknowledged as significant challenges. A Swedish expert described these practical challenges:

“The reality of what it looks like in the municipalities with the difficulty of recruiting staff. combined with the work environment where you don’t have time for... Time is in short supply, time to be able to reflect and do a good job” (EXP-SE-3).

Beyond simple resource limitations, experts noted more fundamental structural resistance, characterised by risk-averse cultures, entrenched working routines that are difficult to change, organisational resistance to innovation and system inertia.

According to EXP-DE-3:

“One major issue in practice is that the professional groups are often not very motivated. this also applies to many qualified nurses. This group is often poorly trained and frequently lacks motivation”.

“There is this obtuseness on the part of the politicians not to understand enough the importance of care partnerships. For example, the LTC workers, must be better paid”.

All countries’ experts mentioned sustainability challenges when initial funding ends. Many promising initiatives fail not because they are ineffective, but rather because they are unable to secure ongoing financial support after pilot funding expires, suggesting projects are not designed for long-term sustainability.

Table 2: Barriers to care partnership practices

Factor	Description
Resource constraints	Financial, human and temporal limitations
Structural resistance	Institutional and organisational resistance to change and innovation, risk-averse cultures, established routines which are difficult to break, system inertia
Sustainability challenges	Failure to secure ongoing funding after pilot/project ends

Other potential stakeholders to involve in care partnership practices

Regarding whom should be included as potential actors in good practices aimed at fostering care partnerships, several experts agreed that care recipients themselves must be central partners. The “triad” concept emerged as a common element, emphasising that care partnership practices should involve not only the formal and the informal caregivers, but also the care recipient as an active participant rather than a passive subject of care.

Healthcare professionals, including general practitioners, nurses, therapists and social workers, and municipal and government representatives were also consistently identified as important stakeholders.

Volunteers were also often mentioned as another potential actor whose duties and tasks should range from intermediaries between families and professional staff to social activities and companionship.

Emerging additional good practices

Experts were also asked to provide information about additional practices they were aware of that could be deemed to be potential models for care partnerships development within the context of LTC and for promoting the mental wellbeing and resilience of informal carers and LTC workers. Fourteen of these practices from three countries (namely Italy, Slovenia and Sweden) were added to the GLR practices database, ranging from organisational approaches to training and education initiatives (even online), as well as bottom-up community-based services. Of these fourteen practices, seven were later (in Task 2.3) assessed and evaluated as being good practices, five were considered as having the potential to foster care partnerships and one (Carers Outcome Agreement Tool - COAT) was included in the top 40 best practices (see Annex G).

Table 3 briefly describes the seven practices highlighted by experts which were subsequently evaluated as good practices by the country partners applying the agreed selection criteria (see Section 2.2 above).

Table 3: Additional good practices mentioned by the experts

Name	Description
<u>Curare con Cura (Cure with Care)</u>	This Italian practice, implemented by ASL (Local Health Authority) Roma2, establishes a network of nursing outpatient clinics for integrated care management of people with cognitive and behavioral disabilities, particularly those with autism. The initiative focuses on developing empathetic relationships and personalised care pathways, ensuring equal access to health services for non-cooperative patients through reasonable accommodation and active involvement of family caregivers as mediators.
A webpage for the family carer	Developed by formal care workers at the <u>Older People's Home Trebnje</u> in Slovenia, this digital initiative created a comprehensive online resource for family carers. The webpage contains information about informal carers' rights, practical care advice, and features an interactive forum where family members can ask questions and receive answers from professional care workers.
<u>Carer Outcome Agreements Tool – COAT</u>	COAT is a structured research-based approach used by the Swedish Jönköping municipality's carer support team. The tool comprises four thematic questionnaires exploring areas central to caregiving, including practical support, emotional wellbeing, and professional help quality. Through collaborative dialogue between carers and staff, COAT facilitates personalised support plans that can be regularly reviewed and revised, promoting a person-centered and participatory approach to carer support.
<u>EU-PROMENS</u>	Led by a consortium including GFA Consulting Group, Trimbos Institute, and Mental Health Europe, this EU level program (funded by the EU4Health Programme) develops and implements multidisciplinary training programs for health and other professionals working in community settings. It addresses mental health from a comprehensive perspective, coordinating across health, education, social affairs, and other sectors through a life-course approach.
<u>Info-formati con noi (Inform/Train Yourself with Us)</u>	This Italian practice, focuses on supporting geriatric users and their caregivers during the discharge phase and initial period of returning home. The program provides transitional care under the supervision of the same professionals who cared for patients during admission. The initiative involves home visits by healthcare professionals before discharge to assess the environment, ensure safety, and organise re-entry phases.
<u>FIRIS - Culture of harmonious relations</u>	This Slovenian model, developed by Firis Imperl, aims to create a new culture in care homes where individuals are heard, understood, and respected. Operating since 1993, the holistic program provided combines lectures, exercises, and sub-group work, targeting institutions implementing the harmonious relationships model. Based on mindfulness principles, this approach has demonstrated positive effects in elder care homes and special social care institutions.

Mario's house (La casa di Mario)	Co-housing project in Italy, led by the mother of Mario, a young man with complex disabilities. The initiative provides three interconnected apartments where Mario's parents live alongside care operators and nine individuals with disabilities (6 residential, 3 daytime). This creates an equal exchange of roles where family caregivers can replace professionals and vice versa. This breaks down the traditional separation between formal and informal care. The practice features participatory training for both groups, fostering mutual understanding and skills sharing.
--	---

More details on country-specific insights

From the qualitative interview data analysis, it was also possible to identify some key specific insights reflecting each country's unique vision and peculiarities depending on their health care system, cultural context and policy environment. They are summarised in Table 4.

Table 4: Summary of country-specific insights regarding good practice development and implementation

Country	Country-specific insights
Germany	German experts identified multiple barriers that hinder good practice development and prevent progression beyond pilot phases, including funding complexity, regional disparities, lack of institutional promotion of care partnership practices, sustainability challenges. They noted that the "ambulant before inpatient" principle and the reality that over 60% of care is provided solely by relatives create additional structural obstacles. Consequently, German experts expressed skepticism about whether good practices aimed at fostering care partnerships can genuinely exist, despite their conceptual appeal.
Italy	Italian experts identified structural challenges as primary obstacles to good practice development, particularly policy-practice implementation gaps where policy intentions fail to translate into actual practice, and inefficient, fragmented institutional frameworks. They emphasised that strong institutional foundations and comprehensive policy frameworks are essential prerequisites for legitimising and sustaining good practices that can foster care partnerships, highlighting the critical importance of an institutional reform.
Netherlands	Dutch experts emphasised that good practices must be deeply embedded in their specific local contexts, arguing that the "breeding ground" is more critical than the practice itself for successful implementation. They noted that practices have greater success in smaller communities with strong social cohesion. However, they identified a significant structural barrier in healthcare resource allocation that prioritises curative care over prevention, which undermines the development of community-based approaches that could foster care partnerships.
Slovenia	Slovenian experts identified the lack of integration between health, social, and psychological dimensions of care as a fundamental barrier to developing effective good practices. Experts expressed that this fragmentation prevents effective collaboration across care sectors. Despite these challenges, Slovenian experts recognised the value of innovative practices even when they lack transferability, acknowledging that context-bound solutions can provide significant benefits within their specific implementation environments.
Sweden	Swedish experts identified structured and documented coordination alongside organisational anchoring as crucial enablers of effective good practices which can foster care partnerships. However, they recognised significant barriers including civil society resistance and professionals' reluctance to share power due to fears of losing control over care processes. They emphasised the importance of developing transferability assessment tools to address the challenge of evaluating good practices across different cultural settings.

3.2.4. Summary remarks

The main expert interview findings highlighted both the potential of and the challenges facing care partnership practices

and their development in LTC. While there is broad consensus on the importance and desirability of care partnerships “per se”, significant work remains to translate these concepts into sustainable and effective interventions.

First of all, experts noted the significant increase in publications on caregiver wellbeing in recent years whilst also revealing how the grey literature captures more innovative and implementable practices compared to the scientific literature which is more constrained by more rigid methodological approaches. A critical finding across all five countries was that good practices should be understood as context-dependent instead of universally transferable, and that they should be tailored to local contexts and country institutional and legal frameworks. Experts also identified common implementation challenges including resource constraints, structural resistance from risk-averse institutional cultures, and sustainability issues once initial funding ends. Enabling factors included formal policy recognition, continuous and customised training and institutional support. The identification of seven additional good practices by the experts spanning organisational, training, and community-based initiatives, illustrates the diverse pathways through which care partnerships can emerge within LTC settings.

3.3. Reporting good practices

3.3.1. Introduction

This section summarises the process for selecting and ranking the good practices satisfying the agreed selection criteria defined in Task 2.2 among the potential good practices identified in the SLR and GLR. The aim is to describe the findings of at least 40 good, effective and innovative European practices implemented in informal care contexts and/or in public LTC organisations and in different settings, preferably covering different groups of LTC workers and informal carers.

This Chapter is structured as follows. Paragraph 3.3.2 illustrates the methodology, including the refinement of the datasets and the description of both the evaluation tool and the evaluation process to identify the good practices. Paragraph 3.3.3 presents the results of the evaluation process, highlighting the main aggregated characteristics of the 40 top ranked good practices. The detailed information describing each of the 40 top ranked good practices are reported in Annex G.

3.3.2. Methodology

3.3.2.1. Refinements of the datasets

The systematic review of scientific and grey literature carried out in Task 2.1 provided a total of 242 practices, divided into two datasets consisting respectively of 139 SLR and 103 GLR practices. The latter were supplemented with 6 practices highlighted by BLN members during Task 2.2 (step 1) and a further 14 additional practices highlighted by experts (step 2). Each of the collected 262 practices were assigned a specific identification number (ID). Before proceeding to the evaluation process, the accuracy and quality of the collected data were checked by the country partners, including eventual reduction/integration of the practices by INRCA in collaboration with the Coordinator.

To this end, the SLR was examined by country partners using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018) aimed to achieve a quality assessment of the selected peer-reviewed papers (step 3). Subsequently, the potential overlaps between the SLR and GLR were checked by INRCA (step 4). However, and finally, the missing or unreliable information collected in the GLR were managed (step 5), as described below.

As for step 1-2, some additional practices were entered into the GLR dataset, highlighted by BLNs (6 practices) as well as by experts (14 practices) during their respective interviews (carried out in Task 2.3, summarised above). The latter set includes also practices having the potential to foster care partnerships, implemented at the LTC organisational/employer level and/or in informal care settings.

Concerning step 3, the MMAT is a tool to provide a quality assessment of the SLR as it includes criteria for appraising the methodological quality of systematic mixed studies reviews, i.e., reviews that include qualitative, quantitative and mixed methods studies, with the exclusion of non-empirical articles, such as theoretical papers or reviews. In this regard, the

MMAT provides two screening questions aimed to exclude non empirical studies, which cannot be appraised using this tool; then it asks questions targeted to evaluate the methodological distinctive specific characteristics of the appraised category of study. Each question is rated on a categorical scale: Yes, No, Can't tell. A quantitative appraisal score was calculated by INRCA via applying the scoring system proposed by Pluye and colleagues (2009). According to these authors, the presence/absence of criteria (Yes/No) have been scored 1 and 0, respectively. Thereafter, a "quality score" is calculated as a percentage: [(number of 'Yes' responses divided by the number of 'appropriate criteria') × 100]. After calculating the above-mentioned appraisal score for each article, the methodological quality is synthesized into three different categories: low score= < 35%, medium score= from 36 to 70%; high score= from 71 to 100%.

The final MMAT results were obtained for a total of 136 studies included in the SLR; 3 of them did not satisfy the screening questions (IDs 201, 516, 523) and they were therefore removed from the SLR dataset. Overall, the findings of the MMAT confirmed the good average methodological quality of the papers collected in the SRL, as 79% falls in the high-score category.

Regarding step 4, some overlaps between the GLR and SLR datasets were found, namely:

- ID 80 (GLR) matched ID 169 (SLR): "Stepped care of eHealth interventions for healthcare workers (HCW) with psychological distress";
- ID 99 (GLR) matched ID 205 and ID 305 (SLR) "Tele.TAnDem.Transfer", a telephone-based cognitive-behavioural therapy intervention for relatives of dementia patients;
- ID 77 (GLR) matched ID 44 (SLR): "Role-focused self-management intervention for reducing and preventing the caregiver distress of workers who combine paid work with informal caregiving".

In these cases, priority was given to the SLR as it provides more detailed, systematic and verified data, although these needed to be supplemented with information belonging to the GLR regarding scalability/transferability and challenges, that were deemed to be more accurate.

Some overlaps were also found within each dataset:

- ID 39 (GLR) matched ID 92 (GLR): "Narrative medicine project: from cure to care". Priority was given to ID 39 because it was more detailed and referred to a larger sample;
- ID M_11 (SLR) matched ID 167 (SLR): "Partner in balance for early-stage dementia caregivers". Priority was given to ID M_11 because it was more detailed.

The overlaps between and within the two datasets were resolved by removing 4 practices from the GLR and 2 papers from the SLR.

The final refinement concerned the GLR dataset (step 5). The completeness of the information collected was checked by country partners, counting for each practice the number of missing information in 16 "core" variables aimed at the identification of a potential good practice. Such a set of variables excludes the "not significant" (few answers, e.g. legislative framework), the "not essential" (e.g. name of the practice), the "unobjective" ones (i.e. some free text answers). Upon request, partners integrated the unreliable or missing data into the core variables, thus enhancing the accuracy of the information collected, and therefore avoiding further reductions of GLR practices.

The final set of data consists of 253 practices: 134 belonging to the SLR and 119 to the GLR (Tab. 1).

Table 1. Refinements - Task 2.1 systematic review findings: summary table

Practices/ Dataset	SLR	GLR	Total
Total from systematic review	139	103	242
(+) Reported by BLNs	0	6	6
(+) Reported by experts	0	14	14
(-) Not appraisable (MMAT)	3	0	3
(-) Overlaps	2	4	6
Total after final refinement	134	119	253

3.3.2.2. Evaluation tool, evaluation process and sorting/ranking of practices

Definition of the evaluation tool

The purpose of the evaluation process was the identification and definition of shared selection criteria to be used to assess whether a practice implemented in LTC organisations/settings or in informal care contexts can be considered as a good practice. As outlined earlier in Section II, as a starting point, the set of criteria used to review and select best practices in health promotion and disease prevention and management of non-communicable diseases in Europe to be included in the EU Public Health Best Practice Portal (European Commission, 2022b; Stepien et al., 2022) was considered by the Consortium. After a thorough discussion among partners and within the BLNs, an agreement was reached to align with the EU document, in particular with regards to:

- the articulation in Exclusion (that were renamed as General), Core and Qualifier criteria;
- the detailed sub-criteria within such three main blocks of criteria.

The decision was taken by the Consortium to maintain some of the sub-criteria included in the EC document, even if in several cases a rephrasing of the text and/or a few integrations was necessary, to adapt them to the project aims/ vocabulary and also for taking on board the inputs received from BLN members. Some sub-criteria were excluded, being considered too restrictive. On the other hand, the evaluation framework included the two additional Qualifier criteria of "Care partnerships" and "Innovation", as suggested by the BLN members for being particularly relevant to the project. In total, the final evaluation tool consists of 20 sub-criteria - out of 48 in the EC document - that are classified according 12 criteria, which, in turn, are included in 2 main blocks of overall criteria (General and Core, grouped together; and Qualifier) (for more details, see Section II and Table 1).

Definition of the evaluation process

After defining the evaluation tool, the various stages of the evaluation process were outlined. First, in order to identify the good practices, partners applied the 20 sub-criteria to each of the 253 practices identified in the final collected set of data, by answering the 20 questions corresponding to the critical evaluation of each sub-criteria. In detail, country partners applied the agreed sub-criteria to select the good practices by using two Excel files (not included in this report, but available on request to the first author): one for the SLR and one for the GLR, including the dataset, a legend with criteria and sub-criteria and a sheet to apply them to allocated practices. Such a task by partners relied on the information collected during the SLR and GLR initial work, which were integrated by partners, where possible, with further research on selected full-text papers (with regards to the SLR), or references, websites and additional information that was available online (with regards to the GLR).

By adapting a methodology used by Stepien et al. (2022) to assess and select good practices to be included in the EU Public Health Best Practice Portal, the evaluation of a good practice is based on the share of criteria met out of the 12 identified criteria. In this assessment, a criterion is met when at least one of its sub-criteria is satisfied: i.e. the criterion "sustainability", which consists of 4 sub-criteria (questions Q4, Q5, Q6, Q7), is met when at least one of these questions is

answered with “yes”. A practice is classified as a good practice if a minimum adequacy threshold of satisfied criteria was reached, for each block (see Stepien et al., 2022), and in particular, if:

- the “Relevance” criterion is satisfied (unique exclusion criteria);
- at least 60% of the remaining General and Core criteria, considered together (3 out of 5) are met;
- at least 50% of Qualifier criteria (3 out of 6) are met.

As a result, a good practice as deemed by the WELL CARE Consortium, was obliged to satisfy at least about 55% of the total criteria (thus 6 out of 11), i.e. a threshold aiming to ensure inclusiveness.

Sorting/ranking the collected practices

The next step involved sorting all the SLR and GLR practices in order to provide a comprehensive classification according to all the 20 sub-criteria. The answers provided by country partners were translated into numerical values (1 for “yes” answer, 0 to “no” and “can’t tell” answer), following a process that is similar to the one adopted in the MMAT. Then, sub-criteria were weighted against the corresponding criteria. In particular, a value of 1 was assigned to each criterion, thus giving each answer a value equal to the number of sub-criteria for each criterion. For example, “sustainability” consists of 4 sub-criteria: each of them has a value, if met, of 0.25 (1/4). The weight of each sub-criterion is then multiplied for the corresponding numerical values reported in the evaluation tool. Practices were ranked according to the sum of these values, that are the evaluation assigned to each sub-criterion weighted against their relative share on the criterion to which it relates.

For example, practice ID 44 has a lower ranking in the Qualifier criteria than practice ID 59, despite meeting a larger number of Qualifier sub-criteria (8 for ID 44, 6 for ID 59). The rationale for this classification can be seen from Table 2.

Table 2. Example of assessment method with regards to Qualifier criteria: practice ID 59 and ID 44

Criteria	Transferability			Sustainability				Collabo- ration	Care part- nerships	Participa- tion	Innova- tion		Sum To- tal
Subcriteria	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	
Weight	0.33	0.33	0.33	0.25	0.25	0.25	0.25	1	1	1	0.5	0.5	
ID 59-Value	1	0	0	0	0	1	0	1	1	1	0	1	6
ID 44-Value	1	1	1	1	1	1	0	1	0	0	1	0	8
ID 59-Weighted value	0.33	0.00	0.00	0.00	0.00	0.25	0.00	1.00	1.00	1.00	0.00	0.50	4.08
ID 44-Weighted value	0.33	0.33	0.33	0.25	0.25	0.25	0.00	1.00	0.00	0.00	0.50	0.00	3.25

Both practices meet the Collaboration criteria and one of the two Innovation sub-criteria. In addition, practice ID 44 fulfils all three Transferability sub-criteria (each weighting 0.33), and three of the four Sustainability sub-criteria (each weighting 0.25, therefore 0.75 overall). These 6 sub-criteria have a weighted value of 1.75 (0.33*3+0.75*3). Practice ID 59 meets only one of the three Transferability and one out of four of Sustainability sub-criteria, but it satisfies the sub-criterion of Participation and the sub-criteria of Care partnership, both with a weighting of 1. Thus, ID 59 fulfils fewer criteria but with a higher weighted value than ID 44; this is reflected in a better ranking.

In sum, the main methodological steps to select the good practices were the following: i) partners applied the agreed criteria to collected practices, by answering the 20 questions (sub-criteria); ii) practices were then evaluated through adequacy thresholds of satisfied criteria to identify good practices; iii) they were classified according to all the sub-criteria with the aim to select the 40 highest ranked good practices. Then, a standardisation process was finally applied (see

Paragraph 3.3.3.1 for details), in order to “mitigate” the impact of the subjectivity (implicit in each research activity) in the assessment carried out by the country partners. All this procedure was firstly developed by the INRCA team (WP2 leader), shared/refined with the Coordinator and discussed/refined/agreed with all the partners.

3.3.3. Results

3.3.3.1. Aggregate results of the selected good practices

As mentioned, the dataset includes 253 practices, 20 of which, during the process of application of selection criteria, were classified as not relevant for the purposes of the project. The analysed dataset therefore consists of 233 relevant practices, which have undergone an evaluation process (Tab. 3).

After the assessment, 170 practices were classified as “good practices”; this result confirms the effectiveness of the selection process followed in the first phase of the project (e.g. the search in 8 different scientific databases for the SLR, and the GLR search). In addition, this finding also offers a wide range of options among which to draw from for the subsequent development of solution prototypes in WP3. It is notable that the share of good practices is higher in the GLR than in the SLR; in particular, in the GLR the General and Core criteria are less satisfied and the Qualifier criteria are more satisfied.

Furthermore, more than 90% of the good practices (74 out of 81) show a potential to foster care partnerships.

Table 3. Main results of the evaluation process

Practices	SLR	GLR	Total
Total	134	119	253
Not relevant	5	15	20
Relevant	129	104	233
Good Practices (GP)	80	90	170
Fostering Care Partnerships (FCP)	30	51	81
GP & FCP	28	46	74

Differing results were noted among partners after the application of criteria to the allocated practices, showing that subjectivity, as usual in research, played a role in the evaluation process. For example, by taking the highest and lowest ratios of good practices (GP on total) within the sample we noted the following: all the practices assessed by Slovenia resulted in being assessed as good practices, whereas Sweden had much lower percentages. Such results stem from strong differences in some responses, e.g. collaboration or participation sub-criteria (Tab. 4).

Table 4. Evaluation of a good practice, by partner

Country Partner	SLR				GLR			
	GP	Not GP	Total	GP/total	GP	Not GP	Total	GP/total
Germany	14	8	22	0.64	17	2	19	0.89
Italy	25	5	30	0.83	20	1	21	0.95
Netherlands	9	7	16	0.56	12	2	14	0.86

Slovenia	26	0	26	1.00	20	1	21	0.95
Sweden	6	29	35	0.17	21	8	29	0.72
Total	80	49	129	0.62	90	14	104	0.87

Subjectivity also emerged in the ranking of practices, based on the weighted sum of sub-criteria. The average values diverged by partners: Slovenia has a high score for almost all examined practices (as suggested by a low Standard deviation) whereas the Netherlands has a low score but with large fluctuations among examined practices (Tab. 5).

Table 5. Evaluation scores by partners: average (μ), standard deviation (σ) and coefficient of variation

Country Partner	SLR			GLR		
	μ	Σ	c.v.	μ	Σ	c.v.
Germany	6.57	1.84	0.28	7.28	1.24	0.17
Italy	7.38	1.56	0.21	8.77	1.46	0.17
Netherlands	9.44	0.80	0.08	9.01	1.37	0.15
Slovenia	5.85	1.05	0.18	6.49	1.57	0.24
Sweden	5.94	1.63	0.27	7.65	1.91	0.25
Total	7.06	1.90	0.27	7.84	1.79	0.23

Due to the above, a standardisation of values was applied (Mazziotta and Pareto, 2021). This meant that each value is subtracted from the mean and divided by the Standard deviation, as illustrated here below:

The standardisation of the results allows to mitigate for the impact of the subjectivity in the evaluation carried out by the project country partners. This process makes comparable quantitative variables with different means and variances, hence different measurement scales. In this way, unusually high values with respect to the distribution are selected, i.e. those that deviate significantly from the evaluation method adopted.

3.3.3.2. Main aggregate results for the top 40 ranked good practices

Following the evaluation and standardisation process outlined above, the 170 good practices were ranked according to a baseline method, which relied on the absolute values obtained, and standardised values, in which the assessment subjectivity was considered. The ranking obtained through the standardised values led to the identification of the top 40 good practices, reported in this D2.1 (see Tab. 6 for an overview of some of their main characteristics; see Annex G Templates of the 40 selected practices, for detailed descriptions of each of these top 40 ranked practices).

Table 6. Top 40 ranked good practices: name, typology, country of implementation, brief description, potential to foster care partnerships

Rank	Name	Typology/ies	Country/ies	Brief description	Potential to foster care partnerships (Yes/No)
1	Culturally Informed Psychoeducational Course for Charedi Orthodox Jewish Community	3, 6	United Kingdom	This culturally informed psychoeducational course is designed to raise awareness of mental health and improve the wellbeing of carers in the Charedi Orthodox Jewish community based in North London, by improving mental health knowledge, reducing stigma, and promoting early intervention, through education, collaboration with professionals, and integration into Continuing Professional Development programs for Rabbis and Rebbetzins.	Yes
2	Early Positive Approaches to Support for Families of Young Children with Intellectual Disability	1	United Kingdom	This is a co-delivered support programme for parents/family caregivers of young children with intellectual disabilities, aiming to improve family wellbeing and resilience through structured, evidence-based group sessions and resources.	Yes
3	Family Carers Training	5, 3	Slovenia	This training - taking the form of a course followed up in a self-help group led by volunteers - aims to equip family and informal carers of mainly older people who are effectively supported by the health and social care system through a good long-term care system and other support services, with skills and support to provide quality care and learn best from good personal experiences (improving their resilience and mental wellbeing), through interactive group sessions covering key caregiving topics over eight weeks.	Yes
4	Carers' Alert Thermometer for Stroke Family Caregivers	1	United Kingdom	The study developed the Carers' Alert Thermometer for Stroke Family Caregivers screening tool for early identification of needs and support of stroke family caregivers, aimed to comprehensive assessments for maintaining their wellbeing and caring role. The tool received positive feedback from both staff and caregivers on its clarity, usefulness, and person-centred approach.	Yes

5	Augmentative and Alternative Communication Intervention	6, 4	Germany	This augmentative and alternative communication intervention including an initial counselling, 4 training sessions, 20 therapy sessions, collaboration between involved stakeholders and caregivers, is developed to support both people with a congenital or acquired disability associated with loss of natural speech, and their informal caregivers. The aims are to identify stressors, resources, and coping strategies among informal caregivers. The intervention has a positive impact on caregivers' self-perceived care burden.	Yes
6	LIVIND - A lifestyle Monitoring System to Support (In) Formal Caregivers of People With Dementia	2, 4	Netherlands	Livind home-based monitoring system connected to an online platform collects information on e.g. patterns of everyday life activities of people with dementia (in which room, time, intensity of movement), day-night rhythm to help informal caregivers and case managers provide care to people with dementia who are living alone. In this way it contributes to reduce negative aspects of caring and/or working in long-term care (LTC) (e.g. anxiety, stress).	Yes
7	E – Qalin – Quality Management Model	2	Slovenia, Austria, Czech Republic, France, Croatia, Italy, Germany, Luxembourg United Kingdom	E-Qalin (European quality-improving learning) is a pan-European model for improving the quality of services in social care settings (e.g. care homes for older people, day-care social centres and welfare training institutions, home care providers, social work centres), offering the possibility of continuous improvement of social and health services, further development of standards and comparability of performance, thereby increasing the satisfaction (and the mental wellbeing) of service users and staff (e.g. nurses, personal care workers, occupational therapists, physiotherapists, social workers, social care managers, primary care workers in social care organisations).	No
8	Norwegian Version of the Relatives Education and Coping Toolkit	3, 2, 6	Norway	This intervention aims at supporting (by increasing their knowledge, and reducing stress and emotional burden) relatives/carers of people with psychosis through a web-based psychoeducational platform with structured 12 modules (covering psychosis-related knowledge, symptom management, crisis handling, stress reduction, and available services), and cognitive-behavioural therapy-based exercises, provided by trained family therapists in booklet form and actively used during weekly phone consultations	Yes

9	Digital Support for Quality Assurance in 24-hour Care-giving at Home	5	Austria	This intervention consists in a client-server software solution for the support and quality assurance of 24-hour live-in migrant care workers, including: a e-learning platform, a comprehensive electronic care documentation, an integrated emergency management, a networking platform providing links to translation pages or networking opportunities. It contributes to potentially increase the migrant care workers' resilience, mental wellbeing, and job satisfaction.	No
10	pflegen-und-leben.de (care and live) - Psychological Online Counseling for Family Caregivers	1	Germany	This online platform offers personalised psychological support to informal caregivers of individuals in need of LTC. Its goal is to reduce caregiving-related stress, anxiety, and depressive symptoms through low-threshold, anonymous, and free-of-charge counselling. The intervention focuses on strengthening self-efficacy, providing caregivers with tailored, evidence-based psychological support delivered by trained psychologists.	No
11	Assertive Community Treatment (ACT) Teams	2	Norway, Sweden, United Kingdom, Australia, Canada, USA, Japan	ACT is a treatment form in which active outreach multidisciplinary teams provide comprehensive and holistic early support to people with serious mental illness and complex care needs living at home, to prevent deterioration of their condition and re-hospitalisation and promote sustained community living, also reducing their informal carer's stress and workload.	Yes
12	Supporting Families Living with Dementia in Rural Areas	3, 2, 6	Germany	This psychosocial intervention trains "family companions" to provide structured volunteer-led counselling/supervision and systemic, individualised, dementia-specific support not only to the primary caregivers but to the entire family system who are caring for adult/older individuals with dementia living in under-resourced rural areas, by addressing carer's emotional, relational, and logistical challenges.	Yes
13	Rosetta: a Web-Based E-Learning Platform for Informal Carers of People with Dementia	3, 1	United Kingdom, Finland, Netherlands, Sweden, Germany	This electronic, personalisable, e-learning platform aims to support informal carers of people with dementia across Europe, by helping recognise their emotional stress and educational needs deriving from managing complex caregiving tasks, and by offering flexible, tailored content in the carers' native languages, including modules on understanding dementia, managing stress, coping with emotions, and accessing support services.	Yes

14	Care at Home	3	Czech Republic	This initiative offers both online and in-person courses, hosts seminars, and publishes guides to equip informal caregivers and personal care workers of adult/older family members with LTC needs (e.g. physical, cognitive, geriatric syndromes) living at home. It aims to enhance their ability to manage care responsibilities effectively, through encouragement, advice, information, education, sharing spaces, and individual guidance for effective home care, resulting in carer's increased competence, mental resilience and emotional wellbeing, reduced isolation, and a more cohesive, respectful, and coordinated care environment.	Yes
15	Mobile Technology for Personalised Reminiscence for People Living with Dementia and their Carers	3	United Kingdom	This project uses home-based technology-supported personalised reminiscence intervention to improve mutuality (relational closeness), emotional wellbeing, and the quality of caregiving relationships between adult/older people with early to moderate dementia living at home and their family carers. It was realised through the creation of the InspireD app, a cross-platform, device-agnostic mobile application that allows users to upload and access personalised multimedia memorabilia (such as photos, videos, and music) to facilitate reminiscence activities and support relational closeness.	Yes
16	Video Conferencing Peer Support and Rarer Forms of Dementia	3	United Kingdom	This initiative provides video-conferencing peer support groups and a safe, accessible, and relatable space for family carers of adult/older people with rarer forms of dementia, allowing them to share experiences, access emotional tailored support, fostering meaningful trust-based interactions and build knowledge about managing complex care needs and also to reduce isolation and improve their emotional wellbeing.	Yes
17	Partner in Balance	3	Netherlands	This is a blended care self-management program combining face-to-face coaching with trained coaches and web-based modules to help informal caregivers of older people with early-stage dementia, who are at high risk for depression and anxiety, to formulate and achieve personal change plans, manage their lives, and engage in social activities together with the care recipient. It contributed to improve carers' mental wellbeing (e.g. coping with stress).	Yes

18	Psychoeducation Program for Patients with Bipolar Disorder and their Caregivers	3, 4	Netherlands	This initiative developed a 12-session psychoeducation group program to reduce stress and level of expressed emotion in informal caregivers of adult/older patients with bipolar disorder, by improving interaction pattern towards the patient with a mental illness. The content of the sessions was based on themes common in effective psychoeducation programs aiming at improvement of illness awareness, early detection, treatment adherence, and lifestyle adjustments	Yes
19	Open Dialogues	2	Sweden	Open Dialogues advocate for open dialogue meeting formats where everyone has the opportunity to speak, be listened to, respected, involved in care and recognised as knowledgeable and significant to ongoing care, thus establishing an equal relationship between older care recipients, family members, and professionals (mainly nurses) invited by the patients/carers, and possibly reducing stress for all involved.	Yes
20	Act Belong Commit	6	Denmark, Australia	This universal mental health promotion initiative aimed at the general population (all ages; thus involving informal and formal carers), promotes public mental health and supports active and meaningful communities by creating the best possible conditions and environments for psychological/mental health and wellbeing, by encouraging individuals to: Act (stay physically and mentally active); Belong (build and maintain social connections); Commit (engage in meaningful activities) and by sharing research-based information, building capacity among front personnel, sharing knowledge, and by collaborating across different disciplines and sectors.	Yes
21	Staff Training Programme and Family Liaison Service	4	United Kingdom	This three-day training programme implements whole-team training for nurses and care staff working in inpatient wards for adult/older people and is specifically designed to shift staff attitudes and practice towards more inclusive, empathetic engagement with informal carers, involving them in care planning and support, recognising their needs and critical role in care, thus creating also more family-sensitive mainstream services.	Yes

22	Inclusive Culture Program	3, 7	Slovenia	Programs in various areas (e.g. sports, arts and culture, education, leisure, social care) and professionally led support groups for families of children, adolescents, and adults with intellectual or developmental disabilities, aimed at improving mental health, coping with challenges, enhancing the resilience of parents and caregivers. These support groups are led by professionals with expertise in this field and supervised by qualified supervisors and allow parents to connect, expand their social networks, share experiences and receive important advice on mental health, childcare, and navigating health and legal systems related to raising children with disabilities.	Yes
23	Meeting Centres Support Programme	3, 4, 6	Italy, Poland, United Kingdom	This psychosocial support program was developed to offer a combined approach to provide informational, practical, emotional and social support to mainly older people with mild/moderate dementia and their family carers in the community, in order to promote independent and active living and to counteract the fragmentation of dementia services, and resulting in reduced burden and improved ability to maintain emotional balance.	Yes
24	Care Companion Web-Based Information Resource for Supporting Informal Carers of Older People	3	United Kingdom	Care Companion is a co-designed, free-to-use, web-based tool providing access to a broad range of user-friendly, timely, accessible, relevant, reliable and tailored information and guidance to informal carers of older people who are ill, disabled, or frail, empowering them with knowledge and confidence, and contributing to improve their mental wellbeing.	Yes
25	Carer Supporter Programme	3, 2, 6	United Kingdom	This peer-to-peer intervention matches current family carers of older people with dementia living at home, with experienced former family carers acting as volunteer peer "care supporters", who provide emotional support, encouragement, and signposting to relevant services, contributing to improve carers' mental wellbeing. Before being matched with current carers - based on socio-demographic background, caring experience, common interests, and availability - "care supporters" completed a structured awareness and orientation programme.	Yes
26	Carers Outcome Agreement Tool	4	Sweden	This is a structured tool consisting of four questionnaires for co-developing, planning, monitoring, and evaluating/accessing personalised support for and with informal carers of people with any LTC needs and of all ages, by carer advocates/ LTC workers working in the municipality. It offers a structured method for documentation, follow-up, and evaluation of support interventions for informal carers, and aims to reduce their workload and stress.	Yes

27	Web-based Mindfulness Intervention for Families Living with Mental Health Problems	3	Sweden	This 8-week web-based mindfulness training program is specifically tailored for families of people with mental health conditions, aimed to enhance their mental and emotional wellbeing and foster self-awareness, emotional regulation, and self-compassion, and to provide coping strategies. The intervention includes 960 minutes of audio/video-guided exercises such as breathing techniques, mindful yoga, and compassion meditation. It also featured written instructions and a private diary, allowing participants to tailor the experience to their schedules and environments.	Yes
28	Colourful Un-burdening	4	Netherlands	This is a culturally sensitive program offering in-home support, weekend respite care, Saturday respite group, and intercultural consultancy and trust-building to families, particularly those with a migration background, caring for young adults with intellectual disabilities at home. Families are supported in navigating the care system in a way that respects their language, culture, and values. The programme also includes training and workshops for care teams (led by the "intercultural consultant") on culturally sensitive practices, enabling LTC workers and staff to better engage and improve communication with families.	Yes
29	Rehabilitation Enablement in Chronic Heart Failure	6, 4	United Kingdom	This is a novel, home-based, health-professional-facilitated self-management program for heart failure older patients and their informal caregivers, aiming to improve their confidence in self-management and in being supported in their caregiver role, improving their mental wellbeing and resilience. The intervention was delivered at the patient's home via a mixture of face-to-face and telephone contacts over 12 weeks. The intervention includes four core elements: a "Manual" with information for understanding/managing heart failure; "Progress tracker", allowing patients to record symptoms, physical activity and other actions related to self-care; "Family and friends resource" for caregivers, including advice on providing support, managing own health/wellbeing, and getting help; "Facilitation" by cardiac nurses or physiotherapists.	Yes

30	The Renaissance of Workforce Models in France's Mental Healthcare	1	France	This initiative integrates advanced practice nurses and professional peer/family peer helpers into psychiatric hospital teams to redesign mental healthcare for adults with psychological/mental health issues, by introducing collaborative, recipient-centred care models aligned with WHO and EU strategies. The programme involves informal blended learning, including the use of OpenWHO resources, and integrated these roles into multidisciplinary teams, thus promoting co-production, shared decision-making, the recognition of lived experience as a professional contribution, and reducing negative aspects of working in LTC settings (e.g. depression, anxiety, stress).	Yes
31	Meeting Centres Support Program	6	Netherlands	This initiative provides integrated, community-embedded support for mainly older people with mild to moderate dementia and their informal carers, aiming to prevent caregiver burden, promote social engagement, and enhance the overall wellbeing of both. Tailored activities for individuals with dementia and various forms of support for carers are provided, including discussion groups, informative meetings, consultations, and joint social activities, such as the bi-monthly centre meeting, parties and outings.	Yes
32	Community Care Dongen	6	Netherlands	This is a collaborative, cross-domain initiative aiming to provide integrated care for vulnerable older adults experiencing combined physical, psychological, and cognitive challenges, to enable them to live independently in their own homes and communities for as long as possible, while delaying or preventing the need for more intensive institutional care such as nursing homes. The practice addresses existing fragmentation in care by integrating informal and formal care systems and providers, including healthcare professionals, social workers, volunteers, and informal carers	Yes
33	Community Houses	2	Italy	Community Houses are Italian social and healthcare facilities acting as a unified point of access for citizens, where all professionals - doctors, specialists, nurses, midwives, health assistants, physiotherapists, social workers and other health, social and administrative professionals - work in an integrated and multidisciplinary manner. In this way, they offer integrated, multidisciplinary health, social and healthcare services and prevention activities to the general population 0+ and for all health conditions, with the participation of the local community in its various forms: citizens' associations, patients, caregivers, volunteers.	Yes

34	Integrated Care Intervention for the Frail Elderly on Informal Caregivers	4, 1, 2	Netherlands	This is a comprehensive intervention targeting frail older people living independently and their informal caregivers, by combining several integrated care components to improve support for both groups (e.g. proactive screening, comprehensive needs assessment, multidisciplinary care planning, integrated information system, referrals to relevant organisations or professionals, practical guidance on how to reduce care burden and improve mental wellbeing, emotional support delivered through contact with the case manager). Informal caregivers are also actively involved in care planning and receive structured, ongoing support.	Yes
35	The Wulverhorst	6	Netherlands	It is a Dutch residential care center and home care provider offering integrated, holistic, inclusive, person-centered support to older people with any condition, living at home or in residential care settings, aimed to promoting social inclusion, facing social isolation and respecting their cultural or religious backgrounds, by addressing both medical and social needs. Stakeholder collaboration, staff training, and adapting services over time to meet evolving needs are assured. Informal carers are treated as equal partners, together with LTC professionals, in the care process. Their insights, emotional investment, and lived experience are recognised and valued. This shared decision-making approach reduces the emotional burden on both sides and builds relationships of trust that function as mutual emotional support systems.	Yes
36	MOST project – Integrated Care in Krško Municipality	4	Slovenia	It is an integrated care program, acting as a single entry point, providing comprehensive social health services and home-based support for adult/older people living at home with reduced physical and cognitive abilities, who are dependent on another person for basic and supportive activities of daily living over a prolonged period of time. The vision of integrated care is to enable people to live better, longer and more fulfilled lives through appropriate guidance, social health services and support in the home environment at the right time. The project brought together different social and health and social professions (e.g. social workers, physiotherapists, occupational therapists, kinesiologists) who collaborate to provide targeted support to beneficiaries of LTC in the home environment, by also contributing to enhance their working satisfaction.	Yes

37	Cognitive-Behavioural Intervention for Dementia Caregivers' Coping with Pre-Death Grief	3	Germany	This cognitive-behavioural intervention, delivered via telephone in twelve 50-minute individual therapy sessions over a duration of six months, aims to increase dementia caregivers' coping with pre-death grief and reduce their burden related to loss, by teaching strategies for managing painful emotions and restructuring dysfunctional cognitions. The intervention manual comprised 10 modules that focused on different challenging aspects of the caregiving situation (e.g. changing dysfunctional cognitions or coping with behavioural problems) and was based on cognitive-behavioural techniques that had been adapted for use with dementia caregivers.	No
38	The Conversation with (Caring) Relatives	1	Austria	This is a psychosocial preventing and supportive service offering up to 10 free, confidential, counseling sessions to informal caregivers of people receiving Austrian care allowance and experiencing psychological strain. The service is offered by trained professionals at the caregiver's home, via phone, or online. The goals of the sessions include: offering space for emotional relief and reflection, supporting carers in recognising personal limits and resources, promoting self-care and health maintenance, providing information on coping strategies and available services, contributing to reduce their psychological stress.	No
39	The Online Training with App for LTC Workers (RESIST)	3	Germany	RESIST is an evidence-based online resilience training program designed for LTC workers working in institutional or ambulatory care settings with care recipients with LTC needs, offering six weekly sessions to strengthen psychological resources and reduce stress by training four core resilience skills: self-efficacy, optimism, relationships, and self-care. It contributes to improve LTC workers' mental wellbeing and resilience, stress management, and occupational health, by addressing emotional overload, shift work, staff shortages, and increased demands due to demographic ageing and pandemics.	No
40	Training Informal Caregivers to Care for Older People After Stroke (InCARE Program)	3, 4	Portugal	The InCARE programme is a structured, nurse-led training and telephone counselling intervention designed to support informal caregivers in providing effective post-stroke care to adult people, aiming to reduce caregiver burden, prevent health deterioration, and improve caregiving performance and skills through structured, personalised, skill-based training and emotional support led by nurses, thereby addressing both the practical demands and the psychological burden of caregiving.	Yes

a Typology (the first code listed is the main typology of the good practice/intervention; in case the practice has characteristics that could be related to more types, are reported other codes):

1. Primary, secondary and tertiary prevention interventions
2. Interventions or programmes dealing with organisational models and management approaches and/or targeted at the individual level
3. Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives
4. Integrated approaches and strategies
5. Interventions and programs targeted at LTC workers and/or informal carers with pre-existing mental health conditions
6. Community-based initiatives/measures
7. International or national strategies and initiatives launched/implemented by various institutions

It is important to note that 34 out of the 40 top ranked good practices (85%) have the potential for fostering care partnerships. Moreover, the set of top 40 practices is balanced among the datasets: 23 of them are from the SLR and 17 from the GLR (Tab. 7).

Table 7. Top 40 ranked good practices, main results

Method	Good practice	FCP	SLR	GLR
Standardised	40	34	23	17

A key feature of the set of top 40 practices is a good balance of numbers of practices assessed by each project partner country (Fig. 1).

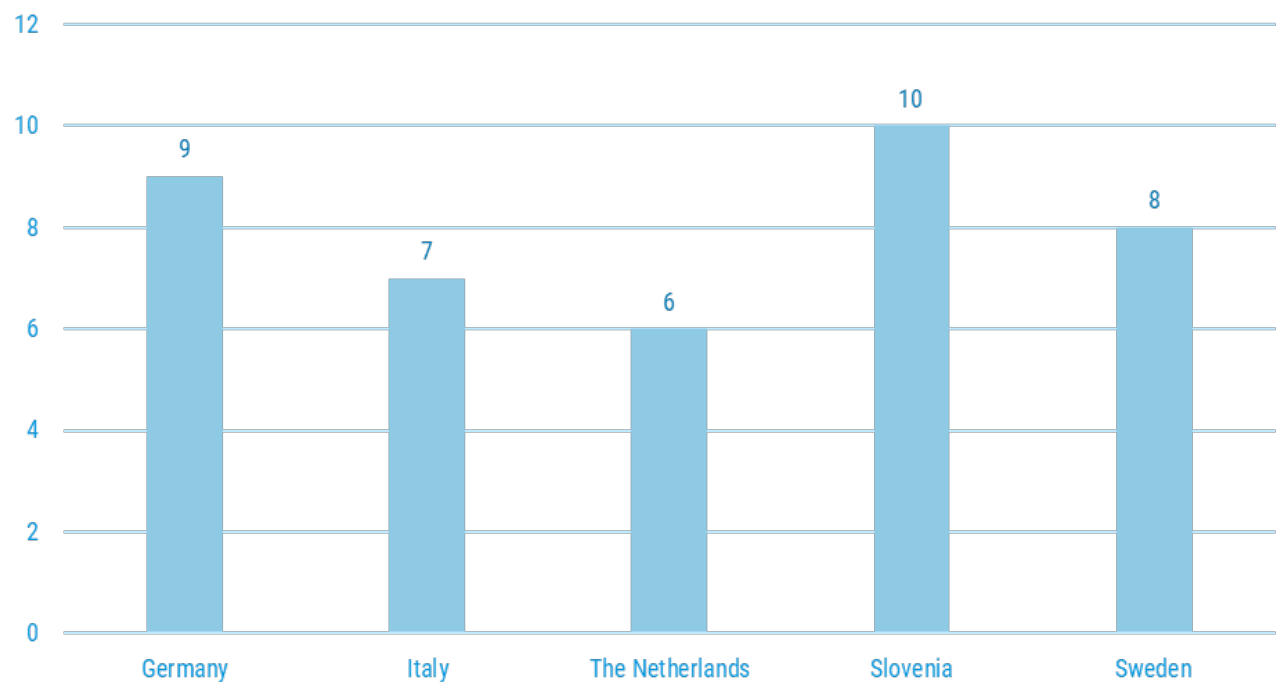


Figure 1. Top 40 ranked good practices within the five project partner countries (a.v.)

In addition, the 40 highest ranked practices are implemented in various countries (Fig. 2). The only exception is Italy, because some SLR practices assessed by INRCA were related to practices implemented in the UK, a context characterised by a richness in innovative care interventions. However, it can be highlighted that among the whole set of 170 identified good practices, the majority (57.6%) are implemented in the five project partner countries, i.e. 20 in Italy, 22 in Germany, 30 in the Netherlands, 14 in Slovenia, 12 in Sweden, plus the UK with 29 good practices, while less than 10 good practices are implemented in other countries.

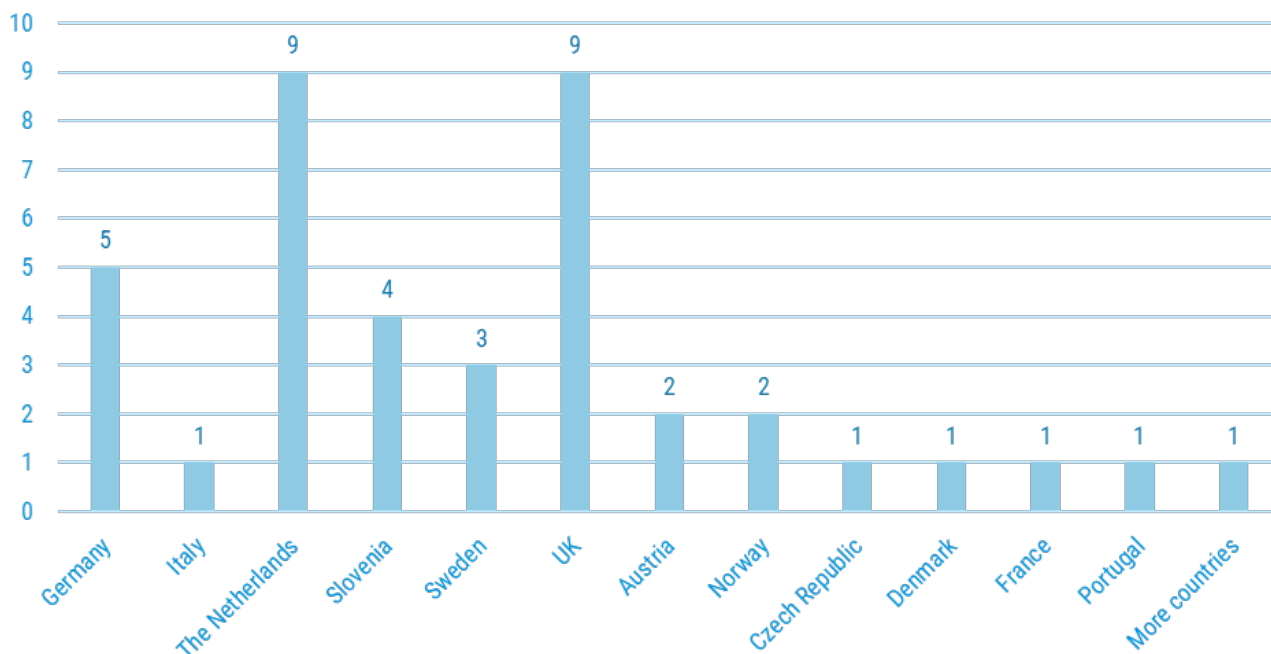


Figure 2. Top 40 ranked good practices, by country of implementation (a.v.)

The set of top 40 ranked good practices is also balanced by the range of seven typologies identified in the conceptual framework described above (section 1) and reported in Figure 3. The prevalence of type 3 (Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives) and type 2 (Interventions or programmes dealing with organisational models and management approaches and/or targeted at the individual level) is due to the greater presence of these categories in the dataset. Type 3 has the largest number of practices among the top 40 ranked good practices (14 practices), but they represent a low percentage of the whole type 3 (112 practices) and rather one of the lowest values among the different typologies of all 170 collected good practices.

More than half of the practices (25 out of 40) can be attributed to type 3, i.e., training initiatives and interventions aimed at mental health/wellbeing and resilience promotion (14), and type 2, that are programmes dealing with organisational models and management approaches and/or targeted at the individual level (11). Type 3 encompasses some technology-enabled toolkit (i.e. online resilience training program, video conferencing peer support groups; web-based mindfulness programme), training strategy (i.e. psychoeducation group program; training on practical skills involved in providing care, blended self-management program), and meeting centres support programme that offers practical, emotional and social support to family carers.

Type 2 explores several organisational models based on web-based tools (i.e. internet-based psychological counselling for family carers; lifestyle-monitoring system to help informal caregivers and case managers providing care to people with dementia who are living alone) or specific places/settings (i.e. training of multidisciplinary teams using an informal blended learning method at hospital; a residential care centre offering both in-house and home high-quality care services, including activities and communal dinners). Type 2 also includes new support programmes (i.e. life coach to support ageing people with memory problems and often physical symptoms; programmes aimed to enhance mental health and wellbeing at individual, community, and societal levels, focusing on sports communities; regular meeting between patient, informal carers and professionals that emphasise unconditional listening and space for reflection) and new quality management model in social care that is nationally and European recognised.

However, other types of good practices also emerge, such as type 4 integrated approaches, through assistive technology (i.e. the Rosetta system) or integrated comprehensive social and health services by bringing together different social and health professions to provide targeted care support in the home environment (nursing technicians, social worker, physiotherapist, kinesiologist). Other examples of practices involve community-based initiatives (type 6) providing proximity assistance to patients and their informal carers through meeting centres or community houses (a physical and easily identifiable place to which citizens can access for health, social and social assistance needs). The type 7 practices involve institutions such as the Association of Inclusive Culture, which aims to achieve social inclusion and independence in their daily activities to individuals with disabilities and their families, or others which provide training and support

to family carers for several years. Finally, the 40 top ranked practices also include preventive tools (type 1) such as a Carers' Alert Thermometer for stroke family caregivers, and recovery programmes (type 5) targeted at LTC workers and/or informal carers with pre-existing mental health conditions (i.e. providing quality information relating to mental health and teach proactive strategies that facilitate healthy responses and reduce carer burnout or offering free of charge and confidential discussion with caregivers, by telephone or online).

In summary, the set of 40 top ranked practices focuses on two main types of practices, type 3 i.e., training initiatives and interventions aimed at mental health/wellbeing and resilience promotion, and type 2, that are programmes dealing with organisational models and management approaches and/or targeted at the individual level. However, this set of 40 top ranked practices also provides several insights into other types of interventions (also taking into consideration that in some cases, the boundaries among the types of interventions are blurred and thus some practices have certain elements of more types).

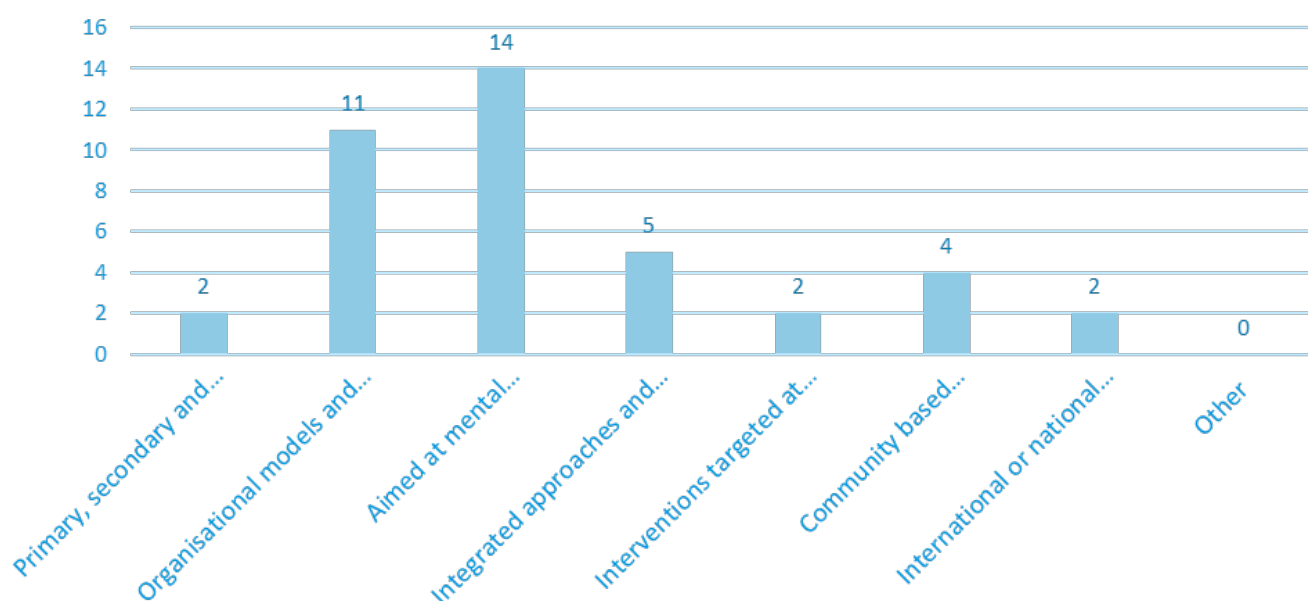


Figure 3. Top 40 ranked good practices, by typology (a.v.)

The top 40 ranked good practices are also fairly varied by setting, with home, online and local community being predominant settings (Fig. 4). This question allowed for multiple choices and some practices referred to a single setting, while others indicated multiple settings, thus the total answers were considered.

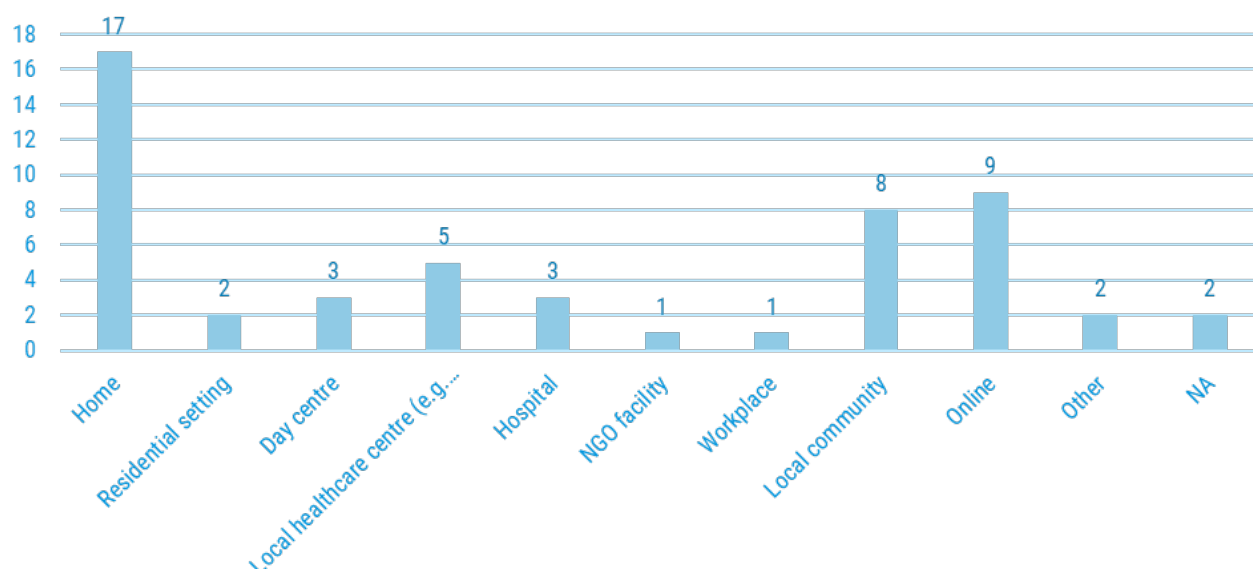


Figure 4. Top 40 ranked good practices, by implementation setting/s (a.v., multiple responses: total=53)

The 40 top ranked practices mainly have a national or local/regional geographical coverage, whereas only a few of them extend to an international scale (Fig. 5). It can be noted that this represents a strength of the project that collects, assesses and also disseminates information about rather less well-known practices because they are oriented to more local contexts.

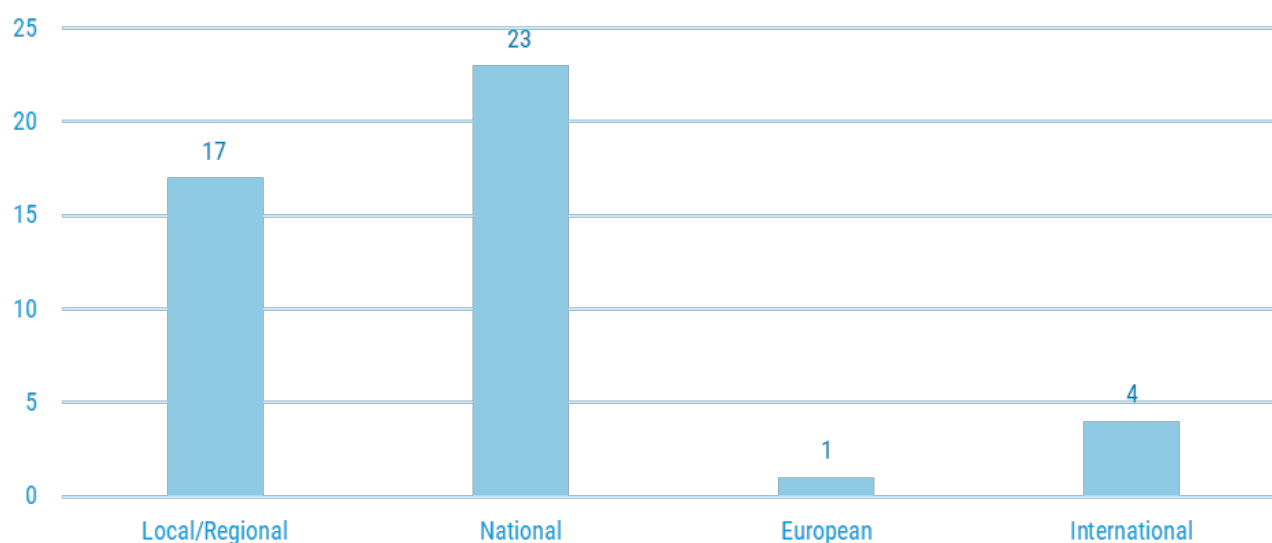


Figure 5. Top 40 ranked good practices, by geographical coverage (a.v., multiple responses: total=45)

Although almost all the 40 practices at the top of the rank are targeted at informal carers. However, they are not only limited to them (Fig. 6), given that most of the interventions are addressed to a wide range of formal carers, roughly equally divided between nurse, other LTC care workers and personal care workers. It should also be noted that working carers (informal carers who combine paid work with care of a family member or friend) often represent a subset of informal carers.

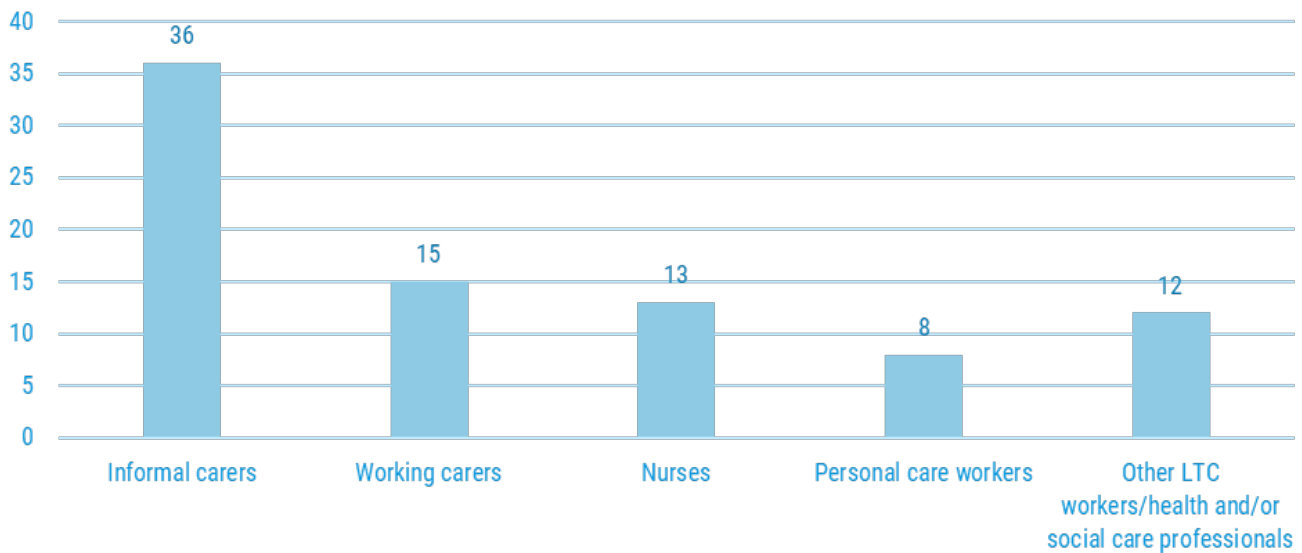


Figure 6. Top 40 ranked good practices, by target group (a.v., multiple responses: total=84)

The target group of the top 40 good practices encompasses several age groups (Fig. 7) and almost always includes both women and men (Fig. 8).

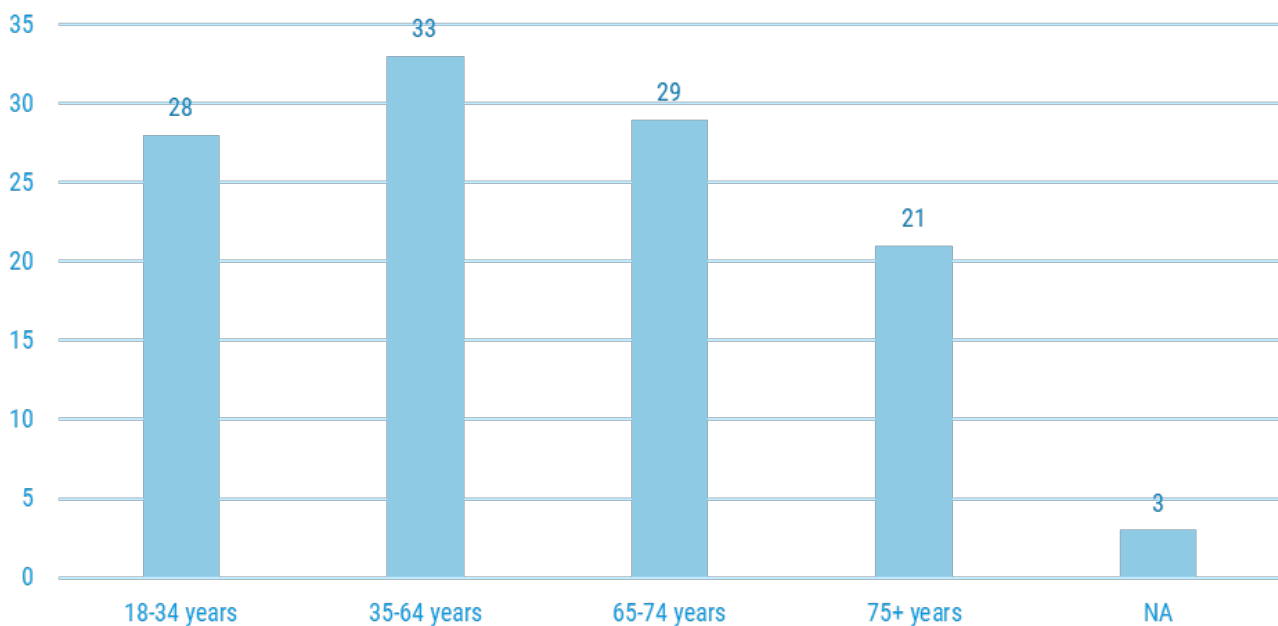


Figure 7. Top 40 ranked good practices, by age of the target group (a.v., multiple responses: total=114)

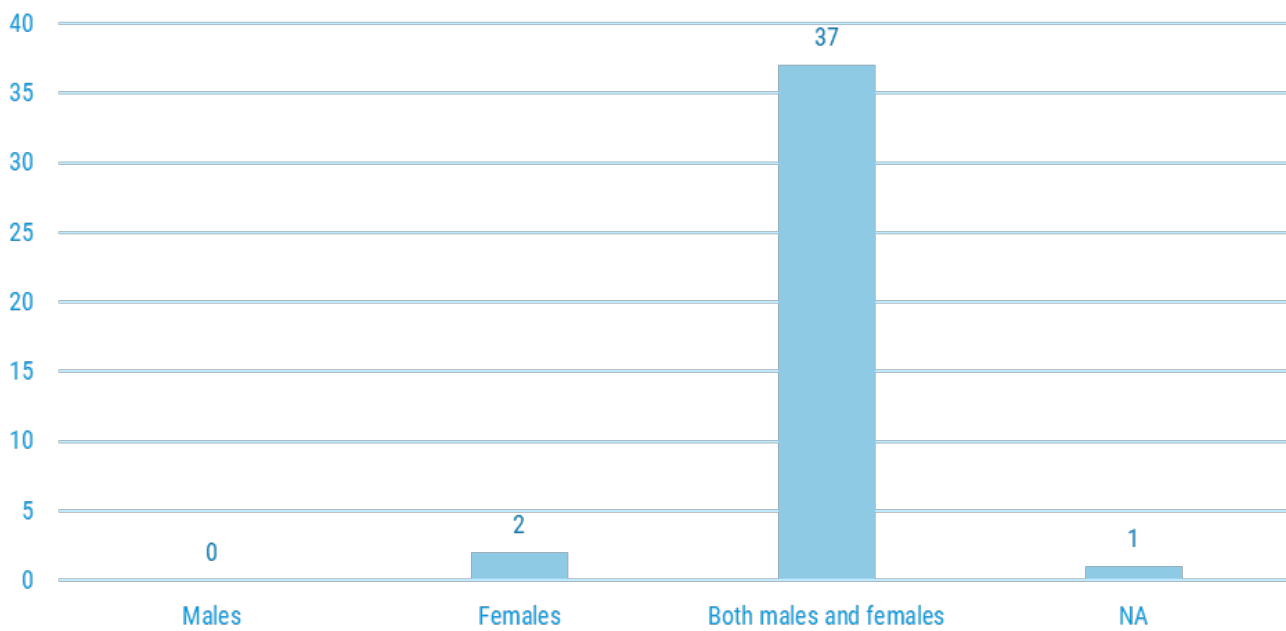


Figure 8. Top 40 ranked good practices, by gender of the target group (a.v., unique response: total=40)

The sample from among the top 40 good practices is therefore targeted to a large base of caregivers, irrespective of their age and especially gender.

The top 40 practices are also well balanced according to the health problems of the care recipients, although there is a particular emphasis on people affected by mental and cognitive impairments (Fig. 9). This confirms that patients affected by mental health issues strongly impact on the wellbeing of the caregivers, who in turn can be seen to require timely, appropriate support.

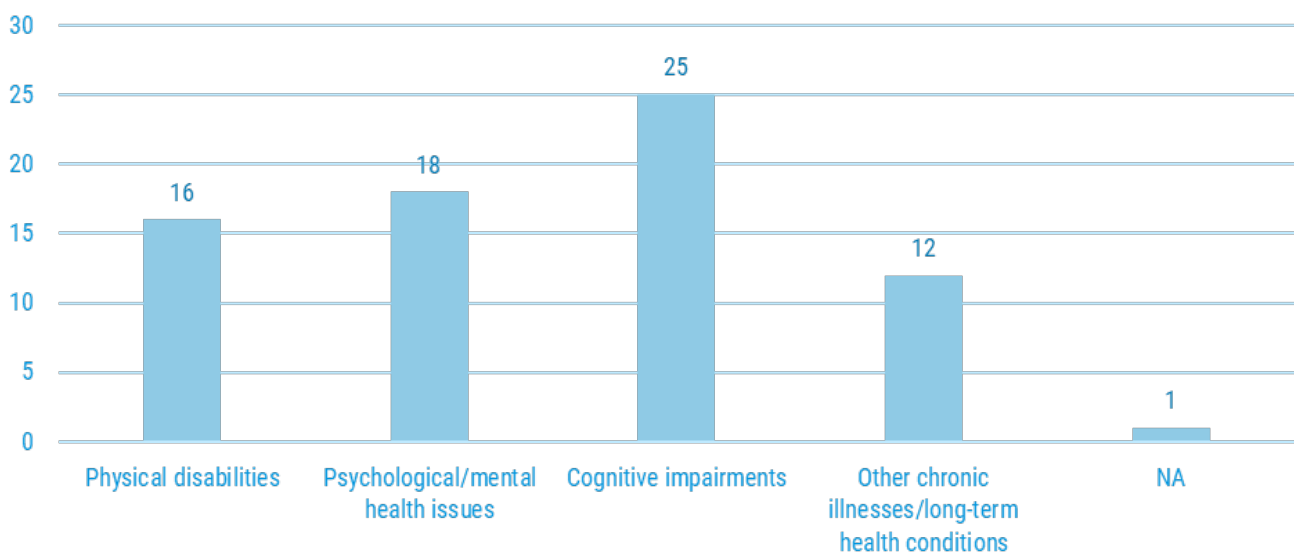


Figure 9. Top 40 ranked good practices, by health problems of the care recipients assisted (a.v., multiple responses: total=72)

Care recipients comprise mainly working age adults and older people (Fig. 10). This is likely due to the fact that LTC provision increasingly concerns older people due to ageing demographic trends.

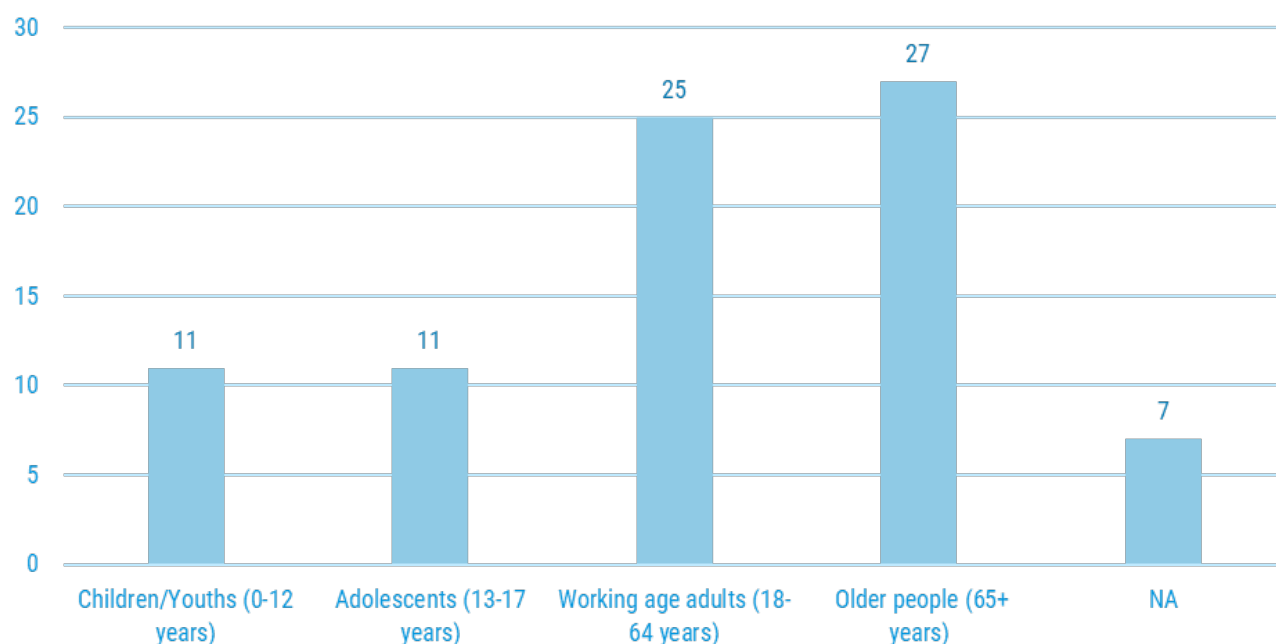


Figure 10. Top 40 ranked good practices, by age of the care recipients assisted (a.v., multiple responses: total=81)

With regards to the 20 sub-criteria used within the evaluation process, almost the whole of the top 40 ranked good practices meet the General and Core criteria, with the partial exception of “equity”. This is most likely due to the fact that information on aspects of equity was not always easily detectable by partners assessing the scientific literature (Fig. 11). Negative answers to such question do not necessarily mean indifference to ethical aspects, but it may simply highlight the lack of information about such issues within the published scientific articles reviewed.

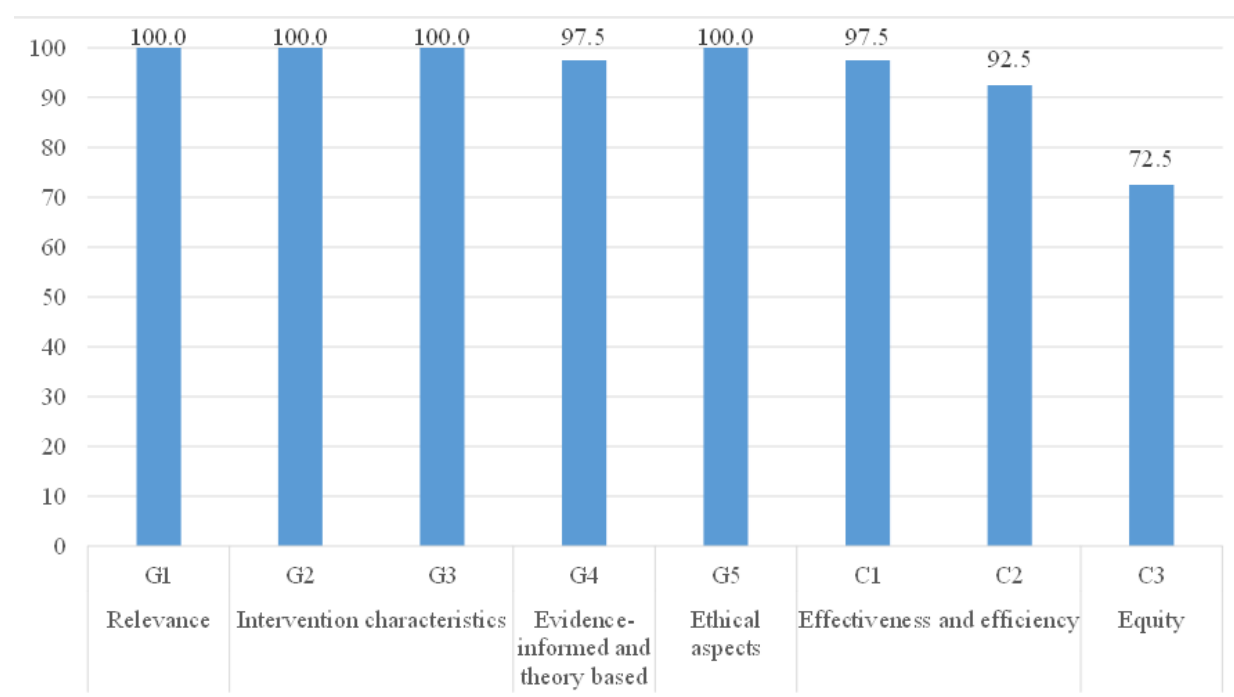


Figure 11. Top 40 ranked good practices, by General and Core criteria (% share of sub-criteria met)

The share of practices satisfying the Qualifier criteria is also high, but slightly lower than that of General and Core criteria. Against this overall finding, there stands out the low share of positive answers for some sub-criteria, that were more difficult to meet (Fig. 12). Nearly half of the top 40 practices have not already been successfully transferred/repeated

(sub-criterion Q2), or there is a lack of reliable information. However, the high share of practices meeting the sub-criteria Q1 (the practice uses instruments that allow for repetition/transfer) and Q3 (the practice is adequately defined, showing potential adaptability, flexibility, and user-friendliness/acceptance that allow for repetition/transfer to different contexts and/or settings) underline the presence of a potential for transferability.

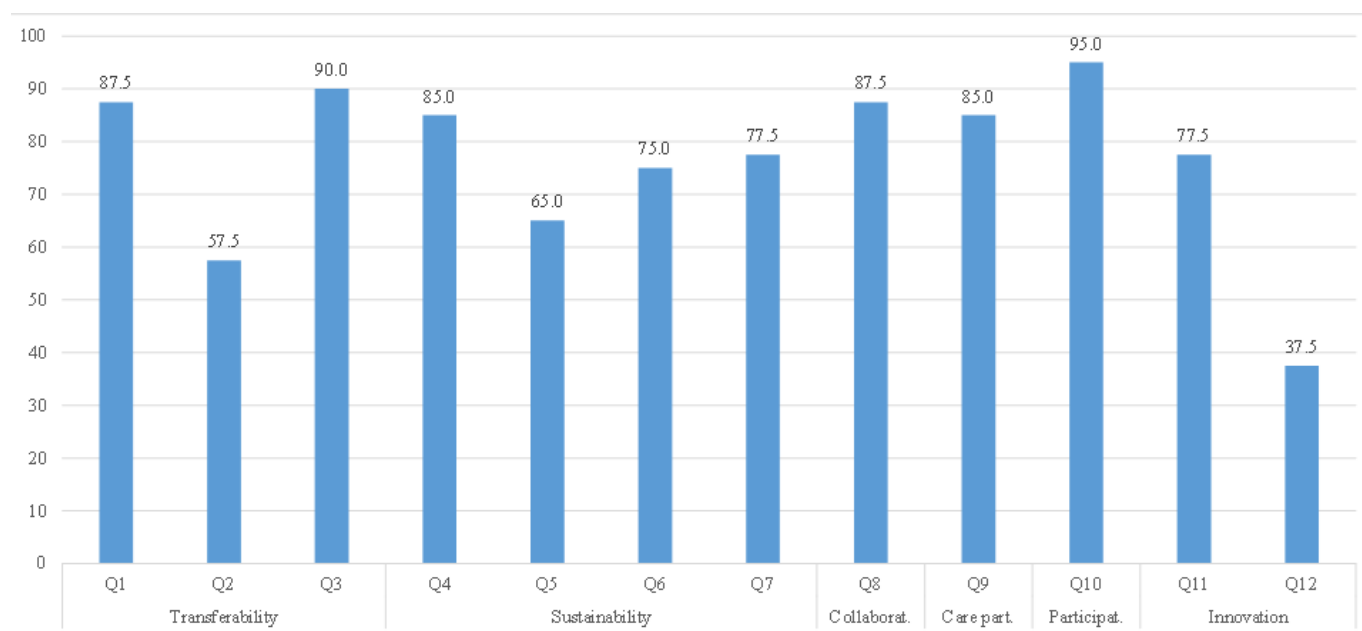


Figure 12. Top 40 ranked good practices, by Qualifier criteria (% share of sub-criteria met)

Sustainability also shows a below average share of positive answers among the top 40 ranked good practices, in particular with regards to the disclosure of the sources of financing (sub-criterion Q5). This critical issue largely potentially impacts on both transferability and long-term sustainability of the practices.

Other sub-criteria such as collaboration, care partnerships and participation are instead largely met within the top 40 good practices; this confirms the effectiveness of the selection process, which provides results that are in line with the goals of the project, geared on improving collaboration and care partnerships between formal and informal carers. Specifically, the care partnerships requirement (sub-criterion Q9) is met by 21 out of the 23 practices in the SLR included in the top 40, and by 13 out of the 17 practices in the GLR included in the top 40 (Fig. 13).

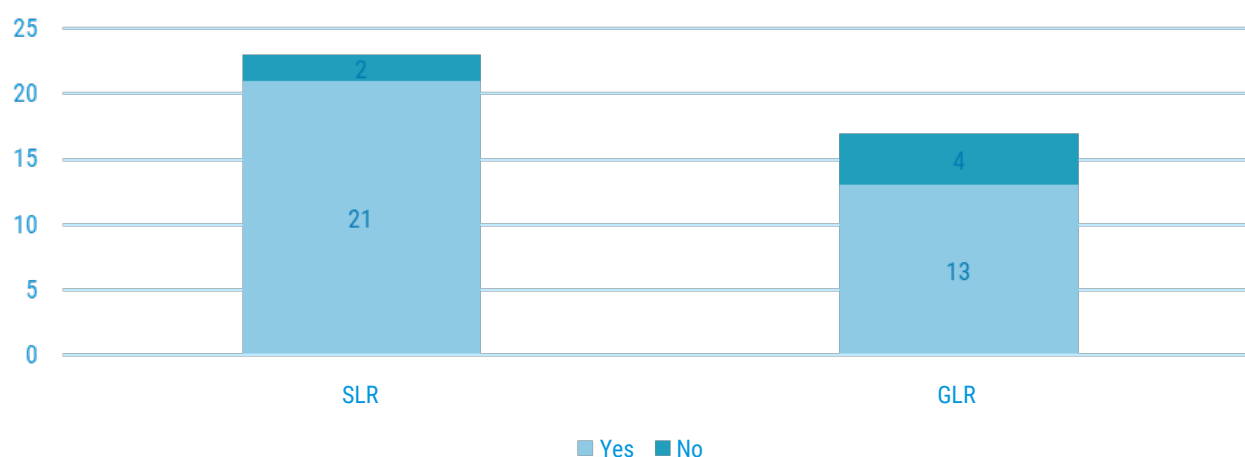


Figure 13. Top 40 ranked good practices, by dataset (SLR and GLR) and care partnerships (number of practices with care partnerships sub-criteria met or not)

More than half of the good practices involving care partnerships in the SLR are classified as type 3, aimed at mental health/wellbeing and resilience promotion and training initiatives. The remaining good practices are equally divided between programmes dealing with organisational models and management approaches and/or targeted at the individual level (3), prevention interventions (2), integrated approaches and strategies (2), and community-based initiatives (2). The GLR has a somewhat different composition, with a prevalence of programmes dealing with organisational models and management approaches and/or targeted at the individual level (5), followed by integrated approaches and strategies (3), community-based initiatives (2), and international or national strategies and initiatives launched/implemented by various institutions (2), while only one practice is oriented at mental health/wellbeing and resilience promotion and training initiatives.

More in detail, care partnerships are evident in some types having distinctive characteristics within the set of top 40 ranked group practices. First, there are partnerships between informal and formal carers, aimed at the management and provision of care, through a shared monitoring of the care recipients' situation and needs (by using digital tools, as e.g. "Carers' Alert Thermometer for Stroke Family Caregiver"; "Livind- lifestyle monitoring system support (in)formal caregivers of people with dementia"), or the introduction of collaborative care models integrating family carers directly into clinical/LTC teams. These initiatives foster mutual recognition, empathy, shared responsibility between professional staff and informal carers, which are no longer passive subjects but active contributors to care design and delivery.

The potential of care partnerships can be found also in support programmes, such those delivered in meeting centres or structured network (e.g. "Open Dialogues") where mutual understanding and shared decision-making between patients, informal carers, and professionals are fostered. Other practices, through LTC workers, provide timely, accessible, relevant, reliable and tailored support to families with a migration background ("Colourful Unburdening") or informal carers dealing with a rehabilitation program for their cared-for (e.g. "Rehabilitation Enablement in Chronic Heart Failure"). Care partnership also means knowledge sharing, coordination of care among LTC workers, informal carers, and other stakeholders. This goal is attained through web-based tools, group discussion, or self-management courses promoting collaboration, mutual recognition, and shared responsibility in caregiving among the three groups of actors. Care partnerships could be pursued by: encouraging collaboration between informal carers and LTC workers (e.g. "Act Belong Commit"); facilitating structured dialogue and shared planning and follow up of tailored carer support initiatives (e.g. "Carers Outcome Agreement Tool"); promoting relationships and knowledge exchange between LTC workers and informal carers (e.g. "Inclusive Culture Program").

The set of top 40 ranked good practices also includes several training programmes specifically designed to share attitudes, skills and experience between LTC workers and informal carers through online courses (e.g. "Care at home") or interactive group sessions (e.g. "Family Carers Training").

Another type of care partnership addresses the existing fragmentation of care, by integrating informal and formal care systems (e.g. "Community Care Dongen") and providers (including healthcare professionals, social workers, volunteers, and informal carers) or coordinating social and healthcare facilities in a "Community House", which offers integrated, multidisciplinary social and healthcare services and prevention activities to the general population. Integrated care programs brought together different social and health professions (the social worker, the physiotherapist, the occupational therapist, the kinesiotherapist) to provide targeted, comprehensive, integrated, inclusive support to care recipients (e.g. "MOST project"; "Wulverhorst").

The greatest deficiencies concern the technological innovation¹² (sub-criterion Q20), which is satisfied only by 37% of the top 40 ranked good practices. However, such a finding should also be read in conjunction with social innovation, which is more largely met in the top 40 sample. In particular, 14 practices have both the innovation potentials (social and technological), 16 have just one of the two, and 9 do not have any innovative potential. It can be argued that a lack of innovation does not preclude the value of practices, that can be successfully transferred to other settings, whereas it could represent a novelty (innovation is more frequently imitative than disruptive).

3.3.4. Summary remarks

The evaluation process provides promising findings in relation to identified good practices with high potential, in themselves and in keeping with the aims of the WELL CARE project. First, the identification of at least 40 good practices concludes a selection process started with the systematic analysis of 8 distinct scientific datasets (SLR), as well as with an analysis of practices retrieved in several websites, repositories, or by other means (i.e. practices implemented by partners and/or their networks; GLR) and which led (following a standardisation process) to identify a total set of 170 good practices, some of them with a potential for fostering care partnerships. The large number of good practices speaks in favour of the work carried out in WP2 and in turn enhances the opportunities for the subsequent choice of prototypes in WP3 (see the “Conclusions” section for more details). Second, the evaluation method provides a ranking that also considers the subjectivity inherent in research projects. The standardisation of the results allowed us to mitigate subjectivity in the evaluation carried out by country partners, and to identify a well-balanced set of the top 40 ranked good practices according to countries involved, type and setting of implementations.

Moreover, the top 40 ranked set of good practices is well balanced between the two datasets. This result also leaves room for the GLR, despite the possibility of there being “less mature” or more “embryonic” forms of good practices from the GLR in comparison to SLR. The main types of the 40 top ranked good practices clearly show the benefits of conducting two different systematic reviews (SLR and GLR), with a complementary view. The SLR deals more with wellbeing promotion and training initiatives, whereas the GLR captures interventions more related to organisational models and management approaches. The scientific literature relies on previous publications and the measurability of the intervention, therefore referring to type 3, while organisations and partners reporting potential good practices in the GLR refer to interventions observed in their own experience and therefore resulting from international/national institution and local communities but especially linked to organisational and management approaches. The exploration of SLR and GLR allows the project Consortium to integrate complementary interventions that pursue care partnerships through different perspectives and paths. The joint examination of the datasets therefore provides a more complete and holistic view of good practices aimed at addressing the project’s overall goal of strengthening supports available to LTC workers and informal carers for improving their resilience and mental wellbeing through care partnerships. Further, it helps to better define the concept of care partnerships itself, which changes according to different contexts and needs.

The ranked practices mainly have a national or local/regional geographical coverage. It can also be argued that the gathering, description and evaluation of good practices implemented in local settings is a prerequisite for a cross-fertilisation process aimed to promote the discussion and transfer of innovative, good experiences across different national and regional contexts. The high share of practices with a potential for transferability corroborates the usefulness of projects, just like WELL CARE, aimed to help the implementation of this potential, often unexploited because of the lack of knowledge regarding practices implemented at local scale. In addition, the analysis highlights that care partnerships represent an essential component of good practices inherent in care work and LTC, which succeed in pursuing the wellbeing of caregivers and, in turn, care recipients. The result achieved therefore suggests that care partnerships are a key aspect at the root of the project.

It can be argued that an original methodological approach to review, select, and analyse good practices was designed, by adapting previous methodologies (Stepien et al., 2022). The review was refined according to a participatory and robust refinement process, where the partners have supplemented the missing information (participatory), and oriented to improve the quality of data (robust). Moreover, we developed a selection mechanism that was inclusive (i.e. in the adequacy thresholds), selective, consistent with the project objectives (i.e. addressing the resilience and mental wellbeing of LTC workers and informal carers via the role of fostering care partnerships), and simple to operationalise. Further, it can be argued that the classification method was objective, reproducible (it is based on quantitative metrics),

12 See Table 1 in Section II, for a definition of both social and technological innovation adopted in the project.

multidimensional (since it considers the multiple characters of the practice) and transparent, because it makes explicit the core dimensions, which were previously discussed and agreed on with partners.

In summary, the systematic literature review and subsequent identification and selection of good practices, adopted a holistic view, which integrated a rigorous quantitative method with qualitative evaluations in order to achieve shared, inclusive and innovative results.

Section IV

Next steps

Case studies

After the work carried out and described in this Report, the next WP2 activity will be to carry out, between M21-24 (October-December 2025), case studies on a total of 10 selected good practices in each of the five partner countries. This represents the third specific research activity envisaged in Task 2.3 and follows both the “Expert interviews” (M13-15) and “Reporting good practices” (M16-20).

In detail, in each of the five countries, the findings of the top 40 ranked good practices across Europe included in D2.1, will be discussed in the national BLNs, facilitated by prior preparatory work carried out by country partners. The two most effective and promising practices at country level will be carefully identified by project partners, in accordance with stakeholders participating in the national BLNs, by use of the criteria set up in Task 2.2 and with special attention to the practices’ transferability potential and their adaptability and implementability in other (national and/or regional/local) contexts. Through desk research and interviews (individual/focus group), two in-depth case studies of two selected good practices¹³ will be conducted in each partner country (Germany, Italy, The Netherlands, Slovenia and Sweden). Using common guidelines and methods (e.g. face-to face or online key informant interviews with LTC workers/informal carers’ employers, health and care and mental health organisations representatives, trade unions, LTC workers and informal carers,) the case study results will be reported using a common template. The main findings of this task will be included in the dedicated WP2 report on in-depth case studies (D2.2 by M24; December 2025).

Dissemination of WP2 findings

More generally speaking, in due course the findings that emerge from WP2 will be further analysed, firstly for the purposes of planning scientific publications, but also for presentations at conferences, with the aim to advance knowledge and understanding with regards to the development, implementation and sustainability of good practices that strengthen the mental wellbeing and resilience of informal carers and LTC workers within diverse long term care contexts in Europe.

Links with other project activities and WPs

Secondly, and equally importantly, they will be used and connected with the next key steps of the project and directly linked with activities of the other related WPs. In particular, the information and characteristics of the selected good practices presented in this Report will be used for example, to provide evidence able in due course to develop general solution prototypes, which will be implemented and tested with interested stakeholders in each of the five partner countries later on in the project (WP3: “Developing resources, prototypes and ecosystems for improving resilience and wellbeing”). In terms of both these aims of the analysis work, a key point of interest concerns those practices/interventions having the potential to foster care partnerships between informal and formal carers. Thus, the results of WP2 will be used to underpin the development of prototypes in WP3, as well in due course with regards to evidence-based and action-oriented recommendations for policy makers and stakeholders (WP4: “Policy analysis, evaluation and recommendations”), and for the ongoing purposes of WP6 (“Dissemination, communication and exploitation”).

¹³ If needed, at country level, it will be possible to select the two good practices for carrying out the two case studies also considering the top 60 ranked good practices (e.g. there is only one good practice implemented in Italy among the top 40 ranked good practices).

Conclusions

The overall aim of this Report is to report the findings of at least 40 effective/innovative practices in Europe, implemented in informal care contexts and/or in public LTC organisations of different settings and preferably covering different groups of LTC workers and informal carers. It represents a public deliverable (D2.1: “Final report on 40 good practices in 5 European countries”) of the WELL CARE project, developed at month 20 (August 2025). This report is based on the main work tasks carried out and respective results achieved, thus far within Work Package (WP) 2 (“Review, selection and analysis of good practices”) of the WELL CARE project. The overall goal of which is to identify, investigate and analyse good practices of innovative solutions that support LTC workers’ and/or informal carers’ resilience and mental wellbeing in five European countries.

In the previous sections, we have presented the main activities carried out so far in the context of Tasks 2.1-2.3, providing methodological details, highlighting the main results and some summary remarks for each respective work task.

As for Task 2.1, we presented an overview of the results of the systematic literature review- SLR and GLR¹⁴- that involved a large number of recent scientific articles and implemented interventions aimed at improving the mental wellbeing of formal and/or informal carers, identified by analysing 8 different scientific databases and a wide set of websites and repositories, including the EU Public Health Best Practice Portal. This research approach helped to ensure that we gathered multidisciplinary insights on the topic. It can be argued that the concordance of the results gained from the two reviews (SLR and GLR) testifies to the robustness and significance of the evidence achieved. Overall, both reviews underlined some key characteristics: practices are mainly targeted at informal carers and to a lesser extent at LTC workers; both genders; care recipients are mostly older people, often with cognitive or mental health issues; a significant number of them are performed in settings outside healthcare facilities, e.g. at home and online; several collected practices have the potential to foster care partnerships. In our view, the study stands out with regards to the depth and breadth of the analysis conducted and for achieving a holistic view about a topic hitherto addressed in a fragmentary way (Cohen et al., 2023; Epps et al., 2021). The analysis delves into dimensions usually examined separately: it covers several countries, multiple types of carers and care recipients, different interventions and application settings.

The creation of a dataset based on a rigorous selection method and process (Task 2.2) allowed the project Consortium to carry out a subsequent evaluation process (Task 2.3), in order to select good practices suitable for the aims of the WELL CARE project. This selection process was conducted by country partners applying 12 agreed inclusion/selection criteria and 20 sub-criteria, after a process of adaptation of these criteria from the EU Public Health Best Practice Portal (EC, 2022; Stepien et al., 2022) and taking into consideration inputs from BLN members in the five partner countries of Germany, Italy, The Netherlands, Slovenia and Sweden. This activity was conducted within Task 2.2, by developing a template to report the findings of the potential good practices responding to the criteria mentioned above.

The activities conducted in Task 2.3 thus far are “Expert interviews” (M13-15) and the “Reporting of good practices” (M16-20). As for the former, a sample of 23 experts were selected in the five partner countries because of their expertise/experience on WP2 issues, representing various stakeholders/sectors (research and academia, policy, LTC employers, associations). The qualitative analysis of the semi-structured interviews with the experts allowed the Consortium to gain overall positive comments on the results of the SLR and GLR carried out in Task 2.1. They noted, among other aspects, the increase in publications on caregiver wellbeing in recent years while highlighting that the grey literature captured more innovative and implementable practices compared to the scientific literature that was constrained by more rigid methodological approaches. According to the experts, good practices must be understood as context-dependent rather than universally transferable, requiring adaptation to the socio-cultural and institutional context. Experts identified common implementation challenges including resource constraints, structural resistance from risk-averse institutional cultures, and sustainability issues, while enabling factors included formal policy recognition, continuous training, and robust institutional support structures. The analysis revealed significant country-specific variations in approaches to the implementation of good practices, reflecting different healthcare systems and cultural contexts. Experts also highlighted fourteen additional practices, seven of which were evaluated as good practices that were added to our data set, and

14 The rationale to also conduct a GLR in addition to the SLR was to search for information on potential good practices not covered by scientific articles (SLR) (in that way contributing to reduce publication bias by including diverse data sources that may not be represented in traditional academic journals). This was carried out by partners and their networks, consulting websites or repositories already containing examples of potential good practices, or by analysing grey literature in national languages, or asking to partners’ networks to indicate potential good practices implemented directly in their respective countries. See GLR in section 1).

they offered opinions and considerations on key aspects related to the practices that have the potential to foster care partnerships.

The second key activity conducted in Task 2.3, involved an original methodological approach that was designed by INRCA in collaboration with the Coordinator and partners (via adapting previous methodologies; Stepien et al., 2022). This evaluation method was subsequently applied by country partners to review and analyse the collected practices in Task 2.1, supplemented by some practices highlighted by BLN members and experts interviewed, in order to select and rank the good practices satisfying the agreed selection criteria defined in Task 2.2. Key characteristics of the methodology applied were to implement an evaluation and selection mechanism which was objective, scientifically grounded, inclusive, selective, consistent with the project objectives, transparent, reproducible and simple to operationalise. The methodology is objective because it relies on quantitative metrics set *ex ante*, and scientifically grounded because it is based on criteria adopted by the EU. It is inclusive in the choice of adequacy thresholds, set below the values indicated in the literature (Stepien et al., 2022), but also selective because it is able to identify good practices and classifies them according to multiple characteristics. The methodology is consistent with the project's objectives (for example, considering the project focus of mental wellbeing and resilience of the project's target groups-informal carers and LTC workers, various types of care, formal and informal, and highlighting the role of care partnerships), reproducible by other researchers and easy to implement. Finally, it is a transparent and shared method, as it explicitly states the fundamental criteria which have been discussed and agreed upon with the partners and within BLNs.

The evaluation process resulted in 170 practices classified as good practices, mainly implemented in the five partner countries (57.6%). On the one hand, the large number of good practices confirms the effectiveness of the work carried out in the previous phases of the project (i.e. the search strategy and the selection process of SLR and GLR practices conducted in Task 2.1 allowed to collect practices with an overall good quality in terms of contents, the majority of which were then assessed - through a rigorous methodology - to be good practices). On the other hand, it means that we have made available a wide *répertoire* of good practice that are both publicly available and which will help to inform the subsequent work activities in the project with regards to the solution prototypes, policy recommendations and broader project dissemination activities.

After the ranking process, it was possible to identify the top 40 ranked good practices. The aggregated results reveal that these good practices are balanced among the SLR and GLR databases. This provides a more comprehensive list of good practices aimed at the project's overall goal and that pursue care partnerships through different perspectives: wellbeing promotion and training initiatives (SLR) or organisational models and management approaches (GLR). The set of top 40 ranked good practices is also balanced by typologies (albeit with a large presence of training initiatives and interventions aimed at mental health/wellbeing and resilience promotion, and programmes dealing with organisational models and management approaches and/or targeted at the individual level), quite varied by setting of implementation (mainly at home, online and in the local community) and targeted especially at informal carers and to a lesser extent at LTC/formal carers. The focus on informal carers highlights the growing recognition of the role they play within our LTC systems in Europe; but at the same time there remains a relative lack of research focusing on LTC workers' mental wellbeing and resilience. Care recipients within the top 40 ranked good practices are mainly older people, with especially cognitive impairments and psychological/mental issues, which can heavily affect the wellbeing and the mental resilience of caregivers. Among the top 40 practices, 85% (i.e. 34 out of 40) have the potential (with different gradients and characteristics) of fostering care partnerships. Such potential can be found in support programmes tailored to specific needs and contexts, in knowledge sharing and coordination among LTC workers, informal carers, and other stakeholders, and training initiatives specifically designed to share attitudes, skills and experience between formal and informal carers. The care partnership good practices are also characterised by integrated care programs, which enhance integration of informal and formal care systems and providers, and some management approaches as collaborative care, where informal carers become active contributors to care design and delivery. In this way, these overall results of the top 40 ranked good practices are substantially in line with the characteristics and findings of the SLR and GLR practices collected in Task 2.1, underlying common main features of both the overall collected practices and the top 40 good practices (e.g. practices involving mainly informal carers rather than LTC workers, of diverse types and implemented in different settings, several of them with the potential to foster care partnerships, with older people being the main group of care recipients).

This set of good practices will be the basis for the process aimed to develop prototypes (in WP 3), by also involving local implementation teams (LITs) and BLNs within the development process. The large number of identified good practices enhance indeed the opportunities for the choices on which to build the prototypes, as the Consortium has 170 available options, which is arguably a large dataset from which to draw on. In particular, country partners are able to draw among the set of the highest ranked 40 practices (or to choose some of their "ingredients"), but they can also select another good practice(s) (i.e. good practices ranked 41-170), "justifying" their choices accordingly. It is thus an inclusive

approach, reproducible, controllable, allowing flexibility in choices, and based on an EU-adopted set of criteria (European Commission, 2022b; Stepien et al., 2022).

More in general, the findings that emerged from both the SLR and GLR and from the process to select and rank good practices applying agreed selection criteria, help to advance knowledge and understanding in the field of mental health, informal care, LTC (for older people, people living with disabilities and with other chronic illnesses).

The results also have strong policy implications with regards to how best to ensure that practices are efficient, sustainable, scalable and transferable. Sustainability was seen, within the GLR and expert interviews, to be first and foremost an economic issue, given the need for long term funding of a good practice, but it was also seen to need political support, the availability of well-trained carers, and the ability to coordinate with other stakeholders. The findings also emphasise the role of informal carers, who can no longer be ignored or disconnected from LTC workers as they provide the bulk of all LTC within the European Union. In this view, care partnerships between informal and formal carers should be promoted, with the aim of alleviating the care burden and mental health issues of both groups, and to improve the quality of care provided. In this regard, most of the identified top 40 ranked good practices have the potential to foster care partnerships, even though it is variously shaped: the list of initiatives encompasses e.g. web-based tools, group discussions, training courses, interactive group sessions, meeting centres, social and healthcare facilities. Care partnerships within the top 40 ranked good practices were seen to be the foundation of support interventions promoting collaboration, mutual recognition of roles and shared responsibility in caregiving; of initiatives aimed at knowledge sharing or integration of care among informal and formal care systems and providers; of programs to improve the management and provision of care through a more active role of informal carers in care design and delivery.

Despite the presence of a potential for transferability, part of the good practices collected have not yet been successfully transferred to other settings. In this regard, the collection and evaluation of 170 good practices mainly operating at local scale represents a positive contribution of the WELL CARE project, which provides a rich database of good practices to draw from by policy makers and stakeholders. Dissemination of information about practices promotes the discussion and potential transfer of innovative, promising practices across different national and regional contexts. Innovation often consists of adopting good practices that have been successfully implemented in other areas, adapting them to one's own context and needs. The top 40 ranked good practices suggest that care partnerships are a key lever to successfully exploit the potential of these good practices in pursuing the mental wellbeing and resilience of informal carers and LTC workers.

References

- Belmonte, M., Nedee, A. (2024). Demographic projections of long-term care needs in the EU up to 2070, European Commission, Ispra, JRC136608.
- Belmonte, M., Grubanov-Boskovic, S., Natale, F., Conte, A., Belanger, A., Sabourin, P. (2023). Demographic microsimulation of long-term care needs in the European Union – Prototype for a microsimulation model projecting the demand for long-term care up to 2070, Publications Office of the European Union, Luxembourg. Available at: <https://data.europa.eu/doi/10.2760/941182>
- Boamah, S.A., Weldrick, R., Havaei, F., Irshad, A., Hutchinson, A. (2023). Experiences of Healthcare Workers in Long-Term Care during COVID-19: A Scoping Review. *Journal of Applied Gerontology*, 42(5), 1118-1136. <https://doi.org/10.1177/07334648221146252>
- Booth, D., Papaioannou, A., Sutton, A. (2012). *Systematic Approaches to a Successful Literature Review*, Sage Publications, Thousand Oaks, CA, USA.
- Cattaneo, A., Vitali, A., Regazzoni, D., Rizzi, C. (2025). The burden of informal family caregiving in Europe, 2000-2050: a microsimulation modelling study. *Lancet Regional Health Europe*, 53:101295. <https://doi: 10.1016/j.lanepe.2025.101295>.
- Chan, C.Y., De Roza, J.G., Ding, G.T.Y., Koh, H.L., Lee, E.S. (2023). Psychosocial factors and caregiver burden among primary family caregivers of frail older adults with multimorbidity. *BMC Prim Care*, 24, 36. <https://doi: 10.1186/s12875-023-01985-y>
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*, Sage Publications, Thousand Oaks, CA, USA.
- Cohen, C., Pignata, S., Bezak, E., Tie, M., Childs, J. (2023). Workplace interventions to improve well-being and reduce burnout for nurses, physicians and allied healthcare professionals: a systematic review. *BMJ open*, 13(6), e071203. <https://doi: 10.1136/bmjopen-2022-071203>
- Epps, F., To, H., Liu, T. T., Karanjit, A., Warren, G. (2021). Effect of exercise training on the mental and physical well-being of caregivers for persons living with chronic illnesses: a systematic review and meta-analysis. *Journal of Applied Gerontology*, 40(1), 18-27. <https://doi: 10.1177/0733464819890753>
- Eurocarers/IRCCS-INRCA (2021). *Impact of the COVID-19 outbreak on informal carers across Europe – Final report*. Brussels/Ancona.
- Eurofound (2025). *Unpaid care in the EU*, Publications Office of the European Union, Luxembourg.
- Eurofound (2023). *Social services in Europe: Adapting to a new reality*, Publications Office of the European Union, Luxembourg.
- Eurofound (2020). *Long-term care workforce: Employment and working conditions*, Publications Office of the European Union, Luxembourg.
- European Commission (2022a). Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions on the European care strategy. COM/2022/440 final. Available at: <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A52022DC0440>
- European Commission (2022b). *Criteria to Select Best Practices in Health Promotion and Disease Prevention and Management in Europe*. Updated version. Available at: https://health.ec.europa.eu/system/files/2021-01/sqpp_bestpracticescriteria_en_0.pdf
- European Commission (2021a). *The 2021 Ageing Report: Economic and Budgetary Projections for the EU Member States (2019-2070)*. Institutional Paper 148. Publications Office of the European Union, Luxembourg.

European Commission (2021b). 2021 Long-Term Care Report. Trends, challenges and opportunities in an ageing society, Volume I, Publications Office of the European Union, Luxembourg.

Florek, K. (2021). Resilience of the Long-term Care Sector Early Key Lessons Learned from the COVID19 Pandemic. The European Federation of Public Service Unions (EPSU). Available at: https://www.epsu.org/sites/default/files/article/files/Resilience_of%20the%20LTC%20sector_V3.pdf

Gioia, D.A., Corley, K.G., Hamilton, A.L. (2013). Seeking qualitative rigor in inductive research: Notes on the Gioia methodology. *Organizational Research Methods*, 16(2), 15-31. <https://doi.org/10.1177/1094428112452151>

Hong, Q. N., Pluye, P., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., Gagnon, M.G., Griffiths, F., Nicolau, B., O'Cathain, A., Rousseau, M.C., Vedel, I. (2018). Mixed Methods Appraisal Tool (MMAT), version 2018. Registration of copyright (#1148552). Canadian Intellectual Property Office, Industry Canada. Available at: http://mixedmethodsappraisaltoolpublic.pbworks.com/w/file/fetch/127916259/MMAT_2018_criteria-manual_2018-08-01_ENG.pdf

Kim, G., Allen, R.S., Wang, S.Y., Park, S., Perkins, E.A., Parmelee, P. (2019). The relation between multiple informal caregiving roles and subjective physical and mental health status among older adults: do racial/ethnic differences exist? *The Gerontologist*, 59(3), 499-508. <https://doi.org/10.1093/geront/gnx196>

Li, J., Song, Y. (2019). Formal and Informal Care. In: Gu D., Dupre M. (Eds.), *Encyclopedia of Gerontology and Population Aging*. Springer, Cham. https://doi.org/10.1007/978-3-319-69892-2_847-1

Mazziotta, M., Pareto, A. (2021). Everything you always wanted to know about normalization (but were afraid to ask). *Rivista Italiana di Economia Demografia e Statistica - The Italian Journal of Economic, Demographic and Statistical Studies*, 75(1), 41-52.

McCracken, G. (1988). *The long interview*. Vol. 13, Sage Publications, Thousand Oaks, CA, USA.

McPherson, K.M., Kayes, N.K., Moloczij, N., Cummins, C. (2014). Improving the interface between informal carers and formal health and social services: a qualitative study. *International Journal of Nursing Studies*, 51(3), 418-429. <https://doi.org/10.1016/j.ijnurstu.2013.07.006>

Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G., The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement, *PLoS Med* 6(6), e1000097. <https://doi.org/10.1371/journal.pmed.1000097>

OECD (2020). *Who Cares? Attracting and Retaining Care Workers for the Elderly*, OECD Health Policy Studies, OECD Publishing, Paris. <https://doi.org/10.1787/92c0ef68-en>

Or, R., Kartal, A. (2019). Influence of caregiver burden on well-being of family member caregivers of older adults. *Psychogeriatrics*. 19, 482-90. <https://doi:10.1111/psyg.12421>

Page, M.J., McKenzie, J.E., Bossuyt, P.M., Boutron, I., Hoffmann, T.C., Mulrow, C.D. et al. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*, 372:n71. <https://doi:10.1136/bmj.n71>

Pluye, P., Gagnon, M.P., Griffiths, F., Johnson-Lafleur, J. (2009). A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in mixed studies reviews. *International Journal of Nursing Studies*, 40(4), 529-546. <https://doi:10.1016/j.ijnurstu.2009.01.009>

Saldaña, J. (2016). *The coding manual for qualitative researchers* (3rd ed.), Sage Publications, Thousand Oaks, CA, USA.

Socci, M., Di Rosa, M., Quattrini, S., Lamura, G., Hanson, E., Magnusson, L., Yghemonos, S., Cavrini, G., Teti, S., Santini, S. (2024). The impact of the pandemic on health and quality of life of informal caregivers of older people: Results from a cross-national European survey in an age-related perspective. *Applied Research in Quality of Life*, 19(3), 1385-1410. <https://doi.org/10.1007/s11482-024-10296-y>

Stepien, M., Keller, I., Takki, M., Caldeira, S. (2022). European public health best practice portal-process and criteria for best practice assessment. *Archives of Public Health*, 80(1), 131. <https://doi: 10.1186/s13690-022-00892-5>

Yin, R. K. (2014). *Case study research: Design and methods* (5th ed.), Sage Publications, Thousand Oaks, CA, USA.

Annex A:

Additional tables and figures of SLR and GLR

Annex A1 - SLR

Figures

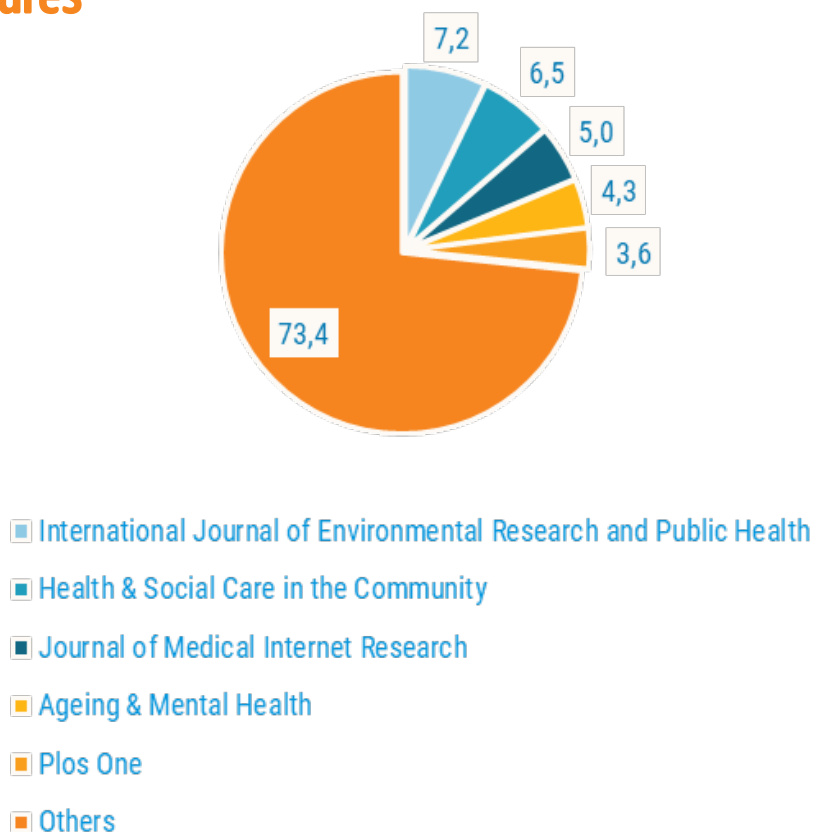


Figure A1.1. Papers by journal of publication (%)

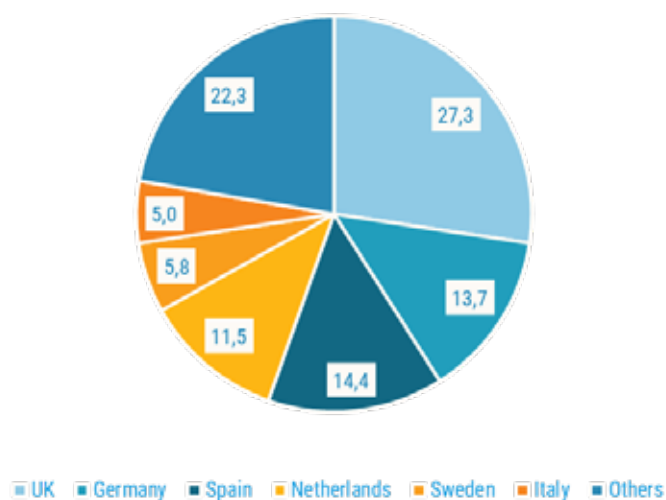


Figure A1.2. Papers by country (%)

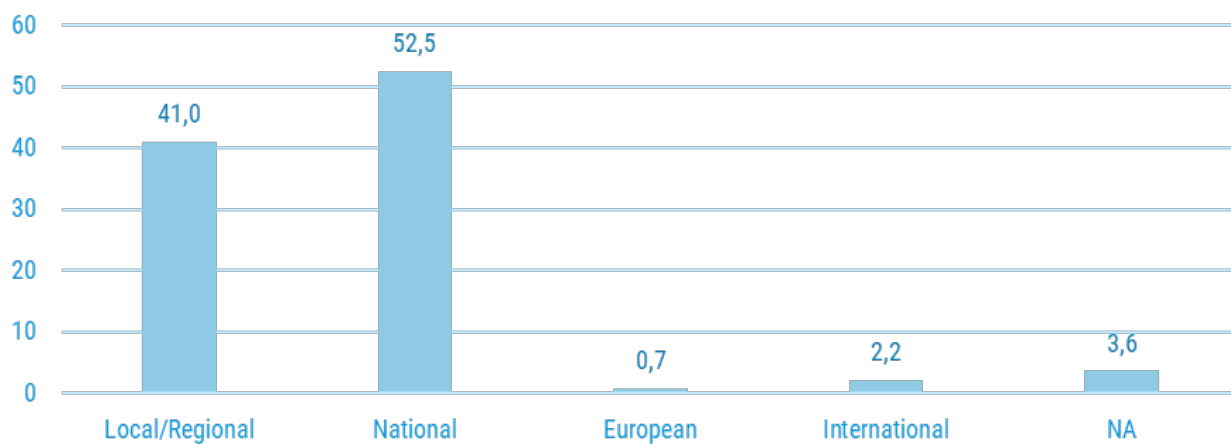


Figure A1.3. Papers by geographic coverage (%)

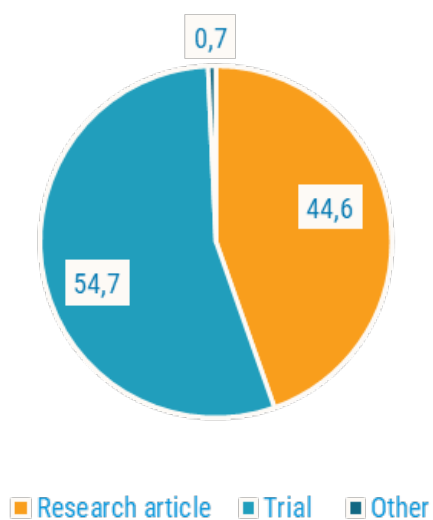


Figure A1.4. Papers by type of study (%)

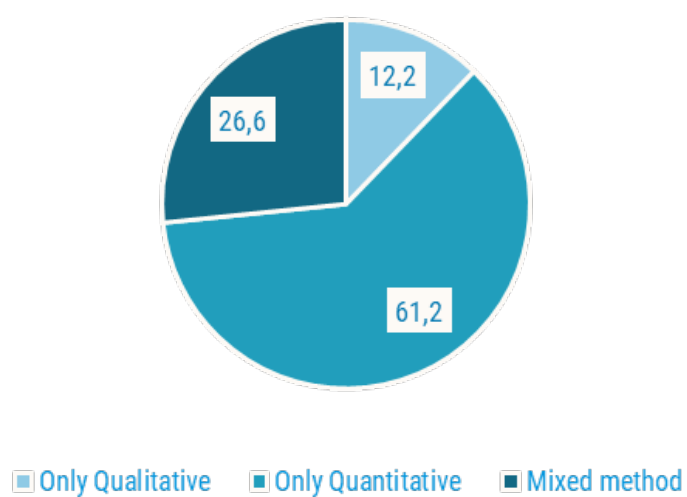


Figure A1.5. Papers by research method (%)

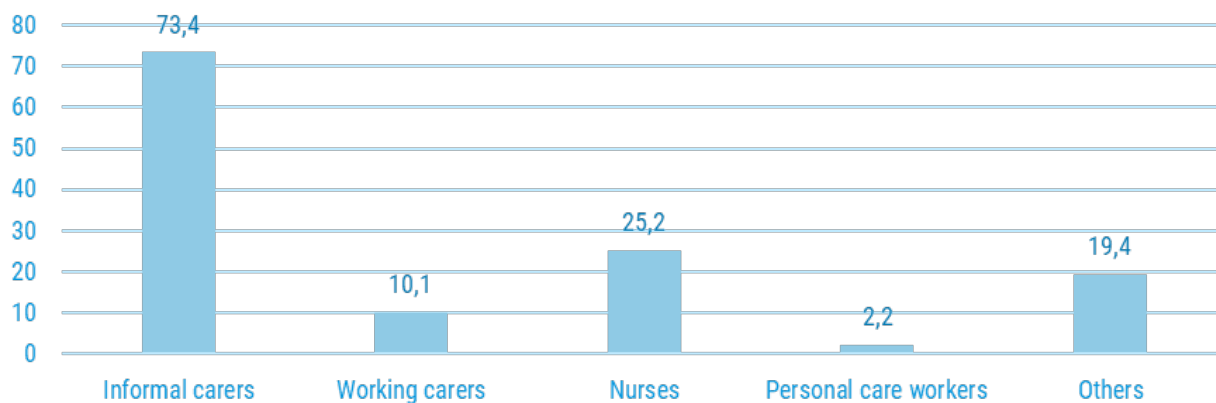


Figure A1.6. Papers by target group (%)

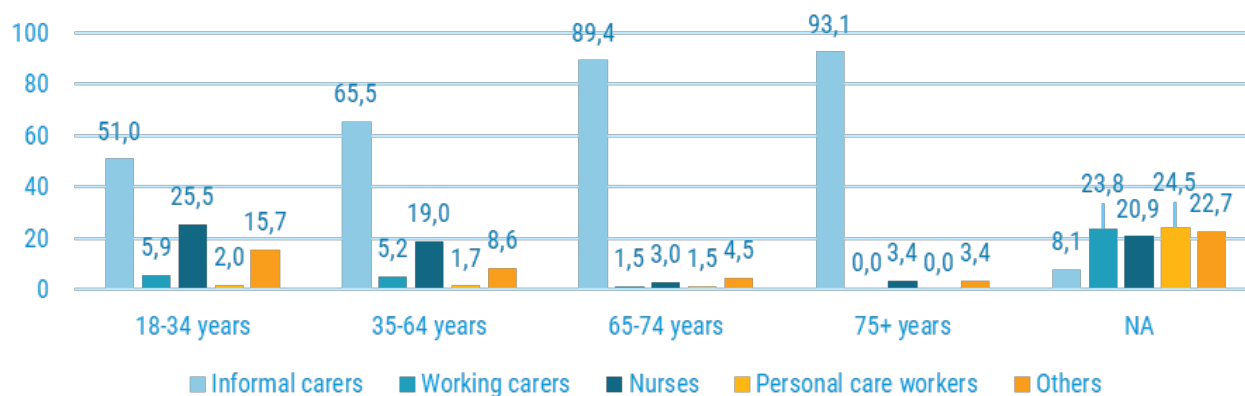


Figure A1.7. Papers by age profile of the target group (% on total)

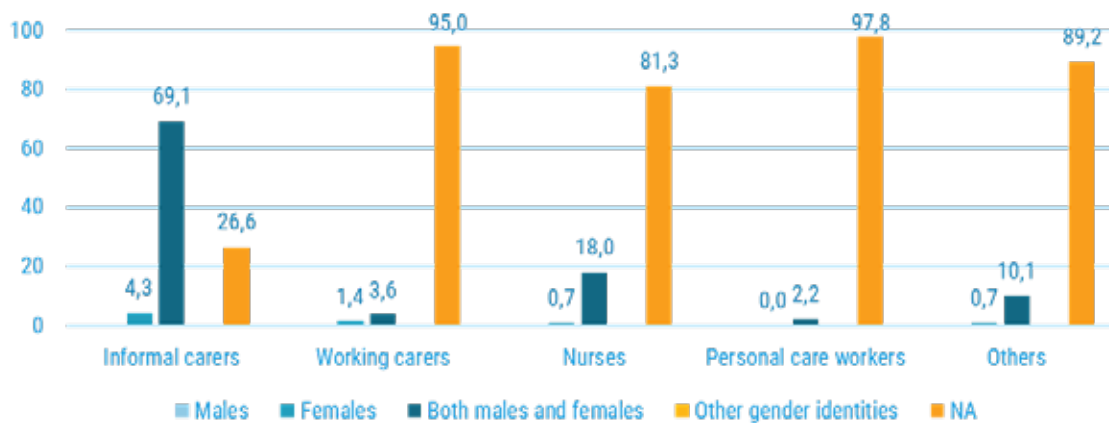


Figure A1.8. Papers by gender composition of the target group (% on total)

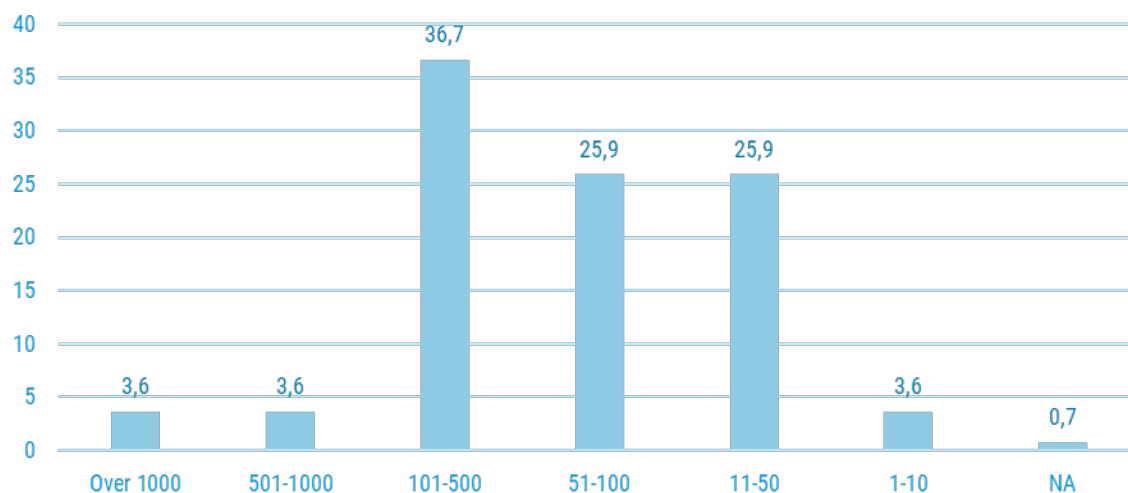


Figure A1.9. Papers by sample size (%)

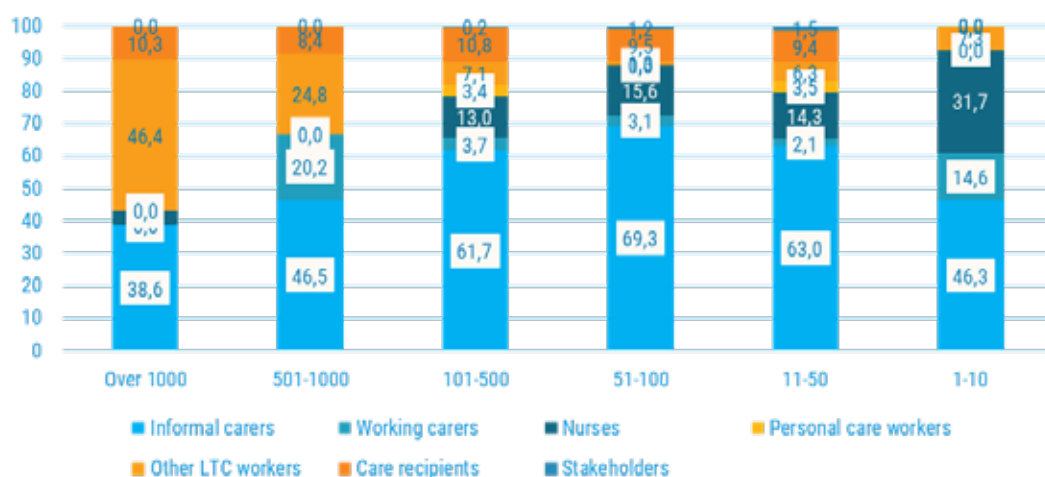


Figure A1.10. Papers by sample size of the target group (% on sample group)

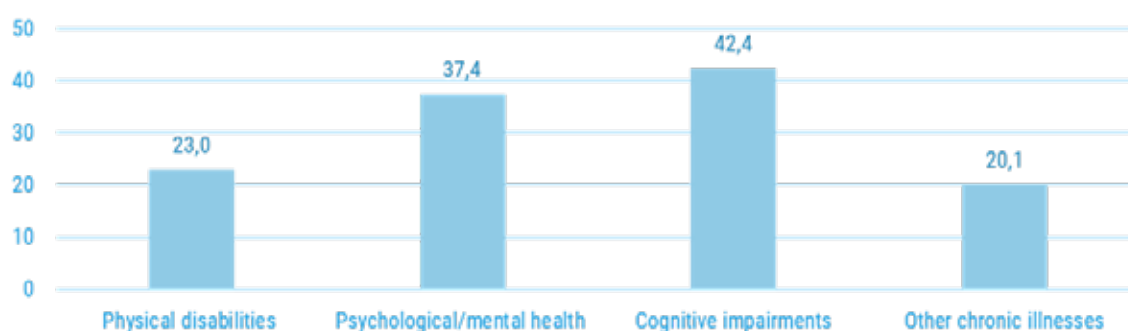


Figure A1.11. Papers by health problems of the care recipient (%)

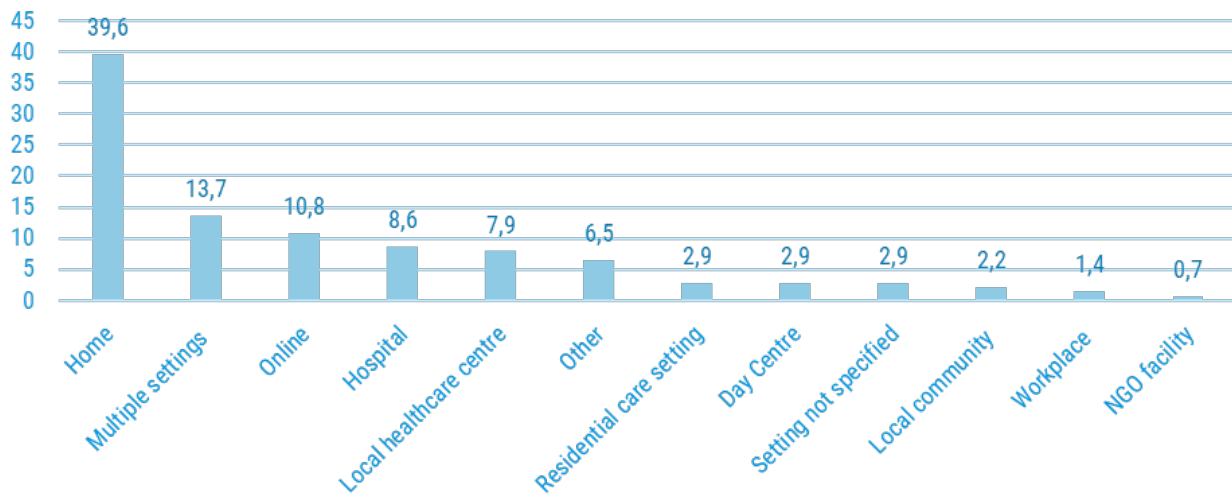


Figure A1.12. Papers by main setting considered (%)

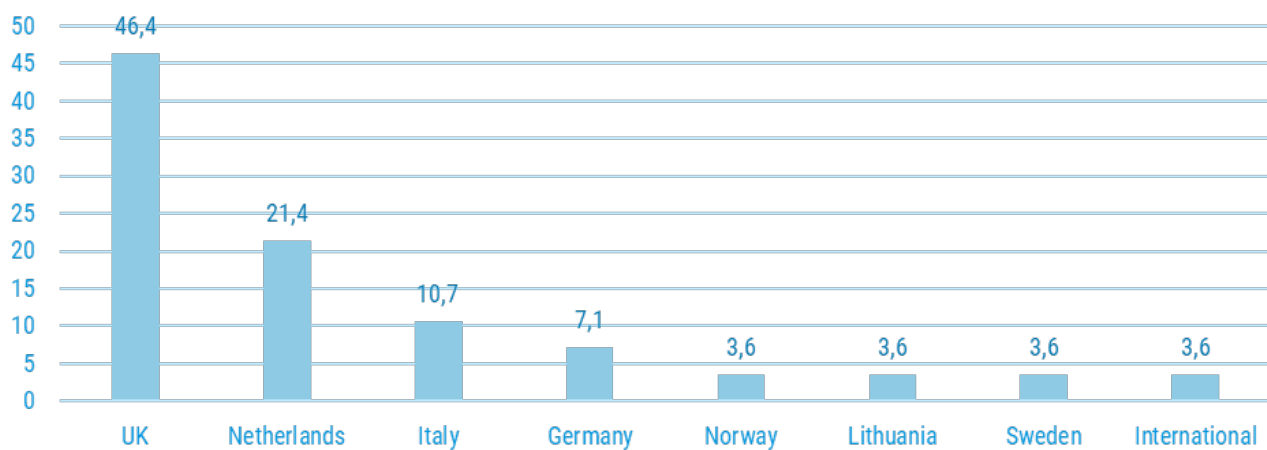


Figure A1.13. Papers with potential for fostering care partnership by country (%)

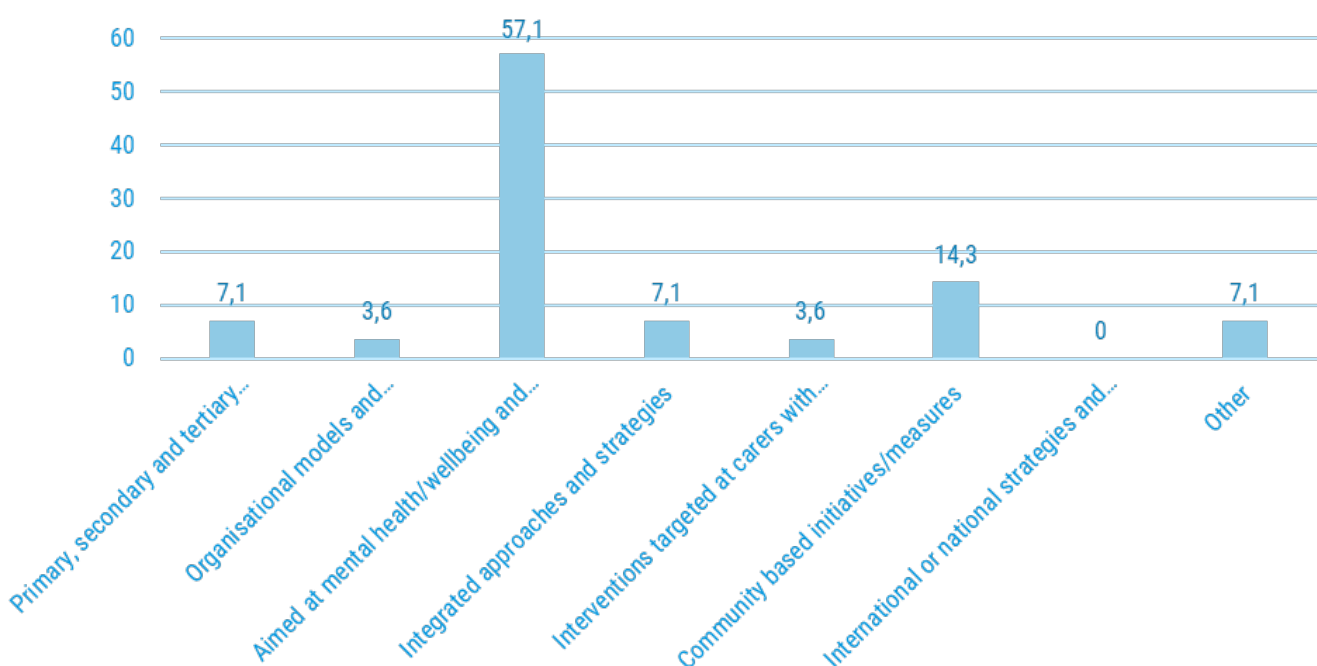


Figure A1.14. Papers with potential for fostering care partnership by main type of practice (%)

Tables

Table A1.1. Papers by number of target groups (absolute values)

Number of target groups	Papers
1	106
2	24
3	9
Total	139

Table A1.2. Papers by number of settings (absolute values)

Number of settings	Papers
0	4
1	113
2	15
3	4
4	2
5	1
Total	139

Annex A2 - GLR

Figures

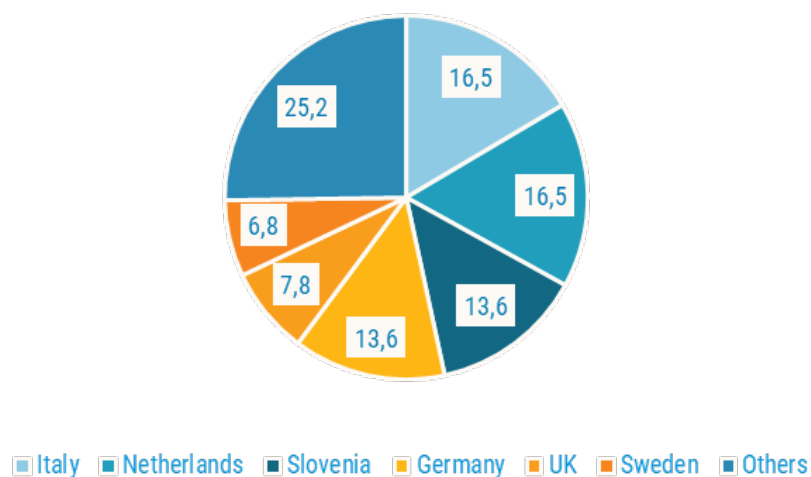


Figure A2.1. Practices by country of origin (%)

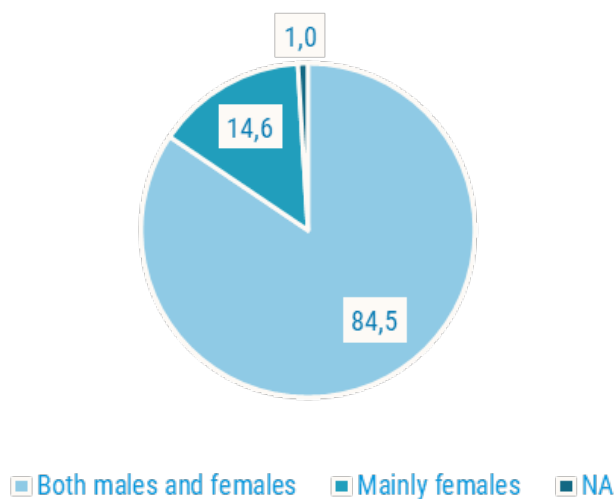


Figure A2.2. Practices by gender composition of the target (%)

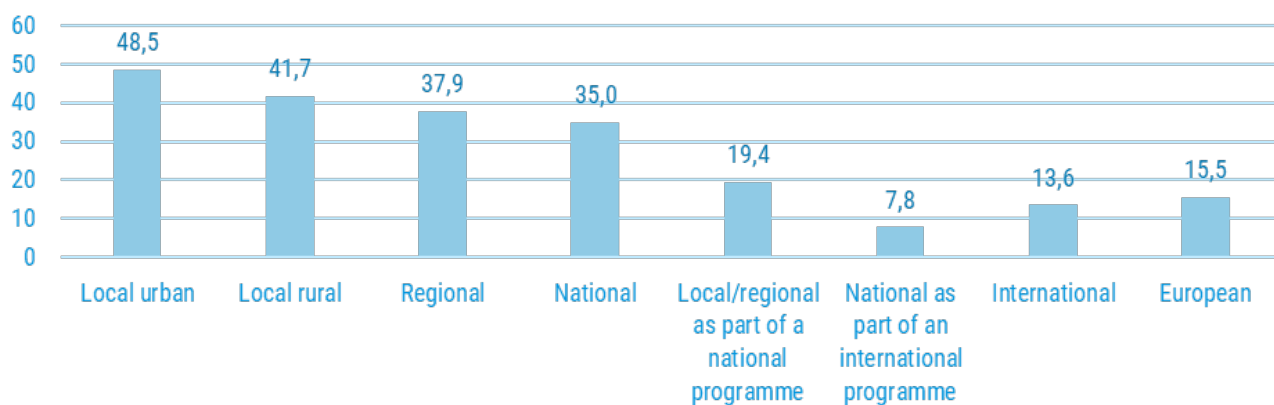


Figure A2.3. Practices by geographic coverage (%)

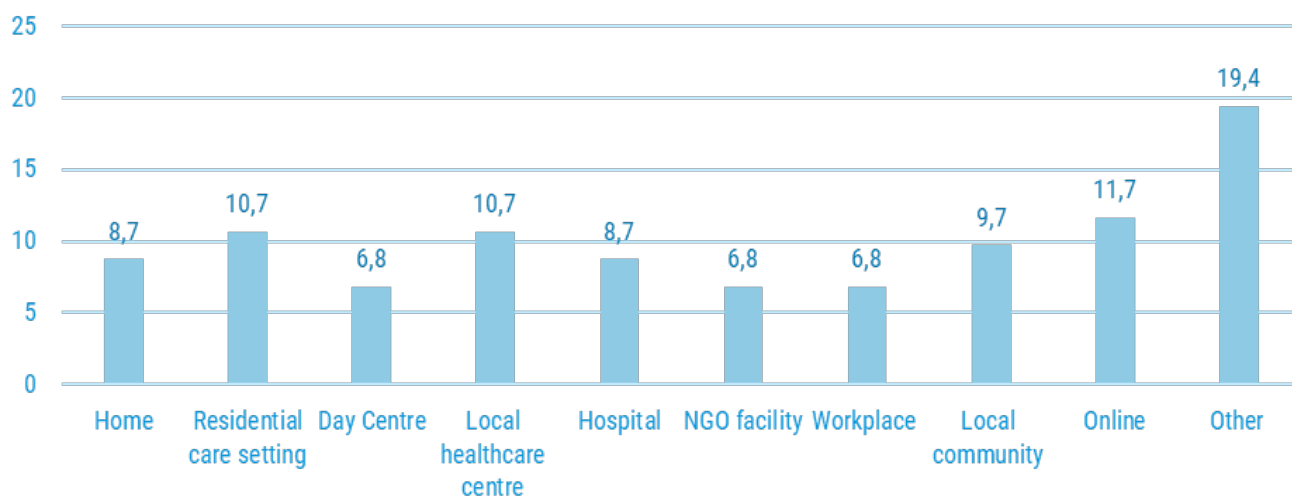


Figure A2.4. Practices by places of delivery (%)

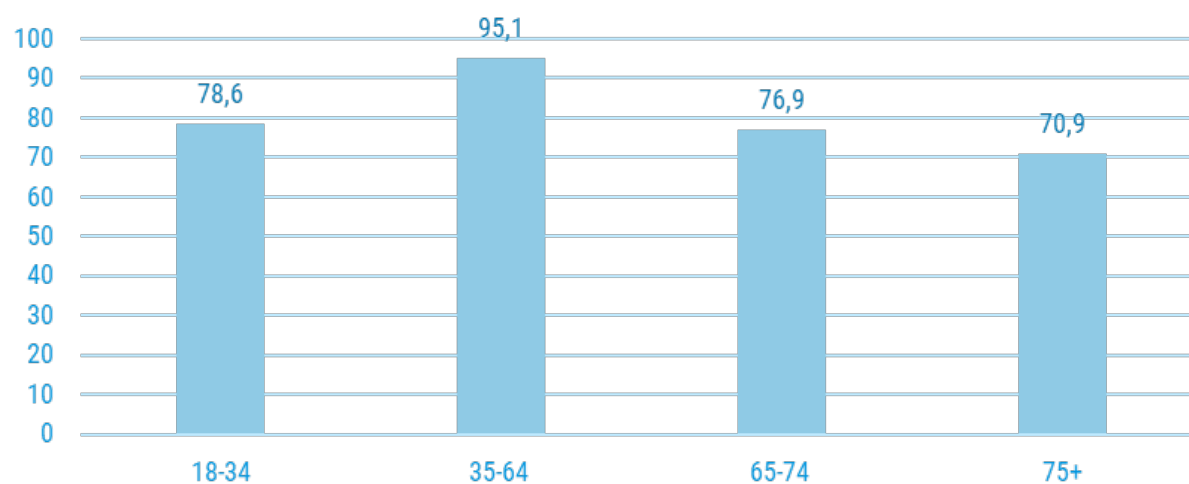


Figure A2.5. Practices by age of the target group (% of total)

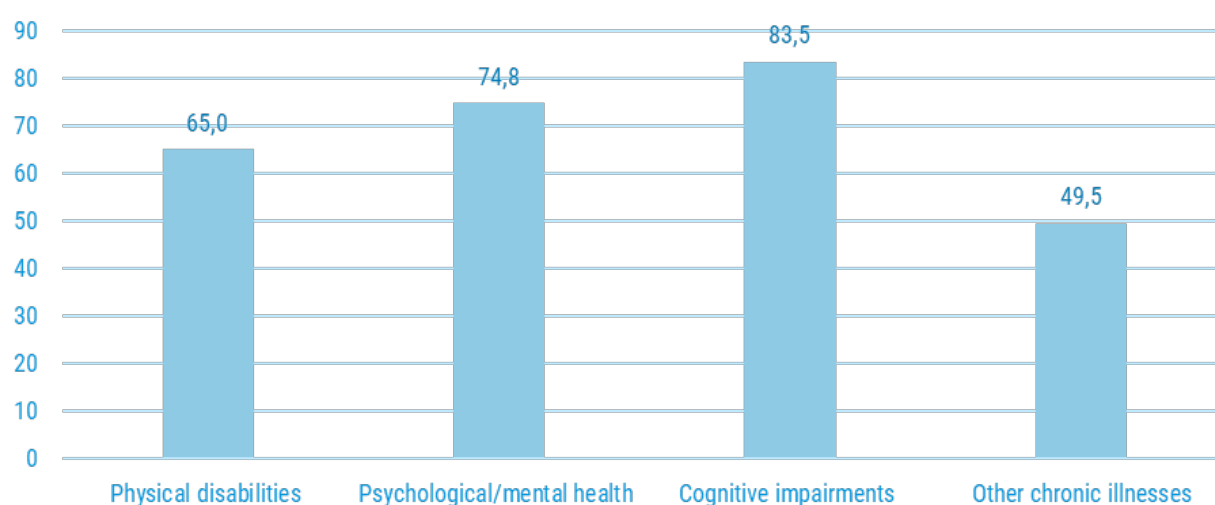


Figure A2.6. Practices by health problems of the care recipients (%)

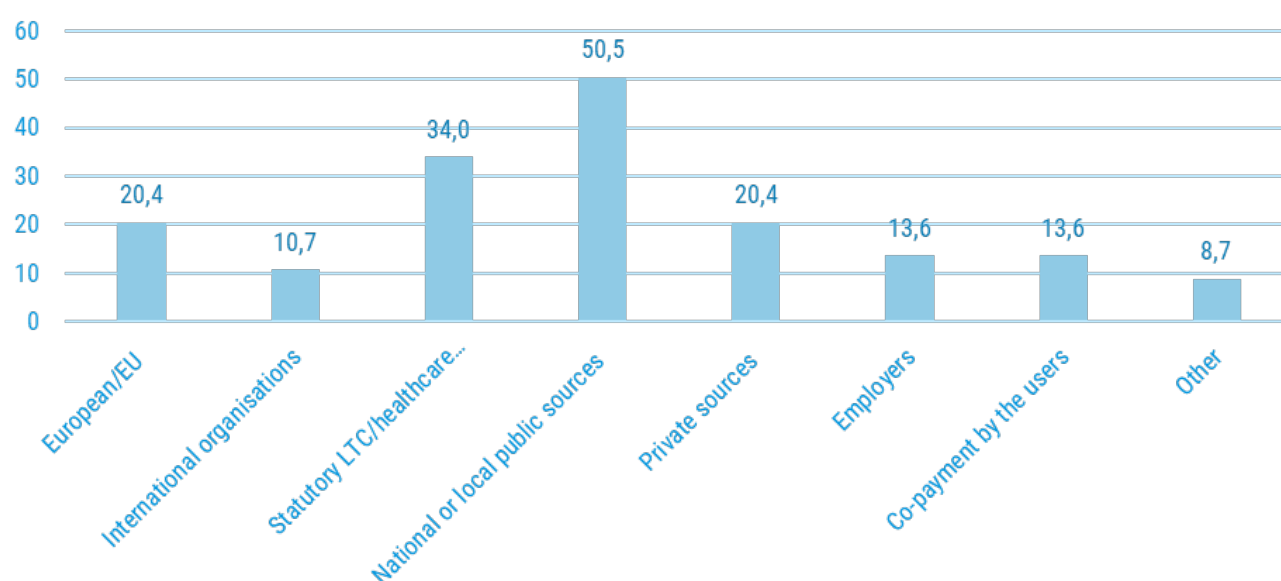


Figure A2.7. Practices by funding sources (%)

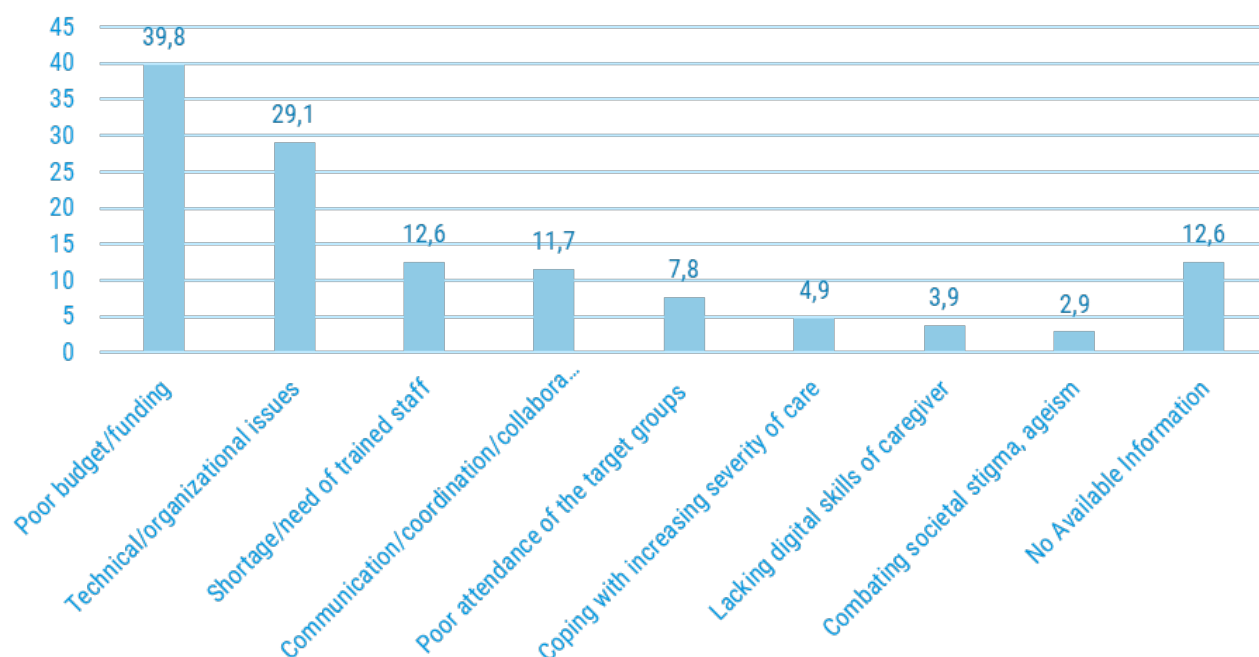


Figure A2.8. Practices by challenges during the implementation (%)

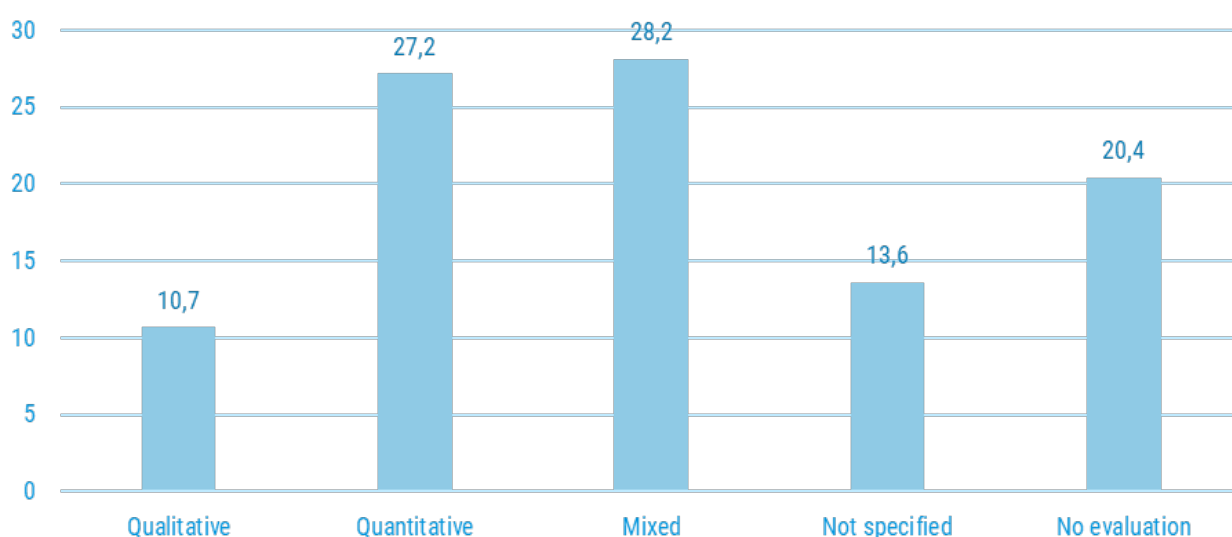


Figure A2.9. Practices by evaluation method (%)

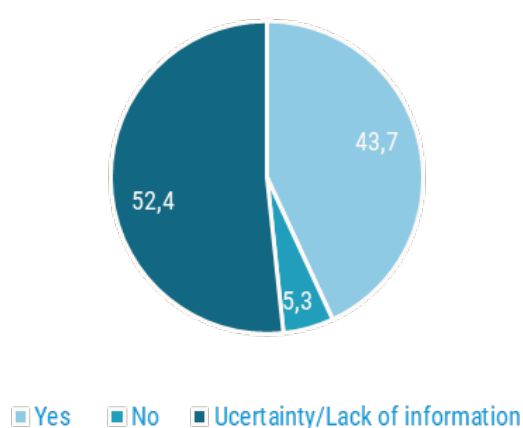


Figure A2.10. Practices by sustainability (%)

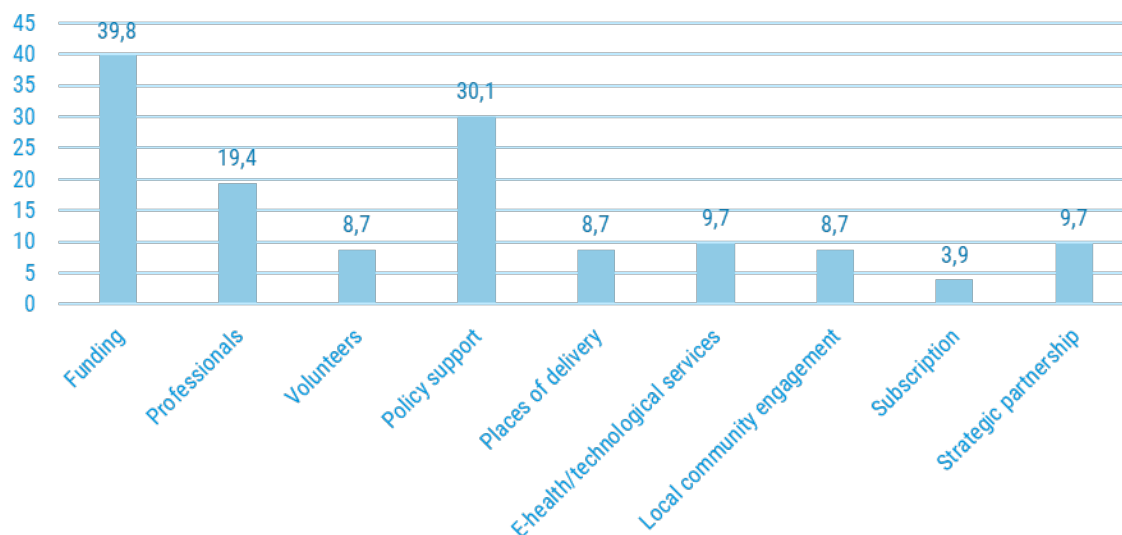


Figure A2.11. Practices by strategy for sustainability (%)

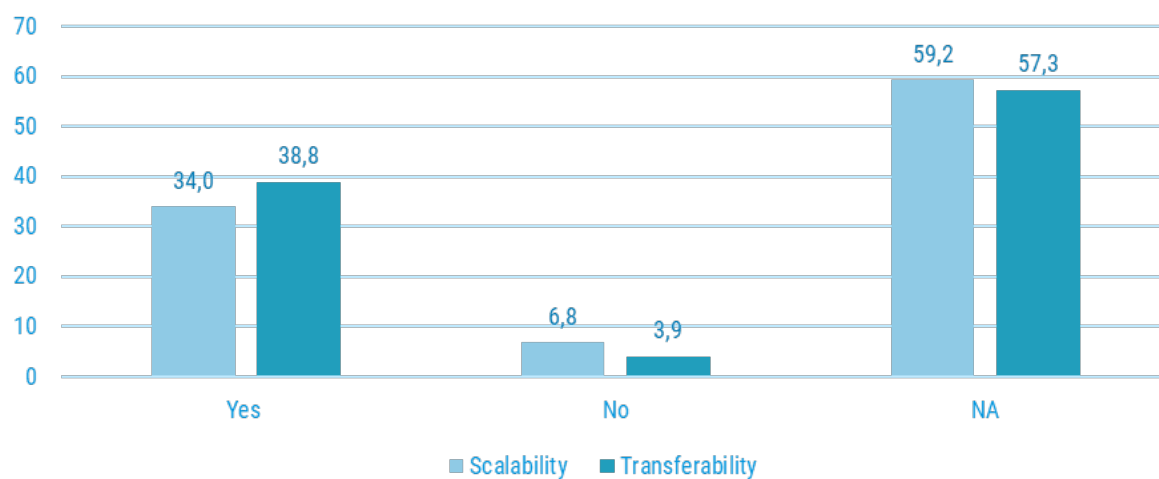


Figure A2.12. Practices by scalability and transferability (%)

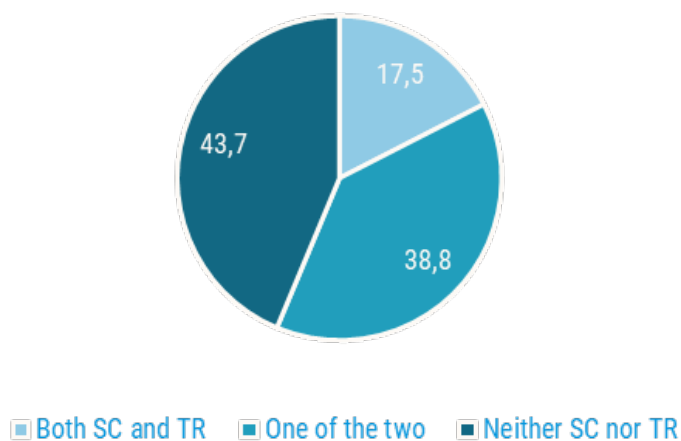


Figure A2.13. Practices by both scalability and transferability (%)

Tables

Table A2.1. Practices by start date and status (% on total)

Start date	Practices	Status	
		Ongoing	Finished
Before 2000	6.8	100.0	0.0
2000-2009	4.9	80.0	20.0
2010-2019	27.2	71.4	28.6
2020-2024	35.9	78.4	21.6
NA	25.2	88.5	11.5
Total	100.0	80.6	19.4

Table A2.2. Practices by number of geographical coverage/levels of operation (absolute values)

Number of geographical coverage/levels	Practices
0	1
1	52
2	20
3	10
4	5
5	8
6	5
7	2
Total	103

Table A2.3. Practices by number of target groups (absolute values)

Number of Target groups	Practices
0	2
1	7
2	34
3	17
4	13
5	11
6	19
Total	103

Table A2.4. Practices by number of outcomes (absolute values)

Number of outcomes	Practices
0	1
1	4
2	15
3	18
4	22
5	29
6	14
Total	103

Annex B: Summary of the main findings from the BLN members' discussions about the criteria

Criteria	Results from BLN session 3	Results from BLN session 4
EXCLUSION CRITERIA		
Relevance	No specific comments.	Importance of the good practices being relevant and aligned with its purpose (DE, SI).
Intervention characteristics	No specific comments.	No specific comments.
Evidence and theory based	The good practices need to be well documented and evaluated (SI).	No specific comments.
Ethical aspects	Importance of high ethical standards, safeguarding autonomy, and ensuring data protection (NL, SI).	Importance of high ethical standards, but it should not be too restrictive and rigid when applied (IT).
CORE CRITERIA		
Effectiveness and efficiency	Important that good practices demonstrably improve the mental well-being of the target groups. Good practices should be successful in various settings. An open, transparent monitoring and evaluation process was deemed necessary. There were variations in the discussions: • Importance of long-term effects • Importance of including both qualitative and quantitative results • Emphasis on the effect • Emphasis on narrative over evidence-based practice. • (DE, NL, SI, SE).	• Measurability of good practices is desirable but can be challenging (NL). • Good practices vary widely, so a single measurement does not work (NL). • Important that the good practices are effective (SI).
Equity	-Fairness was seen to be important. -Equity was also seen to be complex as research on good practices targeting specific groups could then be seen as unfair. -A need for good practices to be accessible to, for example, those with hearing and/or vision impairments. (IT, SE).	Equity is crucial, everyone in the countries should have the same rights (SE).

QUALIFIER CRITERIA		
Transferability	-Transferability was suggested to be a key qualification criterion. -Good practices need to be well-defined, adaptable and flexible for easy transferability (NL, SI, SE).	Transferability was seen as important so that a practice can apply to the larger population (DE, IT, SI, SE).
Sustainability	-Good practices need to include continuity. -Financial, organisational, and environmental sustainability was seen as important. -Follow-up was deemed necessary to assess the long-term effect (IT, NL, SI, SE).	-Sustainability was considered important to ensure the long-term effect (DE, IT, NL, SI, SE). .
Participation	-Importance of listening to all involved throughout the implementation process. -A diversity of informal carers was desirable (e.g., gender, age, and socioeconomic status) (IT, NL, SI, SE).	-Importance of listening to different stakeholders, including various types of informal carers (SI, SE), and to strive for including everyone in the good practice (SI).
Collaboration	-Importance of cooperation among all involved for finding good solutions, improving processes, and achieving goals together (IT, NL, SI, SE).	-Collaboration with multiple stakeholders across domains was deemed essential (NL, SI).
ADDITIONAL CRITERIA, BLN session 3		
Care partnerships	(IT, SE).	-Rather than care partnerships, one should speak of an "alliance between the various actors" to cope with the shortcomings of the service system (IT). -Care partnerships are a core theme in the WELL CARE project and should ideally be incorporated into good practices (NL, SE). -Care partnerships are central to a person-centred approach, ensuring clarity about who does what (SE).
Support	That a good practice supports the target groups (IT, NL).	No specific comments.
A preventive approach	(NL).	-The importance of a preventive approach, prevention is often easier than recovering something that has gone too far (SE).
Caring Communities	Small-scale, community-based care initiatives developed by citizens in villages (NL).	-The Caring communities inspire due to including a broader idea of caring for each other and to build a resilient society (SE).
Different types of good practices	-Those being diverse-sensitive and inclusive. -Urban and rural initiatives should be represented (NL).	No specific comments.

Focus on the care recipient	-Tailor-made care was considered essential. -The care recipient, informal carer, and LTC workers should be seen as equal (NL).	-The focus should not be on the care recipient due to the project goal being the resilience and mental well-being of informal carers and LTC workers. It should be taken for granted that attention to good practices also is beneficial for the care recipients (IT, SE). - The importance of focusing on both the care recipient and informal carers (SE).
Responding to individual needs	(SI).	No specific comments.
Being user-friendly for easy implementation	(NL).	No specific comments.
Being innovative	-Technologies such as AI, eHealth applications, and platforms were seen to facilitate scalability. -If focusing on common practices, there is a risk of overlooking emerging innovations (NL, SI, SE).	-The criterion innovation- if used, should not be too restrictive and exclude a practice that can only develop its innovative potential over time (IT). -Innovation is context-dependent; what is innovative in one setting may not be in another (IT, NL, SE). -A contradiction. Truly innovative suggestions might not fit within the criteria in the EC document, which require thorough documentation and evaluation - something rarely achieved with innovative practices (SE).
Being adaptable	-Possible to adapt to social, cultural, individual, national, or institutional contexts. -Ensuring acceptance and remaining adaptable over time (DE, SI).	No specific comments.
Having a wider impact	-The impact of good practices should extend beyond their initial scope, affecting a wider area. -Success in one area could benefit others (SI, SE).	No specific comments.
Excluding good practices with budget-saving perspective	(NL).	-Importance of choosing practices that focus on managing and optimising costs while ensuring efficiency, rather than simply reducing resources (IT). -The good practice shouldn't only be about saving money, but there's likely no contradiction if the good practice also happens to save money while being beneficial (SE).

Excluding good practices with a system focus	(NL).	The project aims to have practices covering either the micro level (individual level), the meso level (organisational level), or the macro level (the system level) (IT, SE).
ADDITIONAL CRITERIA, BLN session 4		
Social inclusion	-	-To consider the social and cultural foundation as a support and address caregiving more collectively, to foster relationships and care networks (IT). -Social inclusion for persons without family support, offering them options beyond solely formal health services (IT).
Added value	-	- Important to select good practices that add value in some of the perspectives of - effectiveness/evidence-based outcome - financial aspects, c) user experiences of the good practice - practical adoption or acceptance in operational settings (NL).
Focus on both target groups	-	That the good practice focuses on both target groups of informal carers and LTC workers (NL).
Overcome language barriers	-	That the good practice overcomes language barriers for persons who don't speak the local language (SE).

Annex C: Criteria and sub-criteria included in the EC document and the ones selected for the WELL CARE project purposes

Criteria and sub-criteria included in the EC document (European Commission, 2020b) to select best practices for the EU Public Health Best Practice Portal, and their inclusion/not inclusion within the agreed set of criteria and sub-criteria to select good practices in the WELL CARE project

EC document Criteria (Specified eventual renaming and Additional Qualifier criteria- BLNs inputs)	EC document Sub-criteria	EC document sub-criteria included (indicating eventual rephrasing and the code assigned to sub-criteria)/not included (reasons) in the set of agreed criteria (Task 2.2)
EXCLUSION CRITERIA (Renamed as General criteria)		
Relevance	- A priority public health area, a strategy or a response to an identified problem at Local/Regional level, National level or European level, and/or - put in place to support the implementation of legislation	- Included; Rephrased (G1) - Not included (too specific)

Intervention characteristics	• The choice of the target population is clearly described (scope, inclusion and exclusion group, underlying risk factors, etc.) • A detailed description of the methodology used is provided • SMART objectives are defined and actions to take to reach them are clearly specified and easily measurable • The indicators to measure the planned objectives are clearly described (process, output and outcome/impact indicators) • The contribution of the target population, carers, health professionals and/or other stakeholders as applicable was appropriately planned, supported and resourced • The practice includes an adequate estimation of the human resources, material and budget requirements in clear relation with committed tasks • Information on the optimization of resources for achieving the objectives • An evaluation process was designed and developed including elements of effectiveness and/or efficiency and/or equity including information affecting the different stakeholders involved • The documentation (guidelines, protocols, etc.) supporting the practice is presented properly, referenced throughout the text and easily available for relevant stakeholders (e.g. health professionals) and the target population	3. Included; Rephrased (G2) 4. Not included 5. Included and merged with 6; Rephrased (G3) 7-11. Not included (too specific or difficulty to apply in the context of the project)
Evidence and theory based (Renamed as Evidence-informed and theory based)	• The intervention is built on a well-founded theory, is well-documented and is evidence-based • The effective elements (or techniques or principles) in the approach are stated and/or justified	12. Included; Rephrased (G4) 13. Not included (too specific or difficulty to apply in the context of the project)

Ethical aspects	• The expected benefits are superseding the potential harms, including animal welfare • The intervention was implemented proportionally to target group needs • Individuals rights (for example, data protection) have been protected according to national and European legislation • Conflicts of interest (including potential ones) are clearly stated, including measures taken • The practice should not advertise a specific product, device or relate to any commercial initiative • The practice is respectful with the basic bioethical principles of Autonomy (should respect the right of individuals to make their own, informed decisions, based on adequate, timely information); Nonmaleficence (should not cause harm)/ Beneficence (should take positive steps to help others) and Justice (benefits and risks should be fairly distributed)	14. Included; Rephrased (G5) 15-19. Not included (too specific or difficulty to apply in the context of the project)
-------------------------------	---	--

CORE CRITERIA		
Effectiveness and efficiency of the intervention (Renamed as Effectiveness and efficiency)	• Process evaluation: • The practice has been evaluated (internally or externally) taking into account social and economic aspects from both the target population and the perspectives of relevant other stakeholders concerned (e.g. formal or informal caregivers, health professionals, teachers, health authorities), • The evaluation outcomes (e.g. clinical, health, economics) and objectives were linked to the stated goals, • A study has been performed (based on needs and challenges) between the initial and final situation. The purpose of this study would be to determine if the practice was implemented proportionally (i.e. proportional to the identified needs), • The practice has been implemented in an effective and efficient way. • Outcome evaluation: • The outcomes found are the most relevant given the objective, programme theory and the target group for the intervention • All improvements in comparison to the starting point, for example the baseline concerning, e.g. structure, process and outcomes in different areas, are documented and presented • The practice has been evaluated from an economic point of view • The evaluation outcomes demonstrated beneficial impact • Possible negative effects have been identified and stated	20. Included; Rephrased (C1) 21-23. Not included (too specific or difficulty to apply in the context of the project) 24-26 and 28. Not included (too specific or difficulty to apply in the context of the project) 27. Included; Rephrased (C2)
Equity	• The relevant dimensions of equity are adequately and actively considered throughout the process of implementing the practice (e.g. age, gender, socioeconomic status, rural and/or urban area, vulnerable groups), • The practice makes recommendations or guidelines to reduce identified health inequality.	29. Included; Rephrased (C3) 30. Not included (too specific or difficulty to apply in the context of the project)

QUALIFIER CRITERIA		
Transferability	- The practice uses instruments (e.g. a manual with a detailed activity description) that allow for repetition/transfer - The description of the practice includes all organizational elements, identifies the limits and the necessary actions that were taken to overcome legal, managerial, financial, sociocultural or skill-related barriers - The description includes all contextual elements of the beneficiaries (e.g. patients, subpopulation, general population) and the actions that were taken to overcome personal and environmental barriers - A communication strategy and a plan to disseminate the results have been developed and implemented - The practice has already been successfully transferred / repeated - The practice shows adaptability to different contexts and to challenges encountered during its implementation	31. Included; Rephrased (Q1) 32-34. Not included (too specific or difficulty to apply in the context of the project) 35. Included (Q2) 36. Included; Rephrased (Q3)
Sustainability	- The practice has institutional support, an organizational and technological structure and stable human resources, - The practice presents a justifying economic report, which also discloses the sources of financing, - The continuation of the practice has been ensured through institutional anchoring and/or ownership by the relevant stakeholders or communities in the medium and long term in the planning of the practice, - The practice provides training of staff in terms of knowledge, techniques and approaches in order to sustain it - A sustainability strategy has been developed that considers a range of contextual factors (e.g. health and social policies, innovation, cultural trends and general economy, epidemiological trends, environmental impact, migration and cross-border movement).	37. Included; Rephrased (Q4) 38. Included; Rephrased (Q5) 39. Included; Rephrased (Q6) 40. Included; Rephrased (Q7) 41. Not included (too specific/difficult to apply in the context of the project)

Intersectoral Col- laboration (Remamed as Col- laboration)	• Several sectors collaborated to carry-out the practice, • A multidisciplinary approach is supported by the relevant stakeholders (e.g. health and social care professionals at all levels, civil society, public institutions from education, employment and digital services), • It promotes the continuity of care through the coordination between social and health services (if applicable), • The practice creates ownership among the target population and several stakeholders considering multidisciplinary, multi-/inter-sectoral, partnerships and alliances (if applicable).	42. Included and merged with 43; Rephrased (Q8)
Participation	• The structure, organization and content (also evaluation outcomes and monitoring) of the practice was defined and established together with one or more of the following: the target population and families or caregivers and more relevant stakeholders and civil society, • Mechanisms facilitating participation of several agents involved in different stages of the intervention as well as their specific role, have been established and well described, • Elements are included to promote empowerment of the target population (e.g. strengthen their health literacy, ensuring the right skills, knowledge and behaviour).	46. Included; Rephrased (Q10) 47-48. Not included (too specific or difficult to apply in the context of the project)
Care partnerships (Additional Quali- fier criteria - BLNs input)	The practice promotes or has the potential to promote/ foster care partnerships/alliances between informal carers and LTC workers (i.e. the project target population) and/or other relevant stakeholders from several sectors (e.g. LTC, health and social care, civil society, public institutions, policy, academia/research, LTC workers' employer organisations, trade unions, mental health and/or carers' associations, home, community and residential care settings, etc.)	Additional Qualifier sub-criteria (Q9)
Innovation (Additional Quali- fier criteria - BLNs input)	The practice entails social innovation* The practice entails technology innovation**	Additional Qualifier sub-criteria (Q11) Additional Qualifier sub-criteria (Q11)

Annex D: Template to collect information on potential/promising good practices (GLR) in Task 2.1

WELL CARE PROJECT

WP2 - REVIEW, SELECTION, AND ANALYSIS OF GOOD PRACTICES

TASK 2.1. GREY LITERATURE REVIEW

TEMPLATE TO COLLECT INFORMATION ON POTENTIAL/PROMISING GOOD PRACTICES TO SUPPORT LTC WORKERS AND/OR INFORMAL CARERS' RESILIENCE AND MENTAL WELLBEING

Premise

The WELL CARE project aims to identify promising/good practices and innovative solutions implemented mainly in Europe to support Long-Term Care (LTC) workers and/or informal carers' resilience and mental wellbeing, with attention to care partnership (i.e. the coordination, integration, and mutual recognition of care and caring activities performed by LTC workers and informal carers, in a vision of integrated LTC).

This template is aimed to collect information on practices implemented from 2013 to 2024, still active/long-standing (or finished for 1-3 years) in the EU-27 Member States, the United Kingdom, and the EFTA countries (i.e. Norway, Switzerland, Iceland, and Liechtenstein), with a focus for practices in Germany, Italy, the Netherlands, Slovenia and Sweden.

ID (will be filled in by the WELL CARE project staff)	
Name of the organisation implementing the practice	
Website of the organisation, if available	
Country of the organisation	
Name of the practice	
Website of the practice, if available	
Name of the contact person of the practice (or of the organisation) (who fills in this template)*	
Mail of the contact person of the practice (or of the organisation) (who fills in this template)*	
Short summary description of the practice (max 300 words)	Free text
Overall goal and specific objectives (max 300 words)	Free text

Geographic coverage/implementation level Please, tick all that apply	1. Local urban 2. Local rural 3. Regional 4. National (specify the country:) 5. Local/regional as part of a national programme 6. National as part of an international programme 7. International (specify the countries:) 8. European
Main setting/place of delivery	1. Home 2. Residential care setting 3. Day Centre 4. Local healthcare centre (e.g. ambulatory) 5. Hospital 6. NGO facility 7. Workplace 8. Local community 9. Online 10. Other (specify:)
Start date of the practice	Entering start date: Month/Year
Status of the practice	1. Ongoing 2. Suspended for 1-3 years 3. Finished for 1-3 years 3. Finished for 4 years or more
Target group(s) of the practice Please, tick all that apply	1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers) 2. Working carers (combining paid work with informal care) 3. Qualified nurses 4. Assistant nurses 5. Personal care workers (including privately-hired migrant care workers) 6. Other LTC workers/health and/or social care professionals (specify:)

Age profile of the target group(s) of the practice Please, tick all that apply	1. 18-34 years 2. 35-64 years 3. 65-74 years 4. 75+ years
Gender composition of the target group(s) of the practice	1. Mainly males 2. Mainly females 3. Both males and females 4. Other
Care recipients assisted by the target group(s) Please, tick all that apply	1. Physical disabilities (caused, e.g. by frailty, accident, injury, illness, etc.) 2. Psychological/mental health issues (e.g. depression, anxiety, etc.) 3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.) 4. Other chronic illnesses/long-term health conditions (specify:)
Age profile of the care recipients assisted by the target group(s) Please, tick all that apply	1. Children/Youths (0-12 years) 2. Adolescents (13-17 years) 3. Adult people (18-64 years) 4. Older people (65+ years)
Main outcomes/impact of the practice Please, tick all that apply	1. Improving resilience 2. Improving mental wellbeing 3. Reducing/minimising negative aspects of caring and working in LTC settings (e.g. depression, anxiety, stress) 4. Enhancing informal carers' and/or LTC workers' satisfaction 5. Fostering care partnerships 6. Other (specify:)
Challenges/difficulties faced during the implementation (e.g. poor budget, lack of trained professionals, scarce time availability of the target group, lack of adequate spaces, etc.) (max 300 words)	Free text
Measurement/Evaluation (this can be quantitative, qualitative or mixed methods) (reporting any evidence of formal assessments carried out on the practice or the indicators used to measure its effectiveness, also including any list of references (written documentation, reports, articles) where available relating to the practice.) (max 300 words)	Free text

Sustainability (reporting any eventual evidence on how to ensure the sustainability of the practice in the long-term, e.g. availability of funding, professionals, volunteers, places of delivery, e-health/technological services/instruments/devices, policy support, etc.) (max 300 words)	Free text
Scalability and transferability (reporting any eventual evidence related to the potential of scalability of the practice - e.g. its growing potential/performance - and its transferability in other - national, regional, local -geographical contexts, and settings) (max 300 words)	Free text
Legislative framework (if any) (describing/mentioning eventual laws/norms/policy frameworks according to which the practice has been implemented)	Free text
Total budget in Euro	
Funding source Please, tick all that apply	1. European/EU funds 2. International organisations funds 3. Statutory LTC/healthcare financing system 4. National or local public sources (e.g. general tax revenue, social care funds) 5. Private sources (e.g. donations, private insurers) 6. Employers 7. Co-payment by the users/target groups ('out of pocket' money) 8. Other (specify:)
Source/s to collect information (to apply only to practices found in databases/repositories/websites, e.g. EU Health Best Practice Portal, etc.)	

* In the cases where who fill-in the template is a project team member (research partners or EU and national advocacy partners), please insert its name and e-mail in such boxes.

Annex E: Template to report good practices

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

Number of good practice	(report the ID)
Ranking of the good practice	(report the ranking, i.e. the sum of the scores after the application of the criteria)
Type of good practice	Please, select the main type (even in case the practice has characteristics that could be related to more types) 1. Primary, secondary and tertiary prevention interventions 2. Interventions or programmes dealing with organisational models and management approaches and/or targeted at the individual level 3. Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives 4. Integrated approaches and strategies 5. Interventions and programmes targeted at LTC workers and/or informal carers with pre-existing mental health conditions favouring work-life balance for LTC workers who also assume informal caring responsibilities 6. Community-based initiatives/measures 7. International or national strategies and initiatives launched/implemented by various institutions 8. Other
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	
Name of the good practice in original language (if available)	
Initiative in operation since	(i.e. year)
Country/ies of implementation	

Geographic coverage/ implementation level	Please, select all that apply 1. Local 2. Regional, national 3. Cross-country/International
Stage of initiative	Please, select the appropriate one 1. Ongoing 2. Suspended for 1-3 years 3. Finished for 1-3 years 4. Finished for 4 years or more
Name of the Leader/s Organisation/implement- er/s	(i.e. organisation/s in charge of coordinating the initiative: name in original language and in English, where possible)
Contact details	(i.e. name of the contact person - corresponding authors for papers - address, phone number, e-mail)
Type/source(s) of fund- ing	Please, select all that apply 1. European/EU funds 2. International organisations funds 3. Statutory LTC/healthcare financing system 4. National or local public sources (e.g. general tax revenue, social care funds) 5. Private sources (e.g. donations, private insurers, foundations) 6. Employers 7. Co-payment by the users/target groups ('out of pocket' money) 8. Other (specify:)
Webpage/s of the good practice (or link to doi of the paper)	
Summary (abstract)	(max 300 words)
Keywords	(i.e. report 3-5 keywords)

DESCRIPTION OF THE GOOD PRACTICE

	Description of the good practice (<i>e.g. aims and objectives, main characteristics, type, why the initiative was developed, what needs/gaps are covered, and how it was realised</i>) (max 300 words)
	Main setting(s)/place(s) of delivery Please select all that apply. There is the possibility to add additional explanatory text if appropriate/feasible (max 300 words) 1. Home 2. Residential care setting 3. Day Centre 4. Local healthcare centre (e.g. ambulatory) 5. Hospital 6. NGO facility 7. Workplace 8. Local community 9. Online 10. Other (specify:)
	Target group(s)/beneficiaries Please select all that apply. There is the possibility to add additional explanatory text (eventually also including information on gender composition) if appropriate/feasible (max 300 words) 1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers) 2. Working carers (combining paid work with informal care) 3. Qualified/registered nurses 4. Assistant nurses 5. Personal care workers (including privately-hired migrant care workers) 6. Other LTC workers/health-social care professionals (specify:)
	Age profile(s) of the target group(s) of the practice Please select all that apply. There is the possibility to add additional explanatory text if appropriate/feasible (max 300 words) 1. 18-34 years 2. 35-64 years 3. 65-74 years 4. 75+ years

	Health issues of the care recipients assisted by the target group(s) Please select all that apply. There is the possibility to add additional explanatory text if appropriate/feasible (max 300 words) 1. Physical disabilities (caused, e.g. by frailty, accident, injury, illness, etc.) 2. Psychological/mental health issues (e.g. depression, anxiety, etc.) 3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.) 4. Other chronic illnesses/long-term health conditions (specify:)
	Age profile(s) of the care recipients assisted by the target group(s) Please select all that apply. There is the possibility to add additional explanatory text if appropriate/feasible (max 300 words) 1. Children/Youths (0-12 years) 2. Adolescents (13-17 years) 3. Adults (18-64 years) 4. Older people (65+ years)
	Problem being addressed <i>(Please describe occupational risks - e.g. heavy workload, stressful working conditions, night shifts, risk of exposure to infectious agents, precariousness, ethical stress, etc. - and non-occupational risks - based on factors such as gender, age, migration background, socio-economic status, the quality of the care partnership - for the targets)</i> <i>(max 300 words)</i>
	Measurement/evaluation <i>(Please report any evidence of formal assessments carried out on the practice or the indicators used to measure its effectiveness, also including any list of references - written documentation, reports, articles - where available relating to the practice. Evidence can be obtained through quantitative, qualitative or mixed methods).</i> <i>(max 300 words)</i>
	Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency) Please select all that apply. Please add additional explanatory text wherever feasible (max 300 words) 1. Improving resilience 2. Improving mental wellbeing 3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress) 4. Enhancing informal carers' and/or LTC workers' satisfaction 5. Fostering (or potential to foster) care partnerships 6. Improving organisational practices 7. Cost-effectiveness 6. Other (specify:)

	Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked) <i>(e.g. sharing care, sharing knowledge, coordination of care, mutual recognitions of each other's roles and knowledge relationship as its own support/emotional support involving our project target groups, etc. - see the Guide D3.1 for details/more information as a point of reference)</i> <i>(max 300 words)</i>
	Equity (including ethics) <i>(Please report available information about relevant dimensions of equity considered in the design/implementation of the practice, e.g. age, gender, socioeconomic status, rural and/or urban area, vulnerable groups as e.g. people with hearing and/or visual/impairments, chronic illnesses, multimorbidity, without family support, with language barriers, etc. Please also report any ethical aspects related to the practice, e.g. availability of an Ethical Approval, how expected benefits are superseding the potential harms, data protection ensured, etc.)</i> <i>(max 300 words)</i>
	Sustainability <i>(Please report any eventual evidence on how to ensure the sustainability of the practice in the long-term, e.g. availability of funding, professionals, volunteers, places of delivery, e-health/ technological services/instruments/devices, policy support, etc.)</i> <i>(max. 300 words)</i>
	Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/ local) contexts <i>(Please report any eventual evidence related to the potential of scalability of the practice - e.g. its growing potential/performance - and its transferability/adaptability/implementability in other - national, regional, local - geographical contexts, settings, etc.)</i> <i>(max 300 words)</i>
	Collaboration with and/or participation of different stakeholders and sectors <i>(Please report any eventual evidence related to e.g. health and social care, long-term care, civil society, public institutions from education, employment and digital services, policy, academia/research, LTC workers' employer organisations, trade unions, mental health and/or carers' associations - and their representatives - etc.)</i> <i>(max. 300 words)</i>
	Innovative aspects, if any <i>(Please report any eventual evidence related to e.g. social and/or technological innovations of the practice)</i> <i>(max. 300 words)</i>
	Barriers, challenges/points of weakness (and solutions to them, if applicable) <i>(Please report any eventual evidence related to e.g. poor buget, lack of trained professionals, scarce time availability of the target group, lack of adequate spaces, etc. and considering all the above to also describe any identified solutions or major lessons learned to address these existing barriers/challenges/points of weakness)</i> <i>(max 300 words)</i>
	Key success factors/points of strength <i>(Please report any eventual evidence related to e.g. adequate buget, trained professionals, time availability of the target group, adequate spaces, participatory co-design, leadership, political support, community engagement, etc. and considering all the above to try to "summarise" the main positive lessons learned)</i> <i>(max 300 words)</i>

Annex F: Expert interviews: the coding process

Table F1. Example of the coding process of the Italian experts

Quotes	First-order concepts – open coding (Gioia et al., 2013)	Second-order - axial coding (Gioia et al., 2013)	Third-order coding (Gioia et al. 2013)
"We do not have, unlike many Northern European countries, the culture of evaluation, so we activate practices that are often innovative in nature but that are not followed by a path that leads to an effective evaluation of merit" (EXP-IT-1) "Long-term continuity is another important factor" (EXP-IT-2) "What happens is that the family caregiver, but also informal caregivers, when they receive the diagnosis, no longer (consider him/her) a partner... We do a lot to make the diagnosis, but we do little to intercept the family member there (in that context)" (EXP-IT-5)	Lack of evaluation culture in Italy Importance of long-term evaluation Caregiver needs are not evaluated at diagnosis	Weak culture of evaluation in care sector	Systematic and evidence-based evaluation
"In many cases once the project is closed, everything is cancelled and no trace remains of what that type of practice has taught" (EXP-IT-1) "We must always keep in mind the evidence of benefits to stakeholders. In my opinion, a good practice should highlight the benefits provided to all stakeholders" (EXP-IT-4)	Loss of learning from unevaluated practices Multi-stakeholder benefit assessment needed	Lack of systematic and structured evaluation	
"A good practice should show that it has produced benefits for all stakeholders and it should clearly highlight what benefits, in order to allow a comprehensive assessment" (EXP-IT-4)	Need for explicit benefit documentation	Need for indicators to measure effectiveness	
"For example, an association that provides a service to disabled people, maybe carries out a good practice, but does not have the tools or even the funding to be able to pay an evaluating body to monitor this good practice" (EXP-IT-3)	Resource constraints for evaluation	Challenge of obtaining external evaluation	
"Then also having evaluation indicators, because in any case these good practices must then be measured against the objectives" (EXP-IT-2)	Need for objective-aligned metrics	Need for indicators to measure effectiveness	

Annex G: Templates reporting findings of the 40 selected good practices

Index

Culturally informed psychoeducational course for Charedi Orthodox Jewish Community (Charedi OJC)	97
Early Positive Approaches to Support (E-PATs) for Families of Young Children with Intellectual Disability	102
Family Carers Training	107
Carers' Alert Thermometer for Stroke Family Caregivers (CAT-S)	111
Augmentative and Alternative Communication Intervention (AAC)	115
LIVIND - A lifestyle monitoring system to support (in)formal caregivers of people with dementia	119
E – Qalin – Quality Management Model	124
REACT-NOR – Norwegian version of the Relatives Education and Coping Toolkit	128
Digital support for quality assurance in 24-hour caregiving at home	136
pflegen-und-leben.de (care and live)	140
Assertive Community Treatment (ACT) Teams	144
Supporting Families Living with Dementia in Rural Areas	148
Rosetta: a web-based e-learning platform for informal carers of people with dementia	155
Care at home	161
Mobile Technology for Personalised Reminiscence for People Living with Dementia and their Carers	164
Video Conferencing Peer Support and Rarer Forms of Dementia	168
Partner In Balance (PIB)	171
Psychoeducation program for patients with bipolar disorder and their caregivers	176
Open Dialogues	180
Act Belong Commit	185
Staff Training Programme and Family Liaison Service	190
Inclusive Culture Program	194
Meeting Centres Support Programme (MCSP)	199
Care Companion Web-Based Information Resource for Supporting Informal Carers of Older People	204
Carer Supporter Programme	207
Carers Outcome Agreement Tool (COAT)	214

<u>Web-based mindfulness intervention for families living with mental health problems</u>	218
<u>Colourful Unburdening</u>	221
<u>Rehabilitation Enablement in Chronic Heart Failure (REACH-HF)</u>	225
<u>The Renaissance of Workforce Models in France's Mental Healthcare</u>	229
<u>Meeting centres support program (MCSP)</u>	233
<u>Community Care Dongen</u>	240
<u>Community Houses</u>	247
<u>Integrated care intervention for the frail elderly on informal caregivers</u>	251
<u>The Wulverhorst</u>	258
<u>MOST project – Integrated care in Krško Municipality</u>	265
<u>Cognitive-behavioural intervention for Dementia caregivers' coping with pre-death grief</u>	269
<u>The conversation with (caring) relatives</u>	273
<u>The online training with app for LTC workers (RESIST)</u>	277
<u>Training informal caregivers to care for older people after stroke (InCARE program)</u>	281

N.B. The order of the 40 selected good practices in this Annex is based on their ranking, commencing with the highest ranked practice first and so on. For each completed template, in the ID number right hand side column, their source is also specified- namely- if they were identified by the SLR or GLR respectively.

Culturally informed psychoeducational course for Charedi Orthodox Jewish Community (Charedi OJC)

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	260 SLR
Ranking of the good practice	1
Type of good practice	3. Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives Also related to: 6. Community-based initiatives/measures
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Culturally informed psychoeducational course for Charedi Orthodox Jewish Community (Charedi OJC) to raise awareness of mental health and improve the well-being of carers
Name of the good practice in original language (if available)	idem
Initiative in operation since	June 2016 men's course and November 2016 women's course
Country/ies of implementation	United Kingdom
Geographic coverage/ implementation level	1. Local (Stamford Hill Area in North-London; Hackney, population: Charedi OJC)
Stage of initiative	1. Ongoing The pilot was in 2016 but the paper mentions continued delivery: course being part of the educational program for Rabbis and Rebbetsens.
Name of the Leader/s Organisation/implementer/s	The City and Hackney Black and Minority Ethnic (BME) Access Service (East London NHS Foundation Trust - ELFT) Bikur Cholim, a local third-sector organisation
Contact details	East London NHS Foundation Trust, Raybould Centre, Homerton Hospital, London E9 6SR, UK, aradhana.perry@nhs.net
Type/source(s) of funding	4. National or local public sources (e.g. general tax revenue, social care funds) The project was funded by The Psychological Therapies Alliance through the City and Hackney Clinical Commissioning Group (CCG), which is part of the UK National Health Service (NHS).
Webpage/s of the good practice (or link to doi of the paper)	DOI: https://doi.org/10.1177/0020764018756935

Summary (abstract)	This article describes a community-based partnership project for the Charedi Orthodox Jewish community (OJC). The City and Hackney Black and Minority Ethnic (BME) Access Service (East London NHS Foundation Trust) collaborated with Bikur Cholim, a local third-sector organisation within the Charedi community based in North London, to develop a brief culturally tailored psychoeducational course focusing on mental health promotion and prevention. In total, 34 informal and formal carers were provided with general information on mental health, availability of support services, and self-care. Overall improvements in well-being, increased intentions to access services—particularly talking therapies—and qualitative feedback indicated the group was very well received. The project endorses the value of culturally relevant psychoeducation, enabling suggestions for culturally appropriate service development.
Keywords	Psychoeducation, Mental Health, Charedi, Orthodox Jewish

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

The initiative aimed to empower Charedi OJC carers by enhancing their knowledge, attitudes, and behaviors related to mental health. It sought to teach proactive strategies to facilitate healthy responses and reduce carer burnout. Additionally, it aimed to reduce stigma associated with mental health conditions and improve access to statutory services. The initiative was a culturally informed psychoeducational course designed to raise awareness of mental health and improve the well-being of carers in the Charedi OJC. It involved providing quality information on recognizing early changes in mental states and managing difficult periods. The initiative was a psychoeducational intervention, with a strengths-based approach focusing on education, collaboration, acceptance, and empowerment. It was developed to address the need for education to improve local community knowledge of mental health and promote awareness of appropriate services available. This was identified through initial discussions and consultations. The initiative fostered to cover gaps in mental health knowledge and service accessibility within the Charedi OJC. It aimed to facilitate earlier help-seeking and intervention from appropriate services, potentially leading to better health outcomes for both carers and care recipients. The course was delivered through a partnership with mental health professionals and was integrated into the Continuing Professional Development (CPD) Educational Programme for Rabbis and Rebbetsens.

Main setting(s)/place(s) of delivery

4. Local healthcare centre (e.g. ambulatory): Bikur Cholim's facility, local (NHS) mental health clinic
8. Local community: The course was delivered within the community, specifically targeting the Charedi Orthodox Jewish community in Stamford Hill, North London.

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)
6. Other LTC workers/health-social care professionals (health professionals, mental health support workers, family workers, Rabbis/Rebbetsens, teachers, trustees, and welfare officers)

The course was attended by informal caregivers, including service users, family, friends, neighbors, and volunteers, who are involved in caring roles.

The participant population included formal care providers.

Age profile(s) of the target group(s) of the practice

1. 18-34 years
2. 35-64 years
3. 65-74 years

The majority of participants in the study were aged between 25 and 34 years.

Health issues of the care recipients assisted by the target group(s)

2. Psychological/mental health issues (e.g. depression, anxiety, etc.)

The primary focus of the intervention was on mental health conditions, aiming to improve the knowledge and attitudes of carers towards mental health issues such as depression and anxiety.

Age profile(s) of the care recipients assisted by the target group(s)

The provided context does not specify the age profiles of the care recipients assisted by the participants.

Problem being addressed

- Heavy Workload and Stressful Conditions: Carers in the Charedi OJC face significant stress due to the demanding nature of caregiving, which can lead to burnout. The psychoeducational course aims to address these issues by providing strategies for self-care and stress management;
- Cultural and Ethical Stress: The Charedi OJC experiences unique cultural pressures, including concerns about violating religious laws and mistrust of outsiders, which can exacerbate stress and hinder access to mental health services;
- Gender and Socio-Economic Status: The Charedi OJC is characterized by large family sizes and a structured lifestyle, which can impose additional socio-economic pressures on carers, often women, who may have limited access to external support;
- Migration Background: As a community primarily composed of Holocaust refugees and their descendants, there may be historical trauma and a heightened sensitivity to mental health issues, impacting their willingness to seek help;
- Quality of Care Partnership: The lack of sufficient information and awareness about available support services, coupled with concerns about confidentiality and stigma, affects the quality of care partnerships and the community's engagement with statutory services.

Measurement/evaluation

- Quantitative assessment: The effectiveness of the psychoeducational course was measured using the Warwick-Edinburgh Mental Well-Being Scale (WEMWBS), a self-report measure assessing general well-being;
- Qualitative Feedback: Participants provided qualitative feedback through an evaluation questionnaire, which was analyzed thematically;
- Mixed-Method Design: The study employed a mixed-method design, combining quantitative pre- and post-test measures with qualitative feedback to assess the course's effectiveness and acceptability;
- References: The study cites the National Institute for Health and Care Excellence (2014) and Interlink, Orthodox Jewish Voluntary Action (2014) as part of its literature review and contextual background.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience

The course helped participants feel more empowered and better connected, which is an indicator of increased resilience. Participants expressed that they received new strategies and information to cope with their roles, suggesting that the course may contribute to building personal resilience over time.

2. Improving mental wellbeing

Quantitative measures showed statistically significant improvements in mental wellbeing scores among participants following the course. Although the effect was small, the change was considered important on an individual level, indicating enhanced mental wellbeing.

3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)

Enhancing knowledge on early signs of mental health issues and available support services might contribute to lowering risks of severe psychological distress among carers.

4. Enhancing informal carers' and/or LTC workers' satisfaction

Feedback from the evaluation questionnaire indicated high satisfaction with the course, with the majority of participants strongly agreeing that the course was helpful, relevant, and well structured

5. Fostering (or potential to foster) care partnerships.

The initiative integrated a range of stakeholders from informal and formal care with access to the psychoeducational course. It fosters shared learning, mutual understanding.

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

The project can foster care partnerships among LTC workers, informal carers, and other stakeholders by bringing together trusted community figures, mental health professionals, and statutory service representatives. Furthermore, the intervention promoted the sharing and exchange of knowledge between all involved parties. Mutual recognition of roles can play an important role in breaking down traditional barriers. The project highlighted the benefits of sharing care responsibilities through coordinated efforts.

Equity (including ethics)

- **Urban Focus and Vulnerable Communities:** the intervention specifically targeted the Charedi Orthodox Jewish community in North London, a distinct ethnic minority with unique cultural practices and challenges;
- **Age, Gender, and Social Roles:** the project recognized the diversity within the community, implementing gender-separated sessions to adhere to cultural customs. This approach ensured that both men and women received tailored information in an environment where they felt comfortable and respected, thus promoting inclusivity in care delivery;
- **While the content was designed for those in caregiving roles,** which could include any age group, the focus on informal carers meant engaging people regardless of age, ensuring that the benefits of the course were shared among a broad spectrum of community members;
- **Socioeconomic Considerations:** the initiative included aspects of reaching out to carers who might face socioeconomic challenges, such as large family dynamics and limited resources, that typically inhibit access to private sector support. By collaborating with trusted community organizations like Bikur Cholim and local statutory services, the course sought to reduce inequalities in service awareness and access;
- **Ethical Aspects and Data Protection:** the project ensured that the intervention was culturally acceptable and respectful of community norms. The course was designed after extensive consultation with community leaders and stakeholders, respecting religious and cultural practices throughout its planning and implementation. The paper does not specify an Ethical Approval process explicitly.

Sustainability

- The initiative has planned for continued delivery by mental health professionals in the third sector, which indicates that trained professionals are already in place to provide the service on an ongoing basis;
- The Rabbinical Council of United Synagogues (RCUS) has requested the inclusion of the course in their Continuing Professional Development (CPD) Educational Programme;
- The course's collaboration with statutory services and third-sector organisations indicates that it is part of a larger framework aimed at reducing mental health disparities among under-represented groups;
- The course was organised under the auspices of the Chief Rabbi of the United Synagogue of Great Britain and the Commonwealth, which provides significant credibility and encourages trust both within the community and among service providers;
- The partnership between Bikur Cholim, the City and Hackney BME Access Service, and other statutory organisations strengthens the financial sustainability by pooling resources and shared expertise;
- Sustainability is also supported by the course's deep cultural alignment, making it highly acceptable within the target community. By addressing cultural norms and leveraging respected community figures, the intervention remains relevant and appealing, which is important for continued participation and support. The course's design, which includes culturally appropriate delivery techniques such as gender-segregated sessions and the use of community-relevant materials, helps maintain engagement over the long term.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

This initiative - psychoeducational course - is specifically adapted for the Charedi Orthodox Jewish Community, but aspects of the course design can be transferred after adaptation:

- The integration of both mental health professionals and community leaders (such as Rabbis) in the delivery of the course provides a robust framework that can be expanded. This dual delivery approach can be replicated in different settings where community trust is essential;
- The course content, which combines psychoeducational material with local anecdotes and religious narratives, provides a template that can be tailored to meet the cultural and social preferences of other under-represented or ethnic communities.

Collaboration with and/or participation of different stakeholders and sectors

The initiative was the result of collaboration between various sectors:

- The course was delivered in partnership with Bikur Cholim, a leading third-sector organization in mental health care for the Charedi community, and the City and Hackney BME Access Service (ELFT);
- The involvement of a Rabbi and a Charedi Orthodox Jewish psychotherapist, acted as gatekeepers and bridges between the community and formal services;
- Public institutions like the Rabbinical Council of United Synagogues (RCUS) and support from the Chief Rabbi;
- The integration of this program within a Continuing Professional Development (CPD) framework for Rabbis and Rebbetsens.

Innovative aspects, if any

- Culturally Tailored Content and Delivery: The course was developed following community consultation to ensure that its content was culturally adapted for the Charedi Orthodox Jewish community. This means that the programme was crafted to respect religious norms, traditions, and values, thereby making it more acceptable to its target audience
- Innovative Use of Traditional Storytelling: One innovative aspect was the incorporation of Jewish storytelling during the sessions;
- Bridging Traditional and Statutory Services: An innovative element is the hybrid model involving both trusted religious figures (such as the Rabbi and Charedi psychotherapist) and statutory mental health professionals (including consultant psychiatrists).

Barriers, challenges/points of weakness (and solutions to them, if applicable)

- A significant barrier was the deep-rooted stigma associated with mental health in the Charedi Orthodox Jewish community. Concerns about confidentiality, shame, and damaging family reputation discouraged help-seeking behavior. The traditional reliance on the Rabbi as a first responder to mental health issues further complicated engagement, as individuals preferred culturally familiar guidance over mainstream services. A solution that emerged was integrating respected community figures, such as Rabbis and mental health professionals with cultural competence, to deliver the course. Strong community consultation is essential. Involving multiple stakeholders including religious leaders, community-based organisations, and mental health professionals ensures that interventions are better tailored to the community's needs
- The intervention had to be adapted to gender-segregated sessions in line with religious customs. This meant separate sessions for men and women, making scheduling more complex and potentially limiting the number of sessions that could be run in a given period. To address these issues, careful planning and tailoring of session timing to ensure availability and comfort for all participants was implemented. The use of a community-friendly venue that was familiar and accessible also helped mitigate these constraints. Future programs should consider flexible scheduling and alternative venues to accommodate larger groups.

Key success factors/points of strength

- Culturally Informed and Participatory Co-Design: The course was developed through a strong partnership between community-based organisations (Bikur Cholim), religious leaders (Rabbis), and mental health professionals.
- Leadership played a key role, with the involvement of respected figures such as Rabbis and trusted mental health practitioners enhancing the credibility of the initiative.
- The initiative underlines the importance of community consultation, leadership endorsement, culturally sensitive content, and flexible, accessible implementation methods.

Early Positive Approaches to Support (E-PAtS) for Families of Young Children with Intellectual Disability

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	161 SLR
Ranking of the good practice	2
Type of good practice	1. Primary, secondary and tertiary prevention interventions
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Early Positive Approaches to Support (E-PAtS) for Families of Young Children with Intellectual Disability
Name of the good practice in original language (if available)	idem
Initiative in operation since	No information on the start year of the E-PAtS is identified. The papers were published in 2021-2022.
Country/ies of implementation	UK
Geographic coverage/ implementation level	1. Local 2. Regional, national
Stage of initiative	1. Ongoing
Name of the Leader/s Organisation/implementer/s	TIZARD University of Kent
Contact details	Dr Nick Gore, N.J.Gore@Kent.ac.uk
Type/source(s) of funding	4. National or local public sources (e.g. general tax revenue, social care funds) The project was funded by the National Institute for Health Research (NIHR), but there is no information in the article if the funding is ongoing.

Webpage/s of the good practice (or link to doi of the paper)	DOI of the main reviewed extended article: https://doi.org/10.3310/hey3556 DOI of the main review shorted article: https://doi.org/10.3389/fpsy.2021.729129 Information about the E-PATs from the Tizard Centre, University of Kent: https://www.challengingbehaviour.org.uk/wp-content/uploads/2021/03/Early-Positive-Approaches-to-Support-general-information-ng.pdf Information about the E-PATs from the Challenging Behaviour Foundation: https://www.challengingbehaviour.org.uk/what-we-do/projects-and-research/early-positive-approaches-to-support-e-pats/
Summary (abstract)	Background: Parents of children with intellectual disabilities are likely to experience poorer mental wellbeing and face challenges accessing support. Early Positive Approaches to Support (E-PATs) is a group-based programme, co-produced with parents and professionals, based on existing research evidence and a developmental systems approach to support parental mental well-being. This study aimed to assess the feasibility of community service provider organisations delivering E-PATs to parents/family caregivers of young children with intellectual disability, to inform a potential definitive randomised controlled trial of the effectiveness and cost-effectiveness of E-PATs. Methods: This study was a feasibility cluster randomised controlled trial, with embedded process evaluation. Up to two parents/family caregivers of a child (18 months to <6 years old) with intellectual disability were recruited at research sites and allocated to intervention (E-PATs and usual practice) or control (usual practice) on a 1:1 basis at the cluster (family) level. Data were collected at baseline and at 3 and 12 months post-randomisation. The following feasibility outcomes were assessed: participant recruitment rates and effectiveness of recruitment pathways; retention rates; intervention adherence and fidelity; service provider recruitment rates and willingness to participate in a future trial; barriers and facilitating factors for recruitment, engagement, and intervention delivery; and feasibility of collecting outcome measures. Results: Seventy-four families were randomised to intervention or control (n=37). Retention rates were 72% at 12 months post-randomisation, and completion of the Early Positive Approaches to Support proposed primary outcome measure (WEMWBS) was 51%. Recruitment of service provider organisations and facilitators was feasible, and intervention implementation was acceptable. Adherence to the intervention was 76% and the intervention was well-received by participants; exploratory analyses suggest that adherence and attendance may be associated with improved wellbeing. Health economic outcome measures were collected successfully, and evidence indicates that linkage with routine data would be feasible in a future trial. Conclusions: The E-PATs Feasibility RCT has demonstrated that the research design and methods of intervention implementation are generally feasible. Consideration of the limitations of this feasibility trial and any barriers to conducting a future definitive trial does, however, need to be considered by researchers.
Keywords	Care Partnership, Children With Disabilities, Group Sessions, Parents, Support

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

The aim of the practice is supporting parents/family caregivers of young children with intellectual disability/ies, who are described as more likely to experience poorer mental well-being and face challenges accessing support. E-PAtS aims to bolster family resources and resilience to achieve positive outcomes for parents who attend, as well as for their children and other family members.

Group sessions for parents of young children with intellectual disability (E-PAtS) are facilitated by a trained professional employed by the community organisation and trained family carer who work in partnership. Programme facilitators are professionals who are employed by third-sector organisations, but have included a range of health and social care professionals (and could include education professionals). Each programme is also delivered with a parent/family carer co-facilitator employed by the organisation specifically to deliver the E-PAtS programme. Facilitators deliver the programme in pairs (one professional and one parent/familycarer facilitator) after completing a 5-day training programme and a period of supervised practice. Supervised practice consists of between two and three supervision meetings with the E-PAtS programme trainer during the first facilitation of a programme. Materials and sessions have been co-produced by family carers and professional experts and provide strategies for use now and in the future. The sessions were co-delivered by a family carer facilitator and a professional facilitator (either health or social care). Group sessions were designed to be emotionally supportive and meet the needs of a diverse range of families, supporting children with a variety of needs.

E-PAtS comprises:

an individual, supportive preparatory interview with the co-facilitator or a representative from their organisation, to support attendance and engagement;

eight (typically weekly) 2.5 hourly group sessions, delivered in community settings;

a personalised accompanying workbook and associated resources that can be completed throughout the programme, and that also facilitate dissemination of information to other family members and supporters.

Each group session focuses on supporting parents'/family carers' well-being and behaviour in the context of parenting a child with intellectual disability and provides evidence-based content in the form of oral and video presentations, structured exercises, and group discussion.

Main setting(s)/place(s) of delivery

1. Home (initial telephone interviews)

6. NGO facility

8. Local community

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)

6. Other LTC workers/health-social care professionals (not clear in the article but most likely a trained staff member from a community organization working with children with intellectual disabilities and their families)

Age profile(s) of the target group(s) of the practice

1. 18-34 years

2. 35-64 years

Health issues of the care recipients assisted by the target group(s) 3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.)
Age profile(s) of the care recipients assisted by the target group(s) 1. Children/Youths (0-12 years)
Problem being addressed Parents of children with intellectual disabilities are likely to experience poorer mental well-being and face challenges accessing support. E-PaTS meets parents' needs for support and thereby strengthens their mental well-being, resilience and resources and to achieve positive outcomes for those who attend, as well as for their children and other family members.
Measurement/evaluation The reviewed study was a feasibility cluster randomised controlled trial, with embedded process evaluation. Seventy-four families were randomised to intervention or control (n = 37). Up to two parents/family caregivers of a child (18 months to <6 years old) with intellectual disability were recruited at research sites and allocated to intervention (E-PaTS and usual practice) or control (usual practice) on a 1:1 basis at the cluster (family) level. Data were collected at baseline and at 3 and 12 months post-randomisation. The following feasibility outcomes were assessed: participant recruitment rates and effectiveness of recruitment pathways; retention rates; intervention adherence and fidelity; service provider recruitment rates and willingness to participate in a future trial; barriers and facilitating factors for recruitment, engagement, and intervention delivery; and feasibility of collecting outcome measures. The exploratory regression analysis showed that the mean Warwick-Edinburgh Mental Well-Being Scale well-being score was 3.96 points higher in the intervention group (95% confidence interval 1.39 to 9.32 points) at 12 months post-randomisation. Moreover, E-PaTS was described as fostering partnership between the parents and the family carer facilitator and professional facilitator (either health or social care).
Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency) 1. Improving resilience 2. Improving mental wellbeing 5. Fostering (or potential to foster) care partnerships
Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked) There is the potential for care partnerships to be developed between the parents and the facilitators who meet regularly during the initial interview and the group sessions. The E-PaTS program is co-delivered by a family carer facilitator and a professional facilitator (either from health or social care). Moreover, the results showed that E-PaTS was described as fostering a partnership between the parents and this facilitator dyad.
Equity (including ethics) Regarding equity and ethics, adult females and males of diverse ethnicities and with various relationships to the child were included in the study. The co-design approach used in developing E-PaTS further enhances equity. Moreover, the study was approved by the University of Warwick Humanities and Social Sciences Research Ethics Committee.
Sustainability To ensure the sustainability of the practice, suitable funding model/s for local community organisations is needed so that they can continue to run the service. Furthermore, a structure for offering the practice regularly to parents and training for the facilitators involved in the practice is judged as essential.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

There is potential for scalability, transferability, and adaptability of E-PAtS. A larger randomised controlled trial (RCT) is currently underway, aiming to recruit 450 families across the UK. The potential is supported by the availability of practice materials in English, which possibly could be translated, adapted, and transferred to other countries.

Collaboration with and/or participation of different stakeholders and sectors

Regarding collaboration, the reviewed study involved two key partners: third-sector organisations supporting families of children with intellectual disabilities and academia. Furthermore, the development of E-PAtS employed a co-produced design that included both parents and professionals.

Innovative aspects, if any

No innovative aspects were identified in the E-PAtS.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

No barriers or challenges related to E-PAtS were reported in the article. However, potential barriers to implementing E-PAtS could include a lack of funding and limited time availability among parents to attend the sessions.

Key success factors/points of strength

The potential strengths of E-PAtS could be that the material and structure of the group sessions are co-produced with informal carers and LTC workers, and that the results indicate good feasibility. Parents also report higher well-being compared to the control group. Moreover, there is potential for a care partnership to develop between the parents and the two trained facilitators, who meet during the initial interview and at every group session.

Key factors for successful implementation could possibly include commitment and sufficient ongoing funding, partnership between the provider organisations and PPI partner organisation, and with family carers themselves, and that they have trained facilitators.

Family Carers Training

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	86 GLR
Ranking of the good practice	3
Type of good practice	5. Interventions and programs targeted at LTC workers and/or informal carers with pre-existing mental health conditions favoring work-life balance for LTC workers who also assume informal caring responsibilities. Training often includes stress management, mental wellbeing, care techniques, which supports both their mental health and work-life balance. Often inclusive of those already experiencing stress, burden or early signs of burnout. Also in part related to: 3. Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives (if the focus is on resilience and emotional support). But not always, as the focus is broader than resilience and emotional support.
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Family carers training
Name of the good practice in original language (if available)	Usposabljanje za družinske in druge neformalne oskrbovalce
Initiative in operation since	2005
Country/ies of implementation	Slovenia
Geographic coverage/ implementation level	1. Local 2. Regional, national
Stage of initiative	1. Ongoing
Name of the Leader/s Organisation/implementer/s	Inštitut Antona Trstenjaka za gerontologijo in meġeneracijsko sožitje (Anton Trstenjak Institute for Gerontology and Intergenerational relations)
Contact details	Ajda Cvelbar, ajda.cvelbar@iat.si
Type/source(s) of funding	5. Private sources (e.g. donations, private insurers, foundations)
Webpage/s of the good practice (or link to doi of the paper)	Webpage: https://www.inst-antonatrstenjaka.si/sozitie/projekti/39.html

Summary (abstract)	Anton Trstenjak Institute has been providing training and support to family carers for several years. Hundreds of relatives and other informal carers of older people who already need help or will need it soon, have been trained and networked. The training takes the form of a course, which is then followed up in a self-help group, i.e. a local relatives' club, led by volunteers. The relatives' club provides a permanent space for the exchange of good experiences and for addressing the challenges that home care brings to informal carers. It is attended by family carers who wish to do so; meetings are usually held once a month for two hours at the same place and time as the course.
Keywords	Informal Care, Family Carers, The Relatives Club, Psychosocial Support

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

The goal of the training is that the carers will be able to provide good care for their less able family members, effectively supported by the health and social care system through a good long-term care system and other support services. Education of family carers, mutual support based on the principle of self-help, and relief for carers are also important.

The meetings take place over eight consecutive weeks and last for two full hours in a group of 15 to 25 participants. Participants are encouraged to take an active part, because in these courses we are all teachers and all students, as we all learn best from good personal experience.

Each session also includes a lecture on: interpersonal relationships, understanding old age, combating burnout, dementia, caregiving, how to prepare for a relative going into a nursing home, and dying and mourning. The trainees also receive a handbook, published in 2012, entitled: "Family Care for an Elderly Relative". The courses are regularly attended by nurses, a physiotherapist and other professionals.

Main setting(s)/place(s) of delivery

8. Local community

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)
2. Working carers (combining paid work with informal care)

Age profile(s) of the target group(s) of the practice

1. 18-34 years
2. 35-64 years
3. 65-74 years
4. 75+ years (all mostly female)

Health issues of the care recipients assisted by the target group(s)

1. Physical disabilities (caused, e.g. by frailty, accident, injury, illness, etc.)
3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.)

Age profile(s) of the care recipients assisted by the target group(s)

3. Adults (18-64 years)
4. Older people (65+ years)

Problem being addressed

Each session also includes a lecture on: interpersonal relationships, understanding old age, combating burnout, dementia, caregiving, how to prepare for a relative going into a nursing home, and dying and mourning. The trainees also receive a handbook, published in 2012, entitled: Family Care for an Elderly Relative.

Participants are encouraged to take an active part, because in these courses we are all teachers and all students, as we all learn best from good personal experience.

The method is in-group social learning.

Measurement/evaluation

As the training is a part of the national social welfare program a formal evaluation scheme is carried out, which measures satisfaction, skills learned and notes suggestions for improvement.

Also, the training takes the form of a course, which is then followed up in a carer's self-help group - i.e. a local relatives' club, led by volunteers - where carers can share what was useful for them.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
4. Enhancing informal carers' and/or LTC workers' satisfaction
5. Fostering (or potential to foster) care partnerships
7. Cost-effectiveness (A lot of the content is prevention based, which saves money in the long run)

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

Care partnerships are actively encouraged, so informal carers are working together with formal carers, community nurses, home carers, etc.

Equity (including ethics)

Ethical concerns are not highlighted but the program promotes equity by being accessible to all informal caregivers, regardless of their formal education, income, or professional background. It addresses the needs of individuals who often go unrecognized in the health and social care systems—family members and friends who provide care at home—many of whom are women and older adults themselves. By offering training and psychosocial support free of charge, it helps reduce inequalities in access to knowledge, emotional support, and caregiving skills.

Also, the practice follows GDPR principles and all visiting professionals follow their fields ethical standards, which include respecting the dignity, autonomy, and personal experience of caregivers. It is built on the principles of solidarity, inclusion, and person-centered care, and it emphasizes the value of caregiving work, which is often unpaid and underappreciated.

Overall, the program supports social justice by empowering caregivers and advocating for their recognition and wellbeing.

Sustainability

The use of trained volunteers and peer facilitators reduces dependency on high-cost professionals and supports local ownership. The program is integrated into national strategies on ageing and long-term care, aligning it with policy priorities.

Its modular and replicable structure allows easy adaptation to various local contexts, increasing both cost-effectiveness and reach. Ongoing self-help groups (relatives club) formed after training ensure that support continues beyond the program itself, fostering lasting community networks.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

Anton Trstenjak Institute has been providing training and support to family carers for several years. Hundreds of relatives and other informal carers of older people who already need help or will need it soon, have been trained and networked.

It is an ongoing practice which has been repeated several times.

Most family carers trainings are funded by the local municipality and are promoted by word of mouth. To scale it up they would need to train more trainers and increase the funding.

It is also very structured but still flexible towards users. There is a manual, but the method is in-group social learning.

Collaboration with and/or participation of different stakeholders and sectors

Health and social care professionals (e.g. doctors, nurses, physiotherapists, formal carers) contribute as expert trainers and mentors during the courses. Municipalities support the program financially and logistically by co-financing training and helping identify and reach local family carers.

The Ministry of Labour, Family, Social Affairs and Equal Opportunities provides national-level policy and some funding support, integrating the program into broader ageing strategies. Volunteers and civil society organisations are actively involved—many become trained facilitators, ensuring sustainability and community ownership.

The Institute also collaborates with researchers and academic institutions, who help evaluate and refine the training approach. The creation of intergenerational self-help and peer support groups ensures continued engagement from carers and broader community inclusion.

Innovative aspects, if any

None reported.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

Time constraints are always present. Informal carers often have limited availability due to caregiving duties and employment, making participation in structured training difficult. Limited budget is another important issue. While municipalities finance the program, there are still financial limitations, especially regarding outreach, printed materials, and follow-up services. Also, some training locations may not be easily accessible to all, especially older carers or those in less connected communities.

Key success factors/points of strength

The initiative is an inclusive, community-rooted model that combines professional expertise, peer support, flexible delivery, and increasing policy backing can sustainably empower informal carers and strengthen long-term care systems.

Carers' Alert Thermometer for Stroke Family Caregivers (CAT-S)

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	149 SLR
Ranking of the good practice	4
Type of good practice	1. Primary, secondary and tertiary prevention interventions
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Carers' Alert Thermometer for Stroke Family Caregivers (CAT-S)
Name of the good practice in original language (if available)	idem
Initiative in operation since	Original CAT with a focus on palliative care has been in operation since 2014, and the CAT-S with a focus on care for persons with stroke since 2023.
Country/ies of implementation	UK
Geographic coverage/ implementation level	2. Regional, national
Stage of initiative	1. Ongoing
Name of the Leader/s Organisation/implementer/s	Ete Hill University, Faculty of Health, Social Care and Medicine, Ormskirk, Lancashire L39 4QP, UK
Contact details	eprc@etehill.ac.uk, CAT@etehill.ac.uk
Type/source(s) of funding	There is a lack of information in the reviewed article regarding institutional support or financing of the good practice; however, they used the tool in a stroke unit, so it should be implemented and financed by that unit.
Webpage/s of the good practice (or link to doi of the paper)	Webpage from Ete Hill University with information about the CAT-S: https://www.etehill.ac.uk/research/carers/ DOI: https://doi.org/10.1155/2023/1660169

Summary (abstract)	An estimated 1.3 million stroke survivors living in the United Kingdom (UK) currently rely on family caregivers for daily support. The needs of stroke family caregivers are, however, not routinely assessed by most clinical services. Early identification of their needs and support is crucial to maintain their well-being and caregiver role. At present, stroke-specific caregiver screening tools are lacking. This mixed-methods, multiphase study aimed to develop a Carers' Alert Thermometer for stroke family caregivers (CAT-S) by adapting the CAT, a short screening tool developed in the context of end-of-life care. Underpinned by principles of action research, qualitative and quantitative data were collected sequentially between February 2016 to December 2017 from purposive samples of stroke family caregivers (n=76) and staff working within stroke services (n=238) in the UK. Semistructured interviews were conducted to inform the contents of the CAT-S. Key items for inclusion were identified through a modified Delphi survey and consultation with an expert panel. The CAT-S was then piloted in North West England to test its usability and usefulness in practice to identify the needs of stroke family caregivers. Thematic and content analysis were used to analyse qualitative data. Quantitative data were analysed using descriptive statistics. The CAT-S comprises the key challenges that are experienced by stroke family caregivers. Two additional items not present on the original CAT were identified and included: training needs of family caregivers to provide care and support for caregivers' emotional needs. The CAT-S was found to be useful and acceptable by both staff and stroke family caregivers and resulted in action plans and support being provided. The CAT-S is a supportive tool for achieving person-centred care and prioritising stroke family caregivers requiring comprehensive assessments.
Keywords	Informal Caregivers, Needs Assessment, Screening Tool

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

The study aim is the development of the Carers' Alert Thermometer for Stroke Family Caregivers (CAT-S), for early identification of family caregivers' needs and support.

Two additional items not present on the original CAT (with focus on palliative care) were identified and included in the CAT-S: training needs of family caregivers to provide care, and support for caregivers' emotional needs.

The CAT-S is a supportive tool for achieving person-centred care and prioritising stroke family caregivers requiring comprehensive assessments. Before this study a stroke-specific caregiver screening tools were lacking.

The evaluation indicated that the CAT-S was highly valued by staff. They reported that the instructions and questions on the CAT-S were easy to follow and read. Staff also suggested the CAT-S could be completed electronically. Similarly, family caregivers welcomed the CAT-S and provided some positive comments regarding the time taken to complete the CAT-S and its usefulness. Family caregivers expressed positive views regarding regular assessment with the CAT-S.

Main setting(s)/place(s) of delivery

5. Hospital

8. Local community

The article does not specify the actual setting but states "stroke settings".

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)

3. Qualified/registered nurses

6. Other LTC workers/health-social care professionals (specify: formal carers involved in the care for the person affected by stroke)

Even if the tool itself focuses on the informal carers, the work with the tool and the beneficiaries possibly positively affects even the formal carers involved in the care for the person affected by stroke.

Age profile(s) of the target group(s) of the practice

1. 18-34 years

2. 35-64 years

3. 65-74 years

4. 75+ years

Health issues of the care recipients assisted by the target group(s)

4. Other chronic illnesses/long-term health conditions (specify: stroke)

Age profile(s) of the care recipients assisted by the target group(s)

3. Adults (18-64 years)

4. Older people (65+ years)

Problem being addressed

When informal carers receive timely support, it can reduce their risk of burnout and enable them to care for the care recipient over a longer period. This screening tool has the potential to help identify the needs of stroke-specific informal carers at an early stage. Moreover, it also helps formal carers gain insight into the needs of informal carers, thereby increasing their ability to provide appropriate support.

Establishing a structured routine for identifying the needs of informal carers may also enhance formal carers' satisfaction in their role, both in supporting the informal carer and the care recipient. By making the informal carer's needs visible to both parties, the tool can foster a shared understanding of the situation and needs, thus facilitating a care partnership between informal and formal carers.

Measurement/evaluation

Underpinned by principles of action research, qualitative and quantitative data were collected sequentially between February 2016 to December 2017 from purposive samples of stroke family caregivers (n=76) and staff working within stroke services (n=238) in the UK. Semistructured interviews were conducted to inform the contents of the CAT-S. Key items for inclusion were identified through a modified Delphi survey (with a relatively high number of participants in some rounds, and fewer in the pilot phase) and consultation with an expert panel. The CAT-S was then piloted in North West England to test its usability and usefulness in practice to identify the needs of stroke family caregivers. Thematic and content analysis were used to analyse qualitative data. Quantitative data were analysed using descriptive statistics. The evaluation indicated that the CAT-S was highly valued by staff. They reported that the instructions and questions on the CAT-S were easy to follow and read. Staff also suggested the CAT-S could be completed electronically. Similarly, family caregivers welcomed the CAT-S and provided some positive comments regarding the time taken to complete the CAT-S and its usefulness. Family caregivers expressed positive views regarding regular assessment with the CAT-S.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
4. Enhancing informal carers' and/or LTC workers' satisfaction
5. Fostering (or potential to foster) care partnerships

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

Making the informal carer's needs visible for both the informal carer and the formal carers when using the tool may foster a shared understanding of the situation and needs, thus facilitating a care partnership between informal and formal carers.

Equity (including ethics)

Regarding equity and ethical aspects, both adult females and males of different ages were included in the study. Ethical approval to perform the study was obtained from Ete Hill University's Research Ethics Committee.

Sustainability

The article provides no information regarding institutional support or financing of the good practice. However, it is reasonable to assume that support in the form of commitment and funding from stroke health care services and organisations would be necessary to implement such a practice.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

The practice has the potential to be transferred to other settings and countries if translated and, if necessary, adapted to the new context.

Since 2014, 15 countries have registered to access the CAT and its resources. However, the specific countries are not listed.

CAT-S has been adapted and transferred from palliative care to stroke care.

Collaboration with and/or participation of different stakeholders and sectors

Informal carers and LTC workers were involved when testing and evaluating the pilot CAT-S through the study's Delphi design. Through this involvement, their experiences were included in the development phase.

Innovative aspects, if any

None reported.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

The formal carers suggested that the tool could be offered in an electronic format rather than paper-based, to facilitate its use. No barriers or challenges were reported.

Key success factors/points of strength

Possible key success factors include the involvement of both informal carers and formal carers in the evaluation of the tool, which helps ensure that it is developed to meet their needs and fit within the organisation. Informal carers highlighted that the tool was easy to complete and did not require much time. Formal carers were reported to value the tool.

The main positive lesson learned is that the tool is accepted and viewed positively by both target groups, indicating that it may be feasible to implement.

The early identification of informal carers' needs through this tool may enable all actors involved in care to gain a better understanding of the carer's situation and support needs, and provide tailored support. This may help informal carers to continue in their role over a longer period.

Additionally, the tool may offer formal carers a structured routine for assessing and addressing the needs of informal carers, potentially increasing their job satisfaction and improving the quality of care provided to the care recipient.

Augmentative and Alternative Communication Intervention (AAC)

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	98 SLR
Ranking of the good practice	5
Type of good practice	6. Community-based initiatives/measures Also related to: 4. Integrated approaches and strategies
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Augmentative and Alternative Communication Intervention (AAC)
Name of the good practice in original language (if available)	Info not available in German
Initiative in operation since	This quasi-experimental study was conducted between June 2018 and April 2021
Country/ies of implementation	Germany
Geographic coverage/ implementation level	1. Local. Three AAC counselling centres. Probably in Oldenburg (but the exact location is not indicated in the paper)
Stage of initiative	4. Finished for 4 years or more. The study was conducted between June 2018 and April 2021
Name of the Leader/s Organisation/implementer/s	School of Medicine and Health Sciences of the University of Oldenburg
Contact details	Anna Zinkevich, Department of Health Services Research, Carl von Ossietzky University of Oldenburg, Germany. e-mail: anna.zinkevich@uni-oldenburg.de
Type/source(s) of funding	3. Statutory LTC/healthcare financing system. Innovation Fund of the Federal Joint Committee (G-BA), Germany. The Federal Joint Committee (G-BA) is a public legal entity comprising the four leading umbrella organizations of the self-governing German healthcare system
Webpage/s of the good practice (or link to doi of the paper)	DOI: https://doi.org/10.1186/s12913-022-08824-3

Summary (abstract)	People with disabilities and without natural speech often rely on care provided by informal caregivers. The main objective of the study was to examine whether AAC can reduce care-related burden of informal caregivers. The AAC intervention includes counselling/training/therapy sessions, and collaboration between the involved stakeholders and caregivers. Within a quasi-experimental intervention study, survey data on self-perceived burden were collected at three time points between June 2018 and April 2021 from a postal survey. Moreover, qualitative interviews with 16 informal caregivers were conducted. Caregivers reported diverse resources and effective coping strategies, a reduced burden, and better communication skills. The AAC intervention seems to have a positive impact on self-perceived burden.
Keywords	Caregiver, Burden, Mixed-methods, Interviews, Complex Intervention

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

The initiative was developed to support both people with a congenital or acquired disability associated with loss of natural speech, and their informal caregivers, often burdened. These caregivers have indeed little studied. The aim/objectives were 1) to identify stressors, resources, and coping strategies among these informal caregivers, and 2) to examine whether a complex intervention in AAC can reduce care-related burden. According to the inclusion criteria, only insured persons of one health insurance company could participate in the intervention group (for providing the cared-for person with necessary assistive devices). Also, participation in the study required the naming of two caregivers (for each cared for) to whom the questionnaires would be sent. The main components of the AAC intervention were (1) initial counselling session to identify the most appropriate system, (2) four training sessions to ensure the technical use of the system, (3) twenty therapy sessions to enable the use of the system in different contexts, and (4) collaboration between the involved stakeholders, with continuous involvement of caregivers in the exchange with other stakeholders about the AAC training and therapy process. Caregivers must participate in the initial counselling session, and can (if they want) to participate also in AAC training and therapy sessions. According to the results, diverse resources and effective coping strategies, which the caregivers refer to when dealing with stressors, were identified. Self-perceived burden was significantly reduced in the intervention group compared to the control group. AAC use also led to better communication skills and a reduction in behavioural problems. The AAC intervention is mainly a "community-based initiative" (type 6), but also it represents an example of "integrated approach and strategy" (type 4), since family caregivers, health professionals, and insurance companies are involved.

Main setting(s)/place(s) of delivery

4. Local healthcare centre (e.g. ambulatory).

The complex intervention was evaluated in three AAC (augmentative and alternative communication) counselling centres.

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age, older retired carers).

Both males and females.

Age profile(s) of the target group(s) of the practice

1. 18-34 years

2. 35-64 years

3. 65-74 years

Range <29-69 years.

Health issues of the care recipients assisted by the target group(s)

4. Other chronic illnesses/long-term health conditions (specify: Disabled people without natural speech). People who have no intelligible natural speech due to a congenital or acquired disability.

Age profile(s) of the care recipients assisted by the target group(s)

1. Children/Youths (0-12 years)

2. Adolescents (13-17 years)

3. Adults (18-64 years)

Range 2-49 years.

Problem being addressed

People with disabilities and without natural speech often rely on care provided by informal/family caregivers. These particular caregiving situations have however been poorly researched. These caregivers suffer from several stressors, such as limited communication with the cared-for person and concerns about the living situation in adulthood. This study thus examined how a complex intervention in AAC can reduce care-related burden among a group of informal caregivers of people who have no intelligible natural speech (due to a congenital or acquired disability).

Measurement/evaluation

Quantitative data focus on burden level, the qualitative data address specific stressors, resources, and coping strategies. Data on self-perceived burden (Burden Scale for Family Caregivers, BSFC-s) from informal caregivers of people without natural speech were collected at three time points. Caregiver burden was measured with the validated German short version of the Burden Scale for Family Caregivers. Qualitative interviews with informal caregivers were also conducted. The qualitative part of the study allows to gain better understanding of how the AAC intervention affects caregiver burden.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
5. Fostering (or potential to foster) care partnerships

In particular, burden was indeed significantly reduced in the intervention group compared to the control group. The caregivers interviewed consistently rated the intervention as beneficial, both in terms of improving the cared-for person's communication skills and in terms of reducing their own burden in the caregiving situation. According to the results of the qualitative study, AAC use led to better communication skills and reduction in behavioural problems. The AAC intervention also seems to have a positive impact on self-perceived burden of caregivers.

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

Informal caregivers were continuously involved in the exchange with other stakeholders about the training and therapy process. Insurance companies were also involved since only insured persons of specific health insurance company can participate in the intervention group (to have the necessary assistive devices).

Equity (including ethics)

This study was approved by the Ethics Committee of the School of Medicine and Health Sciences of the University of Oldenburg. All participants were informed about the study's aims and the data protection measures and were asked to give their written informed consent prior to data collection. Regarding equity, the method of purposeful sampling was used to ensure a diverse sample in terms of the relation of the interviewed person to the cared-for person, age, and sex. Also, the need for AAC can occur at any age and be associated with a variety of disabilities; therefore, people of all ages and disabilities can be included to address this heterogeneity.

Sustainability

The practice presents information which discloses the sources of financing, which potentially can allow continuity as financial sustainability. The study is funded by the Innovation Fund of the Federal Joint Committee (G-BA), Germany (Grant No 01NVF17019). The same funding is mentioned in a further expansion of the study: Uthoff, S.A.K., Zinkevich, A., Boenisch, J. et al. Process evaluation of a complex intervention in augmentative and alternative communication care in Germany: a mixed methods study. BMC Health Serv Res 25, 373 (2025). <https://doi.org/10.1186/s12913-025-12452-y>. Moreover, the continuation of the practice could be ensured through the involvement of relevant stakeholders. However, the intervention already includes stakeholders.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

Intervention and instruments are well described in the paper. Another publication presents the protocol: Zinkevich A, Uthoff SAK, Boenisch J, Sachse SK, Bernasconi T, Ansmann L. Complex intervention in augmentative and alternative communication (AAC) care in Germany: a study protocol of an evaluation study with a controlled mixed-methods design. *BMJ Open*. 2019;9(8): e029469. The practice is thus adequately defined. Moreover, authors state that within the intervention it is intended and encouraged flexibility, i.e., that AAC training and therapy sessions can take place in different settings (e.g., school, kindergarten, residential home). The aim is indeed to ensure the successful use of the AAC system in many contexts and with various stakeholders. In another more recent publication <https://doi.org/10.1186/s12913-025-12452-y> (with similar aim and topic) authors state that the intervention was largely acceptable to participants.

Collaboration with and/or participation of different stakeholders and sectors

In the AAC intervention process the functioning collaboration between the involved stakeholders is strengthened. Informal caregivers are also continuously involved in the exchange with other stakeholders about the AAC training/therapy process, and the use of the AAC system in other contexts. AAC counselling centres led to improved and more effective communication with stakeholders (importance of external professional support services). Moreover, the intervention implies the mandatory participation of informal caregivers in the initial counselling session. This allows a detailed assessment of the different activities and settings that are important for the care recipient, with the aim of selecting the most appropriate AAC system. The participation of caregivers in the AAC training and therapy sessions is not mandatory, but desirable at any time according to the needs and possibilities of participants and their caregivers.

Innovative aspects, if any

Data were collected within the research project "New Service Delivery Model for Augmentative and Alternative Communication (AAC) Devices and Intervention". This new service merges/integrates counselling session, training, therapy, and collaboration between the involved stakeholders. Moreover, informal caregivers are continuously involved about the AAC training and therapy process and the use of the AAC system. The AAC also includes aided systems (e.g., communication boards or devices with voice output). The protocol <https://bmjopen.bmj.com/content/bmjopen/9/8/e029469.full.pdf> mentions the satisfaction of caregivers with the aided AAC systems, that will be measured using the German version of the "Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST 2.0)" which is validated for measuring user satisfaction with assistive technology.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

It is not clear if the practice has institutional support, and/or an organisational and/or technological structure and dedicated human resources. Also, it is not clear if the practice provides training of staff. Also, generally, it can be assumed that highly burdened caregivers did not participate in the study in the first place or were not willing to be interviewed. Following the theoretical model components in the development of the interview guide may have limited the interview situation and thus the findings of the qualitative study. In particular, due to the COVID-19 pandemic, telephone interviews were conducted in addition to face-to-face interviews. Moreover, only insured persons of one health insurance company could participate in the intervention group. The affiliation of participants with a health insurance company is requested because one aspect of care is providing the cared-for person with necessary assistive devices (depending on the disability), and health insurance companies are involved in applying for/financing these devices.

Key success factors/points of strength

This study focuses on examining self-perceived care related burden, resources, and coping strategies among informal caregivers (of people who have no intelligible natural speech) who has been little studied to date. The results provide evidence that AAC interventions can have a meaningful and subjectively perceived positive impact on caregiver burden. The results also reveal linkages between specific intervention components and burden reduction, providing an evidence base for developing interventions that take a holistic view of families with individuals without natural speech. Study results are suitable for extrapolation and regard also people with disabilities in general. It is important to mention that within the intervention it is intended and encouraged that AAC training and therapy sessions can take place in different settings (e.g., school).

LIVIND - A lifestyle monitoring system to support (in)formal caregivers of people with dementia

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	25 SLR
Ranking of the good practice	6
Type of good practice	2. Interventions or programmes dealing with organisational models and management approaches and/or targeted at the individual level 4. Integrated approaches and strategies
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	A lifestyle monitoring system to support (in)formal caregivers of people with dementia: Analysis of users need, benefits, and concerns
Name of the good practice in original language (if available)	Not available.
Initiative in operation since	The study took place from February 2015 to June 2016, in the rural area of the northern Netherlands.
Country/ies of implementation	Netherlands
Geographic coverage/ implementation level	1. Local
Stage of initiative	4. Finished for 4 years or more
Name of the Leader/s Organisation/implementer/s	Department of Health Psychology, University Medical Center Groningen, University of Groningen, Groningen, the Netherlands; Vilans, Dutch Centre of Expertise for Long-term Care, Utrecht, the Netherlands; Research group Living, Wellbeing, and Care for older People, NHL Stenden University of Applied Sciences, Leeuwarden, the Netherlands; Research group iHuman, NHL Stenden University of Applied Sciences, Leeuwarden, the Netherlands; Department of Psychology, Health and Technology, University of Twente, Enschede, the Netherlands; Livind company (operating in the Internet Service Providers, Website Hosting & Internet-related Services industry)
Contact details	Erik Zwierenberg BSc Enga, Department of Health Psychology, University Medical Center Groningen, Groningen, the Netherlands, e.zwierenberg@umcg.nl

Type/source(s) of funding	4. National or local public sources (e.g. general tax revenue, social care funds) 8. Other (ZonMw, within the public-private Breakthrough Project “De zorg ontzorgd met ICT”) The Dutch government provided a Grant to Vilans and Livind to organize a field trail). No information is available whether there also was a continues funding for the practice.
Webpage/s of the good practice (or link to doi of the paper)	DOI: https://doi.org/10.4017/gt.2018.17.4.001.00
Summary (abstract)	Introduction Dementia is a syndrome that predominantly affects people in old age. Many older people with mild to moderate dementia live at home alone. When dementia poses problems, they must rely on informal caregivers, who have lives of their own in other places, as well as on professional home care organized by case managers. Assistive technologies, such as lifestyle monitoring, are being developed to assist informal caregivers and case managers by making remote caregiving possible. In this study, people with dementia were provided with a lifestyle monitoring system consisting of activity sensors in the home connected to an online platform, with the aim to help informal caregivers and case managers provide care to people with dementia who are living alone. Methodology In the study, 63 lifestyle-monitoring systems were installed in 63 homes of people with mild to moderate dementia who were living alone. Telephone interviews with informal caregivers (50) where conducted when the system was installed, and again after 300 days of use (41). Case managers (13) were also interviewed at the beginning and at the end of the project (7). Each interview lasted about 30 minutes and consisted of closed and open questions about topics including expectations, experiences, quality of life, and care. The study took place in the rural area of the northern Netherlands from February 2015 to June 2016. Results/conclusion The results indicate that informal caregivers perceive lifestyle monitoring as a support tool that fills a need in the provision of care for people with dementia and that its benefits outweigh the concerns. Lifestyle monitoring makes it possible to expand the informal care network such that care duties can be shared among more people, thereby relieving informal caregivers of a sense of constant responsibility.
Keywords	Older Adults, Dementia, Home Care, Assistive/Home Monitoring Technology, eHealth

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

In this study, people with dementia (PWD) were provided with the Livind, a lifestyle monitoring system installed in their homes, consisting of activity sensors in the home connected to an online platform. The sensors collected information on e.g. patterns of everyday life activities (in which room, time, intensity of movement), day-night rhythm. This monitoring system was used for the purposes of this study and participants got it for free during the trial period. This study aims to generate insight into needs, benefits, and concerns relating to a lifestyle-monitoring system to help informal caregivers and case managers, who are its users, provide care to people with dementia who are living alone. In detail, 63 lifestyle-monitoring systems were installed in 63 homes of people with mild to moderate dementia who were living alone. Telephone interviews were carried out with informal caregivers (all women) (50) near the date on which the system was installed, and again when it had been in use for approximately 300 days (41).

Case managers/nurses (13) who served the involved caregivers, were also interviewed at the beginning and at the end of the project (7). The system was used without charge until the end of the trial.

Main setting(s)/place(s) of delivery

1. Home
8. Local community

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)
3. Qualified/registered nurses
4. Assistant nurses

Age profile(s) of the target group(s) of the practice

2. 35-64 years

Health issues of the care recipients assisted by the target group(s)

3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.)

Age profile(s) of the care recipients assisted by the target group(s)

4. Older people (65+ years)

Problem being addressed

The study aimed to test the Livind lifestyle-monitoring system to help informal caregivers and case managers (i.e. nurses who support people with dementia from the time of diagnosis until the end of their lives) providing care to people with dementia who are living alone, by also evaluate if this can improve the mental wellbeing of carers.

Measurement/evaluation

An in-depth qualitative interview method was adopted. Two semi-structured interview guides were developed both for informal caregivers and for the case managers, consisting of closed and open questions about topics including expectations with lifestyle monitoring, experiences with technology, quality of life, quality of care, expectations regarding lifestyle monitoring. Authors conducted telephone interviews with informal caregivers (50) near the date on which the system was installed (July 2015, T1), and again when it had been in use for approximately 300 days (41) (June 2016, T2). They also interviewed case managers (13) at the beginning and at the end of the project (7). The lower number of interviewed at T2 was mostly due to changes in the care provided (informal caregivers) and organisational problems (case managers). A spreadsheet program was used to conduct the qualitative analysis. The interview data were labelled using a semi-open coding technique.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
5. Fostering (or potential to foster) care partnerships
6. Improving organisational practices

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

The tested lifestyle monitoring system contributes to develop conditions for create and strengthen care partnership between informal caregivers and case managers in managing and providing care to people with dementia. Lifestyle monitoring system makes it possible to expand the informal care network and provide relatives of PWD with a means with which to delegate care more efficiently and effectively, in addition to relieving informal caregivers of a constant sense of responsibility.

Equity (including ethics)

As for Equity, the informal caregivers (n = 50, Mage = 54.9, SDage = 7.5, 35 female) involved in the study were interviewed twice. The time (Mmonths = 6.5, SDmonths = 1.5) between the two interviews was long enough to allow the respondents to internalize the operations and use the system routinely. There were considerable variations in the distance between the homes of the PWD and informal caregivers (Mkm = 37.4, SDkm = 55.6). Informal caregivers travelled by car (n = 29), bicycle (n = 13), or other means of transportation, and many (n = 39) had professional obligations in addition to their care duties. Most of the informal caregivers (n = 29) visited the PWD for whom they were providing care once or twice a week. The informal caregivers were regular users of desktop computers (n = 30), laptops (n = 22), smartphones (n = 35), and tablets (n = 25).

No information is available on socio-demographic profile of case managers involved in the study.

As for Ethics, each participating informal caregiver and case manager signed an informed-consent document. The PWD were not interviewed. The lifestyle-monitoring system was used supplementary to any other technologies in use for the safety and security of the PWD, that were left unchanged. The results were anonymized to make it impossible to trace them back to the people who were interviewed. To ensure privacy, numbers were instead of names to identify the participants: informal caregivers (IC1–IC63) and case managers (CM1–CM13).

Sustainability

The Dutch government provided a Grant to Vilans (the national Centre of Expertise for Long-term Care in the Netherlands) and to Livind company to organize a field trial with four care-organizations (who provided lists of participants) to gain more experience with the concept of lifestyle monitoring. Livind was one of the two major lifestyle monitoring developers at that moment in the Netherlands. The practice was implemented through an ad hoc technology (with e.g. door/window sensors and gateway to internet router, online dashboard of the lifestyle-monitoring system displaying the measurement of each sensor) which could be accessed by its users using a Personal Computer, tablet or smartphone, and had dedicated humane resources (e.g. professional system installer, helpdesk with dedicated professionals available to provide support in the event of problems).

Based on the available information it is not clear if the “Living” monitoring system could be continued after the end of the project funding the study.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

The Livind lifestyle-monitoring system was used for the purposes of this study and participants got it for free during the trial period. A helpdesk was available to provide support in the event of problems with configuration or the installation of the sensors.

Informal caregivers and case managers (nurses who serve as the primary contact for PWD) could consult the Livind website or Webapp on a tablet or smartphone at any time to learn the daily pattern and whereabouts of those for whom they are providing care.

As for adaptability and flexibility, given the differences in the interior design of individual homes, the placement of sensors needed to be customized. A professional system installer visited each respondent included in the study and discussed the locations for the sensors with the informal caregiver. When an animal (for example a dog) was in the house, placement of the sensors was critical to prevent wrong signals. This was done to ensure that the system would work without problems from the start of the study. The lifestyle-monitoring system did not replace any other assistive technologies (e.g. personal alarm systems) already in use, since it was a supplement to them. The main setting for a potential repetition/transfer is the house.

Collaboration with and/or participation of different stakeholders and sectors

Researchers were involved, together with Livind company (which developed the lifestyle-monitoring systems used in the study), in carrying out the practice.

Innovative aspects, if any

The characteristics of this practice are in line with the concept of social innovation. In fact, assistive technologies, such as lifestyle monitoring, are being developed to assist informal caregivers and case managers by making remote caregiving possible. This study is intended to generate insight into needs, benefits, and concerns relating to a lifestyle-monitoring system to help informal caregivers and case managers provide care to people with dementia who are living alone.

As for technological innovation, people with dementia were provided with a lifestyle monitoring system installed in their homes, consisting of activity sensors in the home connected to an online platform, for collecting information on e.g. patterns of everyday life activities (in which room, time, movement), day-night rhythm. It is highlighted that Livind was one of the two major lifestyle monitoring developers in the Netherlands in the period where the study was carried out.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

The employed method provides qualitative information about the concept of lifestyle monitoring, but the results might be biased due to the particular system (Livind) that was used. Although the original research goals also included the collection of longitudinal quantitative data, the sample size and the data collected were insufficient to justify any valuable conclusions.

Another weakness of the study is that only people who agreed to participate were included. This might have resulted in bias, as the participants are likely to have had a positive attitude with regard to the use of a lifestyle-monitoring system.

Authors state that additional research in which also quantitative outcomes (e.g. satisfaction among users, time to admission to specialized care and the like) over time are assessed is needed in order to confirm the positive results on the concept of lifestyle monitoring. In future research, it would be advisable also to get PWD themselves more involved and asked them how they experience the use of lifestyle-monitoring systems.

Informal caregivers have reported some several problems and ideas for improving the lifestyle-monitoring system, such as:

The system generates too many reports, which often contain the same information. Informal caregivers feel that the information is not reliable;

The configuration of the reports should have more options for customizing them to the situations of the PWD being monitored;

The system does not issue alarms in a timely manner (e.g. when the PWD wanders away from home). Informal caregivers perceive a need for such alarms;

The system generates false reports and alarms when guests are present in the PWD's home;

The location of the sensors should be more customized than it currently is.

Key success factors/points of strength

One major strength of this study is the number of participants (63 ICs, 13 CMs), which far exceeds that of previous studies.

Informal caregivers report feeling reassured knowing what is happening with the PWD and how the day-night rhythm is developing.

E – Qalin – Quality Management Model

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	59 GLR
Ranking of the good practice	7
Type of good practice	2. Interventions or programmes dealing with organisational models and management approaches and/or targeted at the individual level
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	E – Qalin – Quality Management Model
Name of the good practice in original language (if available)	E – Qalin
Initiative in operation since	2004
Country/ies of implementation	Slovenia, Austria, Czech Republic, France, Croatia, Italy, Germany, Luxembourg, United Kingdom
Geographic coverage/ implementation level	2. National 3. Cross-country/International
Stage of initiative	1. Ongoing
Name of the Leader/s Organisation/implementer/s	FIRIS Imperl d.o.o. (Slovenia) IBG (Austria) E.D.E. European Association for Directors of residential care homes for elderly a.S.b.L. (Luxembourg) Andragogik konkret e.V. (Germany) Emme&erre S.p.A. (Italy) Dachverband der Alten- und Pflegeheime Österreichs (Austria) All organisations are equal partners.
Contact details	Eva Imperl, eva@imperl-firis.si
Type/source(s) of funding	6. Employers
Webpage/s of the good practice (or link to doi of the paper)	Webpage: http://www.firis-imperl.si/izobrazevanje/e-qalin/

Summary (abstract)	E-Qalin (European quality-improving learning) is a pan-European model for quality management in social care settings, the development of which has been supported by the European Community under the Leonardo da Vinci Fund. It was developed in response to the requirements of the development of social care organisations, their need for quality standards and for a specific model of quality management that would be nationally and European recognised. The model is tailored to 4 sectors: care homes for the older people (E-Qalin/A); day-care centres and social welfare training institutions (E-Qalin/B); home care providers (E-Qalin/C); social work centres (E-Qalin/D). The active partner for E-Qalin in Slovenia is FIRIS IMPERL d.o.o. The Quality Management System or Business Excellence System includes the structures, processes and results of the institution. The quality of all three areas is verified through Self Assessment. E-Qalin is characterised by its operational orientation, covering all hierarchical levels in the organisation and fostering the active involvement of employees. For the legislator, the nursing home provider, professional associations and users, the E-Qalin model offers the possibility of continuous improvement of social and health services, further development of standards and comparability of performance. This is supported by the focus on staff competences and the involvement of the various stakeholders (residents, relatives, staff, external partners), whose feedback and reflection play an important role and stimulate the further development of the institution as a learning organisation. The E-Qalin model is based on basic ethical attitudes and values that ensure humane living and working in nursing homes and care homes, i.e. dignity, fairness, tolerance, willingness to dialogue and resolve conflicts, empathy, freedom and autonomy of decision-making and personal integrity.
Keywords	Quality Management, Self-Assessment, Inclusiveness, Learning Organisation

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

The overall objective is to improve the quality of services in social care institutions, thereby increasing the satisfaction of users and staff.

The specific objectives are, in particular: improved quality of life for users, increased motivation and satisfaction of staff, assisting the management and staff of the institutions in providing and improving quality services, national and international comparability of institutions and certification of specific activities and branding (for more details see "Summary").

Main setting(s)/place(s) of delivery

2. Residential care setting

Target group(s)/beneficiaries

3. Qualified/registered nurses

4. Assistant nurses

5. Personal care workers

6. Other LTC workers/health-social care professionals (social carers, occupational therapists, physiotherapists, social workers, social care managers, primary care workers in social care organisations)

Age profile(s) of the target group(s) of the practice

1. 18-34 years (mostly women)

2. 35-64 years (mostly women)

Health issues of the care recipients assisted by the target group(s)

1. Physical disabilities (caused, e.g. by frailty, accident, injury, illness, etc.)

2. Psychological/mental health issues (e.g. depression, anxiety, etc.)

3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.)

4. Other chronic illnesses/long-term health conditions (persons with special needs)

Age profile(s) of the care recipients assisted by the target group(s)

1. Children/Youths (0-12 years)

2. Adolescents (13-17 years)

3. Adults (18-64 years)

4. Older people (65+ years)

Problem being addressed

Improving the quality services, by addressing quality management in social care settings. Every institution has specific challenges. Some of the more common ones are: low staff/users morale/satisfaction, high turnover, mental health strain caused by emotional labor, high workloads, poor care quality and reputational risk. The overall objective is to improve the quality of services in social care institutions, thereby increasing the satisfaction of users and staff.

Measurement/evaluation

A certification system is in place, based on an external audit by the QSocial auditing organisation.

The certificate is international and valid for 3 years.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
4. Enhancing informal carers' and/or LTC workers' satisfaction
6. Improving organisational practices
8. Other (greater information flow, awareness of shared mission and responsibility)

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

Not applicable.

Equity (including ethics)

Equalin is designed to promote equity in residential care homes by supporting safe, high-quality care for vulnerable groups, including older adults, people with disabilities, chronic illnesses, or language barriers. It ensures fair working conditions for a diverse staff, including those from different socioeconomic or cultural backgrounds, and is accessible in both rural and urban settings.

The E-Qalin model is based on basic ethical attitudes and values that ensure humane living and working in nursing homes and care homes, i.e. dignity, fairness, tolerance, willingness to dialogue and resolve conflicts, empathy, freedom and autonomy of decision-making and personal integrity.

The platform complies fully with GDPR, protecting personal data through encryption, access controls, and secure storage. Ethical considerations are respected, and approvals are obtained when used in research or evaluative contexts. The benefits—improved safety, compliance, and transparency—clearly outweigh any minimal risks associated with digital implementation, etc.)

The model is tailored to 4 sectors:

care homes for the older people (E-Qalin/A);

day-care centres and social welfare training institutions (E-Qalin/B);

home care providers (E-Qalin/C);

social work centres (E-Qalin/D).

Sustainability

E-Qalin employs the Plan-Do-Check-Act (PDCA) methodology, promoting an ongoing cycle of planning, implementation, evaluation, and refinement. This approach ensures that organizations continually assess and enhance their processes, contributing to sustained quality improvements.

Since its introduction in 2004, E-Qalin has been adopted by numerous care institutions.

While some organizations discontinued its use due to management perspectives on workload, many have sustained its implementation, underscoring its role in long-term quality development.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

Its scalability and transferability have been demonstrated through successful implementations in various European countries, including Austria, Germany, Italy, Luxembourg, and Slovenia. The model's adaptability to different organisational structures and cultural contexts highlights its robustness and effectiveness in diverse settings.

A key factor contributing to E-Qalin's scalability is its emphasis on continuous improvement and stakeholder involvement. By engaging all levels of staff in the quality management process, E-Qalin fosters a culture of collaboration and shared responsibility, which facilitates the model's expansion within and across organizations.

Collaboration with and/or participation of different stakeholders and sectors

Equalin was developed and implemented through strong collaboration with a range of stakeholders across the health and social care sectors. Care home managers, frontline staff, and quality officers were actively involved in co-design to ensure practical usability. Long-term care employers and networks supported integration into safety and compliance routines, while academic and research partners contributed to evaluation and evidence generation. Input from carers' associations and mental health advocates helped make the tool inclusive and responsive to real-world challenges.

Innovative aspects, if any

None reported.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

In some care settings, the implementation of Equalin faced typical barriers such as lack of funding for institutions wishing to introduce E-Qalin, especially in smaller or publicly funded care homes, restricting investment in digital infrastructure.

Lack of trained professionals with digital literacy or familiarity with quality management systems is present.

Also, scarce time availability among staff due to high workloads and understaffing.

Key success factors/points of strength

Equalin has been successfully implemented in residential care settings where enabling factors were present. These factors are adequate budget for digital tools, trained and safety-conscious professionals, and strong leadership support. Time constraints of frontline staff were addressed through intuitive design and minimal training requirements, while implementation benefited from dedicated spaces (e.g. staff rooms, admin offices) for digital use. Participatory co-design with care managers and workers ensured practical usability, while leadership and policy support (especially from care home operators and quality assurance bodies) were key in adoption. Community engagement was reflected in the tool's ability to support inclusive care practices for vulnerable resident populations.

Main positive lessons learned include the importance of involving staff early in the process (co-design builds ownership), ensuring data protection and simplicity to gain trust, and embedding the tool into daily workflows to ensure long-term use.

With the right support and environment, E-Qalin strengthens both workforce safety and care quality.

REACT-NOR – Norwegian version of the Relatives Education and Coping Toolkit

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	371 SLR
Ranking of the good practice	8
Type of good practice	3. Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives Also related to: 2. Interventions or programmes dealing with organisational models and management approaches and/or targeted at the individual level (because REACT-NOR is designed for self-paced, individual use and includes personalised CBT-based exercises). 6. Community-based initiatives/measures (as the intervention was made available online and via phone support, accessible from participants' homes across rural and urban areas).
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	REACT-NOR – Norwegian version of the Relatives Education and Coping Toolkit
Name of the good practice in original language (if available)	REACT – Veiledet selvhjelp til pårørende (Norwegian: Guided self-help for relatives)
Initiative in operation since	2016-2017 (initial pilot)
Country/ies of implementation	Norway
Geographic coverage/ implementation level	1. Local 2. Regional, national
Stage of initiative	1. Ongoing as of 2025 (based on current training activities and continued implementation)

Name of the Leader/s Organisation/implementer/s	The REACT-NOR programme was implemented and coordinated by a collaboration between: Vestfold Hospital Trust (Sykehuset i Vestfold HF), where the pilot study was conducted; Oslo University Hospital (Oslo universitetssykehus), which now hosts national training and oversight; University of Oslo, Institute of Clinical Medicine, Norwegian Centre for Mental Disorders Research (NORMENT) (Universitetet i Oslo Institutt for klinisk medisin, NORMENT), which provided academic leadership and research support. These organisations were responsible for implementation, training, research, and dissemination of REACT-NOR in Norway.
Contact details	Kristin Lie Romm, MD, PhD, Division of Mental Health and Addiction, Oslo University Hospital, Oslo, Norway, Phone: +47 97009863, k.l.romm@medisin.uio.no
Type/source(s) of funding	4. National or local public sources (e.g. general tax revenue, social care funds)
Webpage/s of the good practice (or link to doi of the paper)	Webpage: https://www.oslo-universitetssykehus.no/fag-og-forskning/nasjonale-og-regionale-tjenester/tips-sor-ost/react-veiledet-selvhjelp-til-parorende#kurs DOI: https://doi.org/10.2196/19497

Summary (abstract)	The REACT-NOR programme is a Norwegian adaptation of the UK-based Relatives Education and Coping Toolkit (REACT), designed to support relatives of people with psychosis through a blended approach combining online self-help materials and telephone-based guidance by trained family therapists. The aim was to increase accessibility to psychoeducation and reduce emotional burden among informal caregivers. The intervention included access to a Norwegian-translated REACT web platform with 12 structured modules covering psychosis-related knowledge, symptom management, crisis handling, stress reduction, and available services. Participants could use the platform at any time and work through it at their own pace. Cognitive-behavioural therapy (CBT)-based exercises were provided in booklet form and actively used during weekly phone consultations (up to 1 hour/week for 26 weeks). The programme also included proactive therapist outreach if participants did not initiate contact. A mixed-methods pilot study conducted at Vestfold Hospital Trust involved 19 relatives (mostly parents and spouses). Quantitative assessments using the Family Questionnaire and Relatives Stress Scale showed a statistically significant reduction in both stress and expressed emotion levels from baseline to 26 weeks. Digital analytics indicated that content on symptom handling and stress management was most frequently accessed. Qualitative interviews with relatives and family therapists revealed that the toolkit helped turn knowledge into action, strengthened the relatives' feeling of being involved, and offered flexible, confidential support. Participants valued having access to structured information without requiring patient consent and appreciated the professional background of the supporters. Barriers included limited digital communication functions (due to budget constraints), difficulty in clinician engagement, and a lack of formal reimbursement structures. Despite these, the programme was well received and continues to be offered in Norway, with national-level training courses scheduled for 2025. The study concludes that REACT-NOR is a promising approach to improving mental well-being and involvement of relatives in psychosis care.
Keywords	REACT, Psychosis, Psychoeducation, Informal Carers, eHealth

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

REACT-NOR is a blended intervention aimed at supporting relatives of people with psychosis through a combination of web-based psychoeducation and telephone-based support provided by trained family therapists. The intervention includes access to a web-based platform (available 24/7), where participants can independently work through 12 modules:

8. What is REACT?
9. What is psychosis?
10. How to handle positive symptoms
11. How to handle negative symptoms
12. How to handle crisis
13. How to handle difficult behavior
14. Coping with stress by thinking differently
15. Coping with stress by acting differently
16. Mental health services – How do I get the help I need?
17. Treatment options
18. Resources
19. Terms and dictionary

Each module includes psychoeducational content followed by cognitive-behavioural therapy (CBT)-based exercises. In REACT-NOR, these exercises were provided in a printed workbook, since the online interactive elements from the UK version could not be implemented due to limited funding.

In addition to the digital material, participants were offered weekly telephone consultations (up to 1 hour) with one of two trained family therapists, for a period of 26 weeks. These therapists were trained in psychoeducational family therapy and provided guidance on navigating the modules and discussing individual challenges. Therapists initiated monthly follow-ups if participants did not make contact.

The programme aimed to increase knowledge, reduce stress and emotional burden, and empower relatives through flexible and accessible support. It was piloted at Vestfold Hospital Trust and supported by Oslo University Hospital.

Main setting(s)/place(s) of delivery

1. Home
5. Hospital
9. Online

The intervention was primarily delivered as a blended digital model:

- Participants accessed the REACT-NOR web platform from home, at any time;
- Telephone consultations with trained family therapists were also conducted while participants were at home;
- The first face-to-face meeting between participant and therapist took place at the hospital (Vestfold Hospital Trust);
- The therapists themselves were based in the hospital's mental health division, where they also conducted interviews and coordination.

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)

The intervention targeted relatives of people with psychosis, including parents, spouses, and siblings. These were informal carers providing emotional and practical support. The article specifies that the participants were non-professional family members.

Gender composition: Among the 19 participants were 11 mothers, 6 fathers (including 1 stepfather), 1 sibling, and 1 spouse. The majority of those who completed the programme were mothers (10 out of 16 final participants).

There is no information provided about participants' employment status, so "working carers" cannot be confirmed.

Age profile(s) of the target group(s) of the practice

2. 35-64 years (majority of participants)
3. 65-74 years (upper range of the sample)

The median age of the participants was 54 years, with an age range of 42 to 68 years.

Health issues of the care recipients assisted by the target group(s)

2. Psychological/mental health issues (e.g. depression, anxiety, etc.)

The care recipients were individuals diagnosed with psychosis, including both first-episode and long-term cases. Psychosis is a severe mental health condition that can include hallucinations, delusions, and disorganized thinking.

There is no indication of physical disabilities, cognitive impairments (in the sense of dementia), or other chronic illnesses being the focus of care.

Age profile(s) of the care recipients assisted by the target group(s)

3. Adults (18-64 years)

The intervention targeted relatives of people with psychosis, including first-episode psychosis, which typically occurs in late adolescence or early adulthood. Although the exact ages of the care recipients are not reported, the context and diagnostic focus clearly indicate that the recipients were adults under 65 years of age. There is no evidence of children, adolescents, or older people (65+) as care recipients in this study.

Problem being addressed

The REACT-NOR programme addressed the non-occupational psychological burden experienced by informal carers of people with psychosis. Relatives of individuals with severe mental illness often face chronic stress, emotional overload, and social isolation, while receiving little support from the healthcare system. Many feel overlooked by professionals and excluded from treatment processes; particularly when patient consent for family involvement is lacking.

High levels of expressed emotions (e.g. criticism, emotional overinvolvement) in family members have been linked to negative outcomes for both the patient and the carer. Carers also report difficulties accessing reliable information, emotional support, and coping strategies tailored to their needs.

This burden is influenced by various non-occupational risk factors, including:

- Gender: Most participants in the pilot were female (predominantly mothers), reflecting a gendered caregiving role.
- Age: Participants ranged from 42 to 68 years, often caring for adult children, which can coincide with mid-life stress and caregiving for ageing parents.
- Social context: Many carers lacked adequate support from mental health services, contributing to a sense of isolation and helplessness.

The programme was developed in response to these unmet needs and aimed to provide flexible, low-threshold access to psychoeducational materials and professional guidance without requiring patient consent. It sought to empower relatives, reduce distress, and help them feel recognised and included by the healthcare system.

Measurement/evaluation

The REACT-NOR intervention was evaluated using a mixed methods pilot study. The assessment focused on both the effectiveness of the programme in reducing caregiver burden and the experience of users (relatives and therapists).

Quantitative methods included:

- Relatives Stress Scale (RSS): Assessed emotional and social distress among carers;
- Family Questionnaire (FQ): Measured levels of expressed emotions (e.g. criticism, emotional overinvolvement).

Pre- and post-intervention data showed a statistically significant reduction in both stress and expressed emotion.

Digital analytics:

Google Universal Analytics was used to monitor webpage usage. The most visited and read sections related to stress management and handling symptoms of psychosis.

Qualitative methods included:

- Semi-structured interviews with 7 relatives and 2 family therapists after the intervention.
- Thematic analysis was conducted using systematic text condensation.
Key themes included:
 - “The toolkit turns knowledge into action”;
 - “The service strengthened the feeling of being involved”;
 - “Factors important for engagement and implementation”.

The evaluation demonstrated that the blended model was acceptable, accessible, and valued by users, and showed preliminary effectiveness in improving carers’ emotional well-being.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
4. Enhancing informal carers' and/or LTC workers' satisfaction
5. Fostering (or potential to foster) care partnerships.

The intervention led to:

- A statistically significant reduction in relatives' stress and expressed emotions (quantitative results).
- Improved mental wellbeing, as participants gained knowledge and coping skills tailored to their needs.
- Enhanced resilience, as the toolkit helped relatives regain a sense of control and develop action-oriented strategies.
- High user satisfaction, with participants reporting that they felt seen, supported, and better equipped to handle caregiving challenges.

No data was collected on organisational change or cost-effectiveness, so those points cannot be confirmed.

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

Although the support was provided by trained family therapists through one-on-one guidance via telephone and not embedded in broader care planning or coordination, the programme shows a potential to foster care partnerships, thanks to the presence of these family therapists.

Equity (including ethics)

REACT-NOR addressed equity in access by offering flexible, remote delivery of psychoeducation and emotional support. The web-based platform and telephone consultations allowed participants from both urban and rural areas to engage with the programme, overcoming geographic barriers. Although no specific measures were reported for socioeconomic status, disability, or migration background, the intervention was designed as a low-threshold service that did not require patient consent. This made it more accessible to carers who are often excluded from formal services due to confidentiality issues.

Regarding gender, the majority of participants were female relatives (mostly mothers), reflecting the gendered nature of caregiving. No targeted recruitment strategies were reported to address gender balance or underrepresented groups.

From an ethical perspective:

- The study received ethical approval from the Regional Committees for Medical and Health Research Ethics in Norway (2015/2169);
- All participants gave informed consent before enrolment;
- The REACT-NOR platform was hosted securely on the national health network (Norsk Helsenett), ensuring data protection;
- The design aimed to minimise risk by limiting therapist contact to guided support and avoiding direct clinical intervention.

No information was provided about adaptations for people with hearing, visual, or cognitive impairments, or about multilingual access for non-Norwegian speakers.

In summary, the intervention promoted equity in terms of geographic access and independent caregiver support, while adhering to ethical research standards. However, specific equity strategies for vulnerable subgroups were not documented.

Sustainability

While the original pilot study of REACT-NOR was conducted in 2016–2017, there is evidence of continued implementation beyond the research phase:

- The REACT-NOR programme is now promoted through the Oslo University Hospital website as part of the national initiative TIPS Sør-Øst;
- Website: <https://www.oslo-universitetssykehus.no/fag-og-forskning/nasjonale-og-regionale-tjenester/tips-sor-ost/react-veiledet-selvhjelp-til-parorende>;
- A national training course for new REACT facilitators is scheduled for spring 2025, indicating ongoing investment in capacity-building and implementation;
- The programme includes a system of mandatory supervision (monthly guidance groups and post-course follow-up), suggesting that structures have been developed to ensure quality and continuity;
- REACT-NOR is embedded in existing specialist mental health services, using trained family therapists with a background in psychoeducational family collaboration or cognitive behavioural therapy. This integration supports professional sustainability.

The programme uses a web-based platform hosted on the secure Norwegian Health Network (Norsk Helsenett), ensuring long-term accessibility and compliance with data protection regulations. While the Norwegian version does not yet include all interactive features of the original UK platform (due to limited initial funding), the basic digital infrastructure is already in place and in active use.

No specific information is provided about long-term funding sources, policy frameworks, or formal inclusion in standard care pathways. However, the ongoing coordination by major institutions (Oslo University Hospital, TIPS Sør-Øst) and national-level training efforts indicate a strong potential for institutional sustainability.

In summary, although formal funding structures are not discussed in the article, current evidence from the official website confirms that REACT-NOR is operational, expanding, and supported by national health institutions.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

The REACT-NOR programme demonstrates clear potential for scalability and transferability, both within Norway and in other countries with similar healthcare infrastructures.

National level:

The practice is currently being expanded beyond the pilot site. Oslo University Hospital offers national training courses for professionals across Norway, and a structured system for supervision and facilitator certification is in place. This indicates that the programme is already being scaled regionally and nationally, supported by specialist mental health institutions.

Adaptability:

REACT-NOR was successfully adapted from the UK version of the Relatives Education and Coping Toolkit (REACT). This included:

- Translation and cultural adaptation of 12 psychoeducational modules;
- Use of printed CBT exercises to compensate for missing digital functions (due to funding limitations);
- Integration into existing Norwegian specialist mental health services.

These adaptations demonstrate the flexibility of the model to different healthcare and digital contexts.

Transferability to other countries or regions is supported by:

- The modular structure of the toolkit;
- The blended format (digital content + phone-based therapist guidance);
- The use of non-diagnostic, low-threshold language and materials;
- The possibility to implement it without requiring patient consent.

However, successful transfer depends on:

- Availability of trained family therapists or similar professionals;
- Access to secure digital infrastructure;
- Institutional support from mental health services.

There is no formal evaluation of transfer to new countries, but the successful adaptation from the UK to Norway, and current national rollout, suggest a high level of implementability in comparable systems.

Collaboration with and/or participation of different stakeholders and sectors

The REACT-NOR programme was developed and implemented through interdisciplinary collaboration between actors in the healthcare sector, research institutions, and national service networks.

Key stakeholders included:

- Vestfold Hospital Trust (Sykehuset i Vestfold), where the pilot was conducted. This is part of the Norwegian specialist mental health care system and served as the main implementation site;
- Oslo University Hospital (Oslo universitetssykehus), which currently hosts and coordinates national training and supervision activities for REACT-NOR through the TIPS Sør-Øst initiative (early psychosis intervention programme);
- University of Oslo – NORMENT (Norwegian Centre for Mental Disorders Research), which provided research leadership and academic support;
- Norwegian Directorate of Health, which funded the pilot project.

These collaborations brought together clinical practice, research, and national policy support.

The programme also indirectly aligns with the goals of mental health and family support services, by providing structured, therapist-guided psychoeducation to relatives; though there is no evidence of direct involvement from civil society organisations, trade unions, or employers.

In summary, REACT-NOR was implemented through strong collaboration within the mental health service sector and academic institutions, with support from public authorities, but without broader cross-sectoral involvement.

Innovative aspects, if any

REACT-NOR represents a social innovation in the field of mental health and caregiver support by combining evidence-based psychoeducation with guided self-help in a blended care format.

Key innovative aspects include:

- Blended delivery model: The programme integrates a web-based psychoeducational toolkit with individual telephone support from trained family therapists. This combination allows for both flexible, self-paced learning and personalised emotional guidance;
- Independent access without patient consent: A significant innovation is that relatives can participate without requiring consent from the person with psychosis, which addresses a common barrier to caregiver involvement in mental health services. This empowers carers and supports early, confidential access to help;
- Adaptation of a UK-based digital intervention to the Norwegian context: The successful cultural and linguistic adaptation of the Relatives Education and Coping Toolkit (REACT) shows how international evidence-based practices can be localised. The Norwegian version maintained core content but adapted the format (e.g. replacing interactive online exercises with printed CBT materials due to budget limitations);
- Therapist-guided CBT components for non-patients: The inclusion of cognitive-behavioural therapy (CBT) tools tailored for informal carers, rather than patients, is an innovative way to strengthen carers' own coping and resilience.

There is no technological innovation in terms of new platforms or digital tools. The programme relies on a translated version of the UK REACT website hosted on the Norwegian health network. However, its low-threshold, remote-access format offers a scalable and user-friendly model for caregiver support.

In summary, REACT-NOR introduces a novel, low-intensity intervention model that empowers informal carers through a structured, professionalised, and accessible approach to emotional and educational support.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

Several barriers and weaknesses were identified during the implementation and evaluation:

- Limited funding: due to budget constraints, the Norwegian version of the REACT platform could not include interactive digital features from the original UK version. As a workaround, CBT-based exercises were delivered in printed booklets rather than integrated into the web platform.
- Lack of digital communication features: participants and therapists noted that the absence of in-platform messaging or email functions limited communication flexibility and continuity. This reduced the sense of ongoing connection and made scheduling more difficult.
- Clinician engagement: a lack of active involvement from other clinicians in the mental health service (beyond the two therapists delivering REACT-NOR) was seen as a weakness. This limited integration into the wider care team and may have reduced the potential for broader uptake and support.
- No reimbursement structure: there was no established reimbursement system for therapists providing REACT-NOR, which poses a barrier to long-term sustainability and institutionalisation in standard care pathways.
- Small pilot sample and limited data: the study involved only 19 participants, with 16 completing the programme. This limited generalisability and made it difficult to evaluate outcomes across different demographic groups.

Lessons learned:

- The use of printed CBT materials ensured that core therapeutic components were still delivered despite digital limitations;
- Therapist-initiated contact was used to maintain engagement when participants were passive;
- The pilot provided useful insights for refining the model, highlighting the importance of digital functionality, integration into clinical services, and system-level financial support for long-term implementation.

Key success factors/points of strength

The programme demonstrated several key strengths that contributed to its effectiveness and user acceptance:

- Blended care approach: the combination of a web-based psychoeducational toolkit and weekly telephone guidance provided both flexibility and personalised support, meeting carers' needs for accessible, low-threshold intervention.
- Trained professionals: support was delivered by family therapists with formal training in psychoeducational family collaboration or cognitive behavioural therapy (CBT). Their expertise ensured high-quality, empathetic guidance and helped relatives apply the CBT-based exercises in practice.
- Relevance and acceptability of content: both the digital modules and printed exercises were experienced as highly relevant. Relatives appreciated the non-diagnostic, user-friendly language and the focus on practical coping strategies. Frequently accessed modules included topics on stress management, symptom handling, and how to access services.
- Independent access and confidentiality: the programme allowed relatives to participate without the patient's consent, which removed a major barrier to engagement. This enabled carers to seek help early, confidentially, and without navigating complex legal or ethical constraints.
- Flexible delivery from home: the intervention could be completed from the participant's home, at any time, which was especially valued by carers balancing multiple responsibilities or living in rural areas.
- Positive psychosocial outcomes: the programme led to statistically significant reductions in stress and expressed emotions among carers. Qualitative feedback highlighted improved coping, increased involvement, and a sense of being heard and supported.

Summary lesson learned:

REACT-NOR shows that a low-intensity, professionally supported self-help model can effectively reduce caregiver burden and empower relatives; especially when it is delivered flexibly, respectfully, and with clinical expertise.

Digital support for quality assurance in 24-hour caregiving at home

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	152 SLR
Ranking of the good practice	9
Type of good practice	5. Interventions and programmes targeted at LTC workers and/or informal carers with pre-existing mental health conditions favouring work-life balance for LTC workers who also assume informal caring responsibilities
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Digital support for quality assurance in 24-hour caregiving at home: a randomised controlled trial investigating the effects on quality of life and professional skills of paid 24h-caregivers (the research project 24hQuAALity)
Name of the good practice in original language (if available)	idem
Initiative in operation since	The article was published in 2024; however, the reviewed article lacks information regarding when the good practice was implemented.
Country/ies of implementation	Austria
Geographic coverage/ implementation level	2. Regional, national
Stage of initiative	4. Finished for 4 years or more The research project finished for 4 years or more. However, there is a lack of information in the reviewed article on whether the technology is still used.
Name of the Leader/s Organisation/implementer/s	Austrian Academy of Science
Contact details	Ulrike Bechtold, ubecht@oeaw.ac.at
Type/source(s) of funding	4. National or local public sources (e.g. general tax revenue, social care funds) It lacks information in the reviewed article whether the practice was supported (institutional support/finances) after the study ended.
Webpage/s of the good practice (or link to doi of the paper)	Webpage of the Austrian Academy of Science with information about the practice: https://www.oeaw.ac.at/en/ita/projects/24h-quality DOI: https://doi.org/10.1186/s12877-023-04454-4

Summary (abstract)	Background: Regarding the care of older adults, 24-h home-care represents a cornerstone, with > 32,000 service users in Austria, the research project 24hQuAALity aimed to develop and evaluate a distributed client-server software solution for the support and quality assurance of this home-care service. In this trial, the effects of this intervention on the quality of life and professional skills of paid 24h-caregivers in Austria were investigated. Methods: The application used in the study comprises an e-learning platform, an integrated emergency management system, networking opportunities, and an electronic care documentation system in the native language of the 24h-caregivers. The trial was conducted using a parallel three-arm study design to evaluate (i) a control group, which performed usual home care, (ii) a partial intervention group, which used the e-learning and networking platforms, and (iii) a full intervention group, which used the entire intervention (e-learning platform, networking platform, and digital care documentation). Primary self-reported outcomes were the standardised ASCOT for Carers score and a score based on responses to project-specific efficacy questions. Results: Among the 110 24h-caregivers who were randomly classified into the three groups, ASCOT for Carers score data were available for 57 and 35 24h-caregivers at 5- and 9-month follow-up examinations, respectively. At 9 months, 24h-caregivers receiving any intervention rated the ASCOT for Carers score (not significantly) better than the controls ($p = 0.05$, $\eta^2 = 0.15$), mainly in the domain "feeling encouraged and supported". At 9 months, 24h-caregivers receiving any intervention rated the project-specific Efficacy score significantly better than the controls ($p = 0.02$, $\eta^2 = 0.20$), mainly due to better ratings in the subitems "satisfaction with current docu", "docu supports doing my job", "I'm well prepared for emergencies", "my professional skills are adequate for doing my job", and "communication with contacts". Conclusions: Providing e-learning and e-documentation devices to 24h-caregivers improved their care-related quality of life, mainly because they felt more encouraged and supported. Moreover, these interventions improved their self-perceived professional skills. As an extrapolation of findings, we found that these interventions could empower 24h-caregivers and improve the quality of home-care services provided by them.
Keywords	24-h Home Care, Digital Care Documentation, Learning, Support

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

Based on the results of a qualitative requirements study, emergency management skills and information about common geriatric conditions and legal aspects of 24-h care were identified as the main needs of the 24h-caregivers.

The research project 24hQuAALity was aimed to develop and evaluate a distributed client-server software solution for the support and quality assurance of 24-h home care.

The application developed in the project 24hQuAALity comprises the following features:

- an information and education portal (e-learning platform) with interactive learning content (33 courses) about common diseases and short videos on recurrent 24h-homecaregiving situations (on the topics of work settings, legal principles for 24-h caregiving (e.g., delegation), German language training, emergency skills, geriatric diseases, and nursing care as well as measures in daily care and housekeeping);
- a comprehensive electronic care documentation that supports quality assurance and ensures transparency between the involved individuals. The electronic care documentation is individually adjustable according to the diseases of the clients. It is mainly completed by checkboxes, and the remaining free-text fields are supported by a translation function;
- an integrated emergency management, enabling 24h-caregivers to react quickly and professionally to emergencies;
- a networking platform providing links to translation pages or networking opportunities with members and relatives. The networking platform is facilitated via a moderated Facebook group and the messenger service Signal. The intervention was administered via a device (a tablet with the client-server software solution and instructions for use until follow-up 2) in German as well as in Slovak, Hungarian, and Romanian – the most common languages spoken by the 24h-caregivers.

Main setting(s)/place(s) of delivery

1. Home

Target group(s)/beneficiaries

5. Personal care workers (including privately-hired migrant care workers)

The practice is targeted at 24-hour live-in migrant care workers in Austria.

Age profile(s) of the target group(s) of the practice

1. 18-34 years
2. 35-64 years

Health issues of the care recipients assisted by the target group(s)

4. Other chronic illnesses/long-term health conditions (older people with potential 24 hour care needs- the exact health conditions of the care recipients are not specified in the article)

Age profile(s) of the care recipients assisted by the target group(s)

3. Adults (18-64 years)
4. Older people (65+ years)

Problem being addressed

The good practice addresses the needs of 24-hour caregivers by providing knowledge and skills for emergency management, as well as information on common geriatric conditions and legal aspects of 24-hour care. This could be interpreted as support for caregivers by decreasing their stressful working conditions.

Measurement/evaluation

A trial was conducted using a parallel three-arm study design to evaluate:

- a control group, which performed usual home care;
- a partial intervention group, which used the e-learning and networking platforms;
- a full intervention group, which used the entire intervention (e-learning platform, networking platform, and digital care documentation). Primary self-reported outcomes were the standardised ASCOT for Carers score, and a score based on responses to project-specific efficacy questions.

Among the 110 24h-caregivers who were randomly classified into the three groups, ASCOT for Carers score data were available for 57 and 35 24h-caregivers at 5- and 9-month follow-up examinations, respectively. At 9 months, 24h-caregivers receiving any intervention rated the ASCOT for Carers score (not significantly) better than the controls ($p = 0.05$, $\eta^2 = 0.15$), mainly in the domain "feeling encouraged and supported". At 9 months, 24h-caregivers receiving any intervention rated the project-specific Efficacy score significantly better than the controls ($p = 0.02$, $\eta^2 = 0.20$), mainly due to better ratings in the subitems "satisfaction with current docu", "docu supports doing my job", "I'm well prepared for emergencies", "my professional skills are adequate for doing my job", and "communication with contacts".

Providing e-learning and e-documentation devices to 24h-caregivers improved their social care-related quality of life, mainly because they felt more encouraged and supported. Moreover, the interventions led to improved self-perceived professional/communication skills, satisfaction with the documentation used, and readiness for emergencies. Independent of the provided e-learning and e-documentation, 24h-caregivers self-rated their professional/communicational skills as high. As an extrapolation of findings, these interventions could empower 24h-caregivers and improve the quality of their home-care services.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
4. Enhancing informal carers' and/or LTC workers' satisfaction

While increasing knowledge and skills to manage their work, it is reasonable to assume that the resilience, mental wellbeing, and job satisfaction of LTC workers also potentially increases.

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

Not applicable

Equity (including ethics)

Regarding equity, both adult female and male 24h-caregivers at different ages were included in the study. There is a high probability, due to the participants being migrant workers, that they had language barriers to some degree and a low socioeconomic status. Ethical approval for the study was obtained from the Ethics Committee of the Evangelical Hospital Vienna, Austria.

Sustainability

The article lacks information on the sustainability of the good practice, particularly regarding funding. However, it is likely that the practice requires ongoing financial support and that the e-learning platform is maintained and updated by someone responsible and knowledgeable about the technology.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

It would be possible to transfer the good practice to other contexts and countries, although some adjustments may be needed. The application is already available in four languages: German, Slovakian, Hungarian and Romanian.

Collaboration with and/or participation of different stakeholders and sectors

There was no information available in the article regarding potential collaboration between different stakeholders and sectors in the reviewed article. However, the 24-hour carers were able to communicate with other carers via the platform.

Innovative aspects, if any

The good practice could be an example of social innovation due to meeting the unmet needs of 24-hour caregivers in Austria at the social, knowledge, and structural level.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

No barriers regarding the good practice were reported in the article.

Key success factors/points of strength

The main positive lessons learned were that good practice has the potential to improve the social care-related quality of life of 24-hour caregivers, primarily by helping them feel more encouraged and supported. The interventions led to improvements in self-perceived professional and communication skills, satisfaction with the documentation tools used, and preparedness for emergencies. These interventions may empower 24-hour caregivers and enhance the quality of the home care they provide. There is a lack of information regarding the budget for the good practice; however, as it is an online application, the required budget may be relatively modest but would need to be updated and maintained.

Key success factors could therefore include committed support from the municipality—both financial and organisational—as well as clear information provided to 24-hour caregivers about the e-platform.

pflegen-und-leben.de (care and live)

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	101 GLR
Ranking of the good practice	10
Type of good practice	1. Primary, secondary and tertiary prevention interventions
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	pflegen-und-leben.de (care and live) Psychological online counseling for family caregivers
Name of the good practice in original language (if available)	pflegen-und-leben.de – Psychologische Online-Beratung für pflegende Angehörige
Initiative in operation since	3rd January 2014
Country/ies of implementation	Germany
Geographic coverage/ implementation level	2. Regional, national
Stage of initiative	1. Ongoing
Name of the Leader/s Organisation/implementer/s	Zentrum ÜBERLEBEN gGmbH (Center Surviving non-profit organisation)
Contact details	Jana Toppe (Zentrum ÜBERLEBEN), j.toppe@pflegen-und-leben.de Franziska Jentsch (WiPF), f.jentsch@wir-pflegen.net
Type/source(s) of funding	3. Statutory LTC/healthcare financing system
Webpage/s of the good practice (or link to doi of the paper)	Webpages: https://www.pflegen-und-leben.de/ https://www.thieme-connect.de/products/ejournals/abstract/10.1055/s-0032-1305133
Summary (abstract)	pflegen-und-leben.de (care and live) is a low-threshold psychological online counselling service for informal caregivers in Germany. Launched in 2014, it provides personalised online support for individuals caring for family members in need of long-term care. The platform is staffed by specially trained psychologists and funded by four German long-term care insurance funds (Barmer, TK, DAK, hkk) under §45 SGB XI. The goal is to reduce stress, anxiety, and depressive symptoms among caregivers while strengthening self-efficacy. The service addresses the underutilization of support structures due to stigma, lack of awareness, and regional disparities, particularly in rural areas. It offers anonymous, confidential, and professional mental health support accessible nationwide.
Keywords	Informal Caregiving, Mental Health, Online Counselling, Prevention, Self-Efficacy

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

The online platform pflegen-und-leben.de offers psychological support to informal caregivers (family members or relatives) of individuals in need of long-term care. Its goal is to reduce caregiving-related stress, anxiety, and depressive symptoms through low-threshold, anonymous, and free-of-charge counselling. The intervention focuses on strengthening self-efficacy, providing caregivers with tailored, evidence-based psychological support delivered by trained psychologists.

Funded by four long-term care insurance funds (Barmer, TK, DAK, hkk) under § 45 SGB XI, the service has been available nationwide since 2014. It was developed in response to the fact that many family caregivers do not access available support services, often due to stigma, emotional burden (e.g., guilt, shame), or lack of access in rural regions. The service is scientifically grounded and quality-assured through intervision and professional supervision of staff.

Main setting(s)/place(s) of delivery

9. Online

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)
2. Working carers (combining paid work with informal care)

Age profile(s) of the target group(s) of the practice

1. 18-34 years
2. 35-64 years
3. 65-74 years
4. 75+ years

Health issues of the care recipients assisted by the target group(s)

1. Physical disabilities (caused, e.g. by frailty, accident, injury, illness, etc.)
2. Psychological/mental health issues (e.g. depression, anxiety, etc.)
3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.)
4. Other chronic illnesses/long-term health conditions

Age profile(s) of the care recipients assisted by the target group(s)

1. Children/Youths (0-12 years)
2. Adolescents (13-17 years)
3. Adults (18-64 years)
4. Older people (65+ years)

Problem being addressed

Despite the high emotional and physical demands of caregiving, support services for informal carers in Germany are underutilised. Barriers include low awareness, lack of access in rural areas, and emotional hurdles such as shame and guilt associated with seeking help. Many carers feel isolated and overwhelmed, leading to increased risk of mental health issues.

pfllegen-und-leben.de addresses these barriers by offering accessible, anonymous, and free counselling. It provides a low-threshold entry point into psychological support and thus contributes to early prevention of stress-related disorders, improved self-awareness, and reduced psychological burden.

Measurement/evaluation

In a pilot phase, 23 participants were evaluated through a short-term intervention based on cognitive-behavioural and systemic methods. Sociodemographic and psychopathological data were collected at two time points to measure outcomes. Results showed positive effects on mental health and stress reduction. Continued evaluation and quality assurance are ensured through regular professional supervision and the structured nature of counselling. DOI: <http://dx.doi.org/10.1055/s-0033-1349507>

Pilot data and qualitative feedback suggest that participants experience reduced stress, anxiety, and emotional overload. Many participants report feeling more understood and supported, and more capable of handling daily caregiving tasks. The intervention also improves carers' perceived self-efficacy and helps to normalise the act of seeking help.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
4. Enhancing informal carers' and/or LTC workers' satisfaction

Pilot data and qualitative feedback suggest that participants experience reduced stress, anxiety, and emotional overload. Many report feeling more understood and supported, and more capable of handling daily caregiving tasks. The intervention also improves carers' perceived self-efficacy and helps to normalise the act of seeking help.

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

Despite above point 9.5 is not selected, the main focus of pfllegen-und-leben.de is on supporting informal carers individually; it does not actively aim to strengthen the coordination between informal carers and LTC professionals. Therefore, in terms of the WELL CARE definition of care partnerships – involving mutual recognition and integration of formal and informal care – the direct potential is limited.

However, by empowering informal carers emotionally and psychologically, the service may indirectly enable them to engage more confidently with formal services, express their needs more clearly, and participate more effectively in collaborative care arrangements. This may create space for more equal partnerships over time, especially in home-based care settings. Nonetheless, the platform currently does not provide interfaces or joint structures with formal LTC services.

Equity (including ethics)

The service is free of charge and available to all statutorily insured caregivers in Germany. Its online, anonymous format reduces barriers for those living in rural or underserved areas, those with mobility restrictions, and those who fear stigma. Confidentiality is strictly maintained, and all psychologists are bound by professional codes of conduct. Data protection complies with legal standards (GDPR). Ethical guidelines are embedded in the structure and training of the counselling team.

Sustainability

Since 2014, the service has been integrated into the benefits system of four major care insurance funds. This stable financial backing through statutory long-term care insurance ensures high sustainability. The digital model allows for cost-effective scaling and ongoing provision of services. Professional supervision and a long-term implementation structure further support the continuity and quality of the service.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

The programme is highly transferable and adaptable. Its format can be easily extended to other federal states or health systems, especially where psychological support for carers is underdeveloped. Its digital infrastructure and preventive, low-threshold character make it attractive to other health insurance providers and policymakers. The model could also be adapted for other caregiving contexts or languages.

Collaboration with and/or participation of different stakeholders and sectors

The psychological counselling service pflegen-und-leben.de was developed and implemented by the non-profit Zentrum ÜBERLEBEN and is financially supported by four statutory long-term care insurance funds (Barmer, TK, DAK, hkk). According to the evaluation study (DOI: 10.1055/s-0033-1349507), the programme was designed by a professional team of psychologists drawing on short-term therapeutic methods rooted in cognitive-behavioural and systemic approaches.

There is no evidence of direct co-creation with informal carers or civil society actors in the development phase. However, the programme was built upon empirical knowledge about the psychological strain experienced by informal carers and aims to fill a recognised gap in psychosocial support within the German long-term care system.

Innovative aspects, if any

The practice is innovative in combining evidence-based psychological counselling with a digital, anonymous and personalised interface tailored specifically to informal carers. Its proactive outreach and structured support format go beyond general helplines or information portals. It fills a major gap in the German care system, where mental health needs of carers often go unaddressed.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

Key challenges include the low visibility of the offer, emotional barriers such as guilt and shame among carers, and the digital divide among older carers. Solutions have included targeted awareness campaigns, easy-to-use online tools, and cooperation with carers' associations to build trust. Nonetheless, further work is needed to reach vulnerable and marginalised carer populations.

Key success factors/points of strength

- Free, low-threshold and anonymous access;
- High professional quality and supervision;
- Stable public funding;
- Clear focus on mental health in caregiving;
- Cross-institutional collaboration between insurers and civil society;
- Long-term availability and trust built over time.

Assertive Community Treatment (ACT) Teams

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	219 SLR
Ranking of the good practice	11
Type of good practice	2. Interventions or programmes dealing with organisational models and management approaches and/or targeted at the individual level
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Assertive Community Treatment (ACT) Teams
Name of the good practice in original language (if available)	idem
Initiative in operation since	2007
Country/ies of implementation	Norway (described in this study). The ACT teams have also been implemented in Australia, Canada, UK, USA, Sweden, Japan.
Geographic coverage/ implementation level	2. Regional, national
Stage of initiative	1. Ongoing
Name of the Leader/s Organisation/implementer/s	The name of the implementers is not provided in the article.
Contact details	Bente Weimand, bente.weimand@ahus.no
Type/source(s) of funding	There is no information in the article about how the practice is funded. However, it may be funded by national or local sources, given that it has been implemented in large parts of Norway.
Webpage/s of the good practice (or link to doi of the paper)	Report: Assertive Community Treatment: Building Your Program https://library.samhsa.gov/sites/default/files/sma08-4344-buildingyourprogram.pdf PowerPoint presentation: Implementation of Assertive Community Treatment Teams in Norway. Preliminary results: https://eaof.org/wp-content/uploads/2020/05/01-EAOF-Congress-Rotterdam-Netherlands-Presentations-09.pdf DOI: https://doi.org/10.1007/s10597-017-0207-7

Summary (abstract)	International research shows that relatives of people with mental illness are rarely involved in mental health services. Assertive Community Treatment (ACT) has been recently implemented in Norway. The experience of relatives of ACT users is largely unknown. This study aimed to explore relatives' experience with ACT-teams in Norway. Data was collected using the family involvement and alienation questionnaire, consisting of experiences of approach, and alienation from the provision of professional care. 38 Relatives participated in this study. A majority experienced a positive approach (openness, confirmation, and cooperation) from the ACT teams, which was also considered better compared to previous services. They considered openness and cooperation as essential aspects of the professionals. Almost half did not feel alienated (powerlessness and social isolation). The higher level of being approached positively was significantly associated with the lower level of feeling alienated. The knowledge of what constituted relatives' positive experiences with the ACT teams should be transferred into practice regarding how to form a positive alliance with informal carers.
Keywords	ACT Teams, Care Partnership, Cooperation, Home Visits, Informal Carers, Mental Wellbeing, Multidisciplinary Support

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

ACT is a treatment form in which active outreach multidisciplinary teams provide all necessary services for people with serious mental illness and complex care needs.

The Norwegian ACT teams are established as a partnership between a District Psychiatric Center (as part of the specialist mental health services) and the community mental health services. The teams are multidisciplinary and consist of health- and social care personnel, in order to provide service users with comprehensive and prolonged follow-up in several areas. A core staffing consists of a team leader, psychiatrist and nurse/social educator—and a specialist staffing in various areas, including a user specialist.

Why the initiative was developed: Patients with serious mental illnesses were discharged from inpatient care in stable condition, only to be readmitted relatively soon afterwards. This likely also placed a heavy burden on informal carers as the condition of the care recipient deteriorated at home.

Multidisciplinary teams were created, which gave patients the support, treatment, and rehabilitation services they needed to continue living in the community, for example, medical and psychosocial services in addition to meeting other basic needs such as housing and maintenance, practical assistance, social support, help to safeguard their economic rights as well as help and support to obtain meaningful activities, such as education or employment. The types of services that were provided and how long those services were provided depended on consumers' needs. Team members pooled their experience and knowledge and worked together to ensure that consumers had the help they needed and that the treatment they received was effective.

The ACT team provided medical and psychosocial services in addition to meeting other basic needs such as housing and maintenance, practical assistance, social support, help to safeguard their economic rights as well as help and support to obtain meaningful activities, such as education or employment.

Main setting(s)/place(s) of delivery

1. Home

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)

6. Other LTC workers/health-social care professionals (multidisciplinary health care staff: psychiatrist, nurse/social educator)

Age profile(s) of the target group(s) of the practice

No specific age profiles of the target groups are specified in the article.

Health issues of the care recipients assisted by the target group(s)

2. Psychological/mental health issues (e.g. depression, anxiety, etc.)

Age profile(s) of the care recipients assisted by the target group(s)

No specific age profiles of the care recipients are specified in the article.

Problem being addressed

The ACT teams supported individuals with serious mental illness, which also benefited informal carers by reducing their stress and workload—either by preventing the deterioration of the care recipient's condition or by providing early support. Health care workers may also experience greater job satisfaction and reduced ethical stress when able to work preventively and offer comprehensive support to care recipients, which also positively affects the informal carers.

Measurement/evaluation

Data was collected using the family involvement and alienation questionnaire, consisting of experiences of approach, and alienation from the provision of professional care. 38 Relatives participated in this study.

The results indicated that the majority of the informal carers experienced a better approach from the ACT teams compared to encounters with previous services. A majority experienced a positive approach from the ACT professionals. They considered openness and cooperation as essential aspects of the professionals. The participants, to a large extent, did not feel alienated from the current provision of care by the ACT teams. However, nearly half did not experience any change regarding the aspect “feelings of alienation”, compared to earlier encounters with mental health services. A higher level of being approached positively was significantly associated with a lower level of feeling alienated.

More references about ACT teams:

Salyers, M. P., & Tsemberis, S. (2007). ACT and recovery: integrating evidence-based practice and recovery orientation on assertive community treatment teams. *Community mental health journal*, 43(6), 619–641. <https://doi.org/10.1007/s10597-007-9088-5>

Wright-Berryman, J. L., McGuire, A. B., & Salyers, M. P. (2011). A review of consumer-provided services on assertive community treatment and intensive case management teams: implications for future research and practice. *Journal of the American Psychiatric Nurses Association*, 17(1), 37–44. <https://doi.org/10.1177/1078390310393283>

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)

5. Fostering (or potential to foster) care partnerships

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

The good practice has the potential to foster care partnerships due to improved possibilities for collaboration between the family and the multidisciplinary health care professionals.

Equity (including ethics)

From an equity and ethics perspective, adult female and male participants of various ages were involved in the study. The family study was approved by the South-East Regional Ethics Committee for Medical and Health Research (Reg No. 2010/1196a).

Sustainability

For the sustainability of the practice, it is reasonable to suggest that support from the health care sector—both in terms of commitment and financial resources—is needed, along with engaged and motivated multidisciplinary health care workers.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

The practices demonstrate potential transferability, having been implemented in several countries including Australia, Canada, Norway, the UK, the USA, Sweden, and Japan.

Collaboration with and/or participation of different stakeholders and sectors

ACT is a treatment form in which active outreach multidisciplinary teams provide all necessary services for people with serious mental illness and complex care needs, which points out the importance of collaboration with different stakeholders and sectors.

Innovative aspects, if any

No innovative aspects have been identified.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

Barriers for implementing ACT teams could include limited financial resources; however, when evaluating financial aspects, it is important to also consider the potential savings from reduced extended care needs for both the care recipient and the informal carer that result from adequate, timely support.

Key success factors/points of strength

The key success factors appear to be the multidisciplinary team providing all necessary services/support and conducting home visits. This enables care to be tailored to the needs of the care recipient and also facilitates collaboration with informal carers/ family.

Supporting Families Living with Dementia in Rural Areas

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	411 SLR
Ranking of the good practice	12
Type of good practice	3. Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives Also related to: 2. Interventions or programmes dealing with organisational models and management approaches and/or targeted at the individual level (the intervention uses a structured, trained volunteer model (family companions), and supports the entire family system in an individualised way). 6. Community-based initiatives/measures (the programme was implemented in rural communities in collaboration with local actors like Caritas and support groups, using local volunteers and embedded support systems).
Name of the good practice in English	Supporting Families Living with Dementia in Rural Areas – A Randomized Controlled Trial of Quality of Life Improvement Using Qualified Volunteers
Name of the good practice in original language (if available)	Zugehende Familienbegleitung bei Demenz im ländlichen Raum (FABEL)
Initiative in operation since	November 2012
Country/ies of implementation	Germany
Geographic coverage/ implementation level	1. Local 2. Regional, national
Stage of initiative	4. Finished for 4 years or more Ended in March 2015.
Name of the Leader/s Organisation/implementer/s	• Catholic University of Applied Sciences Freiburg, Institute for Applied Research (Katholische Hochschule Freiburg) • Caritas Association of the Breisgau-Hochschwarzwald District (Caritasverband für den Landkreis Breisgau-Hochschwarzwald) • Center for Geriatrics and Gerontology Freiburg (Zentrum für Geriatrie und Gerontologie Freiburg - ZGGF) • Center of Psychiatry Emmendingen (Zentrum für Psychiatrie Emmendingen)
Contact details	Prof. Dr. phil. Cornelia Kricheldorf (retired since 2020), Institute for Applied Research, Catholic University of Applied Sciences, Karlstr. 63, 79104 Freiburg, Germany, cornelia.kricheldorf@t-online.de
Type/source(s) of funding	4. National or local public sources (e.g. general tax revenue, social care funds)

Webpage/s of the good practice (or link to doi of the paper)	DOI: https://doi.org/10.3238/arztebl.2016.0681
Summary (abstract)	This randomised controlled trial evaluated the effectiveness of a psychosocial intervention aimed at supporting families living with dementia in rural areas of Germany. The intervention involved specially trained “family companions” who provided structured support not only to the primary caregiver but to the entire family system. The training included dementia-specific knowledge, systemic counselling approaches, and emotional support strategies. A total of 76 informal caregivers were enrolled and randomly assigned to either the experimental group (family support with specially trained companions) or the control group (conventional caregiver support). The primary outcome was health-related quality of life (HRQOL) of the informal caregivers, measured using the 12-Item Short Form (SF-12). Secondary outcomes included caregiver burden and integration into supportive care systems. In the intention-to-treat (ITT) analysis, no significant differences were found between the two groups regarding mental or physical HRQOL. However, the per-protocol (PP) analysis revealed a statistically significant improvement in mental HRQOL for the family support group (effect size $d = 0.57$; $p = 0.047$). Additionally, this group showed reduced burden in specific areas, such as family role conflict. Both groups demonstrated increased awareness and usage of supportive services, but the differences were not statistically significant. The study highlights the potential of dementia-specific volunteer training to enhance caregiver well-being, particularly in under-resourced rural settings. The findings suggest that individualized and systemic approaches, combined with structured supervision, can improve caregiver resilience and mental health. However, limitations such as small sample size and incomplete blinding must be considered.
Keywords	Dementia, Informal Caregivers, Rural Areas, Family Support, Quality of Life

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

The initiative was developed to address the emotional, relational, and logistical challenges faced by informal caregivers of people with dementia (PWD), especially in rural areas with limited access to formal support services. The core intervention was a structured training program for volunteers, aiming to expand their competencies from conventional caregiving support to systemic, dementia-specific family support.

This advanced training qualified existing care companions to become “family companions” through a curriculum of 68 units.

The training covered:

- 24 units on dementia-specific knowledge (e.g. symptoms, disease progression, communication);
- 32 units on systemic family approaches and solution-oriented counselling;
- additional sessions on networking (4 units), organization (4 units), review (4 units), and continuous self-reflection.

The aim was to enable volunteers not only to assist the primary caregiver, but to understand and support the entire caregiving family system. All volunteers had completed a previous caregiver support training and were supervised monthly by a psychotherapist and a gerontologist.

Following the training, family companions provided 16 weeks of psychosocial support to families, involving regular contact (5–20 times), either in person or remotely.

A randomized controlled trial compared this training-based intervention with standard caregiver support. While intention-to-treat (ITT) analysis showed no significant differences, the per-protocol (PP) analysis revealed a statistically significant improvement in caregivers’ mental health-related quality of life (effect size $d = 0.57$). Some reductions in caregiver burden were also observed, particularly regarding family role conflicts.

FABEL thus represents a community-based, resilience-oriented training initiative that enhances mental well-being in families affected by dementia and closes the gap between informal volunteering and professional care, especially relevant for underserved rural areas.

Main setting(s)/place(s) of delivery

1. Home
2. Residential care setting
3. Day Centre

Support was delivered primarily in the home setting of informal caregivers through visits, phone calls, and emails by trained family companions. The training sessions and coordination were organized by local partners such as Caritas, an NGO, and took place in community-based settings within the local community of the Breisgau-Hochschwarzwald district.

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)

The intervention targeted informal caregivers of persons with dementia (PWD) living in rural areas. The majority of participants were older adult family members, with an average age of 64.26 years, and 74% were women. Most were caring for a spouse or parent and were not in paid employment during the trial. The program aimed to support these carers emotionally and practically through structured volunteer-led counseling.

Age profile(s) of the target group(s) of the practice

2. 35-64 years

3. 65-74 years

The average age of informal caregivers in the study was 64.26 years, with an age range of 33 to 89 years. This, places the majority of participants in the 35–74 age range, covering both working-age and retired caregivers.

Health issues of the care recipients assisted by the target group(s)

3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.)

The care recipients in the study were exclusively persons with dementia (PWD), with varying degrees of cognitive decline as measured by the Global Deterioration Scale (stages 3–7). The intervention specifically targeted families caring for individuals with cognitive impairments due to dementia in a home care setting.

Age profile(s) of the care recipients assisted by the target group(s)

The article does not provide explicit information on the age of the care recipients (persons with dementia). While the Global Deterioration Scale stages (3–7) are reported, no numerical age data for the care recipients is included. Therefore, no age profile can be selected based solely on the information given in the article.

Problem being addressed

The intervention addresses the significant psychosocial burden experienced by informal caregivers of persons with dementia (PWD), especially in rural areas. These caregivers face high levels of emotional and relational stress, including role reversal, masked grief, and the progressive loss of relationship with the person being cared for. The caregiving situation is often accompanied by a lack of understanding of dementia-related behaviors and a sense of being left alone, particularly where professional support is scarce.

These are non-occupational risks, shaped by several factors:

- Gender: 74% of the informal caregivers in the study were women.
- Age: The mean age of the informal caregivers was 64.26 years (range: 33–89 years).
- Socio-relational context: 89% of caregivers lived in a committed relationship. The majority cared for a spouse or a parent, and most had no prior experience with dementia care.
- Rural isolation: The caregiving took place in rural areas, where caregivers reported limited access to professional services and fewer options for respite or guidance.

In addition, caregivers often lacked awareness of available supportive services, which contributed to underutilization and increased burden.

The intervention was developed to address these stressors by providing a specialized training program for volunteers, enabling them to offer psychosocial support to the entire family system, not just the primary caregiver. The program aimed to improve emotional coping, strengthen resilience, and facilitate better connection with local care infrastructures.

Measurement/evaluation

The practice was formally evaluated through a randomized controlled trial (RCT) comparing the effects of a training-based intervention ("family support") with standard volunteer caregiver support. The evaluation was carried out using quantitative methods and included both intention-to-treat (ITT) and per-protocol (PP) analyses.

Primary indicator:

- Health-related quality of life (HRQOL) of informal caregivers, measured by the 12-Item Short Form survey (SF-12), focusing on mental and physical health scales.

Secondary indicators:

- Caregiver burden, assessed via the Berlin Inventory for caregivers' burden with dementia patients (BIZA-D), which includes 20 subscales covering both objective and subjective burden dimensions;
- Awareness and use of supportive services, measured with a separate questionnaire.

Key findings:

- In the ITT analysis, no significant differences were found in HRQOL between groups at the end of the intervention;
- In the PP analysis, a significant improvement in mental HRQOL was observed in the family support group (effect size $d = 0.57$; $p = 0.047$);
- Some reductions in caregiver burden were observed, particularly in family role conflicts ($d = 0.81$);
- Both groups showed increased use and awareness of supportive services, but differences were not statistically significant.

Statistical analysis included t-tests, χ^2 -tests, and ANCOVA, using IBM SPSS Statistics 22.0 and G-Power 3.1. The trial was registered in the German Clinical Trials Register (DRKS00004260).

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
4. Enhancing informal carers' and/or LTC workers' satisfaction
5. Fostering (or potential to foster) care partnerships.

The intervention led to a significant improvement in mental health-related quality of life (HRQOL) for informal caregivers in the per-protocol analysis (effect size $d = 0.57$; $p = 0.047$), which directly reflects improved mental wellbeing and resilience.

Caregivers in the intervention group also reported reduced burden, particularly in the area of family role conflict (effect size $d = 0.81$), addressing negative aspects of informal care. Although overall caregiver burden did not differ significantly between groups in the ITT analysis, the intervention helped participants become more emotionally aware of masked grief and relationship changes, suggesting emotional processing and improved coping.

The support provided by trained volunteers was appreciated and included regular personal contact (5–20 times), indicating a likely enhancement in caregiver satisfaction and perceived support.

No data on cost-effectiveness or organizational improvements was provided in the article.

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

This training structured intervention - consisting in a curriculum of 68 units, ranging from dementia-specific knowledge, systemic family approaches and solution-oriented counselling; networking/organization/review/continuous self-reflection - was addressed to lay volunteers, who had completed a previous caregiver support training and were supervised monthly by a psychotherapist and a gerontologist, it closed the gap between informal volunteering and professional care, especially relevant for underserved rural areas. The program aimed to improve informal caregivers's emotional coping, strengthen resilience, and facilitate better connection with local care infrastructures.

Thus, a potential to foster care partnerships might be assumed also because such an intervention might be used also by formal caregivers like migrant care workers with minor adaptations.

Equity (including ethics)

The practice explicitly addresses geographic equity by targeting informal caregivers in rural areas, where access to professional support is more limited and feelings of isolation are more pronounced. The intervention aims to reduce this structural disadvantage by offering trained volunteer-based psychosocial support directly in the home setting.

Gender and age dimensions are reported:

- 74% of the caregivers were women, and
- The average age was 64.26 years (range: 33–89). However, these factors were not actively addressed in the intervention design (e.g. no gender-specific approaches or age-specific adaptations are mentioned).

There is no indication that other equity dimensions were explicitly considered in the design or implementation of the intervention (socioeconomic status, migration background, language barriers, disability, or lack of family support).

Ethical aspects:

- The study received ethical approval from the Ethics Committee of the Albert-Ludwig University of Freiburg;
- Data collection was conducted through standardized questionnaires by social workers in the participants' home environments;
- The article does not provide details on data protection measures, but it mentions that randomization was initially blinded and that participants gave informed consent;
- The intervention was low-risk and built on voluntary support, with regular supervision of volunteers, reducing the likelihood of harm.

In summary, the practice addresses geographic equity and includes basic ethical safeguards, but does not systematically address other equity dimensions beyond what is passively reflected in the sample.

Sustainability

The article does not provide explicit information on how the practice is to be sustained long-term beyond the trial period.

The intervention relied on trained volunteers (family companions), who were recruited through existing structures (e.g. Caritas) and supervised by professionals (a psychotherapist and a gerontologist). While this suggests a potentially scalable model, there is no indication of secured long-term funding, institutional anchoring, or integration into existing care infrastructures.

The training and implementation were funded by the German Federal Ministry of Health as part of a time-limited project ("Zukunftswerkstatt Demenz"), which ended in March 2015. Moreover, none of the involved researchers remain affiliated with the university at which the study was conducted. These circumstances further limit the potential for institutional continuity or follow-up development.

In summary, the article describes a promising volunteer-based model for rural dementia care support, but offers no concrete evidence or strategy for ensuring its financial, structural, or policy sustainability beyond the funded project phase.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

The intervention presents a conceptually transferable model based on volunteer training, systemic family support, and community-level implementation. Its reliance on existing structures (e.g. Caritas), flexibility of delivery (home visits, phone, email), and focus on dementia-specific family support suggest theoretical potential for adaptation in other regions.

However, the article provides no evidence of actual transfer, scaling, or policy integration beyond the original trial site. There is no discussion of implementation in other local, regional, or national contexts, nor any framework for how such transfer might be supported.

Given the lack of ongoing institutional affiliation (the project ended in March 2015 and none of the researchers are currently at the original institution), scalability remains untested. To realize transferability, it would require a coordinated strategy involving municipalities, health or care insurance providers, and national stakeholders. This includes long-term financing models, policy backing, and integration into existing care systems.

In conclusion, while the practice has theoretical adaptability, there is no concrete evidence of real-world transferability, scalability, or broader implementation.

Collaboration with and/or participation of different stakeholders and sectors

The intervention involved cross-sectoral collaboration between several local and academic actors:

Health and social care sector:

- The intervention was implemented in cooperation with the Caritas Association of the Breisgau-Hochschwarzwald district, a major welfare organization active in social and care services;
- Support was delivered by trained volunteers, recruited and coordinated through Caritas.

Academic/research institutions:

- The project was developed and evaluated by the Institute for Applied Research at the Catholic University of Applied Sciences Freiburg A
- and the Center for Geriatrics and Gerontology at the University Hospital Freiburg;
- as well as the Clinic for Geriatric Psychiatry, Center of Psychiatry, Emmendingen.

Policy/funding level:

- The intervention was funded by the German Federal Ministry of Health within the national program Zukunftswerkstatt Demenz.

Mental health/psychosocial expertise:

- Volunteers received regular supervision from a psychotherapist and a gerontologist, ensuring psychological and ethical oversight.

However, the article provides no information about collaboration with:

- LTC workers' employer organisations,
- trade unions,

carers' associations,

representatives from education, employment, or digital sectors.

The primary collaborative structure remained local and health/social-care focused, without indication of broader sectoral integration or national stakeholder involvement beyond funding.

Innovative aspects

The article highlights one key social innovation: the expansion of an existing volunteer caregiver support model into a dementia-specific, family-oriented intervention.

This innovation consists of:

- A new training programme for volunteers who had already completed a general caregiver support qualification. The training added dementia-specific content (24 units), systemic and solution-oriented family support (32 units), and modules on networking, organization, and self-reflection;
- A shift in focus from supporting the individual primary caregiver to supporting the entire caregiving family system. This systemic perspective is not standard in most volunteer-based support models;
- Integration of monthly supervision by professionals (a psychotherapist and a gerontologist), which enhanced the quality and reliability of volunteer-delivered psychosocial support.

These elements distinguish the practice from standard care companion models. The article notes that existing training for volunteers often lacked dementia-specific content and did not address the broader family dynamics affected by dementia. The newly developed curriculum aims to close this gap and to offer structured emotional and relational support within families.

No technological innovations (e.g. digital tools, e-health solutions) were included or mentioned in the intervention.

In summary, the innovation lies in the conceptual and structural enhancement of volunteer engagement in dementia care, adding professionalized content and a systemic family approach, implemented in a rural community setting.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

- Small sample size: the required number of participants (128) was not reached. Only 76 informal caregivers were included, and 63 completed the full pre-post evaluation. This reduced the statistical power and limited the ability to perform multivariate analyses, increasing the risk of α -error inflation in exploratory analyses;
- Differences in group composition despite randomization: there were significant baseline differences in dementia severity between the intervention and control groups, affecting comparability. This was addressed methodologically by conducting per-protocol analyses with covariates (e.g. dementia stage), but it still challenges internal validity.
- Incomplete blinding: due to the nature of the intervention (personalized conversations and knowledge transfer), blinding of participants and second-round interviewers was not possible, which may have introduced bias.
- Lack of long-term structures: although the training was well received and the intervention showed positive effects, the article does not describe any follow-up strategy or institutional continuation after the project ended. This represents a barrier to sustainability and scalability.
- No professional integration: the practice did not involve LTC professionals in the support process, which limits its systemic embedding and may reduce the potential for coordinated care.
- Solutions or mitigating strategies described:

Use of monthly supervision by professionals to support volunteers and enhance quality.

Application of per-protocol analysis with covariates to compensate for initial group imbalances.

Overall, while the intervention was well-conceived, the article points to methodological, structural, and systemic barriers that would need to be addressed for broader implementation.

Key success factors/points of strength

The project identifies several key strengths that contributed to the success of the intervention:

- Specialized volunteer training: a major success factor was the development and implementation of a structured, dementia-specific training curriculum for existing care companions. The 68-unit program combined clinical knowledge with systemic family counselling approaches, thus filling a gap in conventional volunteer training.
- Supervision and quality assurance: volunteers were supervised monthly by a psychotherapist and a gerontologist, ensuring consistent quality, emotional support for the volunteers, and professional oversight of the intervention. This ongoing supervision likely contributed to the intervention's effectiveness and credibility.
- Community-based delivery: the use of local actors, particularly the Caritas Association of Breisgau-Hochschwarzwald, allowed for close proximity to target families and increased accessibility, especially in rural settings. Delivery through home visits, phone, and email provided flexibility and personalization.
- High acceptance and engagement: the intervention achieved a relatively low dropout rate and included regular contact between volunteers and families (5–20 times over 16 weeks), indicating good acceptance by the target group and feasibility of implementation in everyday life.
- Positive mental health outcomes: in the per-protocol analysis, the intervention showed a statistically significant improvement in mental HRQOL and reduced family role conflict, demonstrating that the approach can effectively strengthen emotional well-being and family dynamics in dementia care.

In summary, the success of the practice was driven by a well-designed training programme, professional supervision, and community-based implementation. The combination of structured volunteer engagement and systemic family support proved to be a promising model for improving mental health outcomes among informal carers in rural areas.

Rosetta: a web-based e-learning platform for informal carers of people with dementia

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	445 SLR
Ranking of the good practice	13
Type of good practice	3. Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives Also related to: Primary, secondary and tertiary prevention interventions (by providing preventive support to reduce caregiver stress and potentially delay burnout).
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Rosetta: a web-based e-learning platform for informal carers of people with dementia
Name of the good practice in original language (if available)	ROSETTA System
Initiative in operation since	Not specified in the article. The project started in 2009 and was funded for 3 years
Country/ies of implementation	UK, Finland, The Netherlands, Sweden, Germany
Geographic coverage/ implementation level	3. Cross-country/International
Stage of initiative	4. Finished for 4 years or more The article was published in 2016 and it reports on pilot testing and evaluation, indicating that the project had already concluded by then. No information is given on continuation or ongoing implementation.
Name of the Leader/s Organisation/implementer/s	VU University Medical Centre, Department of Psychiatry, Valeriusplein 9, 1075 BG Amsterdam, The Netherlands
Contact details	Bart Hatting, Phone: +31207885622, b.hattink@vumc.nl
Type/source(s) of funding	1. European/EU funds
Webpage/s of the good practice (or link to doi of the paper)	Webpage: https://www.aal-europe.eu/projects/rosetta/ DOI: https://doi.org/10.3109/17483107.2014.932022

Summary (abstract)	This article presents the development and pilot evaluation of Rosetta, an electronic, personalisable e-learning system designed to support informal carers of people with dementia across Europe. The system was developed in five countries (Germany, Finland, Sweden, the Netherlands, and the UK) under an EU-funded initiative. Rosetta aimed to address the educational and emotional support needs of informal carers by offering flexible, tailored content in the carers' native languages. The platform included modules on understanding dementia, managing stress, coping with emotions, and accessing support services. The study employed a mixed-methods design, including pre- and post-intervention surveys (n = 42) and seven focus groups with both informal carers and professionals. Participants reported a high level of acceptability and user-friendliness, and valued the relevance, accessibility, and cultural adaptability of the system. Many noted increased knowledge and awareness of dementia-related challenges, as well as improvements in emotional self-management and coping strategies. While the platform was positively received, technical issues (e.g. login difficulties, occasional complexity of language) were reported, especially by older users. Nonetheless, participants appreciated the flexibility of learning and the potential of such tools to reduce isolation and improve wellbeing. The article concludes that Rosetta is a promising, scalable approach to support informal carers of people with dementia through personalised e-learning. It highlights the need for further development, technical refinement, and wider testing to confirm effectiveness across different care settings and populations.
Keywords	Dementia, Informal Carers, E-Learning, Emotional Support, Personalised Training

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

Rosetta is a web-based, personalisable e-learning system developed to support informal carers of people with dementia. The system was developed in response to growing recognition of the emotional stress and educational needs of informal carers, who often lack adequate support while managing complex caregiving tasks. Rosetta was designed to provide flexible, self-directed learning that could be tailored to individual carers' preferences, literacy levels, and emotional states. The e-learning platform consisted of nine modules, covering topics such as:

- understanding dementia and its progression
- managing stress and emotions
- improving communication
- accessing formal and informal support
- balancing caregiving with personal wellbeing.

Content included text, video clips, and interactive features, and was available in multiple languages. The system incorporated personalisation tools, allowing users to navigate content based on their specific needs and priorities. A preliminary survey helped adapt the content to the user's level of experience and emotional resilience. The practice was piloted with 42 informal carers, followed by seven focus groups involving carers and professionals. Feedback highlighted the system's relevance, user-friendliness, and potential to reduce caregiver isolation and burden. Participants valued the emotional support embedded in the language and design, as well as the cultural sensitivity of the platform.

Overall, Rosetta represents an innovative digital intervention combining knowledge transfer, emotional support, and self-paced learning to strengthen the resilience and mental wellbeing of informal carers of people with dementia.

Main setting(s)/place(s) of delivery

1. Home
9. Online

Rosetta is an online e-learning platform designed for self-directed use by informal carers in their home environment. All content was accessed digitally, with no indication of in-person delivery or use in institutional settings.

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)
2. Working carers (combining paid work with informal care)

Rosetta was specifically developed for informal carers of people with dementia, including those who are employed. The article notes that participants varied in age and employment status but does not focus on professional caregivers.

Age profile(s) of the target group(s) of the practice

2. 35-64 years
3. 65-74 years

While the article does not report detailed age data, it states that participants included a mix of middle-aged and older carers. No indication is given that carers under 35 or over 75 participated.

Health issues of the care recipients assisted by the target group(s)

3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.)

The Rosetta e-learning platform was specifically developed for informal carers of people with dementia. No other health conditions are addressed in the article.

Age profile(s) of the care recipients assisted by the target group(s)

4. Older people (65+ years)

The care recipients were people with dementia, a condition predominantly associated with older adults. The article makes no mention of younger individuals receiving care.

Problem being addressed

The Rosetta system was developed to address non-occupational risks experienced by informal carers of people with dementia.

These include:

- Emotional burden and stress: carers frequently reported high emotional strain, including feelings of frustration, isolation, sadness, and difficulty coping with the progression of dementia;
- Lack of accessible information: many carers lacked sufficient knowledge about dementia and how to manage related behaviours, which increased anxiety and uncertainty;
- Cultural and linguistic barriers: carers across different countries highlighted the importance of culturally adapted and language-appropriate content to support their understanding and reduce feelings of exclusion;
- Limited time and flexibility: the unpredictable nature of dementia care made in-person training difficult, creating a need for self-paced, home-based solutions.

No occupational risks (e.g. related to formal employment in LTC) or data on migration background, income level, or physical health risks are provided. However, the intervention responds to age- and gender-related challenges, as many carers were older women providing extensive daily care.

Measurement/evaluation

The Rosetta intervention was evaluated using a mixed-methods design, combining quantitative surveys with qualitative focus group discussions.

Quantitative component:

- A pre- and post-intervention questionnaire was completed by 42 informal carers;
- While specific measurement instruments are not named, carers were asked about their emotional well-being, understanding of dementia, and confidence in caregiving;
- The surveys aimed to capture changes in perceived knowledge and emotional self-management after using the e-learning system.

Qualitative component:

- Seven focus groups were conducted (at least one per country site), including both informal carers and professionals;
- Discussions explored users' experiences with the system, perceived benefits, technical barriers, emotional impact, and suggestions for improvement;
- Key outcomes included improved emotional awareness, appreciation for tailored support, and feedback on accessibility and content relevance.

No validated psychological scales (e.g. for burden, depression, resilience) are reported. The results remain exploratory and descriptive, and the article suggests that further evaluation with larger samples is needed to confirm effectiveness.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
4. Enhancing informal carers' and/or LTC workers' satisfaction
5. Fostering (or potential to foster) care partnerships.

Informal carers reported:

- Improved emotional coping, self-awareness, and management of stress, indicating both enhanced resilience and mental wellbeing;
- Reduced feelings of isolation, and greater understanding of dementia-related behaviours, which helped lower emotional strain;
- Increased confidence and satisfaction in their caregiving role due to better access to practical information and emotional support.

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

The article does not describe any structured coordination, or mutual recognition between informal carers and LTC workers as part of the Rosetta system (thus, the intervention does not meet the WELL CARE definition of a care partnership in strict sense). However, although Rosetta was developed as a self-directed training tool for informal carers and does not include joint training modules, interactive features for collaboration, or any mechanism that would enable shared care planning or integrated decision-making between carers and professionals, the system was evaluated through focus groups that included both carers and professionals, and provides emotional and educational support to informal carers, thus the overall potential to foster care partnerships is minimal but still present.

Equity (including ethics)

The Rosetta intervention was designed with attention to cultural and linguistic equity. The platform was available in multiple languages and was adapted to five European countries, allowing carers to access content in their native language and within their cultural context. This was seen as essential to reduce barriers related to language, literacy, and emotional expression.

The system also included personalisation features, which allowed carers to select content based on their own needs, emotional readiness, and caregiving experience. This approach supports equity in terms of user autonomy and emotional accessibility.

However, the article does not specify whether the system was adapted for users with impairments, low digital literacy, or socioeconomic disadvantage. There is also no reference to implementation differences between rural and urban settings or to access among particularly vulnerable groups (e.g. isolated carers, those without internet access).

Ethical aspects:

- Ethical approval is not explicitly mentioned in the article;
- It is implied that participants consented to participation in the evaluation (surveys and focus groups), but no detailed information is given on data protection, anonymisation, or risk–benefit considerations.

In summary, the intervention supports language and cultural equity, and offers personalisation to individual learning needs, but lacks explicit design features or ethical documentation for addressing structural vulnerability, accessibility, or formal ethical oversight.

Sustainability

The article provides no information on long-term sustainability measures for the Rosetta system. The platform was developed with European funding under the Leonardo da Vinci programme, which was time-limited and project-based. There is no mention of follow-up funding, integration into national care systems, or institutional ownership of the platform after the project's conclusion.

While Rosetta was technically designed for scalability (as a digital e-learning tool), the article does not address:

- whether the system remained available after the pilot phase;
- who would maintain or update the platform;
- or whether any host organisation took responsibility for its continuation.

No details are provided on technical infrastructure, professional support, or potential integration into health or social care services that could ensure ongoing implementation. In summary, based on the article, there is no evidence of a sustainability strategy, and the future use or availability of the Rosetta system after project funding ended remains unclear.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

The Rosetta e-learning system was developed from the outset for use in multiple European countries (UK, Germany, Finland, the Netherlands, Sweden) and was designed to be linguistically and culturally adaptable. This indicates a strong potential for transferability and adaptability across different national contexts. The system's online format, modular structure, and personalisation features support scalability, as it can be delivered without requiring physical infrastructure or professional facilitation. Informal carers can access the program independently from home, which enhances its implementability in diverse settings, including rural or underserved areas.

However, the article provides no information about broader implementation beyond the pilot, nor about any formal efforts to integrate Rosetta into national care or training systems. There is also no evidence of performance tracking beyond the initial evaluation.

Sustainability remains a limiting factor: the lack of long-term funding or institutional anchoring raises questions about who would maintain or update the system if transferred to other contexts.

In summary, Rosetta shows technical and conceptual potential for transfer and scaling across countries and care systems. However, practical implementation and sustainability conditions are not addressed in the article, which limits confidence in its long-term replicability.

Collaboration with and/or participation of different stakeholders and sectors

The Rosetta project involved cross-sectoral and international collaboration across five European countries, supported by the AAL Joint Programme, including:

- Academia and research: Led by De Montfort University (UK), with contributions from other research institutions such as Fraunhofer, VU Medical Center, TNO, and Novay, covering health policy, ICT, and ageing research;
- Healthcare and LTC providers: Organisations such as Westpfalz-Klinikum GmbH (Germany) and Zorgpalet Baarn-Soest (Netherlands) participated as end-user partners, providing insight from real-world care settings;
- Industry and SMEs: Several technology and service providers contributed, including Eaton Electric BV, AVICS BV, CIBEK technology, and CPS Europe BV, focusing on the development and implementation of the digital platform and its sensor integration;
- Civil society and user organisations: Partners like Christelijke Mutualiteit (CM, Belgium) ensured the involvement of mutual health organisations and carer networks, strengthening the practice's user orientation;
- European public funding and policy support: The project received over €2.2 million from the Ambient Assisted Living (AAL) Programme, reflecting structured policy-level support for innovation and implementation.

In addition to informal carers and professionals participating in the evaluation, this broad public-private consortium ensured that multiple perspectives (technological, social, institutional, and user-based) were integrated in the design and testing of the intervention.

This collaborative structure contributed to the system's cultural adaptability, technical feasibility, and user-centred design, even though the article itself provided limited detail on these partnerships.

Innovative aspects, if any

Rosetta demonstrates several key social and technological innovations:

- Personalisation of e-learning: The platform allowed carers to customise content based on their emotional readiness, caregiving experience, and personal preferences, supporting individualised learning paths.
- Cultural and linguistic adaptability: Rosetta was translated and adapted for use in five countries, offering content in multiple languages and reflecting country-specific caregiving realities (a rare feature in dementia care education tools).
- Integration of emotional and practical support: Unlike many carer training programs focused solely on knowledge transfer, Rosetta included modules on emotional coping, stress management, and personal wellbeing, tailored to informal carers' needs.
- Fully digital, self-directed format: The system was designed for home use without professional facilitation, increasing accessibility for carers who may lack time, mobility, or formal support.

These elements represent a novel combination of flexibility, inclusiveness, and cross-national design, particularly in the context of dementia care education for informal carers.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

- Technical usability issues: several carers encountered difficulties navigating the system, including login problems and unclear instructions, especially among older users with limited IT skills;
- Complexity of language: some participants found the content too abstract or linguistically demanding, which could reduce accessibility for users with lower education or health literacy levels;
- Limited personalisation in practice: although the system was designed to be personalised, in some cases users felt that the adaptation to individual needs was insufficient, or that too much content was presented at once;
- No formal integration into care systems: the platform functioned as a stand-alone digital tool, without links to existing care pathways, professional guidance, or follow-up support, limiting its impact and sustainability;
- Lack of long-term implementation planning: there is no mention of continued funding, host institutions, or update mechanisms after the project's conclusion, raising concerns about the platform's ongoing usability.

The evaluation suggests that digital support tools for informal carers must offer low-threshold access, clear and intuitive guidance, and the ability to adapt content to individual needs. Involving carers in the design process and conducting iterative usability testing are critical to ensure that the system is both accessible and emotionally supportive. Additionally, long-term success would require institutional integration, ongoing technical support, and connection to broader care and counselling structures, rather than functioning as a stand-alone solution.

Key success factors/points of strength

- Cross-national co-development and language adaptation: The system was developed and tested in five countries, offering content in multiple languages and with cultural adaptations. This enhanced relevance and acceptance across diverse user groups;
- Participatory design approach: informal carers and professionals were involved in the pilot testing and focus groups, ensuring that feedback on usability, content, and emotional tone directly informed the development;
- Personalisation and flexibility: the e-learning platform allowed carers to navigate content according to their emotional readiness and caregiving experience, supporting individual learning paths and self-efficacy;
- Accessibility and convenience: the online, self-paced format enabled carers to access support from home and at flexible times, reducing barriers related to time constraints or geographical distance;
- Focus on both knowledge and emotional wellbeing: unlike many carer training tools, Rosetta addressed not only informational gaps but also emotional coping, stress management, and isolation, which were central concerns for carers.

Rosetta demonstrates that a well-designed, culturally adaptable, and emotionally supportive digital tool can be an effective means of reaching informal carers across different countries. Participatory development, combined with personalisation and ease of access, were key to the system's acceptance and impact. These strengths offer important guidance for future interventions aiming to support carers through scalable, user-centred technology.

Care at home

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	24 GLR
Ranking of the good practice	14
Type of good practice	3. Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Care at home
Name of the good practice in original language (if available)	Pečuj doma
Initiative in operation since	1st January 2013
Country/ies of implementation	Czech Republic
Geographic coverage/ implementation level	1. Local 2. Regional, national
Stage of initiative	1. Ongoing
Name of the Leader/s Organisation/implementer/s	Diakonie Českobratrské církve evangelické (Diaconia of the Evangelical Church of Czech Brethren)
Contact details	Sarah Huikari, sarah.huikari@pecujdoma.cz
Type/source(s) of funding	1. European/EU funds 2. International organisations funds 8. Other (specify: cofinancing is covered by the Diaconia of the Evangelical Church of Czech Brethren)
Webpage/s of the good practice (or link to doi of the paper)	Webpage: https://www.pecujdoma.cz/sluzby
Summary (abstract)	Pečuj doma offers both online and in-person courses, hosts seminars, and publishes guides to equip people with essential skills for caring for their loved ones at home. This initiative reaches out to those caring for family members, aiming to enhance their ability to manage care responsibilities effectively.
Keywords	Family Carers Support, Home Care Services, Multidisciplinarity

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

Pečuj doma, initiated by Diaconia of the Evangelical Church of Czech Brethren, supports informal caregivers across the Czech Republic by providing comprehensive support since 2013. Their mission is to empower caregivers through encouragement, advice, information, education, sharing spaces, and individual guidance for effective home care.

Main setting(s)/place(s) of delivery

1. Home

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)
2. Working carers (combining paid work with informal care)
5. Personal care workers (including privately-hired migrant care workers)
6. Other LTC workers/health-social care professionals (Social workers in Czech republic mostly don't know the caregiving itself but lead the teams of caregivers. It is very useful to teach them how to care)

Age profile(s) of the target group(s) of the practice

1. 18-34 years
2. 35-64 years
3. 65-74 years

Health issues of the care recipients assisted by the target group(s)

1. Physical disabilities (caused, e.g. by frailty, accident, injury, illness, etc.)
3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.)
4. Other chronic illnesses/long-term health conditions (Geriatrics syndromes, chronic pain. Care for individuals suffering from chronic pain should include specific practices like positioning to prevent pressure ulcers and similar conditions).

Age profile(s) of the care recipients assisted by the target group(s)

3. Adults (18-64 years)
4. Older people (65+ years)

Problem being addressed

The main objective is to empower informal carers to manage home care better. The greatest challenge is sustaining free courses. There is significant interest, and they collaborate with hospitals, but the most difficult question is always funding, which is entirely dependent on EU projects funding and contributions from the Evangelical Church of Czech Brethren.

Measurement/evaluation

“Pečuj doma” is not only an important activity of the Evangelical Church of Czech Brethren but also a key educational initiative of Diaconia. It involves top experts as lecturers, enhancing its impact and outreach in caregiver training. An annual report should be found here:

<https://scps.diakonie.cz/res/archive/004/000540.pdf?seek=1687159349>

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings
4. Enhancing informal carers' and/or LTC workers' satisfaction
5. Fostering (or potential to foster) care partnerships
8. Other (They offer a variety of courses, some of which specifically address the mental health of caregivers. The lectures vary based on needs and project funding.)

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

The “Pečuj doma” initiative exemplifies a powerful model for fostering care partnerships between long-term care (LTC) workers, informal carers, and community stakeholders. It fosters robust care partnerships by combining shared learning, emotional support, and collaborative planning, resulting in increased caregiver competence, reduced isolation, and a more cohesive, respectful, and coordinated care environment. Through free educational courses and monthly thematic events (e.g., on dementia care, communication, legal rights), both informal carers and LTC professionals learn together.

Equity (including ethics)

“Pečuj doma” integrates equity through free, accessible, and geographically inclusive services targeting a wide range of vulnerable caregivers. Specific content and counselling are geared towards carers of people with dementia, chronic illnesses, multimorbidity, and those caring for relatives without wider family support. Ethical safeguards are embedded in its counselling and data practices, with a strong focus on minimising harm and empowering informal carers through dignified and respectful support.

Sustainability

This initiative provides free courses for participants and does not require any payment from them. Most related costs are covered by the Evangelical Church of Czech Brethren with the combination of state and other private donors. The project includes accredited courses for caregivers and public administration workers, support groups, and counseling including case management, validating the advisor role for caregivers and fostering cooperation with local government. It also benefits the sustainability that the program is run by the Diaconia of the Evangelical Church of Czech Brethren, which its network includes over 2,000 paid staff and 800 volunteers across the Czech Republic.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

The courses provided by “Pečuj doma” are highly transferable to various settings because they focus on caregiving principles that are universal and not dependent on specific legal environments. While local legislative frameworks for benefits or financial support for caregivers may differ, the fundamental principles of care remain the same across different contexts.

Collaboration with and/or participation of different stakeholders and sectors

Pečuj doma brings together a wide range of stakeholders—from professional carers and psychologists to church leaders, policymakers, and digital partners—creating a holistic, well-integrated support system that strengthens the role of informal carers within the broader care ecosystem.

Innovative aspects, if any

None reported.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

Carers often face mental exhaustion and burnout due to ongoing emotional and physical strain, especially in dementia or chronic care. Their limited time, especially when juggling work and family, makes regular program participation difficult. A shortage of mental health professionals, particularly in rural areas, restricts access to needed support. Persistent stigma prevents many, especially older carers, from seeking help.

Pečuj doma effectively addresses the emotional toll of caregiving by offering flexible, community-based, and psychologically supportive structures. While challenges remain, especially around professional resources and time limitations—the initiative offers adaptable and empathetic strategies that prioritise carers' mental resilience and emotional wellbeing.

Key success factors/points of strength

The Pečuj doma initiative benefits from stable co-funding by the European Social Fund and the Czech government, allowing it to offer free services nationwide. It involves trained professionals—psychologists, counsellors, and care experts—who deliver tailored mental health and educational support. The use of online formats increases accessibility and adapts to the limited time availability of informal carers. The program is shaped through user feedback and participatory approaches, ensuring relevance and responsiveness. Strong leadership by Diakonie and community engagement through church networks have been crucial for trust-building and sustainability.

The main lesson learned are about a flexible, person-centred model—backed by stable funding, professional support, and community-rooted delivery—that can effectively meet the emotional and practical needs of carers, especially when co-designed with them.

Mobile Technology for Personalised Reminiscence for People Living with Dementia and their Carers

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	514 SLR
Ranking of the good practice	15
Type of good practice	3. Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Using Mobile Technology to Provide Personalised Reminiscence for People Living With Dementia and Their Carers: Appraisal of Outcomes From a Quasi-Experimental Study
Name of the good practice in original language (if available)	idem
Initiative in operation since	2016
Country/ies of implementation	UK
Geographic coverage/ implementation level	1. Local
Stage of initiative	Not available.
Name of the Leader/s Organisation/implementer/s	Institute of Nursing and Health Research, Ulster University
Contact details	Elizabeth A Laird, ea.laird@ulster.ac.uk
Type/source(s) of funding	4. National or local public sources (e.g. general tax revenue, social care funds)
Webpage/s of the good practice (or link to doi of the paper)	DOI: https://doi.org/10.2196/mental.9684
Summary (abstract)	Reminiscence is an intervention that prompts memories and has been widely used as a therapeutic approach for people living with dementia. A novel iPad app (Inspired app) to support home-based personalised reminiscence was developed. A 19-week personalised reminiscence intervention using an iPad app improved mutuality, quality of relationship, and subjective wellbeing for individuals with early to moderate dementia. Carers experienced non-significant changes in these measures. The results indicate that individual-specific reminiscence supported by an iPad app may be efficient in the context of early to moderate dementia.
Keywords	Intervention, Informal Carers, Wellbeing, Mobile Apps, Carer and Patient Relationship

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

The InspiredD project represents a pioneering example of good practice in supporting people living with dementia and their family carers through technology-enabled personalised reminiscence. Developed in response to the global public health priority of dementia, the initiative sought to address the growing need for effective non-pharmacological interventions that enhance well-being and relational quality in home settings.

The main objective of the initiative was to improve mutuality (relational closeness), emotional wellbeing, and the quality of caregiving relationships for people with early to moderate dementia. It was realized through the creation of the InspiredD app, a cross-platform, device-agnostic mobile application that allows users to upload and access personalized multimedia memorabilia—such as photos, videos, and music—to facilitate reminiscence activities.

The intervention was developed collaboratively with user groups and employed a user-centered, agile development process. It was delivered through a 19-week home-based program involving structured training in both reminiscence and IT use. Each participant dyad—comprising a person with dementia and a family carer—received an iPad with the InspiredD app pre-installed, along with a series of guided sessions to ensure effective use.

The outcomes measured using validated tools (Mutuality Scale, QCPR, and WHO-5), demonstrated statistically significant improvements in mutuality, caregiving relationship quality, and subjective well-being among participants with dementia. Although improvements among carers were not statistically significant, trends were positive.

Main setting(s)/place(s) of delivery

1. Home
9. Online

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)

Age profile(s) of the target group(s) of the practice

1. 18-34 years
2. 35-64 years
3. 65-74 years
4. 75+ years

Health issues of the care recipients assisted by the target group(s)

3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.)

Age profile(s) of the care recipients assisted by the target group(s)

3. Adults (18-64 years)
4. Older people (65+ years)

Problem being addressed

Family carers often endure intense emotional and physical demands in providing daily care. The caregiving role is associated with a heavy workload, chronic stress, and limited respite, contributing to carer burnout and poor mental health. On the other hand, for people living with dementia, the risks include emotional and social isolation, cognitive decline, and a diminishing sense of identity and agency. These risks are exacerbated by age-related barriers to technology use and digital exclusion. The quality of the relationship can deteriorate over time as the disease progresses, reducing mutuality and emotional closeness between the carer and the person with dementia.

Measurement/evaluation

The InspiredD project employed a robust mixed-methods evaluation framework to assess the effectiveness of its home-based, technology-supported reminiscence intervention for people living with dementia and their family carers.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
4. Enhancing informal carers' and/or LTC workers' satisfaction
5. Fostering (or potential to foster) care partnerships
7. Cost-effectiveness

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

The InspiredD project has strong potential to foster meaningful care partnerships between informal carers, people living with dementia, and other stakeholders, including long-term care (LTC) professionals. By providing a platform for personalized digital reminiscence, InspiredD enables both carers and individuals with dementia to co-create and share memories in a way that supports relational closeness. This process not only enhances emotional connection but also promotes mutual validation of knowledge—the person with dementia contributes their lived history, while the carer facilitates and supports the process. This shared activity builds trust and deepens the care relationship, transforming it from a task-oriented dynamic into a reciprocal partnership. The app also supports emotional resilience by validating the caregiving role and reinforcing shared identity and purpose. In doing so, InspiredD fosters a supportive ecosystem where carers, individuals with dementia, and LTC staff engage as partners, each contributing their own expertise and experience.

Equity (including ethics)

All participants gave informed consent after being fully briefed on the purpose, risks, and benefits of the study. Ethical considerations principally pertained to voluntariness, supporting separate informed consent for the people living with dementia and their carers, handling and storage of data, and right to withdraw from the study. The study received ethical approval (REC Ref 16/NI/0002) in line with regional and National Health Service Trust research governance.

Sustainability

The InspiredD app is designed as a cross-platform, device-agnostic solution, compatible with commonly available tablets and smartphones. The app can be updated and scaled to meet evolving digital standards. The intervention is home-based and does not require continuous involvement of healthcare professionals. Training and support were provided initially, but ongoing use relied on the self-direction of dyads (carer and person with dementia), minimizing costs and human resource demands. The project's participatory development process and commitment to user feedback make it adaptable to diverse cultural and linguistic contexts, further enhancing sustainability through localization.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

The app and training materials are suitable for users with varying levels of digital literacy. With modest localization (e.g. language translation, cultural tailoring of examples), InspireD could be adapted for use in different countries and care environments, including urban, rural, and underserved areas.

Collaboration with and/or participation of different stakeholders and sectors

The InspireD project was built on a foundation of multi-sectoral collaboration, engaging a wide range of stakeholders from health, social care, academia, and civil society to ensure a holistic, inclusive, and evidence-based approach to dementia care.

Innovative aspects, if any

At the heart of InspireD is a custom-designed, cross-platform mobile application that facilitates personalized digital reminiscence. Unlike generic memory aids, the InspireD app allows users to upload and interact with their own multimedia content—photos, music, and videos—transforming passive technology use into an active, emotionally engaging experience. Its device-agnostic design ensures broad accessibility, while the app's intuitive interface is tailored to older adults and users with cognitive impairments. InspireD redefines the caregiving relationship by introducing a shared activity that reinforces mutuality. It places the emotional and relational dimensions at the center, enhancing care partnerships through joint engagement in storytelling and reminiscence.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

A significant initial barrier was participants' limited experience with digital devices, especially among older carers and people living with dementia. Many expressed hesitancy or anxiety about using new technology. The project addressed this by providing structured, one-to-one digital skills training tailored to each dyad's pace and needs. Family carers often had limited time and high emotional demands, which could make participation in structured sessions challenging. The intervention was flexibly delivered in-home, allowing dyads to engage with the app at their own convenience.

Key success factors/points of strength

A major strength was the active involvement of people with dementia and their carers throughout the development process. Their input shaped the app's functionality, training methods, and overall user experience. By offering the program in participants' homes, InspireD overcame barriers related to transportation, scheduling, and mobility. The self-paced model respected carers' time constraints and adapted to their routines. Recognizing the digital literacy gap among older adults, the project included personalized IT training and device setup, which significantly improved confidence and usability.

Video Conferencing Peer Support and Rarer Forms of Dementia

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	521 SLR
Ranking of the good practice	16
Type of good practice	3. Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Video Conferencing Peer Support and Rarer Forms of Dementia: An Exploration of Family Carers' Positive Experiences
Name of the good practice in original language (if available)	idem
Initiative in operation since	Not available.
Country/ies of implementation	UK
Geographic coverage/ implementation level	2. Regional, national
Stage of initiative	1. Ongoing
Name of the Leader/s Organisation/implementer/s	Rare Dementia Support (UCL)
Contact details	Emma Harding, emma.harding@ucl.ac.uk
Type/source(s) of funding	4. National or local public sources (e.g. general tax revenue, social care funds)
Webpage/s of the good practice (or link to doi of the paper)	DOI: https://doi.org/10.1177/10497323231172880

Summary (abstract)	Little is known regarding the nuanced experiences of family carers for people living with rare dementias (PLWRD), with no known literature exploring their positive experiences of caring discussed within peer support group settings. This article explores family carers of PLWRD's positive experiences reported in video conferencing peer support groups. Six peer support group sessions involving a total of nine participants were qualitatively analysed using thematic analysis, guided by the conceptual framework of positive aspects of caring (CFPAC). Six themes were identified: 1) Protecting, maintaining, enjoying and finding strength in their relationship with the PLWRD; 2) Using tools and resources in response to challenges; 3) Positive impact of interactions and others' responses to the dementia; 4) Overcoming barriers to taking a break while maintaining their wellbeing; 5) Maintaining positive outlooks and showing psychological resilience in adversity; 6) Attributing meaning to the caring role. This article highlights family carers of PLWRD's positive psychological, physical and social resources, balanced against the challenges of caring and maintaining their wellbeing, and identifies ways of promoting family carers' positive caring experiences and resources within healthcare and supportive settings.
Keywords	Rare Dementias, Carers, Positive Aspects of Caring, Peer Support Groups, Video Conferencing, Thematic Analysis

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good

This good practice focuses on the use of video-conferencing peer support groups for family carers of people living with rarer forms of dementia. Developed in response to the unique challenges faced by this group, the initiative aimed to reduce isolation, enhance peer connection, and improve emotional well-being through digital inclusion and tailored support.

The primary goal was to provide a safe, accessible, and relatable space for carers to share experiences, access emotional support, and build knowledge about managing complex care needs associated with rarer dementia (e.g., frontotemporal dementia, primary progressive aphasia). The initiative also sought to overcome geographic and diagnostic isolation by leveraging technology to connect carers regardless of location.

This is a technology-enabled social support intervention, offering regular peer support sessions via video conferencing (e.g., Zoom), typically co-facilitated by professionals and trained peer leaders. Each group was small and diagnosis-specific, fostering meaningful, trust-based interactions.

Main setting(s)/place(s) of delivery

1. Home
9. Online

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)

Age profile(s) of the target group(s) of the practice

2. 35-64 years
3. 65-74 years

Health issues of the care recipients assisted by the target group(s)

3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.)

Age profile(s) of the care recipients assisted by the target group(s)

3. Adults (18-64 years)
4. Older people (65+ years)

Problem being addressed

Family carers face chronic stress, emotional burnout, and role overload due to the complex, unpredictable, and often early-onset nature of rarer dementias. These conditions can involve behavioural changes, language loss, and personality shifts that are particularly distressing and challenging to manage. Carers often take on these responsibilities with little professional support. Relational risks are also high, as the progression of rarer dementias can erode the emotional bond between carer and loved one, leaving carers with profound grief and identity loss even while the person is still alive. Geography can further isolate carers, especially in rural or underserved areas where specialist services are unavailable.

Measurement/evaluation

The evaluation of the video-conferencing peer support initiative for carers of people with rarer dementias was carried out using qualitative methods, by conducting semi-structured interviews.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
4. Enhancing informal carers' and/or LTC workers' satisfaction
5. Fostering (or potential to foster) care partnerships
7. Cost-effectiveness

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

While the initiative is primarily peer-led, it creates a powerful foundation for knowledge sharing and mutual recognition which are critical components of effective care partnerships. Carers gain not only emotional validation but also practical insights into symptom management, communication strategies, and system navigation. These shared experiences can be translated into collaborative dialogues with health and social care professionals, improving care continuity and relational understanding.

Equity (including ethics)

All participants provided written informed consent prior to enrolment in the study. The study was approved by the UCL Research Ethics Committee (reference no. 8545/004).

Sustainability

The use of freely available or widely accessible platforms like Zoom ensures minimal infrastructure costs. As sessions are held online, there is no need for physical spaces, transportation, or extensive administrative overhead, making the model cost-effective and resource efficient. Furthermore, facilitation can be carried out by a combination of trained professionals and peer leaders, reducing reliance on specialist staff.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

The digital format enables simultaneous reach across wide geographic areas, including rural communities where specialist services are limited or absent. Sessions can be delivered in different languages, and culturally relevant facilitators or content can be introduced to make the model inclusive across diverse populations.

Collaboration with and/or participation of different stakeholders and sectors

The video-conferencing peer support initiative for family carers of people with rare dementias is grounded in cross-sector collaboration, bringing together a range of stakeholders from health, research, civil society, and carer communities to deliver a holistic, inclusive support model.

Innovative aspects, if any

One of the core innovations lies in the tailored, diagnosis-specific support groups conducted entirely online. Unlike general dementia services, these groups focus on the specific emotional, relational, and practical issues associated with rarer dementias such as frontotemporal dementia or posterior cortical atrophy. Using widely accessible video-conferencing platforms like Zoom enables high accessibility with minimal resource requirements. The initiative also incorporates former or current carers as co-facilitators, recognising and valuing experiential knowledge alongside professional facilitation. Rather than focusing solely on practical caregiving skills, the groups address deep emotional need and role transformation.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

Some participants, especially older carers, initially lacked the skills or confidence to use video conferencing tools. Internet connectivity and access to appropriate devices (e.g. laptops, tablets) were also inconsistent across participants, particularly in rural or low-income settings. Carers were provided with technical guidance and support prior to and during sessions. In some cases, partnering organisations helped with device access or digital skills training. Ensuring simple interfaces and providing “tech buddy” support were key lessons for improving inclusivity. Some carers expressed concern about feeling overwhelmed by others' stories, or about how much to share. The solution was to keep the groups small, diagnosis-specific, and professionally co-facilitated, creating a safe, confidential environment.

Key success factors/points of strength

By creating small, diagnosis-specific groups, the initiative enabled a sense of deep understanding and emotional connection rarely found in generalised dementia services. In addition, the use of video-conferencing platforms removed geographic and logistical barriers, especially important for rural carers or those with heavy caregiving responsibilities. Groups were co-facilitated by trained professionals and experienced carers, blending clinical insight with lived experience. This structure ensured emotional safety, supported meaningful dialogue, and empowered carers to contribute their knowledge.

Partner In Balance (PIB)

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	M11 SLR
Ranking of the good practice	17
Type of good practice	3. Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives (main type)
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Partner in Balance (PiB). Blended Care Self-Management Program for Caregivers of People With Early-Stage Dementia
Name of the good practice in original language (if available)	Info not available in Dutch
Initiative in operation since	Trial registration 20th August 2014. In the paper authors do not mention the period of the study. They however state that data were collected pre- and post-intervention, and at 3-, 6-, and 12-month follow-up points. Moreover, in the registration form https://www.webcitation.org/6vSb2t9Mg the following time-points are indicated: 20th August 2014 – 13th October 2015.
Country/ies of implementation	Netherlands
Geographic coverage/ implementation level	2. Regional, national
Stage of initiative	4. Finished for 4 years or more. In the registration form, the following time-points are indicated: 20th August 2014 – 13th October 2015
Name of the Leader/s Organisation/implementer/s	Maastricht University Medical Center
Contact details	Lizzy MM Boots, Department of Psychiatry and Neuropsychology, Alzheimer Center Limburg, School for Mental Health and Neurosciences, Maastricht University Medical Center, Faculty of Health, Medicine and Life Sciences. PO Box 616, Maastricht, 6200 MD, Netherlands, Phone: 31 43 3881994, Fax: 31 43 3884092, e-mail: l.boots@maastrichtuniversity.nl
Type/source(s) of funding	4. National or local public sources (e.g. general tax revenue, social care funds). This study is part of a larger study funded by Alzheimer Nederland and the Alzheimer Research Fund Limburg
Webpage/s of the good practice (or link to doi of the paper)	DOI: https://doi.org/10.2196/jmir.7666

Summary (abstract)	The PiB is a blended care self-management program for caregivers of people with early-stage dementia. The main aim was to encourage caregivers to identify solutions for their specific need, by formulating and planning a personal change plan. The program combines face-to-face coaching with tailored Web-based modules. Implementation, sampling, and intervention quality were evaluated with quantitative and qualitative data from coach and participants. Analyses were performed with descriptive statistics and deductive content analysis. Coaches described an intensified relationship with the caregiver post intervention. Caregivers appreciated the tailored content and gave a positive feedback. The blended structure increased their openness. Overall, personal goals were attained after the program. Participants and coaches were satisfied with the intervention, with awareness of the benefits of blended care self-management programs and training in tailored self-management skills.
Keywords	Internet, Caregivers, Technology, Therapeutics

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

The initiative was developed to support carers of relatives with early-stage dementia, and who are at high risk for depression and anxiety. Existing programs regard mainly advanced stages of dementia. Implementation of PiB, that is a programme for caregivers of people with early-stage dementia, can represent a valuable addition to the existing caregiver support. The aim/objectives were: 1) to support caregivers to actively manage their lives, and to engage in social activities together with the care recipient; 2) to encourage caregivers to identify solutions for their specific need, by formulating and planning a personal change plan, to anticipate on stressful situations and gain confidence in their ability to take care of the situation and themselves; 3) to evaluate the process from the perspective of both family caregivers and professionals delivering the intervention (coaches). Caregivers were included if they were (1) spousal caregivers of people with mild cognitive impairment or mild dementia, and (2) had access to the Internet. Inclusion criteria of experts were (1) professional caregiver in the Dutch dementia care field, with (2) daily interaction with people with dementia (PwD) and their caregivers. This blended care self-management program combines face-to-face coaching with tailored Web-based modules. It consists of: 1) face-to-face intake session with a personal coach to familiarize participants with the program, set goals, and select module themes (e.g., coping with stress, social relations and support); 2) tailored online thematic modules, including psychoeducation; and 3) a face-to-face evaluation session with the coach evaluating previously set goals. According to the results, caregivers appreciated the tailored content, and personal goals (e.g., coping with stress) were attained after the program. Coaches described an intensified relationship with the caregiver post intervention. Participants and coaches were satisfied with the intervention. The PiB is mainly "aimed at mental health/wellbeing and resilience promotion and training initiatives" (type 3), but also it represents an example of blended and "integrated approach and strategy" (type 4), with carers and professionals (coaches) collaborating and being involved in the evaluation process.

Main setting(s)/place(s) of delivery

- 4. Local healthcare centre (e.g. ambulatory)
- 5. Hospital
- 9. Online

Family caregivers were recruited within memory clinics and mental health care organizations (with the help of caregiver support services). The intervention was delivered and evaluated within these organizations. The program however combines face-to-face coaching with tailored Web-based modules.

Target group(s)/beneficiaries

- 1. Informal carers (e.g. older carers). Spousal caregivers of both genders.
- 3. Qualified/registered nurses (psychiatric nurses)
- 6. Other LTC workers/health-social care professionals (specify: psychologists)

Trained coaches (psychologist or psychiatric nurse) shared experiences and asked for feedback during the regular supervision meetings. They also participated in the evaluation process.

Age profile(s) of the target group(s) of the practice

- 3. 65-74 years
- Mean age 70.

Health issues of the care recipients assisted by the target group(s)

- 3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.).
- People with mild cognitive impairment or mild dementia of all subtypes,

Age profile(s) of the care recipients assisted by the target group(s)

This info is not available in the paper.

Problem being addressed

Dementia is a syndrome that causes deterioration in cognitive functioning, and affects memory, thinking, orientation, and comprehension. Caring for a family member with dementia puts caregivers at risk of overburdening. PiB is a self-management program guided by a personal coach, developed to help caregivers cope with challenging situations and develop skills to increase resilience and prevent overburdening. Implementation of PiB can represent a valuable addition to the existing caregiver support, with an evaluation process from the perspective of both family caregivers (participants) and professional nurses delivering the intervention (coaches).

Measurement/evaluation

Implementation, sampling, and intervention quality were evaluated with data/answers from both coaches (nurses) and participants. Goal attainment scaling was used to measure treatment-induced change. Analyses were performed with descriptive statistics and deductive content analysis. First-order (sampling and intervention quality) and second-order process data (implementation knowledge) were collected following a process evaluation framework based on earlier research.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
4. Enhancing informal carers' and/or LTC workers' satisfaction
5. Fostering (or potential to foster) care partnerships

Coaches (psychologist or psychiatric nurses) described an intensified relationship with the caregiver post intervention. Caregivers appreciated the tailored content and positive feedback. The blended structure increased their openness. Overall, personal goals (e.g., coping with stress, social relations and support) were attained after the program. Participants and coaches were satisfied with the intervention.

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

Trained coaches (psychologist or psychiatric nurse) shared experiences and provided feedback during the regular supervision meetings. In particular, their tasks were familiarizing participants with the online program, supporting them in module choice and goal setting, and giving feedback on the self-reflective assignments through the online messaging portal of the program, which was accessed via email. They also participated in the evaluation process. Coaches described an intensified relationship with the caregiver post intervention. The professionals were satisfied with the intervention being manageable, considering their busy schedules, giving them time to focus on their feedback. They reported a more profound relationship with the caregiver, since the program allowed them to empathize with the caregiver. The participants emphasized that the coach was essential for motivation and questions. Knowing that someone was available to guide allowed caregivers to feel less alone.

Equity (including ethics)

The Medical Ethics Committee of the Maastricht University Medical Center+ (MUMC+) approved this study. Regarding the aspect of equity, authors only state that caregivers were typically the spouses, mean age 69, both genders. PiB is however for early stage of dementia, and caregivers were excluded when they were not computer literate, had insufficient cognitive abilities to engage in the online self-management program, and had severe health problems. Young age and employment were thus considered recruitment facilitators, whereas unfamiliarity with using the website also caused difficulties among the older age group.

Sustainability

This study is part of a larger study funded by Alzheimer Nederland (Grant no. WE03-2010-08) and the Alzheimer Research Fund Limburg. The Dutch Alzheimer Association supported the dissemination of the information about the program. A further study (2024) mentions the application of the PiB intervention to caregivers of persons with Huntington's disease (HD) and supports the continuation of the practice <https://doi.org/10.1016/j.invent.2024.100782>. Authors also state that involving stakeholders in technological development and evaluation can facilitate implementation in different care settings. Moreover, the personal coaches/experienced professionals (psychologist or psychiatric nurse) were trained, from one of the participating organizations. They attended a 2-hour training session in blended care self-management techniques, goal setting and online help, and regular supervision meetings.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

A detailed description of the PiB intervention/method (apart from the paper), is presented in a previous study <https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-016-1351-z>.

Detailed information about the program components and development is presented in another previous study <https://www.researchprotocols.org/2016/1/e33/PDF>.

A further study (2024) mentions the application of the PiB intervention to caregivers of persons with Huntington's disease (HD) <https://pubmed.ncbi.nlm.nih.gov/39512474/>. The further study (2024) also supports adaptability and flexibility.

Collaboration with and/or participation of different stakeholders and sectors

Trained coaches (psychologist or psychiatric nurse) shared experiences with caregivers and provided feedback during the regular supervision meetings. Family caregivers were recruited with the collaboration of memory clinics, mental health care organizations, and caregiver support services. Furthermore, the participants interacted with other participants via the discussion forum. PiB was also developed together with potential users. Caregivers were indeed encouraged to formulating, planning, and executing personal goals using a proactive 5-step change plan. The participants were however free to set their own personal goals. Also, authors state that including potential users during the design process enabled to gain unique insights into usage behavior and challenges to adapt the technology to the needs of the target audience <https://www.researchprotocols.org/2016/1/e33/PDF>.

Innovative aspects, if any

The program's focus on quantifiable goals and possible solutions, instead of problems, was considered new and valuable for the participants. The availability of the information, assignments, and feedback after the intervention was seen as an advantage over mere face-to-face support. Also, the intervention combines face-to-face coaching with tailored Web-based modules. PiB is indeed mainly a Web-based fully operational self-management program for early stage dementia caregivers. It was developed based on the senior-friendly website checklist <https://pubmed.ncbi.nlm.nih.gov/15602301/>.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

Even though this study is part of a larger study funded by Alzheimer Nederland (Grant no. WE03-2010-08) and the Alzheimer Research Fund Limburg, authors mentioned implementation barriers as lack of financing. Also, the interviewed coaches reported that their caseload comprised several people with dementia living alone without a registered primary caregiver. This was listed as a primary recruitment barrier next to "caregiver does not own a computer" and "caseload only comprises caregivers of people with moderate to severe dementia." Other barriers included high staff workload. Implementation barriers included lack of financing and time. Adapting the content to specific subgroups, for example, younger caregivers, was recommended. Also, before implementing the program on a larger (international) scale, barriers and facilitators for implementation should be identified with regard to possible differences based on different organizational and cultural contexts.

Key success factors/points of strength

PiB encourages caregivers of people with early-stage dementia to actively manage their lives and identify solutions for their specific need, with emotional management (e.g., dealing with fear and insecurity about the future), by formulating and planning a personal change plan, to anticipate on stressful situations and gain confidence in their ability to take care of the situation and themselves. <https://www.researchprotocols.org/2016/1/e33/PDF>. Also, coaches considered the face-to-face intake session (in addition to the Web-based modules) crucial for developing a personal connection with the caregivers. Moreover, electronic health (eHealth) supports for caregivers of person with dementia offer an opportunity for accessible tailored interventions, and also may fill the expected gap in supply and demand caused by demographic aging and the decreasing working population. Further points of strength are the presence of trained personal coaches/experienced professionals (psychologist or psychiatric nurse), and the participatory co-design.

Psychoeducation program for patients with bipolar disorder and their caregivers

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	35 SLR
Ranking of the good practice	18
Type of good practice	3. Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives Also related to: 4. Integrated approaches and strategies
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	A multi-center naturalistic study of a newly designed 12-sessions group psychoeducation program for patients with bipolar disorder and their caregivers
Name of the good practice in original language (if available)	Idem
Initiative in operation since	Not available. The paper was published September 2019.
Country/ies of implementation	Netherlands
Geographic coverage/ implementation level	2. Regional, national
Stage of initiative	1. Ongoing
Name of the Leader/s Organisation/implementer/s	Dutch Foundation for Bipolar Disorders (www.kenbis.nl)
Contact details	Susan Zyto, Mental Health Service Organisation North Holland North, Center for Psychosomatic Medicine, Hoorn, The Netherlands, s.zyto@ggz-nhn.nl
Type/source(s) of funding	5. Private sources (e.g. donations, private insurers, foundations i.e. Dutch Foundation for Bipolar Disorders)
Webpage/s of the good practice (or link to doi of the paper)	DOI: https://doi.org/10.1186/s40345-020-00190-5

Summary (abstract)	Background: Psychoeducation (PE) for bipolar disorder (BD) has a first-line recommendation for the maintenance treatment phase of BD. Formats vary greatly in the number of sessions, whether offered individually or in a group, and with or without caregivers attending. Due to a large variation in formats in the Netherlands, a new program was developed and implemented in 17 outpatient clinics throughout the country. The current study investigated the feasibility of a newly developed 12-sessions PE group program for patients with BD and their caregivers in routine outpatient practice and additionally explored its effectiveness. Methods: Participants in the study were 108 patients diagnosed with BD, 88 caregivers and 35 course leaders. Feasibility and acceptance of the program were investigated by measures of attendance, and evaluative questionnaires after session 12. Preliminary treatment effects were investigated by pre- and post-measures on mood symptoms, attitudes towards BD and its treatment, levels of self-management, and levels of expressed emotion. Results: There was a high degree of satisfaction with the current program as reported by patients, caregivers, and course leaders. The average attendance was high and 83% of the patients and 75% of the caregivers completed the program. Analyses of treatment effects suggest positive effects on depressive symptoms and self-management in patients, and lower EE as experienced by caregivers. Conclusions: This compact 12-sessions psychoeducation group program showed good feasibility and was well accepted by patients, caregivers, and course leaders. Preliminary effects on measures of self-management, expressed emotions, and depressive symptoms were promising. After its introduction it has been widely implemented in mental health institutions throughout the Netherlands.
Keywords	Bipolar Disorder, Psychoeducation, Self-Management, Expressed Emotions, Caregivers

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

The initiative was developed to reduce the stress of the caregivers in coping with patients with bipolar disorders (BD), and to reduce the levels of expressed emotion (EE), i.e. by improving interaction pattern towards the patient with a mental illness, as perceived by the caregiver.

The primary goal of this study was to evaluate the feasibility of the 12-sessions PE group program for patients with BD and their caregivers in routine outpatient practice, based on the evaluation of format and content by participants and course leaders, and attendance and dropout. A secondary goal was to explore effectiveness on mood symptoms, attitudes towards BD and its treatment, levels of self-management, and levels of expressed emotion.

Participants in the study were 108 patients diagnosed with BD, 88 caregivers and 35 course leaders (i.e. psychiatric nurses, psychiatrists, and psychologists conducting the PE groups in the various centers). 90 (83%) patients and 66 (75%) caregivers attended the last session of the program.

The content of the sessions was based on themes common in effective Psychoeducation programs aiming at improvement of illness awareness, early detection, treatment adherence, and lifestyle adjustments. Every Psychoeducation group had a maximum of 16 participants, typically eight patients and eight related caregivers. Each patient was invited to bring one caregiver. The patients and caregivers received a workbook. Two mental health professionals with experience in bipolar disorder treatment led the course following a manual describing content and execution of each session and using a slide set for each session. At least one of the course leaders had specific experience with bipolar disorder Psychoeducation groups.

As for the typology of intervention, this should be considered both as an intervention aimed at mental health/wellbeing and resilience promotion and training initiatives and as an integrated approach and strategy.

Main setting(s)/place(s) of delivery

4. Local healthcare centre (e.g. ambulatory)

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)

Age profile(s) of the target group(s) of the practice

1. 18-34 years

2. 35-64 years

3. 65-74 years

Health issues of the care recipients assisted by the target group(s)

2. Psychological/mental health issues (e.g. depression, anxiety, etc.)

Age profile(s) of the care recipients assisted by the target group(s)

3. Adults (18-64 years)

4. Older people (65+ years)

Problem being addressed

Psychoeducation (PE) is regarded as an effective adjunct to medication and has a first-line recommendation for the maintenance treatment phase of BD. In the Netherlands, PE groups have been part of the regular treatment for patients with BD since the 1990's, typically offering six sessions group PE for patients together with one caregiver. Over the years, format, frequency and content of PE groups offered across the country had deviated from that original format and from evolving research evidence. Therefore, the Dutch Foundation for Bipolar Disorders (www.kenbis.nl) decided to update and harmonize the PE program by integrating evidence from the existing research literature with clinical and patient experience. A task force including professionals and members of the patient and caregiver advocacy organisation, developed a new 12-sessions group PE program for patients together with their caregivers.

Measurement/evaluation

The current program was evaluated using qualitative analyses of answers on the evaluation forms. For the answers to closed questions with semantic differential scales, the mean was calculated. Answers of patients and caregivers were analysed separately to evaluate the impact of the intervention on symptoms, drug attitudes, level of expressed emotions and self-management. After session 12, evaluative questionnaires to evaluate the Psychoeducation program, were administered to caregivers (as well as to patients). Additionally, at session 1 and 12 The Level of Expressed Emotion (LEE) questionnaire was administered to assess levels of expressed emotions as perceived by caregivers.

The LEE was used as a self-report questionnaire to assess the perception of levels of expressed emotions (EE) in family interactions in the past month, higher scores indicating increased levels of expressed EE. A high level of EE is considered to reflect an adverse interaction pattern towards the patient with a mental illness, as perceived by the patient.

The LEE is thus typically administered to the recipient, but for the purpose of the current study, the questions for caregivers were modified in order to measure self-appraised attitudes of the caregiver towards the patient.

Caregivers reported significantly lower expressed emotion (EE) towards the patient post-treatment, and perceived themselves as being less in need of controlling and monitoring the patient, including a less stressful coping with the patient.

Moreover, the opportunity of (guided) group discussion was rated as very useful by caregivers; the majority of course leaders found enough opportunity for group discussion.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

- 3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
- 5. Fostering (or potential to foster) care partnerships.

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

As in the original format, it was assumed that the combined attendance of patients and their caregivers in the same group and during all sessions supports mutual understanding and facilitates a triadic collaborative care approach in the subsequent long-term treatment. The opportunity of (guided) group discussion was rated as very useful by caregivers and considered to offer enough opportunity for group discussion by the majority of course leaders (74.3%), thus resulting as a tool which might potentially foster care partnerships.

Equity (including ethics)

The study was approved by the Institutional Review Board of the VU University Medical Center, Amsterdam, the Netherlands. All study participants provided written consent to participate after given full information about the study.

Regarding the aspect of equity, informal carers of both genders (45.8% female) participated in the program, aged 23-72 years (mean age: 50.1 years).

Care receivers participated in the program: patients aged 18 years or over with psychiatrist confirmed diagnosis of BD; aged 19-72 years (mean age: 40.8 years), both genders (57.7% female).

No socio-demographic information of course leaders are available.

Sustainability

The study was in part funded by the Dutch Foundation for Bipolar Disorders but no information was found about any continued funding for the practice. Nevertheless, it was stated that the 12-sessions Psychoeducation group program, was widely implemented in mental health institutions throughout the Netherlands after its introduction.

Since the manuals (for participants, n. 1808 and for course leaders, n. 156) are distributed by the office of the Dutch Foundation for Bipolar Disorders to 37 different mental health institution in the Netherlands, an indication of the implementation after this study was completed is present. Since manuals were ordered repeatedly by the same institution, this suggests that this PE course has become part of routine practice in these centers.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

All materials (manual for participants and manual for course leaders) are available and distributed by the office of the Dutch Foundation for Bipolar Disorders.

The Psychoeducation group program was widely implemented in mental health institutions throughout the Netherlands.

Collaboration with and/or participation of different stakeholders and sectors

The team consists of researchers and course leaders, the majority of which (80%) had over 5 years of experience in the treatment of patients with BD, and in giving a previous PE course for BD. In total 17 outpatient clinics of 13 mental health institutions throughout the Netherlands participated in the study, and each clinic organized one PE group. For the present study the final PE program was introduced in mental health centers throughout the Netherlands that collaborate in the network of the Dutch Foundation for Bipolar Disorders.

Innovative aspects, if any

None reported.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

Designed primarily to investigate feasibility and acceptability in daily clinical practice, the study has several limitations. Since a control group was not included, the results regarding short-term effects are only indicative, and given the lack of follow-up assessments after the intervention it remains unknown whether there is an effect on recurrence rates, hospitalisations, or medication adherence.

A future study including a control group and follow-up measurements is needed to distinguish the short- and long-term effects of this PE program from the naturalistic course of illness under treatment as usual. In addition, it may be of interest to investigate not only possible moderators, but also the mediators of the effect of PE such as influence of stage of the disorder, the severity of current depressive and manic symptoms, and the influence of residual cognitive impairments.

Key success factors/points of strength

The results of the study in considered highly generalizable, since it was implemented in daily clinical practice in a large number of mental health centers, and offered to all patients and their caregivers who had not yet attended a PE program at that time.

Open Dialogues

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	78 GLR
Ranking of the good practice	19
Type of good practice	2. Interventions or programmes dealing with organisational models and management approaches and/or targeted at the individual level
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Open Dialogues
Name of the good practice in original language (if available)	Öppna samtal
Initiative in operation since	2002
Country/ies of implementation	Sweden
Geographic coverage/ implementation level	1. Local 2. Regional, national
Stage of initiative	4. Finished for 4 years or more
Name of the Leader/s Organisation/implementer/s	Avenymottagningen (Eldrekraft atm)
Contact details	Inger Blennow, Inger.blennow@eldrekraft.se Lars Engkvist, lars.engkvist46@eldrekraft.se
Type/source(s) of funding	8. Other (initially, Avenymottagningen received funding from the health care region, Region Skåne)
Webpage/s of the good practice (or link to doi of the paper)	Webpage: https://www.eldrekraft.se/arbetssatt/

Summary (abstract)	In order for family members of older people to become involved in care, meeting formats are needed where everyone has the opportunity to speak, be listened to, and be recognised as knowledgeable and significant to ongoing care. The goal is to establish an equal relationship between users, family members, and professionals. While professionals may initiate such meetings, it is the client and/or their informal carers who give permission and also invite additional participants. It is also the older person who can lift any confidentiality restrictions. A dialogical conversational climate is created when everyone is given time to express what is important to them, while others listen without interruption or judgment. If reflections are then based on what has been said, participants will feel respected and taken seriously. The development of both theory and practice has continued. However, the open dialogue has not yet gained a foothold in care for older people. We believe there is significant potential here for a positive development in how older people and their informal carers are treated.
Keywords	Dialogue, Informal Carers, Inclusion, LTC Workers, Mutuality

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

Objectives of the good practice:

1. Patient Well-being:

Empowering the patient to have greater control over their own situation, thereby enhancing their overall life satisfaction;

Patient-centred care, means that family and other persons close to the patient need to be involved, as a patient does not exist in a vacuum.

2. Informal Carers' Well-being:

Empowering significant others/carers of the patient to have more control over their own situation;

Inclusion of informal carers in decision-making processes;

Informal carers are kept informed as they are present at all meetings where decisions are made. This means that confidentiality is not an issue, and the informal carers are provided with all necessary information.

3. Staff Well-being:

Staff members feel more secure in their roles as they work in teams, ensuring that responsibility does not fall on a single individual;

Team-based work with various professionals allows staff to continuously learn from each other and develop professionally;

Staff are assigned a supervisor and, if issues arise or they are uncertain about how to assist a patient, the supervisor, team, and other staff members convene a meeting with the patient and their family/informal carers. The supervisor employs the same approach, starting with questioning the team members.

The practice is built on the well-established Open Dialogue approach, which is grounded in systemic family therapy, dialogical theory, and principles of shared decision-making. It is documented in both research and practice, demonstrating positive outcomes for individuals with mental health problems. The method emphasises listening, reflection, and network involvement, and is designed to support both patients and informal carers.

Main setting(s)/place(s) of delivery

10. Other (private clinic)

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)

2. Working carers (combining paid work with informal care)

3. Qualified/registered nurses

4. Assistant nurses

Age profile(s) of the target group(s) of the practice

1. 18-34 years
2. 35-64 years
3. 65-74 years
4. 75+ years

Health issues of the care recipients assisted by the target group(s)

2. Psychological/mental health issues (e.g. depression, anxiety, etc.)

Age profile(s) of the care recipients assisted by the target group(s)

4. Older people (65+ years)

Problem being addressed

In order for family members to become involved in care, meeting formats are needed where everyone has the opportunity to speak, be listened to, and be recognised as knowledgeable and significant to ongoing care. The goal is to establish an equal relationship between users, family members, and professionals, which could possibly reduce stress for all involved.

Measurement/evaluation

Open dialogues are theoretically grounded in systems theory, which has been primarily applied within the field of family therapy. As early as the 1950s, family members were invited to participate in meetings involving people with mental illness or young people with social challenges. Many of the efforts made in the 1960s and 1970s to develop psychiatry and social services included a clear ambition to involve relatives, social networks, and professionals. Already then, many stakeholders were engaged in shared decision-making regarding continued care and support. Joint meetings contributed to more effective interventions and reduced suffering.

There are studies, both internationally and in Sweden, on various forms of family, couple, and systemic therapy. These studies show that systemic interventions are effective for a wide range of issues and provide a solid basis for considering their use from both an effectiveness and cost-efficiency perspective (Cederblad et al., 2015; Bergström et al., 2022).

The Open Dialogue approach has been evaluated internationally. In Finland, it has been used for over 20 years with positive outcomes, including in a longitudinal study showing 19-year positive results in the treatment of first-episode psychosis (Bergström et al., 2018). The method is currently being evaluated in the UK through the large-scale ODDSSI trial (Pilling et al., 2022) and has also been implemented in contexts such as family therapy and social services. At Avenymottagningen in Helsingborg, all patients and informal carers were asked to complete a discharge survey based on the Swedish National Board of Health and Welfare's national tool, "My view on care, support, and services," to allow for comparability at the national level. While all survey data were unfortunately destroyed when the clinic closed, interviews with clinicians suggest that 90–95% of responses from both patients and informal carers were positive. Although no formal publication of evaluation results from Avenymottagningen exists, the systematic use of structured feedback and the alignment with validated national instruments reflect a strong commitment to evaluation.

Reference list

Bergström, T., Seikkula, J., Alakare, B., Mäki, P., Köngäs-Saviaro, P., Taskila, J. J., Tolvanen, A., & Aaltonen, J. (2018). The family-oriented open dialogue approach in the treatment of first-episode psychosis: Nineteen-year outcomes. *Psychiatry research*, 270, 168–175. <https://doi.org/10.1016/j.psychres.2018.09.039>

Bergström, T., Seikkula, J., Alakare, B., Kurtti, M., Köngäs-Saviaro, P., Löhönen, E., Miettunen, J., Mäkiölitervo, H., Taskila, J. J., Virta, K., & Valtanen, K. (2022). The 10-year treatment outcome of open dialogue-based psychiatric services for adolescents: A nationwide longitudinal register-based study. *Early intervention in psychiatry*, 16(12), 1368–1375. <https://doi.org/10.1111/eip.13286>

Cederblad, M., Petit, B. Wirtberg, I. (2015): Par och familjeterapi fungerar. <https://www.sfft.se>

Pilling, S., Clarke, K., Parker, G., James, K., Landau, S., Weaver, T., Razzaque, R., & Craig, T. (2022). Open Dialogue compared to treatment as usual for adults experiencing a mental health crisis: Protocol for the ODDSSI multi-site cluster randomised controlled trial. *Contemporary clinical trials*, 113, 106664. <https://doi.org/10.1016/j.cct.2021.106664>

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
4. Fostering (or potential to foster) care partnerships

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

The practice promotes care partnerships between informal carers and formal carers. Through structured network meetings where patients, carers, and professionals participate as equals, Open Dialogue fosters mutual understanding and shared decision-making. At Avenymottagningen, carers were present at all meetings and had a direct influence on the care process. While formal alliances with broader sectors were not established in this setting, the method has the potential to support wider partnerships across sectors, including education, community services, and public institutions.

Equity (including ethics)

The Open Dialogue approach inherently supports equity by tailoring the care process to the individual and their social network. The method emphasises listening to the person's unique story, conditions, and resources, which allows for flexible and inclusive responses. At Avenymottagningen, patients were encouraged to bring people they considered important, such as parents, siblings, teachers, or others, regardless of family structure or background. The dialogical setting ensures that multiple perspectives are heard and respected, reducing power imbalances. While there is no explicit mention of systematic strategies to address equity dimensions such as socioeconomic status, disability, or language barriers, the foundational principles of Open Dialogue—unconditional listening, shared decision-making, and network inclusion—promote equitable participation across diverse groups. Therefore, it could be argued that the practice fosters equity in implementation, even if this is not always formalised or framed in terms of equity-specific objectives. No formal ethical approval is identified in the material; however, the positive aspects may outweigh potential risks due to the practice structure aligning with ethical standards.

Sustainability

The practice had institutional support during its initial implementation at Avenymottagningen, funded by Region Skåne, which did not continue to fund the practice (1-year extension was on the table) despite good results. Although that support ended, other countries continue to apply Open Dialogue within supported organisational structures, showing that the model remains institutionally viable and sustainable elsewhere.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

The Open Dialogue approach has been successfully implemented in several countries beyond Sweden and Finland, including the UK, Germany, Australia, and the US. Its broad international uptake and ongoing evaluations, such as the ODDSSI trial in the UK, demonstrate that the practice can be transferred and adapted to diverse settings.

The Open Dialogue approach is supported by a range of structured instruments, including manuals, guides, and training programmes, which provide detailed descriptions of how to apply the method in practice. These resources cover key elements such as the structure of network meetings, the role of professionals, principles of dialogical communication, and reflective practices. Fidelity tools have also been developed to ensure that implementation aligns with the core values of the model (Olson, in *The Routledge International Handbook of Psychosis and Experience*). International training programmes and implementation guides—such as those provided by Open Dialogue Pacific and the Open Dialogues network—further support transfer and replication in diverse contexts. Although no local manual from Avenymottagningen is publicly available, the clinic adhered to the established model.

Collaboration with and/or participation of different stakeholders and sectors

At Avenymottagningen, the practice was primarily implemented within the health and mental health care sector, involving interdisciplinary teams, patients, and their informal carers. While the approach allows for broader inclusion of stakeholders—such as schools or other community actors—there is no evidence that formal collaboration with sectors like civil society, academia, or employer organisations took place in this setting. However, in other contexts, such as Finland and the UK, Open Dialogue has been carried out in cooperation with a wider range of stakeholders, indicating its potential for cross-sector collaboration.

Innovative aspects, if any

The Open Dialogue approach can be considered a form of social innovation. It challenges traditional hierarchies in mental health care by promoting equal partnerships between patients, informal carers, and professionals. Its dialogical structure, emphasis on transparency, and active inclusion of the patient's social network represent a shift from expert-driven care to collaborative, person-centred processes. At Avenymottagningen, this model enabled new ways of organising care that responded to complex needs in a flexible and inclusive manner, demonstrating innovative thinking in both structure and practice.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

Staff have reported the perception that this way of working takes more time than the more traditional way. Evidence does, however, suggest that time is saved, as a good emotional connection between caregivers, care recipient, and informal carers means fewer complaints and there is no need to plan meetings without the patient, as all discussed and decided during joint meetings;

Some informal carers did not live close to the clinic. This was solved using this method via modern digital technology;

Getting the staff to accept the changes in hierarchy. The staff members do not have the final say in everything; the informal carers, as well as the patient, are also able to have a real voice;

Funding was an issue after three years had passed, as Region Skåne did not continue to fund the practice (1-year extension was on the table) despite good results. Avenymottagningen was a private clinic, and the patients then had to foot the bill. This also meant that the clinic had to reduce staff, and thus also the number of patients that they could accept.

Key success factors/points of strength

The authors state that one of the most crucial factors for the successful implementation of the Open Dialogue method in healthcare is effective health management. Without the support and trust of management, it becomes exceedingly difficult to transform care practices and uphold the core values of any healthcare facility. Management support is essential in the form of patience, funding, and education for the staff. It is vital to encourage the staff's willingness to shift decision-making processes in favour of the patient and to involve their families and informal caregivers in these decisions. Training and supervision are critical for successful implementation.

Act Belong Commit

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	74 GLR
Ranking of the good practice	20
Type of good practice	6. Community-based initiatives/measures
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Act Belong Commit (ABC)
Name of the good practice in original language (if available)	idem
Initiative in operation since	2016 (in Denmark)
Country/ies of implementation	Denmark, Australia
Geographic coverage/ implementation level	2. Regional, national 3. Cross-country/International
Stage of initiative	1. Ongoing
Name of the Leader/s Organisation/implementer/s	Department of Psychology at the University of Copenhagen
Contact details	abcmamentalsundhed@psy.ku.dk
Type/source(s) of funding	4. National or local public sources (e.g. general tax revenue, social care funds) 5. Private sources (e.g. donations, private insurers, foundations, i.e. Nordea Foundation)
Webpage/s of the good practice (or link to doi of the paper)	The Best Practice Portal: https://webgate.ec.europa.eu/dyna/bp-portal/best-practice/427 Website from the University of Copenhagen, the Department of Psychology: https://psychology.ku.dk/abc/ Website from ISCA: https://www.isca.org/news-detail/1330/abc-study-visit-exploring-successful-implementation-of-the-model%E2%80%9393lessons-from-denmark-and-beyond

Summary (abstract)	The overall goal of the ABCs of Mental Health is to promote public mental health and to support active and meaningful communities by creating the best possible conditions and environments for mental health and wellbeing. This is meant to ensure that everyone can (ABC): A: do something B: do something with someone C: do something meaningful. This is done by sharing research-based information, building capacity among front personnel, sharing knowledge, and by collaborating across different disciplines and sectors. The ABCs of Mental Health is inspired by 'Act-Belong-Commit', a universal mental health promotion initiative developed by Curtin University, Western Australia. In Denmark, the ABC model has been integrated into various sectors, including municipalities, schools, and organisations, demonstrating its broad applicability. The model is often promoted through campaigns and partnerships, such as the International Sport and Culture Association (ISCA) project, aiming to expand the ABC model across Europe.
Keywords	Act-Belong-Commit, Community Level, Mental Health, Promote Social Support

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

At its core, ABC promotes mental well-being through three fundamental pillars:

Act (stay physically and mentally active);

Belong (build and maintain social connections);

Commit (engage in meaningful activities).

Originating in the early 2000s in Australia, ABCs for Mental Health remains, to this day, the country's longest-running mental health promotion campaign.

Since 2016, when the model was introduced in Denmark, it has been developed through collaborations with municipalities, schools, and numerous organisations across sectors.

The ABC initiative targets three levels: individuals (the general population), organisations and communities (e.g. sports clubs, municipalities), and the policy/system level. While not directly targeting LTC workers or informal carers, the broad design allows for inclusion/adaptation to those groups.

The ABC initiative also includes structured training and support for professionals and partner organisations. Training focuses on mental health promotion, use of campaign materials, and local implementation, and is coordinated by the Danish ABC Partnership.

Main setting(s)/place(s) of delivery

8. Local community

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)

2. Working carers (combining paid work with informal care)

3. Qualified/registered nurses

4. Assistant nurses

5. Personal care workers (including privately-hired migrant care workers)

6. Other LTC workers/health-social care professionals

The practice is aimed at the general Danish population, thus also including the above list of target groups/beneficiaries. Moreover (see point 1) it targets also organisations and communities (e.g. sports clubs, municipalities), and the policy/system level.

Age profile(s) of the target group(s) of the practice

1. 18-34 years

2. 35-64 years

3. 65-74 years

4. 75+ years

Health issues of the care recipients assisted by the target group(s)

2. Psychological/mental health issues (e.g. depression, anxiety, etc.)

Age profile(s) of the care recipients assisted by the target group(s)

1. Children/Youths (0-12 years)

2. Adolescents (13-17 years)

3. Adults (18-64 years)

4. Older people (65+ years)

Problem being addressed

Mental health is described as being just as important as physical health. Moreover, mental health is pivotal for the health and the ability to function socially, economically, and educationally. It is increasingly acknowledged both politically and in research that mental health is paramount for the ability to work and contribute positively to society.

Mental illness is one of the biggest disease burdens worldwide, and several studies show that it continues to go in the wrong direction in terms of mental health. For example, the latest National Health Profile in Denmark from 2023 shows that the proportion of people with low mental health is still increasing (2021-2023).

To break this trend and improve mental health among the Danish population, national and international experts point to the necessity of investing in and prioritising mental health promotion, alongside prevention and treatment.

The ABCs of Mental Health aims at:

Increasing knowledge and understanding of what people can do to strengthen their own and others' mental health and well-being through research-based information;

Building organisational capacity and educating qualified staff to work with mental health promotion;

Creating possibilities for more people to be able to take part in communities and activities through initiatives within and across the partnership;

Ensuring that the initiatives are based on a solid scientific foundation through continuous research and evaluation.

Measurement/evaluation

One study from Denmark used questionnaires, individual interviews and group interviews during 2017–2020. The MHP initiatives were grouped according to three strategies: building MHP capacity, campaign activities to promote mental health awareness and knowledge and establishing and promoting opportunities to engage in mentally healthy activities.

The study showed that the ABC framework was positively received and viewed as providing relevant knowledge for working with mental health problems as well as fostering intersectoral and interprofessional collaborations. However, using a bottom-up approach to develop and implement mental health problem initiatives can be time-consuming and resource-demanding, and it requires a deliberate balancing of local adaptability and concrete guidance when engaging stakeholders and implementers. Overall, using the ABC framework to develop and implement mental health problem initiatives holds great promise for advancing and promoting mental health problem practice (Hinrichsen et al., 2020).

Results from evaluations of the ABC partnership indicate that the initiative has been effective in establishing a shared understanding and terminology for mental health promotion, facilitating collaboration across sectors and professions. An impact study in the Danish population showed that increased awareness of the ABC messages influenced how individuals thought about their mental wellbeing, encouraged open conversations with close others, provided practical insights into how to support mental health, and led to concrete actions.

Another study from Australia shows that of those aware of the ABC campaign, 8% stated that the campaign prompted them to seek information, and 4% stated that the campaign prompted them to seek help for mental health problems. Those with a mental illness experience (MIE) were significantly more likely than those without to report that the campaign prompted them to look for information (12% vs 6%) and seek help for a mental health problem (9.5% vs 1.2%). Extrapolating these results to the total adult population of Western Australia indicated that around 120,000 adults had sought mental health information, and around 60,000 had sought help as a result of the campaign (Drane et al., 2023).

Reference list

Drane, C. F., Jalleh, G., Lin, C., & Donovan, R. J.. (2023). Impact of the Act-Belong-Commit campaign on mental health help-seeking behaviour. *Health Promotion Journal of Australia*, 34(1), 232–236. <https://doi.org/10.1002/hpja.605>

Hinrichsen, C., Koushede, V. J., Madsen, K. R., Nielsen, L., Ahlmark, N. G., Santini, Z. I., & Meilstrup, C.. (2020). Implementing Mental Health Promotion Initiatives—Process Evaluation of the ABCs of Mental Health in Denmark. *International Journal of Environmental Research and Public Health*, 17(16), 5819. <https://doi.org/10.3390/ijerph17165819>

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
4. Enhancing informal carers' and/or LTC workers' satisfaction
5. Fostering (or potential to foster) care partnerships
6. Improving organisational practices

These outcomes are largely assumed, and not all have been empirically demonstrated in the research.

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

The overall goal of the ABCs of Mental Health is to promote public mental health and to support active and meaningful communities by creating the best possible conditions and environments for mental health and wellbeing. The goal is also to reduce the complexity related to mental health and to make it more tangible to work with mental health promotion in practice, both for the individual and across organisations. The openness for collaboration to increase mental wellbeing could also possibly include the collaboration between informal carers and LTC workers.

Equity (including ethics)

The ABC initiative actively considers equity by adapting activities to fit diverse local settings and target groups. Implementers are encouraged to tailor communication and activities based on local demographics, including age, gender, and social context. While flexibility supports inclusive reach, the process evaluation notes that balancing local adaptation with structured guidance is a challenge. Academic evaluations of initiatives such as surveys and interviews involving potentially sensitive information—have been conducted in accordance with national ethical standards and reviewed by relevant ethics committees when required. Overall, the expected benefits of increased mental health awareness, reduced stigma, and strengthened wellbeing could possibly outweigh potential risks.

Sustainability

The practice has become part of a new political agreement on a ten-year plan for psychiatry and mental health. Further, the Danish Act Belong Commit (ABC) partnership received the Public Health Prize awarded to projects significantly differing in the Public Health landscape. Also, ABC for mental health has become a strategic focus and has been implemented as a method to strengthen well-being and community culture in sports clubs.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

The ABC initiative is clearly defined through its three-part framework and supported by structured materials, training, and partner guidance. Its flexible design enables adaptation to different cultural, organisational, and geographical contexts, and it has been implemented in various sectors and countries.

Collaboration with and/or participation of different stakeholders and sectors

The practice is described as being widely adopted in Denmark through partnerships with municipalities, schools, and various organisations.

Innovative aspects, if any

The ABC initiative represents social innovation in Denmark by reframing mental health promotion as a shared societal responsibility. It engages diverse sectors—public, civil society, and academia—and translates evidence into simple, actionable concepts (Act, Belong, Commit) to support inclusive, community-based mental wellbeing.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

Using a bottom-up approach to develop and implement the practice can be time-consuming and resource-demanding, and it requires a deliberate balancing of local adaptability and concrete guidance when engaging stakeholders and implementers.

Key success factors/points of strength

Key success factors include:

strong community engagement;

collaborative approach across different levels;

support—both in terms of support and funding—from the Danish government.

The main positive lessons learned is that the ABC strategy has a simple and memorable structure, making it easy to communicate. It effectively highlights the important area of mental wellbeing and offers a practical tool for promoting active and meaningful communities.

Staff Training Programme and Family Liaison Service

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	261 SLR
Ranking of the good practice	21
Type of good practice	4. Integrated approaches and strategies
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Improving partnerships with families and carers in in-patient mental health services for older people: a staff training programme and family liaison service
Name of the good practice in original language (if available)	idem
Initiative in operation since	2002
Country/ies of implementation	UK (Somerset Partnership NHS Foundation Trust)
Geographic coverage/ implementation level	1. Local
Stage of initiative	1. Ongoing
Name of the Leader/s Organisation/implementer/s	Somerset Partnership NHS Foundation Trust
Contact details	Frank Burbach, frank.burbach@sompar.nhs.uk Estelle Rapsley, estelle.rapsley@sumpar.nhs.uk
Type/source(s) of funding	3. Statutory LTC/healthcare financing system
Webpage/s of the good practice (or link to doi of the paper)	Webpage: https://developingopendialogue.com/wp-content/uploads/2015/04/Context138-Somerset.pdf DOI: https://doi.org/10.1111/j.1467-6427.2012.00584.x

Summary (abstract)	In spite of policies advocating the involvement of families in the care of mental health service users in the UK, there are few examples of initiatives to develop staff confidence and skills in partnership working. This article describes a whole team training initiative and family liaison service to promote family inclusive working on in-patient wards for older people in Somerset, UK. A three-day staff-training programme is described and training outcomes are reported. Staff report a substantial increase in confidence and family meetings held. A pre-and post-training case note audit shows increased consideration of the needs of families. To further increase face to face meetings with families a family liaison service has been established, whereby a staff member with systemic family therapy training joins ward staff to hold family meetings as part of the assessment/admission process. Evaluation of this service has shown it to be effective with positive feedback from families and staff.
Keywords	Mental Health, Families, Carers, Staff Training, In-patient Care

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

The practice consists of a three-day training programme in family inclusive ways of working on inpatient wards for older people. The team training initiative has been specifically designed to shift staff attitudes and practice towards more inclusive, empathetic engagement with carers, recognizing their critical role on inpatient care. The aim of the training is not to train large numbers of staff to be family therapists, but rather to increase awareness of the needs of carers and families and to create more family-sensitive mainstream services.

The training itself is a 3-day experiential program delivered by qualified systemic psychotherapists with lived and professional experience. The training kicks off with a family member telling about their experience, followed by a discussion of the research findings into families and carers views on mental health services. The three-day training includes a combination of brief didactic presentations and group exercises. Furthermore, participants receive skills training (interviewing the role-play family) and develop action plans.

Evaluation of the practice revealed that the training did result in positive changes in staff confidence in interacting with carers and more families being seen, it did not lead to all families being routinely involved in the assessment process. Therefore, a family liaison service was established, meaning that a family liaison specialist worked alongside ward staff to hold meetings with families and carers as part of the admission process.

Main setting(s)/place(s) of delivery

2. Residential care setting

Target group(s)/beneficiaries

3. Qualified/registered nurses

4. Assistant nurses

The training was provided to staff who were professionally and not-professionally registered. In case of the latter, no further details are given.

Age profile(s) of the target group(s) of the practice

1. 18-34 years

2. 35-64 years

Health issues of the care recipients assisted by the target group(s)

2. Psychological/mental health issues (e.g. depression, anxiety, etc.)

The practice consists of a three-day training programme in family inclusive ways of working, which (at the time the paper was written) was being delivered throughout the mental health trust by means of a whole-team training approach. The authors began with the acute in-patient wards, after which they moved on to in-patient wards for older people. The structure of the package of the training was similar to the acute adult wards, but the content was adapted to reflect the focus on older people. However, the exact age profiles are not specified.

Age profile(s) of the care recipients assisted by the target group(s)

3. Adults (18-64 years)

4. Older people (65+ years)

Problem being addressed

Despite clear UK policy promoting family involvement in mental health care—especially for older people—practice still falls short. Carers often feel excluded, their expertise undervalued, and their emotional and practical needs unmet. Many report a lack of support, poor communication, and limited involvement in care planning, despite longstanding national guidelines advocating otherwise.

A key issue is that most mental health staff receive no formal training in working with families, leaving them ill-equipped and lacking confidence. This is especially true in older people's in-patient services, where staff may feel unsure how to manage distressed relatives or navigate confidentiality concerns. As a result, carers—who are at increased risk of stress, mental health issues, and isolation—often remain unsupported.

Although models like "The Triangle of Care" highlight best practices, there is little targeted training to help staff develop the skills needed to engage families effectively. Without proper support and training, staff are unable to meet carers' needs or implement policy intentions. This intervention directly addresses this gap by focusing on equipping staff to work confidently and collaboratively with families in older adult mental health settings.

Measurement/evaluation

The training programme aimed to improve staff confidence and practice in working with families in older people's in-patient mental health services. Evaluation was multi-faceted:

Case Note Audits: Audits conducted before, shortly after, and one year post-training showed sustained improvements in key areas: more carers were registered, more carer assessments were completed, and there was greater family involvement in relapse prevention planning;

Staff Surveys: Before training, most staff had no formal training in family work and low confidence in involving carers. Post-training, confidence levels increased significantly—from 16% to 55% of staff rating themselves as confident. Professionally registered staff showed the greatest gains, with more than double the number of family meetings reported. Gains among non-registered staff were more modest;

Action Plans: At the end of the second day of training, staff were asked to develop an action plan to take back to their wards from ideas that had been generated through the training. Staff identified and implemented practical changes, such as improved carer information packs, earlier family contact, and designated "family champions." Progress was made in areas like increased registration of carers and better communication, though holding family meetings within 7 days of admission remained a challenge due to staffing constraints;

Training Feedback: Staff rated the training highly (mean score 4.3/5), citing increased awareness of carers' needs and greater confidence in family engagement;

Family Liaison Service: To address the ongoing gap in routine family involvement, a specialist family liaison post was introduced, enabling more timely family meetings. On two wards, 63% and 55% of eligible families respectively had meetings, with 79% occurring within 14 days of admission. The service was well-received and helped embed family involvement into the care pathway.

Overall, the training and liaison service led to measurable improvements in practice and staff confidence, though structural challenges like time constraints remain.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

5. Fostering (or potential to foster) care partnerships

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

This practice demonstrates strong potential to foster meaningful care partnerships between long-term care (LTC) staff and informal carers by equipping staff with the skills, confidence, and structures necessary for collaborative engagement. The training programme addressed a major gap in staff preparation and improving their confidence in collaborating with carers. Staff became more aware of carers' needs and more proactive in involving them in care planning and support. Importantly, the family liaison service further strengthened this partnership. With a dedicated staff member facilitating early meetings and modelling best practices, more families were engaged early.

Equity (including ethics)

None reported.

Sustainability

Evidence on the sustainability of the good practice is not explicitly reported. However, ongoing support from managers and adequate funding appear critical to its continuation. Staff were trained during working hours, indicating that time had to be scheduled for them—requiring coordination and management support. While the training yielded positive outcomes, it did not result in routine family involvement in the assessment process. To address this gap, a dedicated family liaison specialist post was created. This role requires funding, underscoring the financial commitment needed for sustainability. The authors further highlight active managerial involvement, not only in supporting the initiative but also in implementing the action plans developed during training.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

The training was initially developed for care professionals in acute in-patient wards and later implemented in another setting (in-patient wards for older people), demonstrating its potential for transferability across settings. Although no further evidence on scalability is provided, the article provides detailed information about the training content and related assignments. This supports the potential for adaptation and implementation in other contexts or care environments.

Collaboration with and/or participation of different stakeholders and sectors

Staff and managers of the Trust were involved in the training and implementation of the practice. Furthermore, carers were involved in the training, as each training started with a family member telling their story.

Innovative aspects, if any

The authors conducted an extensive literature search and discovered that there were no training programmes specifically designed to develop the skills of working with families for staff working in older people's in-patient units. Such a training was developed and proved to be successful.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

Barriers, challenges, or points of weaknesses were not explicitly reported in the article.

Key success factors/points of strength

Although the authors do not reflect on potential key success factors/points of strengths, what is mentioned in the article is the support received from the organization's management. Managers also attended the trainings and supported staff in implementing their action plans. This potentially signals to care professionals that managers valued the initiative, which may have enhanced staff engagement and motivation to apply the training in practice.

Inclusive Culture Program

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	85 GLR
Ranking of the good practice	22
Type of good practice	3. Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives 7. International or national strategies and initiatives launched/implemented by various institutions
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Inclusive Culture Program
Name of the good practice in original language (if available)	Kultura inkluzije
Initiative in operation since	2010
Country/ies of implementation	Slovenia
Geographic coverage/ implementation level	1. Local
Stage of initiative	1. Ongoing
Name of the Leader/s Organisation/implementer/s	Društvo za kulturo inkluzije
Contact details	Ajla Cerić, ajlaceric@yahoo.com
Type/source(s) of funding	1. European/EU funds 4. National or local public sources (e.g. general tax revenue, social care funds) 5. Private sources (e.g. donations, private insurers, foundations)
Webpage/s of the good practice (or link to doi of the paper)	Webpage: https://www.drustvozakulturoinkluzije.eu
Summary (abstract)	The Association of Inclusive Culture offers diverse programs and support groups for individuals with intellectual or developmental disabilities and their families, promoting wellbeing and social inclusion.
Keywords	Inclusion Culture, Disability, Social Inclusion

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

The Association of Inclusive Culture conducts diverse activities for individuals with intellectual or developmental disabilities and their families, emphasising their wellbeing. Adopting a holistic approach, the association offers programs in various areas, including sports, arts and culture, education, leisure activities, and social care.

For families of children, adolescents, and adults with disabilities, the association provides support groups aimed at improving mental health, coping with challenges, and enhancing the resilience of parents and caregivers. These support groups are led by professionals with expertise in this field and supervised by qualified supervisors. The groups allow parents to connect, expand their social networks, and receive important advice on mental health, childcare, and navigating health and legal systems related to raising children with disabilities.

Additionally, the association offers both individual and group assistance to people with intellectual or developmental disabilities. By providing a "companion," the association helps these individuals achieve social inclusion and independence in their daily activities. Companions can join monthly groups to discuss challenges and share best practices in caregiving. They also receive mentorship, allowing them to seek individual support whenever they face challenges or simply need someone to talk to. The companion is also responsible for assisting families—parents and siblings of children with intellectual or developmental disabilities—helping them cope with daily challenges and fostering a supportive environment. This comprehensive support aims to enhance the quality of life for individuals with disabilities and their families, fostering a more inclusive and supportive community.

Overall Goals:

1. Enhancing Wellbeing:

Improve the mental and emotional wellbeing of individuals with intellectual or developmental disabilities, their families, and caregivers.

Foster social inclusion and promote independence in daily activities for individuals with intellectual or developmental disabilities.

2. Fostering Integrated Care:

Support care partnerships by coordinating and integrating care activities between LTC workers and informal carers.

Specific Objectives:

1. Support Groups for Families and Carers:

Improve mental health, coping mechanisms, and resilience of parents, caregivers, and LTC workers.

Provide a platform for parents and carers to connect, expand their social networks, and share experiences.

Offer expert advice on mental health, childcare, and navigating health and legal systems related to raising children with disabilities.

Ensure these groups are led by professionals with expertise and supervised by qualified supervisors.

Main setting(s)/place(s) of delivery

8. Local community

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)

2. Working carers (combining paid work with informal care)

Age profile(s) of the target group(s) of the practice 1. 18-34 years 2. 35-64 years 3. 65-74 years 4. 75+ years
Health issues of the care recipients assisted by the target group(s) 2. Psychological/mental health issues (e.g. depression, anxiety, etc.) 3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.) 4. Other chronic illnesses/long-term health conditions (sensory disabilities, invisible disabilities, speech and language disabilities, learning disabilities, chronic illnesses)
Age profile(s) of the care recipients assisted by the target group(s) 1. Children/Youths (0-12 years) 2. Adolescents (13-17 years) 3. Adults (18-64 years)
Problem being addressed High emotional and psychological stress, due to the complexity of supporting people with intellectual or developmental disabilities, including behavioral or emotional dysregulation. Heavy workloads in periods of intensive programming.

Measurement/evaluation

The Association of Inclusive Culture employs mixed methods to evaluate the effectiveness of its activities and support programs, ensuring a comprehensive understanding of their impact on individuals with disabilities and their families.

Quantitative Methods:

1. Evaluation Questionnaires:

Distributed yearly to parents, caregivers, and participants to assess satisfaction, perceived benefits, and areas for improvement;

Results are compiled and analyzed to identify trends, measure progress, and inform future program development;

2. Attendance Records:

Detailed documentation of attendance at support groups, individual and group assistance sessions, and companionship program activities;

Helps track engagement levels and the consistency of participation over time.

Qualitative Methods:

1. Support Group Feedback:

Participants, including parents and caregivers, can express their satisfaction and provide feedback verbally during support group sessions;

Facilitators and supervisors collect and document this feedback to understand the qualitative impact of the programs;

Topics discussed include mental health, coping strategies, resilience, and the effectiveness of integrated care practices.

Documentation and References:

List of Attendees: Maintained for all activities to monitor participation and engagement;

Written Documentation: Includes annual reports, program evaluations, and articles summarizing findings and insights from the evaluation process.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
4. Enhancing informal carers' and/or LTC workers' satisfaction
5. Fostering (or potential to foster) care partnerships

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

The association's holistic approach emphasises coordination, integration, and mutual recognition of care activities performed by LTC workers and informal carers. Cultural, educational, and sports activities bring together professional caregivers, families, and community actors, facilitating natural opportunities for relationship-building and knowledge exchange. LTC workers and informal carers engage jointly in planning and participation, fostering mutual understanding. The association also offers support and informal learning opportunities for family members, helping them build confidence in care roles and recognize themselves as valued partners rather than passive recipients of services. Activities are also tailored to individual needs and preferences, encouraging joint decision-making between all care partners—professionals, families, and the person with disabilities.

Equity (including ethics)

The primary focus is on persons with intellectual disabilities, including those with complex needs (e.g. autism, communication difficulties, behavioral challenges). Activities are adapted to ensure accessibility and meaningful participation. Activities are designed for a range of age groups—from children and youth in inclusive education, to adults participating in lifelong learning, cultural, or social-inclusion programs.

Sustainability

The sustainability of the Association of Inclusive Culture's activities relies on several key factors. Firstly, funding is essential. The support group program is financed by the local municipality, and the companionship program is co-financed by the municipality. To ensure long-term sustainability, the association is exploring additional funding sources, including grants, donations, and partnerships with private organizations.

Secondly, professional and volunteer support is crucial. The association faces challenges in recruiting and retaining caregivers, primarily students. To address this, it is strengthening partnerships with local universities to attract more volunteers and provide training opportunities, ensuring a steady supply of qualified companions.

Thirdly, the association has adequate facilities for its activities, which supports the sustainability of the programs. Continued maintenance and potential expansion of these facilities will be considered as the programs grow.

Fourthly, advocacy for stronger policy support is crucial. The association engages with local policymakers to secure continued and increased support, ensuring the programs receive necessary backing.

Lastly, building strong relationships with the community and stakeholders is vital. The association actively engages with parents, caregivers, and local organizations to foster a supportive network, enhancing program sustainability.

By addressing these areas, the Association of Inclusive Culture aims to ensure the long-term sustainability of its activities, continuing to provide essential support to individuals with disabilities and their families.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

The Association of Inclusive Culture's activities have significant potential for scalability and transferability. Currently, there are around 100 participants in the companionship program, limited by funding and staffing constraints, despite a higher demand. To address this, the association is actively seeking additional funding through European projects and donations. To support scalability, the association is cooperating with faculties to attract new volunteers and is promoting its activities to increase awareness and participation. Furthermore, the association aims to expand its programs to an international level by applying for relevant projects. The adaptability of these programs to different geographical contexts is evidenced by their strong framework and the association's proactive approach in securing necessary resources. By leveraging existing partnerships and pursuing new funding opportunities, the association is well-positioned to scale up its programs and transfer them to other regions effectively.

Collaboration with and/or participation of different stakeholders and sectors

It has a strong multi-stakeholder collaboration strategy, actively engaging partners across diverse sectors, such as NGOs, Civil society, Schools, Health and social care, EU Institutions, government, families and informal carers.

Innovative aspects, if any

The association pioneers inclusive theatre, music, and visual arts projects involving individuals with intellectual disabilities as equal creators and performers, not passive participants. Through different programs the association brings together LTC workers, informal carers, volunteers, and people with disabilities as co-producers of care and well-being, rather than maintaining traditional hierarchies.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

Financial Constraints:

1. Limited Funding:

The support group program is financed by the local municipality, while the companionship program is only co-financed by the municipality.

This limited funding presents a significant challenge, particularly for the companionship program, which requires parents to pay for services due to insufficient financing.

Staffing Issues:

2. Caregiver Recruitment:

Finding caregivers, specifically companions, is problematic as the role is typically filled by students who may not have a long-term commitment.

The association struggles to attract and retain these companions, impacting the consistency and quality of care provided.

Participant Availability:

3. Time Constraints for Parents:

Parents often lack sufficient time to participate in support groups, even with different timeslots offered.

To address this, support groups are organized concurrently with children's sports programs. However, this arrangement is not feasible for all parents, as it requires additional care for their children during these times.

Logistical Problems:

4. Companion Scheduling:

Companions, who are mainly students, face scheduling conflicts due to their academic commitments.

This limits their availability and the frequency of support they can provide, which is less than what parents need.

Insufficient Support Frequency:

5. Demand vs. Supply:

The frequency of support sessions currently offered does not meet the high demand from parents, who require more frequent assistance than the association can provide with its current resources.

Key success factors/points of strength

Activities are developed with and for people with intellectual disabilities and their families. Co-creation ensures that programs respond to real needs, boost self-confidence, and promote agency. The active involvement of both local and international volunteers provides not only manpower, but also intercultural enrichment and continuity across programs. Furthermore, A diversified funding strategy that combines EU grants, national and municipal funding, and donations provides financial stability, enabling long-term planning and the free delivery of programs to beneficiaries. The association maintains long-term collaborations with schools, universities, health professionals, municipalities, NGOs, and ministries.

To summarise, inclusion works best when designed collaboratively, empowerment is the foundation of dignity, and cultural and creative approaches can be powerful vehicles for care and inclusion.

Meeting Centres Support Programme (MCSP)

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	M35 SLR
Ranking of the good practice	23
Type of good practice	3. Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives (main type) Also related to: 4. Integrated approach and strategy 6. Community-based initiatives/measures
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Meeting Centres Support Programme (MCSP)
Name of the good practice in original language (if available)	The practice has been implemented in 3 EU countries, thus the English language is used for all of them.
Initiative in operation since	Data collection took place over a period of 14 months (May 2015 – October 2016)
Country/ies of implementation	Italy (Milan and Bologna) Poland (Wroclaw), UK (Worcester)
Geographic coverage/implementation level	3. Cross-country/International
Stage of initiative	4. Finished for 4 years or more. Data collection took place over a period of 14 months (May 2015 – October 2016)
Name of the Leader/s Organisation/implementer/s	Wroclaw Medical University, Poland; IRCCS Fondazione Don Carlo Gnocchi, Milan, Italy; Association for Dementia studies, University of Worcester, United Kingdom; University of Bologna, Italy.
Contact details	Dorota Szcześniak, Department of Psychiatry, Wroclaw Medical University, Pasteura 10, 50-367 Wroclaw, POLAND. e-mail: dorota.szczesniak@umed.wroc.pl tel.: +48 71 784 16 28 - fax: +48 71 784 16 02
Type/source(s) of funding	3. Statutory LTC/healthcare financing system. Italy, Ministry of Education and Ministry of Health 4. National or local public sources (e.g. general tax revenue, social care funds) Poland, Narodowe Centrum Badań i Rozwoju (governmental agency established to implement tasks in the area of science and innovation policy); UK, Economic and Social Research Council (organisation funding research on economic and social issues).
Webpage/s of the good practice (or link to doi of the paper)	LINK: https://eprints.worc.ac.uk/8811/3/8811-Evans-SB-AAM-with-cover.pdf

Summary (abstract)	The MCSP aims to provide practical, emotional and social support to people with mild/moderate dementia and their family carers. This study is part of the international Joint Programme “Neurodegenerative Disease Research (JPND) – MEETINGDEM”. The MCSP was carried out in nine Meeting Centres in Italy, Poland and the UK. Participants completed a user evaluation survey after three and six months of participation in the programme. A mixed methods explanatory design was used. Also, persons with dementia and carers took part in focus groups after nine months. The share of people with dementia who were very satisfied with the programme increased over time. The majority of carers felt less burdened after three/six months of participation in MCSP. In all countries/centres, participants improved their ability to maintain emotional balance. The MCSP was highly appreciated by people with dementia and carers in all countries. It confirms the results of previous research into MCSP in the Netherlands.
Keywords	Dementia, Carers, Social Support, Day Programs

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

The intervention was developed to provide emotional/social support to people living with mild/ moderately severe dementia and their family carers. The aim/objectives were to identify key factors determining the level of satisfaction of the participants, and to analyse the relationship between user satisfaction and theoretical assumptions defined as crucial for the MCSP model. Regarding inclusion criteria, participants with various backgrounds were recruited. The MCSP represents an adaptation of the Dutch Meeting Centres Support Programme, and offers an integrated package of care and support (e.g., discussion groups for carers, to support psychological and emotional adjustment and to prevent carers from becoming overburdened; social activities for both for practical and emotional support). Depending on the psychosocial diagnosis, support strategies and interventions are applied (re-activation, re-socialization, promotion of the emotional functioning of the person with dementia, and provision of information/practical/emotional/social support for their carers). According to the results, people with dementia were very satisfied with the programme. The majority of carers reported that they felt less burdened after three months of participation in MCSP. After six months, this percentage increased significantly. Focus group analysis showed that participants in all countries/centres improved their ability to maintain emotional balance. The MCSP was highly appreciated by people with dementia and carers in all countries. It confirms the results of previous research into MCSP in the Netherlands. The MCSP is mainly "aimed at mental health/wellbeing and resilience promotion and training initiatives" (type 3), but also it represents an example of "integrated approach and strategy" (type 4), since it operates on the borders of social care, welfare and health, aiming to counteract the fragmentation of services that people and their families need at this stage. MCSP can also be considered an example of "community-based initiatives/measures" (type 6), since meeting centers are new but similar to community-based day care.

Main setting(s)/place(s) of delivery

10. Other (specify: nine new Meeting Centres that were implemented in three countries, however similar to community-based day care centres)

Target group(s)/beneficiaries

1. Informal carers. Both genders (mainly women)

Age profile(s) of the target group(s) of the practice

1. 18-34 years

2. 35-64 years

3. 65-74 years

4. 75+ years

Range 22-84 years.

Health issues of the care recipients assisted by the target group(s)

3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.) Mild/Moderate dementia.

Age profile(s) of the care recipients assisted by the target group(s)

3. Adults (18-64 years)

4. Older people (65+ years)

Range 63-93 years.

Problem being addressed

This psychosocial intervention was developed to offer a combined approach to provide informational practical, emotional and social support to people living with mild to moderately severe dementia and their family carers in the community, in order to promote independent and active living and to counteract the fragmentation of dementia services.

Measurement/evaluation

The evaluation took place after three months and after six months of participation in MCSP. Severity of dementia was based on the Global Deterioration Scale – GDS. User satisfaction of people with dementia and carers was measured with two questionnaires (one with 13 items for people with dementia, and one with 30 items for their carers). Five separate focus groups for people with dementia and for their carers were held (2 Italy, 1 Poland, 1 UK). The texts of focus groups were analysed according to a concept-driven thematic analysis. The categories were grouped into themes that, according to the adopted methodology, corresponded to the theoretical basis of the MCSP model defined as three strategies: S1. (re-)activation, S2. (re-)socialisation, S3. improving emotional functioning. Moreover, in the protocol: <https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-017-0472-x>, authors mention the evaluation of (cost) effectiveness, with regard to service use, psychotropic medication, admissions into a hospital/LTC setting, and time spent on caring. In addition, cost diaries are filled in by the carers during the whole intervention period.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
4. Enhancing informal carers' and/or LTC workers' satisfaction
5. Fostering (or potential to foster) care partnerships

PwD and the carers were satisfied with the different elements of the support programme, the contact with personnel and the atmosphere at the meeting centers. The majority of carers reported that they felt less burdened. The satisfaction of the participants appeared associated with the improvement in some aspects of their quality of life. The carers appreciated the support they received in terms of informational, practical, emotional and social support.

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

The MCSP is offered by a professional team and volunteers in close cooperation with other (multidisciplinary) professionals/organizations that offer dementia care (e.g., general practitioners, memory clinics, home care agencies, mental health care organizations). Also, authors stress the importance of user involvement, i.e., Patient and Public Involvement (PPI), with people with dementia and carers involved in all decisions, with groups of relevant organizations and user representatives in each country exploring pathways to care. Moreover, the staff helps to co-ordinate care services at home. Support strategies for family carers vary from giving information to offering practical, emotional and social support <https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-017-0472-x>.

Equity (including ethics)

The Medical Ethics Committee of the VU University medical center approved the study as non-medical scientific research. Participants of this study were asked to sign an informed consent form before enrollment. Regarding equity, in the paper authors state that majority of carers were women, mean age 64 years, married or cohabiting, mainly spouse of the PwD. In the protocol authors mention only people with mild to moderately severe dementia (no severe). However, they state that there are no restrictions on the age of people with dementia or carers participating in the program <https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-017-0472-x>

Sustainability

The intervention was implemented within the framework of the JPND – MEETINGDEM Project (EU Joint Programme on Neurodegenerative Disease www.meetingdem.eu). Also, the project was supported through several funding organisations (e.g., Italy, Ministry of Education and Ministry of Health; Poland, Narodowe Centrum Badań i Rozwoju; UK, Economic and Social Research Council). In the protocol <https://bmjgeriatr.biomedcentral.com/articles/10.1186/s12877-017-0472-x> authors mention the support of regional welfare and/or a care organization, and the collaboration with the national or regional Alzheimer organization in the involve countries. Authors also state that in each country the local organization who sets up the meeting center is provided with starting-up funding (this was covered by the research project), this as possible positive input stimulating care and/or welfare organizations to be involved in starting up the implementation of the MCSP. This can also help to stimulate other funding organizations to provide additional financial support. Moreover, in the protocol authors state that during the project period a network of interest was established by creating and updating a database with contact details of stakeholders who have interest in the MCSP in the participating and other EU countries. In addition, the staff received a course with detailed information on the MCSP and training in person centered activities and psychosocial interventions for PwD and carers.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

Intervention/instruments are described in the protocol <https://doi.org/10.1186/s12877-017-0472-x>. Also, authors mention an implementation guide <https://doi.org/10.1177/14713012030023011>

This intervention was first developed in the Netherlands, and implemented in three countries in Europe (Italy, Poland, and UK). In The Netherlands the meeting centers have spread across the country and today (2021) there are 144 centers. Together they offer support to 3900 people with dementia and 3900 carers annually. Following the evaluation carried out in Italy, Poland and UK, results suggest an effective adaptation and implementation of the successful Dutch MCSP model in these countries. Several initiatives to develop Meeting Centres are undertaken outside Europe and in Australia, the United States, and Japan <http://doi.org/10.1080/13607863.2019.1683814>. In this respect authors mention country specific implementation plans and state that implementation materials will be developed, taking into account the regional context. This can support the provision of information about the MCSP among various target populations and create interest in the MCSP. Existing materials developed in the Netherlands will be thus adapted/translated as necessary. Moreover, to stimulate further implementation/dissemination of MCSP in the involved countries, a ‘train the trainer course’/pioneer workshop will be developed, and offered in each of these 3 countries, including facilitators and barriers of implementation of MCSP.

Collaboration with and/or participation of different stakeholders and sectors

Authors mention collaboration with a regional welfare and/or a care organization to initiate the project, in addition to collaboration with the national or regional Alzheimer organization in the countries involved. The MCSP is offered by professionals and volunteers, in close cooperation with other (multidisciplinary) professionals/organizations in the region that offer dementia care <https://bmjgeriatr.biomedcentral.com/articles/10.1186/s12877-017-0472-x>. These include general practitioners, memory clinics, home care agencies, mental health care organizations and nursing homes. Collaboration with the local network of available welfare and care services (considering local law and norms regarding care, and implementing dissemination strategies in order to keep contact and interaction with the network on a micro and meso level) is formalized in a written agreement. Importantly, authors also mention the Patient and Public Involvement (PPI). People with dementia and carers are indeed involved in all decisions to be made in these areas rather than being ‘talked about’ and ‘decided for’, for exploring pathways to care and potential facilitators and barriers to implementing the program. To ensure user involvement in the implementation process, the national Alzheimer organization will be invited as advocate of people with dementia and carers. Moreover, every 2 months a center meeting will be arranged with all participants (people with dementia, carers), staff and volunteers to discuss the experiences with the program and to get feedback from the participants to attune the MCSP as much as possible to their needs and wishes. This to stimulate their feeling of having influence on the content of the program and the joint responsibility for the meeting center.

Innovative aspects, if any

The MCSP programme offers an integrated package of care and support both for the person with dementia and for their informal carer(s), including a social club for the person with dementia, psychoeducational meetings and discussion groups for the carers, and social activities and weekly consultation hours for both, as well as regular 'center meetings' for all involved in the program <https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-017-0472-x>. In particular, consultation hours represent a very innovative service in all countries and were positively evaluated by the majority of carers. Consultation hours represent a valuable tool for translating the psychosocial diagnosis for the person with dementia and carer into practice. Regarding technology, a clear innovation is not emerged. Authors mention only (as materials that are already available in the Netherlands) a DVD on the MCSP (also available in English), and a website with information on the meeting centers in the Netherlands <https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-017-0472-x>

Barriers, challenges/points of weakness (and solutions to them, if applicable)

In some case there was a limited participation in some elements of this articulated programme. Probably some carers may have preferred having some extra free time rather than utilising support activities. For persons with dementia, limited or lack of participation in some activities may have been linked to dementia severity or comorbidities. Also, further qualitative research is required to identify psychosocial interventions that have a positive impact on older adults with dementia and their family members. Truly person-centred research must indeed identify and include outcomes the population of interest notices and cares about, and results of this research must be used to inform health decisions. It is also to highlight that the user experiences within the MEETINGDEM project, regarding especially facilitators/barriers of adaptive implementation of MCSP in the three countries, were integrated in practical country-specific guides, which can help care and welfare organisations and professionals to set up more appropriate meeting centres in their own country and region.

Key success factors/points of strength

As a first key/general point, gaining knowledge about how care is experienced by users is of great value for professional/political stakeholders, for planning of care for frail persons, besides professionals' point of view, cost estimation and calculation of existing service use. Also, MCSP is a model that can help users to increase their capacity to deal with the challenges caused by dementia and can promote emotional balance. People with dementia and the carers were indeed particularly satisfied with the contact with trained personnel/professionals, and the communication with/expertise of staff in the day care. Participants also greatly appreciated the integrated approach (social care, welfare and health). In turn, the consistent satisfaction of the users of the meeting centres with the support and assistance they received, can stimulate interest in further appropriate actions to disseminate the MCSP model in other European countries and beyond. Moreover, authors stress the importance of user involvement, i.e., of Patient and Public Involvement (PPI). People with dementia and carers are involved in all decisions. In particular, the voice of people with dementia and the family carers participating in MCSP are heard in the monthly center meetings, and researchers elicited especially the views of many people with dementia themselves.

Care Companion Web-Based Information Resource for Supporting Informal Carers of Older People

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	511 SLR
Ranking of the good practice	24
Type of good practice	3. Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Uptake and Use of Care Companion, a Web-Based Information Resource for Supporting Informal Carers of Older People: Mixed Methods Study
Name of the good practice in original language (if available)	idem
Initiative in operation since	
Country/ies of implementation	UK
Geographic coverage/ implementation level	1. Local
Stage of initiative	1. Ongoing
Name of the Leader/s Organisation/implementer/s	Warwick Medical School, Academic Primary Care Unit at University of Warwick
Contact details	Jeremy Dale, jeremy.dale@warwick.ac.uk
Type/source(s) of funding	National or local public sources (e.g. general tax revenue, social care funds)
Webpage/s of the good practice (or link to doi of the paper)	DOI: https://doi.org/10.2196/41185
Summary (abstract)	Informal carers play a major role in supporting relatives and friends who are sick, disabled, or frail. Access to information, guidance, and support that are relevant to the lives and circumstances of carers is critical to carers feeling supported in their role. When unmet, this need is known to adversely affect carer resilience and well-being. To address this problem, Care Companion was co-designed with current and former carers and stakeholders as a free-to-use, web-based resource to provide access to a broad range of tailored information, including links to local and national resources. Care Companion, a free web-based resource for informal carers, was co-designed with stakeholders but saw limited uptake in a region of England. Despite awareness-raising, only 0.87% of the known carer population registered, with low usage rates. Interviews revealed factors influencing registration, use, and perceived value, suggesting the co-design process may have lacked diverse viewpoints.

Keywords	Informal Carers, Information Technology, Internet, Information Needs, Mixed Methods Evaluation, Reach, Effectiveness, Adoption, Implementation, Maintenance, RE-AIM, Mobile Phone
-----------------	---

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

A UK-based initiative aimed at improving the accessibility and quality of support available to informal carers. Developed as a free, web-based tool, Care Companion provides tailored information and guidance to individuals caring for older people with various health needs.

The main objective of the initiative was to empower informal carers by offering timely, relevant, and localised information that could enhance their confidence, knowledge, and capacity to care. The initiative responded to a critical gap: many carers struggle to find reliable, personalised resources that address their needs, which negatively impacts their well-being, resilience, and ability to provide sustained care.

Care Companion was co-designed with current and former carers, healthcare professionals, and other stakeholders to ensure it was user-friendly, accessible, and responsive to the real-world challenges of caregiving. The platform aimed to deliver tailored content through a user profile system that filtered resources based on individual caregiving situations, including the care recipient's condition, location, and specific needs.

Realised through a mixed-methods research approach, it offered insights into digital support delivery for informal carers and highlighted the importance of diverse input in co-design, targeted promotion, and engagement strategies to improve usage.

Main setting(s)/place(s) of delivery

1. Home
9. Online

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)

Age profile(s) of the target group(s) of the practice

1. 18-34 years
2. 35-64 years
3. 65-74 years
4. 75+ years

Health issues of the care recipients assisted by the target group(s)

1. Physical disabilities (caused, e.g. by frailty, accident, injury, illness, etc.)

Age profile(s) of the care recipients assisted by the target group(s)

4. Older people (65+ years)

Problem being addressed

The Care Companion initiative addresses a range of occupational and non-occupational risks faced by informal carers of older people. Occupational risks include the high emotional and physical workload associated with unpaid caregiving. Informal carers often manage complex care tasks without formal training. Many struggle to balance caregiving with employment, leading to burnout, stress, and reduced quality of life. They frequently lack access to timely, accurate, and relevant information. The quality of the care partnership between the carer, the care recipient, and professionals is often undermined by information gaps, poor communication, and a lack of recognition of the carer's role.

Measurement/evaluation

The Care Companion platform underwent a formal mixed-methods evaluation based on the RE-AIM framework (Reach, Effectiveness, Adoption, Implementation, and Maintenance), providing both quantitative data and qualitative insights to assess its use and impact.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
4. Enhancing informal carers' and/or LTC workers' satisfaction
5. Fostering (or potential to foster) care partnerships
6. Improving organisational practices
7. Cost-effectiveness

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

The Care Companion platform has notable potential to foster collaborative care partnerships between long-term care (LTC) professionals, informal carers, and other stakeholders by promoting knowledge sharing, coordination of care, and mutual role recognition. To fully realise this potential, greater integration into LTC systems and more proactive involvement of healthcare professionals in promoting the platform would be beneficial.

Equity (including ethics)

The study received ethics approval from National Health Service (ID 271605; West Midlands–Edgbaston research ethics committee). All eligible individuals were provided with an information leaflet and consent form to be completed before their participation in the study. Consent was confirmed at the time of interview. Participants had the opportunity to withdraw from the study at any stage of data collection. The information leaflet explained that all study data would be anonymized to ensure the anonymity of participants. Participants did not receive any payment.

Sustainability

A key advantage is its digital format, which reduces reliance on physical infrastructure, personnel, or recurring delivery costs. Once developed, the platform can be maintained and updated at relatively low cost, making it a cost-effective tool for supporting large populations of informal carers across regions. Continued collaboration with public health services, local authorities, and social care organisations will be essential for securing ongoing financial and structural support. However, for sustainability to be achieved, increased uptake and engagement are essential. Evaluation findings emphasised the need for stronger promotion strategies, improved visibility within care settings, and ongoing co-production with end users to ensure relevance and usability.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

In terms of transferability, the tool's structure is built around a user profile system that tailors content to the care recipient's needs, location, and carer's situation. This makes it suitable for adaptation in different national or local health systems, if the resource database is appropriately localised and aligned with regional care pathways.

Collaboration with and/or participation of different stakeholders and sectors

The Care Companion initiative was underpinned by strong cross-sector collaboration, which was central to its design, development, and implementation, i. e. it brought together stakeholders from healthcare, social care, academia, and civil society, reflecting a comprehensive, systems-based approach to supporting informal carers.

Innovative aspects, if any

From a technological standpoint, the platform enables carers to receive resources specific to their unique caregiving context, such as the care recipient's condition, available local services, and the carer's preferences or challenges. The platform's co-design model is a key social innovation. Care Companion was developed through the collaboration with carers, healthcare professionals, social care providers, and voluntary sector organisations. This participatory process ensured that the platform was built around real needs and real-life caregiving scenarios.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

One of the main challenges was low user uptake. A possible solution could be promotion through formal care challenges. A second major barrier was the time constraints and emotional burden experienced by carers. Many found it difficult to explore new tools or digital platforms, especially when already overwhelmed by their caregiving responsibilities. This led to low engagement even among those who had registered. Digital literacy and confidence also presented challenges, particularly for older carers or those less comfortable with online services. Some users faced difficulties with the platform's navigation or registration process, despite its user-centered design. Future versions could include onboarding support, simplified access, or integration with devices and platforms already used by carers.

Key success factors/points of strength

One of the most significant strengths was its participatory co-design process. Involving informal carers, healthcare professionals, social care providers, and voluntary sector stakeholders ensured the platform was user-centered, practical, and relevant to real-world caregiving needs. The digital format enabled low-cost delivery and broad potential reach. Carers appreciated being able to access information on their own terms, without needing appointments or navigating complex systems.

Carer Supporter Programme

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	460 SLR
Ranking of the good practice	25
Type of good practice	3. Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives Also related to: 2. Interventions or programmes dealing with organisational models and management approaches and/or targeted at the individual level 6. Community-based initiatives/measures
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	The impact of volunteering on the volunteer: findings from a peer support programme for family carers of people with dementia
Name of the good practice in original language (if available)	Carer Supporter Programme (The programme involved training experienced former family carers of people with dementia to act as peer supporters for other, current family carers)
Initiative in operation since	2009 (The Programme was implemented between October 2009 and March 2013 in various regions of England)
Country/ies of implementation	UK (Norfolk, Northamptonshire, Berkshire and four London boroughs)
Geographic coverage/ implementation level	1. Local 2. Regional, national
Stage of initiative	4. Finished for 4 years or more
Name of the Leader/s Organisation/implementer/s	North East London NHS Foundation Trust University College London (UCL) – Research Department of Clinical, Educational and Health Psychology University of East Anglia – School of Allied Health Professions Age Concern Havering (Voluntary sector partner)
Contact details	Dr Georgina Charlesworth, Research Department of Clinical, Educational and Health Psychology, University College London, 1-19 Torrington Place, London WC1E 7HB, UK, g.charlesworth@ucl.ac.uk
Type/source(s) of funding	4. National or local public sources (e.g. general tax revenue, social care funds) National Institute for Health Research (NIHR) as part of the SHIELD Programme (RP-PG-0606-1083).
Webpage/s of the good practice (or link to doi of the paper)	DOI: https://doi.org/10.1111/hsc.12341

Summary (abstract)	The Carer Supporter Programme was a UK-based peer support initiative designed to improve the well-being of family carers (FCs) of people with dementia by matching them with experienced former carers acting as volunteer peer supporters. This mixed-methods study explored the characteristics of both volunteers and recipients, and examined the psychological impact of volunteering on the supporters themselves. Volunteers received structured training and provided emotional support, signposting, and encouragement, but no direct caregiving or formal advice. A cross-sectional comparison showed that volunteers were more likely to be female and to have cared for a parent or grandparent rather than a spouse. At baseline, volunteers had significantly higher self-rated health, lower depression scores, and greater personal growth compared to recipients. Volunteers also used a wider range of health services, potentially indicating higher levels of proactive self-care. A longitudinal sub-study with 21 volunteers revealed that psychological well-being was largely maintained over time. There were small but statistically significant reductions in perceived personal growth and autonomy. However, self-rated mental well-being (SF-12 MCS) slightly improved, and longer duration of volunteering was positively correlated with perceived global health (EQ-VAS). These results suggest that volunteering may be beneficial for former carers, particularly those who are already psychologically resilient. Overall, the findings suggest that peer support volunteering can offer psychosocial benefits for former carers without causing harm, making it a promising model for carer support services.
Keywords	Caregiver, Carer, Dementia, Peer Support, Volunteer

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

The Carer Supporter Programme was developed to explore the potential of experienced former family carers (FCs) of people with dementia to provide peer support to current carers. The aim was to improve carers' wellbeing by offering emotional support from someone who had experienced similar caregiving situations.

Volunteer peer supporters, referred to as Carer Supporters (CSs), were required to have prior experience as family carers of people with dementia but no longer held active caregiving responsibilities. They were recruited via NHS and voluntary sector networks and had to meet inclusion criteria such as being more than 18 years old, providing two character references, and passing an enhanced criminal background check. Before being matched with current carers, CSs completed a structured awareness and orientation programme consisting of six modules:

- Experiences of dementia and caring;
- The role of the carer supporter;
- Listening and helping skills;
- Working safely in other people's homes;
- Dementia awareness;
- Resources available to carers.

After successful training, CSs were matched with FCs based on socio-demographic background, caring experience, common interests, and availability. The support relationship lasted up to 10 months: weekly face-to-face or telephone contact (1 hour) during the first 3 months, followed by fortnightly contact over 7 months. The role of CSs was clearly defined: to provide a listening ear, moral support, encouragement, and signposting to relevant services. They were not permitted to give advice, offer respite care, or carry out tasks that would normally be performed by professionals. In total, 87 trained volunteers supported 109 family carers.

Main setting(s)/place(s) of delivery

1. Home
6. NGO facility
8. Local community
9. Online

The peer support was delivered through face-to-face visits or telephone contact, depending on what was feasible for the matched dyad. Face-to-face meetings typically took place in the home of the carer. Telephone support was also used, especially in later phases of the programme, indicating a partial online/remote setting.

The training for volunteers took place through sessions organised by NHS or voluntary sector organisations, which points to the involvement of NGO facilities and the local community during the preparation phase.

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)

The programme targeted informal carers of people with dementia living at home. All participants in the recipient group were adult family carers (aged 18 and older), providing unpaid care for a relative with dementia. No specific information is provided regarding their employment status, so it is not possible to determine whether they were also working carers (i.e. combining paid work with care). Therefore, option 2 (Working carers) cannot be selected based on the article.

The gender distribution shows that 63% of the family carers (recipients) were female and 37% male. The volunteers were predominantly female (89%).

No professional or paid LTC workers (such as nurses or care workers) were involved as target group or beneficiaries.

Age profile(s) of the target group(s) of the practice

2. 35-64 years
3. 65-74 years
4. 75+ years

The family carers (FCs) who received support were on average 68 years old (range: 40–89 years), while the volunteers (Carer Supporters, CSs) were on average 61 years old (range: 33–88 years). Therefore, the target group includes individuals from all three age brackets:

35–64 years (working-age or early-retired carers);

65–74 years (retired or near-retirement carers);

75+ years (older carers).

Although some individuals were in the 18–34 age range (the youngest CS was 33), the article does not provide specific numbers in that bracket.

Health issues of the care recipients assisted by the target group(s)

3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.)

The Carer Supporter Programme specifically targeted family carers of people with dementia. The inclusion criterion for care recipients was a clinical diagnosis of dementia (defined by DSM-IV criteria), including Alzheimer's disease and other forms of dementia. The article does not report other conditions, so only cognitive impairments should be selected.

Age profile(s) of the care recipients assisted by the target group(s)

4. Older people (65+ years)

The care recipients were people with dementia living at home, most of whom were older adults. The article specifies that carers often supported a parent, parent-in-law, grandparent, or spouse, which strongly indicates that the majority of care recipients were in the 65+ age group. There is no indication of care being provided to individuals under 65. Therefore, only option 4 should be selected.

Problem being addressed

The Carer Supporter Programme addressed the psychological and emotional strain experienced by informal family carers of people with dementia, who are known to face elevated risks of depression, anxiety, stress, and reduced quality of life. These risks can persist even after the caregiving role has ended. The paper cites evidence that family carers have significantly poorer general health and higher levels of psychological morbidity compared to the general population, and that former carers may experience prolonged depressive symptoms for several years after caregiving ends. Although the intervention does not concern occupational risks (as neither the carers nor the volunteers are professional care workers), it responds to non-occupational risks related to:

Gender: most carers and volunteers were women, reflecting a gendered distribution of caregiving burdens;

Age: many carers were older adults themselves (average age of FCs: 68 years), making them more vulnerable to physical and emotional exhaustion;

Socio-emotional burden: the emotional toll of witnessing cognitive decline in a loved one and the sense of isolation and lack of support are key stressors;

Transition after caregiving: former carers may struggle with identity loss and social reintegration once their caregiving responsibilities end.

The programme aimed to alleviate these burdens by enabling experienced carers to support current carers through structured, empathic peer support. For volunteers, the opportunity to reframe their caregiving experiences, engage in meaningful activity, and reconnect socially was seen as a way to support post-caring resilience and reintegration.

Measurement/evaluation

The programme was formally evaluated using a mixed-methods research design, comprising both cross-sectional and longitudinal data. The study focused specifically on assessing the impact of volunteering on the volunteers (former family carers) and included comparisons with the recipients of support (current carers). Quantitative methods included validated psychometric instruments to measure mental health, well-being, and social context:

Personal Growth Index (PGI);

Hospital Anxiety and Depression Scale (HADS);

Short Form-12 Health Survey (SF-12) – Mental and Physical Component Scores;

Generalised Self-Efficacy Scale (GSES);

EQ-VAS (EuroQol Visual Analogue Scale);

CASP-19 (Control, Autonomy, Self-realisation, Pleasure);

Practitioner Assessment of Network Type (PANT).

These tools were administered at baseline and again at 3–5 months or 10 months post-intervention. Data from 87 volunteers and 109 recipients were included at baseline; follow-up data were available for 21 volunteers.

Key findings included:

Volunteers showed higher personal growth, lower depression scores, and better self-rated health than recipients at baseline;

Over time, volunteers maintained high levels of well-being, with slight improvements in mental health and small declines in autonomy and personal growth;

A positive correlation was found between duration of volunteering and perceived health (EQ-VAS).

This evaluation provides clear evidence of effectiveness and was embedded in a larger trial (SHIELD Programme, ISRCTN37956201).

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience

2. Improving mental wellbeing

3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)

4. Enhancing informal carers' and/or LTC workers' satisfaction

5. Fostering (or potential to foster) care partnerships.

The programme demonstrated improvements in resilience-related aspects, including personal growth, self-efficacy, and emotional well-being among volunteer carers. These were measured through validated tools (e.g. PGI, EQ-VAS, SF-12 MCS). Mental wellbeing improved slightly over time, and symptoms of depression were significantly lower among volunteers compared to recipients. The intervention also contributed to reduced negative effects of caregiving by creating space for emotional processing, connectedness, and purpose after the caregiving role ended. Volunteers reported high levels of satisfaction, and the opportunity to "give back" was perceived as meaningful and beneficial.

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

The Carer Supporter Programme was a peer-to-peer intervention between former informal carers and current informal carers. Although it did not yet include any involvement of formal or professional LTC workers, the training for volunteers took place through sessions organised by NHS or voluntary sector organisations, which points to the involvement of NGO facilities and the local community during the preparation phase, it might be adapted to formal LTC workers like migrant care workers with previous care experiences, thus representing a potential to foster care partnerships.

Equity (including ethics)

The Carer Supporter Programme addressed gender and age dimensions of equity by including a broad age range of carers (from 33 to 89 years) and by explicitly recruiting volunteers and recipients regardless of gender; although the majority of participants were female (89% of volunteers, 63% of recipients), reflecting broader caregiving demographics. There is no information in the article on whether socioeconomic status, migration background, language barriers, or disabilities (e.g. hearing or visual impairments) were considered in the design or implementation of the practice. Similarly, the article does not address whether carers without family support were specifically targeted or identified.

From an ethical perspective, the study was conducted in line with research governance standards:

Ethical approval was granted by the Outer North East London Research Ethics Committee (09/H0701/54);

Informed consent was obtained from all participants (both volunteers and recipients) at baseline;

Data protection measures were implemented: questionnaire data were anonymised using ID codes, and responses were kept confidential from Carer Support Coordinators;

Carer Supporters were explicitly instructed not to provide medical advice or professional care tasks, helping to mitigate risks of role confusion or boundary overstepping;

Volunteers underwent screening, including Criminal Records Bureau Enhanced Disclosure, and attended training to ensure safe and ethical conduct in the support relationship.

Overall, the programme appears to have adhered to ethical standards for research and volunteer-based interventions. However, no targeted strategies to reach or accommodate specific vulnerable groups were reported in the article.

Sustainability

The article does not provide specific evidence or discussion regarding the long-term sustainability of the Carer Supporter Programme.

There is no mention of continued funding beyond the initial implementation period (2009–2013), which was covered by a time-limited research grant from the UK National Institute for Health Research (SHIELD Programme, RP-PG-0606-1083). While the intervention made use of trained volunteers, which suggests cost-effective potential and community-based feasibility, the article does not discuss mechanisms for recruiting, retaining, or supporting volunteers over the long term. The role of voluntary sector partners and NHS-affiliated Carer Supporter Coordinators was essential for implementation, but their ongoing availability or institutionalisation after the end of the trial is not addressed. There is no mention of policy support, digital tools, or integration into existing health or social care systems.

In summary, the article does not provide information on how the practice could be sustained beyond the scope and funding period of the research project.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

The article does not explicitly discuss scalability or transferability of the Carer Supporter Programme to other contexts. However, some aspects of the intervention suggest a basic potential for transferability, particularly to other regions with similar community and volunteer infrastructures.

The programme was implemented in multiple regions across England (Norfolk, Northamptonshire, Berkshire, and London boroughs), indicating a certain degree of adaptability to diverse local contexts within the UK. The delivery through face-to-face or telephone contact, as well as the use of volunteers and local matching, adds to the flexibility of the model. However, the successful implementation relied on several structural conditions:

Access to experienced former carers willing to volunteer;

Coordinating structures (e.g. Carer Supporter Coordinators based in NHS trusts or voluntary organisations);

Availability of screening procedures, training modules, and ethical oversight.

The article does not provide information on implementation manuals, toolkits, or guidance materials that would support replication elsewhere. Furthermore, no details are given about potential barriers or facilitators in transferring the model to different healthcare systems, welfare regimes, or cultural contexts. In conclusion, while the intervention shows elements of practical adaptability, there is no formal evaluation or planning for scalability or structured transfer provided in the article.

Collaboration with and/or participation of different stakeholders and sectors

Key stakeholders included:

NHS organisations: several regional NHS Foundation Trusts participated in the implementation and coordination of the programme (e.g. North East London NHS Foundation Trust, Berkshire Healthcare NHS Foundation Trust, Northamptonshire Healthcare NHS Foundation Trust);

Voluntary sector organisations: local carer and age-related NGOs were actively involved in recruitment, training, and delivery, including Age Concern Havering, Carers of Barking and Dagenham, Redbribe Respite Care Association, Waltham Forest Carers Association, and Age UK Norfolk;

Academic institutions: the programme was embedded in a research project coordinated by University College London (UCL) and supported by the University of East Anglia and other academic partners through the SHIELD research programme;

National public funder: the initiative was funded by the National Institute for Health Research (NIHR), a UK public research body under the Department of Health and Social Care.

These stakeholders played distinct roles in: designing and coordinating the intervention; recruiting and training volunteer carers; providing research infrastructure and ethical oversight; collecting and analysing evaluation data.

While the programme did not involve formal LTC workers as part of its structure, it did operate at the intersection of mental health, dementia care, and informal caregiving, with strong engagement from carers' associations and community-based services. In summary, the programme reflects robust collaboration between health services, NGOs, and academia, with a clear focus on dementia care and informal carer support.

Innovative aspects, if any

The Programme represents a social innovation by formalising and structuring peer support between former and current informal carers of people with dementia. While peer support itself is not new, the programme's systematic design, recruitment, training, and matching process for experienced carers to act as volunteer supporters distinguishes it from more informal support models.

Key innovative features include:

The role transition of former carers into trained peer supporters, offering a structured pathway for post-caring engagement and resilience-building;

A modular training curriculum for volunteers covering listening skills, boundaries, safety in home visits, and dementia awareness, ensuring consistency and safeguarding;

A match-based model taking into account demographic background, caring experience, and availability, which was coordinated through NHS and voluntary sector partnerships;

The combination of home-based and telephone-based support allowed flexibility and accessibility in the delivery of emotional support.

The intervention also addressed the often-overlooked needs of former carers, providing them with meaningful roles and opportunities for social reintegration and personal growth. This approach reframes former caregiving experience as a valuable asset, which is both empowering for volunteers and supportive for recipients.

In summary, while the innovation is not technological, the programme introduced a novel social model for harnessing lived caregiving experience in a structured and ethically grounded way, offering psychosocial benefits to both sides of the peer support relationship.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

The main challenge was the low response rate to baseline and follow-up questionnaire measures, especially for the longitudinal evaluation. Only 49% of volunteers who completed baseline data returned follow-up data, representing just 24% of the total volunteer sample. This low return rate was partly due to practical and structural barriers:

Data collection depended on third-party coordinators (Carer Supporter Coordinators in NHS or voluntary organisations), who were not directly affiliated with the research team;

The evaluation of volunteer outcomes was secondary to the main trial on peer support effectiveness, leading to lower prioritisation in practice;

Coordinators often experienced workload constraints or did not feel comfortable making repeated requests to volunteers, which further reduced compliance.

Another limitation was that the programme was funded through a time-limited research grant, with no discussion of longer-term funding or structural integration into existing care systems. This raises concerns about sustainability.

No specific solutions to these challenges were proposed in the article. However, lessons learned include:

The importance of integrating data collection processes into core programme delivery rather than treating them as add-ons;

The need for stronger coordination and support structures to ensure volunteer engagement in evaluation activities;

The benefit of targeting psychologically resilient former carers, which appears to minimise risk of harm and enhance programme stability.

In summary, while the intervention was well-structured, challenges in evaluation logistics and long-term sustainability were evident, with limited strategic response reported.

Key success factors/points of strength

Psychological readiness and resilience of volunteers: the programme targeted former carers who had already transitioned out of their caregiving role and demonstrated high levels of well-being and personal growth. This self-selection process ensured that the peer supporters were emotionally stable and benefited from the experience, with minimal risk of psychological burden;

Structured training and role clarity: volunteers underwent a comprehensive training programme covering dementia awareness, listening skills, boundaries, and available resources. Their role was clearly defined as emotional and informational support (excluding any form of direct caregiving or advice);

Strong collaboration between sectors: the initiative brought together NHS trusts, academic institutions, and voluntary sector organisations. This multi-stakeholder collaboration enabled broad recruitment, local adaptation, and delivery across diverse settings;

Flexible and low-cost delivery model: the use of trained volunteers and telephone or home-based contact allowed for personalised, accessible support with limited infrastructure requirements. This model proved adaptable to local community contexts and allowed support to continue regardless of physical distance;

Positive outcomes for both sides: the programme enhanced mental well-being and personal satisfaction for both recipients and volunteers. Volunteers reported benefits such as self-esteem, pride, and social reconnection. Longer involvement correlated with increased self-rated health;

Ethical oversight and safe implementation: the programme operated under formal ethical approval, with data anonymisation, informed consent, and volunteer screening through enhanced criminal background checks.

In summary, the programme's success stemmed from the combination of targeted volunteer recruitment, clear and supportive structures, intersectoral collaboration, and a focus on low-risk, high-impact peer relationships. These elements created a sustainable and empowering environment for experienced carers to support others in similar roles.

Carers Outcome Agreement Tool (COAT)

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	AP_SE_01 GLR
Ranking of the good practice	26
Type of good practice	4. Integrated approaches and strategies
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Carers Outcome Agreement Tool (COAT)
Name of the good practice in original language (if available)	idem
Initiative in operation since	2002
Country/ies of implementation	Sweden

Geographic coverage/ implementation level	1. Local
Stage of initiative	1. Ongoing
Name of the Leader/s Organisation/implementer/s	Jönköping municipality, Sweden
Contact details	Johanna Karlsson, johanna.karlsson@jonkoping.se
Type/source(s) of funding	4. National or local public sources (e.g. general tax revenue, social care funds)
Webpage/s of the good practice (or link to doi of the paper)	NKA's homepage with a description of the implementation of COAT in Jönköping Municipality: https://anhoriga.se/anhorigomraden/anhoriga-till-aldre-personer/intressanta-exempel-pa-anhorigstod/individualisering-utvardering-och-utveckling-av-anhorigstod/ett-anhorigstod-i-partnerskap-foljs-upp-med-hjalp-av-coat-i-jonkoping/ A report from the Swedish Social Welfare Board on the development, implementation and evaluation of the COAT model: https://www.hb.se/globalassets/global/hb---extern/fous/forskning-och-utveckling/aldre/coat/planeringsinstrument-for-anhorigstod-socialstyrelsen.pdf FoU Sjuhärad välfärd's homepage with a description of the COAT model: https://www.hb.se/fous/publikationer/coat/ An research article on implementing COAT in Canada: https://stm.cairn.info/journal-recherche-en-soins-infirmiers-2009-2-page-63?lang=en
Summary (abstract)	The development of COAT has been carried out in Sweden and England and is based on previous research concerning support for informal carers, user involvement, and partnership at ÄldreVäst Sjuhärad, the University of Borås, and the University of Sheffield. The COAT model is explicitly aimed at improving the mental wellbeing and resilience of informal carers by supporting them in identifying their own needs, setting personalised goals, and accessing tailored support. COAT offers a structured method for documentation, follow-up, and evaluation of support efforts led by carer advocates/LTC workers. The completed instrument consists of four questionnaires and is based on areas identified as important by informal carers. Each questionnaire contains a number of statements that the carer, in discussion with the carer advocate, has the opportunity to evaluate. Each area includes a support plan for planning actions, follow-up, and evaluation of the agreed support. A user guide aimed at informal carers and a manual intended for health and social care staff have been developed. It promotes a person-centred and participatory approach where carers are recognised as active partners rather than passive recipients of care. The tool fosters care partnerships between carers and professionals through structured dialogues, shared decision-making, and jointly developed support plans. Implemented at the local level in several Swedish municipalities.
Keywords	Care Partnership, Informal Carers, Assessment of Needs, Support

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

COAT is a tool for planning, monitoring, and evaluating support for and with informal carers by carer advocates working in the municipality.

As the public health and social care sectors continue to shrink, informal carers are increasingly responsible for providing care for their relatives. Despite this, support for informal carers remains underdeveloped and underutilised.

The primary aim of the tool is to enable informal carers and carer advocates/LTC workers to co-develop individually tailored support for the informal carer. Staff work in care partnership with informal carers to plan, monitor, and evaluate the tailored support provided. COAT offers a structured method for documentation, follow-up, and evaluation of support interventions for informal carers.

The instrument consists of four questionnaires:

Helping you care;

Making life better for you;

Making life better for your relative;

Getting good quality help and support.

Each form contains a number of questions where the informal carer has the opportunity to evaluate their individual support needs and situation in discussion with the LTC worker. Each area also includes a support plan for monitoring and evaluating the agreed-upon help and support.

A user guide aimed at informal carers, and a manual aimed at the LTC workers is included with the instrument.

Procedure for using the instrument

Identification of the informal carer;

Letter to the informal carer with the COAT questionnaires and the user guide;

Meeting between informal carers and staff where they discuss all the questions together and draw up a personal support plan together;

Follow-up of the support plan every six months or when the carer and the staff have jointly decided that it should happen. Follow-up is also carried out if the situation changes for some reason.

Main setting(s)/place(s) of delivery

1. Home

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)

Age profile(s) of the target group(s) of the practice

3. 65-74 years

4. 75+ years

Health issues of the care recipients assisted by the target group(s)

1. Physical disabilities (caused, e.g. by frailty, accident, injury, illness, etc.)
2. Psychological/mental health issues (e.g. depression, anxiety, etc.)
3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.)
4. Other chronic illnesses/long-term health conditions

Age profile(s) of the care recipients assisted by the target group(s)

1. Children/Youths (0-12 years)
2. Adolescents (13-17 years)
3. Adults (18-64 years)
4. Older people (65+ years)

Problem being addressed

The COAT instrument supports the identification of informal carers, their support needs, and the development of a care partnership with LTC workers. This may help reduce the workload and stress experienced by informal carers, while also enhancing job satisfaction among LTC workers by enabling them to provide meaningful support. In the long term, it can contribute to improved care for the care recipient.

Measurement/evaluation

The effectiveness of the COAT model has been explored through several phases of testing and evaluation in both Sweden and England (focus groups, pilot testing, interviews with informal carers, focus groups with carer advocates/LTC workers, assessment of the documentation of the instrument, evaluation questionnaires based on the COAT instrument). Early piloting in three Swedish municipalities revealed that the tool enhanced communication between LTC workers and informal carers and helped identify carers' needs in a more nuanced and collaborative manner. Structured dialogues based on the COAT framework were perceived as productive and empowering by carers, who reported feeling listened to and involved in the process. Professionals also noted that the conversations often revealed new insights, even when longstanding relationships with the carers existed.

In some cases, carers gained a deeper understanding of their own situation and articulated needs they had not previously considered. The dialogue was experienced as mutually beneficial, and several participants expressed that the COAT discussion would have been helpful much earlier in their caregiving journey. While some challenges were noted—such as the time required to complete the full tool and the number of questions—the process was overall described as valuable, preventive in nature, and conducive to more individualised support planning.

The tool has since been reviewed and refined, including adjustments to question design, based on pilot feedback. Evaluation results indicate that COAT contributes to shifting practice away from reactive, crisis-driven support towards more proactive, planned, and carer-led interventions.

Additional reference

<https://anhoriga.se/globalassets/media/dokument/metoder-och-vertyg/coat/planeringsinstrument-for-anhorigstod-socialstyrelsen.pdf>

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
5. Fostering (or potential to foster) care partnerships

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

COAT promotes care partnerships by facilitating structured dialogue and shared planning and follow up of tailored carer support between informal carers and carer advocates/LTC workers.

Equity (including ethics)

COAT promotes equity by tailoring support to each carer's situation, regardless of age, gender, or background. It is used in both urban and rural areas and is designed to adapt to diverse needs. Formal ethical approval was not mentioned in the report, however, the COAT model could be argued as aligning with ethical principles of participation and respect, and positive aspects outweighing potential risks.

Sustainability

COAT is, in some parts of Sweden, supported by municipal decisions—such as in Jönköping, where it is the standard method for carer support. It is delivered by dedicated staff within existing care structures. It has also been implemented in different community care settings in Montréal, Québec, Canada.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

COAT includes structured questionnaires, action plans, and user and professional manuals. These materials are available online and support easy repetition and transfer across different settings. It may also be possible to translate the materials into other languages to facilitate cross-country transfer; for example, the tool has been adapted and tested in Québec, Canada. A feasibility study from a Canadian context showed COAT to be a culturally sensitive tool that systematically identifies the support needs of caregivers and indicates the type of help best suited to meet these needs. As with other European studies, the results suggest that the caregiver role comprises a common core of needs and highlights the tool's potential for transfer to the cultural context of French-speaking Europe.

Collaboration with and/or participation of different stakeholders and sectors

COAT was developed through cross-sector collaboration between carers, practitioners, and researchers in Sweden and England and subsequently in Canada. It has been implemented within municipal services, with involvement from public institutions and research organisations. In Jönköping, COAT is implemented within the municipal carer support service.

Innovative aspects, if any

The innovative aspect is the partnership working between the carer and carer advocate/LTC worker.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

In the interviews with carer advocates/LTC workers, a potential challenge that emerged was the time required to assess the needs of informal carers. This may reflect a cultural aspect within the workplace—specifically, the extent to which LTC workers view assessing carers' needs as a prioritised task. This challenge could be addressed through education about informal carers, emphasising how adequate support can help prevent carer burnout, ensure that the care recipient receives optimal care, and enable the informal carer to sustain their caregiving role over a longer period.

Key success factors/points of strength

Key success factors for implementing the practice include support from the municipality in the form of both commitment and financial resources, as well as LTC workers' awareness of the importance of providing support to informal carers, and their role in a care partnership with the informal carer. The COAT evaluation questionnaire can be used to obtain grouped information about the support needs of informal carers that can subsequently help with more responsive support service provision for carers at the level of the municipality.

Web-based mindfulness intervention for families living with mental health problems

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	512 SLR
Ranking of the good practice	27
Type of good practice	3. Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	User value and usability of a web-based mindfulness intervention for families living with mental health problems
Name of the good practice in original language (if available)	Idem
Initiative in operation since	Not available. The paper was first published in 2017.
Country/ies of implementation	Sweden
Geographic coverage/ implementation level	2. Regional, national
Stage of initiative	Not available.
Name of the Leader/s Organisation/implementer/s	Department of Health Sciences, Lund University, Lund, Sweden
Contact details	Sigrid Stjernswärd, Sigrid.Stjernsward@med.lu.se
Type/source(s) of funding	4. National or local public sources (e.g. general tax revenue, social care funds)
Webpage/s of the good practice (or link to doi of the paper)	DOI: https://doi.org/10.1111/hsc.12360
Summary (abstract)	A web-based mindfulness intervention for families with mental health issues was tested in a pilot study. The program was found to be valuable and flexible, providing coping strategies and enhancing wellbeing, though it requires time and discipline.
Keywords	Caregivers, Compassion, Mental Health, Mindfulness, Usability, Web-Based Support

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

This good practice describes the development and implementation of an 8-week web-based mindfulness intervention specifically tailored for families living with mental health problems. The initiative was developed to address the significant psychological burden experienced by caregivers, such as stress, anxiety, and emotional exhaustion, and to fill gaps in accessible, flexible support services. High levels of unpredictability and long-term caregiving responsibilities often result in deteriorated mental health among carers, who may themselves need therapeutic interventions.

The program's main objective was to enhance users' mental and emotional wellbeing through mindfulness training that fosters self-awareness, emotional regulation, and self-compassion. Delivered entirely online, the intervention included 960 minutes of audio/video-guided exercises such as breathing techniques, mindful yoga, and compassion meditation. It also featured written instructions, a time log, and a private diary, allowing participants to tailor the experience to their schedules and environments.

The initiative proved to be a viable, scalable solution for supporting caregivers of individuals with mental health conditions, offering them practical tools to improve their own wellbeing and, by extension, their capacity to support their loved ones.

Main setting(s)/place(s) of delivery

1. Home

9. Online

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)

Age profile(s) of the target group(s) of the practice

Not available

Health issues of the care recipients assisted by the target group(s)

2. Psychological/mental health issues (e.g. depression, anxiety, etc.)

Age profile(s) of the care recipients assisted by the target group(s)

Not available

Problem being addressed

The web-based mindfulness intervention was developed to address the significant psychological and emotional burden experienced by informal caregivers of individuals with mental health problems.

Measurement/evaluation

The web-based mindfulness intervention was formally evaluated using a mixed-methods approach, combining quantitative data with qualitative insights to assess its usability, value, and perceived effectiveness among caregivers of individuals with mental health problems.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
4. Enhancing informal carers' and/or LTC workers' satisfaction
5. Fostering (or potential to foster) care partnerships.

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

Even though the intervention does not present clear signs of coordination, integration, or mutual recognition of roles of formal/informal caregivers, weekly e-mail reminders, including contact information to the research group/technical support (from the Department of Health Sciences), were sent to the participants as reminders/motivators for training and support. Retaining participants in online interventions can be challenging, as also seen in the current study, but features such as technical support, the possibility to contact the research group, and e-mail reminders were incorporated to help sustain motivation and prevent attrition. Moreover, a further potential for fostering care partnerships lies in the possibility of supplementing the current intervention with virtual classrooms in which participants can discuss their experiences with an instructor and/or peers. This may be a useful complement to the web-based program through which potential negative effects can be addressed and managed.

Equity (including ethics)

The project was approved by the Regional Ethical Committee, Lund, Sweden (dnr 2014/402).

Sustainability

The web-based mindfulness intervention demonstrates strong potential for long-term sustainability due to its cost-effective, scalable, and low-resource design. The intervention is delivered entirely online, which significantly reduces the need for physical infrastructure, ongoing staff time, or in-person facilitation. Once developed, digital content such as audio and video exercises, written materials, and tracking tools can be maintained and updated with minimal operational costs.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

Scalability and adaptability: Once the platform and content are developed, it can be offered to an unlimited number of users without significant additional investment. Its asynchronous, self-guided delivery model reduces dependency on human resources and allows for national or regional rollouts via public health websites, caregiver portals, or mental health service platforms. The intervention also offers strong adaptability. Its content can be easily translated and culturally adapted to suit different languages, belief systems, and caregiving norms.

Collaboration with and/or participation of different stakeholders and sectors

The development and implementation of the web-based mindfulness intervention involved cross-sectoral collaboration, particularly between the academic/research sector and the mental health care system.

Innovative aspects, if any

The web-based mindfulness intervention stands out for its social and technological innovation in the context of informal caregiving and mental health support. From a technological perspective, the program leverages digital tools to provide structured, self-guided mindfulness training entirely online. This format allows caregivers to engage with the program at their own pace and in the privacy of their homes. The intervention also shifts the focus toward supporting the mental health of caregivers themselves, rather than solely the individuals they care for.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

Despite the program's flexibility, users noted that discipline and motivation were essential to fully engage with the exercises. This highlighted the importance of integrating motivational prompts or reminders into the platform and potentially offering optional facilitator check-ins or peer support features to enhance engagement. Another barrier was the lack of a quiet or private space in the home to complete the mindfulness exercises. This was especially relevant for those living in small or crowded households. To address this, future adaptations of the program could include shorter or modified exercises designed for more dynamic or shared environments. Some users also experienced technical challenges, such as navigating the platform or streaming videos which indicates a need for user-friendly design, clear instructions, and basic technical support to enhance accessibility.

Key success factors/points of strength

A key strength was the program's flexible, self-guided format, which allowed caregivers to engage with the content at their own pace and within their own home environments. The user-centered design approach further strengthened its impact. While not formally co-designed, the program reflected deep awareness of the lived experiences of caregivers, incorporating simple, guided practices and private journaling to promote reflection and stress reduction.

Colourful Unburdening

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	120 GLR
Ranking of the good practice	28
Type of good practice	4. Integrated approaches and strategies
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Colourful Unburdening
Name of the good practice in original language (if available)	Kleurrijk Ontzorgen
Initiative in operation since	2018
Country/ies of implementation Geographic coverage/ implementation level	Netherlands 1. Local
Stage of initiative	1. Ongoing
Name of the Leader/s Organisation/implementer/s	Cordaan
Contact details	Fenne Verhoeven (project manager at Cordaan), fverhoeven@cordaan.nl
Type/source(s) of funding	3. Statutory LTC/healthcare financing system
Webpage/s of the good practice (or link to doi of the paper)	Webpage: kleurrijk-ontzorgen-bij-cordaan Report: https://bensajetcentrum.nl/assets/2022/03/Ben-Sajet-Magazine-pdf-voor-tablet-klein.pdf

Summary (abstract)	Cordaan's Kleurrijk Ontzorgen program focuses on families – often with a migration background – who largely bear the responsibility of caring for a young adult with an (intellectual) disability at home. This care can be intensive and burdensome; Cordaan offers support to ease that burden and improve the quality of home life. This initiative specifically integrates culturally sensitive care into long-term care practice. The program consists of several components: 1. Culturally sensitive in-home support ("Kleurrijk thuis"): A specialized ambulatory team visits clients and their families at home to provide practical support, including help with daily routines, managing challenging behavior, engaging in activities (walks, games), and assistance with administrative matters or navigating care services. This support is tailored to the family's cultural and background-specific needs; 2. Weekend respite care (Logeren for adults 21+): Cordaan offers weekend stays in a dedicated facility in Amsterdam-Noord. There are 11 spots available each weekend for adults living at home who receive day care, providing crucial respite for family caregivers; 3. Saturday respite group ("Zaterdagbreak"): Once a month in Amsterdam-Zuidoost, home-dwelling adult clients can join a day of group activities—such as cooking, walking, crafting, and games—offered through the "Zaterdagbreak." This provides both social engagement for clients and relief for carers; 4. Intercultural consultant and trust-building: A key innovation is the deployment of an intercultural consultant who builds bridges between families and professional caregivers. They engage with families when there are signs of overload or when cultural and language barriers impede collaboration. They also coach staff and facilitate workshops on cultural sensitivity to strengthen mutual understanding and trust; 5. Training, coaching & organizational responsiveness: The program includes training and workshops for care teams—led by the intercultural consultant—on culturally sensitive practices. This enables staff to better engage with families. Cordaan also encourages staff to flag emerging needs and co-design bespoke solutions, fostering organizational flexibility.
Keywords	Culturally Sensitive Care, Respite Care, Family-Centered Support, Partnership Working

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

Within the Kleurrijk Ontzorgen program, an innovative and effective approach has been developed to better support families, primarily those with a migration background, who care for a young adult with an (intellectual) disability at home. A specialised ambulatory team provides tailored home-based support to both the client and the family. In addition, weekend respite care for adult clients has been introduced to temporarily ease the burden on caregivers.

Key to the program is the involvement of an intercultural consultant. They are brought in when there are signs of overload in the home situation, but communication with family members—often hindered by language barriers or cultural differences—is difficult. The consultant acts as a bridge, with special attention for the, often invisible, primary caregiver, such as the mother.

Furthermore, the intercultural consultant coaches LTC workers on how to improve communication with families and provides workshops on culturally sensitive practices. These activities aim to reduce the distance between professional care and families, foster mutual understanding, and strengthen collaboration.

Main setting(s)/place(s) of delivery

1. Home
3. Day Centre

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)
3. Qualified/registered nurses
4. Assistant nurses

Age profile(s) of the target group(s) of the practice

1. 18-34 years
2. 35-64 years
3. 65-74 years
4. 75+ years

Health issues of the care recipients assisted by the target group(s)

1. Physical disabilities (caused, e.g. by frailty, accident, injury, illness, etc.)
4. Other chronic illnesses/long-term health conditions (disabled adults who remain living at home)

Age profile(s) of the care recipients assisted by the target group(s)

3. Adults (18-64 years)

Problem being addressed

The problem addressed by Kleurrijk Ontzorgen is the high burden on families—often with a migration background—who care for a young adult with a (mild) intellectual disability at home, often with limited formal support. These families face multiple challenges, including intensive, long-term caregiving responsibilities, language and cultural barriers that hinder access to professional care, a lack of trust with care providers, and limited use of respite care. This situation can lead to caregiver overload, social isolation, and missed opportunities for support or relief. Kleurrijk Ontzorgen responds by bridging gaps between families and professional care through culturally sensitive, trust-based support, intercultural mediation, and practical respite options.

Measurement/evaluation

The program has been evaluated by the Ben Sajat Centre, which conducted research involving 12 case studies, interviewing employees, caregivers, relatives, and the intercultural consultant. The research found that the program ‘breaks the ‘negative spiral’ experienced by families and works as a flywheel,’ highlighting its positive impact on family dynamics.

It is also based on practice-based knowledge (knowledge from practical experiences) and experience-based knowledge (knowledge based on the experiences of clients or relatives).

Families have reported improvements: ‘Family members now feel better heard, and it has become clear that they also need support at home and for respite care’.

For information about the evaluation, please contact Ludo Glimmerveen – who is involved in the evaluation of the initiative: ludo.glimmerveen@bensajetcentrum.nl.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
4. Enhancing informal carers’ and/or LTC workers’ satisfaction
5. Fostering (or potential to foster) care partnerships

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

Kleurrijk Ontzorgen fosters care partnerships by building trust and mutual understanding between families and professional caregivers, especially in contexts where this trust is not automatic. Through the involvement of an intercultural consultant, families are supported in navigating the care system in a way that respects their language, culture, and values. This personalised, culturally sensitive approach helps reduce communication barriers and ensures that families feel heard, understood, and included. As a result, families are more likely to engage with support services and take an active role in shaping care.

At the same time, the program strengthens the capacity of care teams to work effectively with families. Professionals receive coaching and training in culturally sensitive practices, improving their ability to build rapport and respond to families’ unique needs. By working closely with families in the home and community, and by offering flexible respite and practical support, Kleurrijk Ontzorgen promotes a model of shared responsibility. This collaborative, relational approach transforms the dynamic from one of service provision to one of partnership—laying the groundwork for more inclusive, responsive, and sustainable care.

Equity (including ethics)

The program is explicitly designed for families with a migration background. It offers culturally sensitive support (see also responses to Q8 and Q10).

Sustainability

During the development of the program, the regional funding office for long-term care has been closely involved and supported the program's development and expansion. They were involved to find a suitable way forward around individual 'complex' cases, but also to make sure that structural funding would become available for the work of the intercultural counselor and other specialized care teams ('Kleurrijk Thuis'). This has improved the sustainability of the care practices that were developed under the program.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

The program's activities have been scaled up within the context of Amsterdam, and also attracted considerable attention from the Dutch Ministry of Health, Welfare and Sports. The program has a dedicated website on the knowledge repository that Vilans (and others) host around caring for people with disabilities, ensuring wide dissemination of the lessons learned. While the program's activities are particularly tailored to families with a migration background, several 'native' Dutch families have also benefited from the enhanced support it provides.

Collaboration with and/or participation of different stakeholders and sectors

The program is implemented by Cordaan, a large care organisation, involving professionals from health, social care, and community support. Families (including those with a migration background) are directly involved, making them key stakeholders. The Ben Sijet Centrum (a research organization) conducted an evaluation of the program, adding an academic perspective. The program is supported by the Dutch Ministry of Health, Welfare, and Sport (VWS), ensuring a link with public policy.

Innovative aspects, if any

The program is innovative, as it introduces culturally sensitive support (cultuursensitief werken), recognising and respecting the cultural, religious, and personal backgrounds of families with a migration background. It shifts the focus from standard care to customized support, adapting to the unique needs of each family. The involvement of an intercultural consultant who provides direct support and advice to both families and staff is an innovative approach to bridging cultural gaps. Families are empowered to maintain care at home, while professionals receive training to communicate and build trust more effectively.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

An important barrier is the way the care system is structured: families' needs often do not align neatly with existing policy domains or funding streams. The support families require may fall outside reimbursable services, such as the role of the intercultural consultant. This raises the question of who pays for non-traditional supports, which remains a structural gap. At the same time, the regional funding office for long-term care has been closely involved and supported the program's development and expansion (see also question 12).

Another challenge is the fragility of trust and the difficulty of maintaining it across an entire care team. While one professional might successfully build rapport with a family, that trust can easily erode if other team members fail to engage with the same sensitivity or consistency. In those cases, it helps when there is support from higher up within the organization. For example, by engaging in a dialogue with colleagues who feel uncomfortable about stretching the boundaries of their role or the standard care offering.

Key success factors/points of strength

The research (evaluation) conducted by the Ben Sijet Centre showed that a success factor of Kleurrijk Ontzorgen lies in responding to small, concrete help requests from families. Rather than focusing immediately on formal care procedures, staff prioritize what truly matters in the daily lives of families, often seemingly minor but urgent needs. Addressing these requests builds trust. Another key success is the support of the intercultural consultant, who thinks along with the families and supports them.

Rehabilitation Enablement in Chronic Heart Failure (REACH-HF)

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	105 SLR
Ranking of the good practice	29
Type of good practice	6. Community-based initiatives/measures Also related to: 4. Integrated approach and strategy
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Rehabilitation EnAblement in Chronic Heart Failure (REACH-HF)
Name of the good practice in original language (if available)	idem
Initiative in operation since	Between January 2015 and February 2016, patients were randomly allocated to the REACH-HF group and control group.
Country/ies of implementation	UK
Geographic coverage/ implementation level	2. Regional, national (Birmingham, Cornwall, Gwent, York)
Stage of initiative	4. Finished for 4 years or more. The study was conducted between January 2015 and February 2016
Name of the Leader/s Organisation/implementer/s	University Hospitals of Leicester NHS Trust, UK; Sandwell & West Birmingham Hospitals NHS Trust, Birmingham, UK; Royal Cornwall Hospitals NHS Trust, Truro, UK
Contact details	Rod Taylor, Institute of Health and Well Being, MRC/CSO Social and Public Health Sciences Unit, University of Glasgow, Top floor, 200 Renfield Street, Glasgow, G2 3AX, Scotland, UK. e-mail: rod.taylor@gla.ac.uk Phone number not available in the paper
Type/source(s) of funding	3. Statutory LTC/healthcare financing system. This work was supported by the National Institute for Health Research (NIHR).
Webpage/s of the good practice (or link to doi of the paper)	DOI: https://doi.org/10.1177/1474515119850011

Summary (abstract)	REACH-HF is a novel home-based, health-professional-facilitated, self-management programme for patients with heart failure (HF) and their informal caregivers. Caregivers were allocated to receive the intervention over 12 weeks plus a control group. Outcomes were compared between groups at 4, 6 and 12-month follow-up. Twenty caregivers receiving REACH-HF were purposively selected for qualitative interviews at 4 and 12 months. Compared with controls, the caregiver in the REACH-HF group reported positive changes to how they supported the HF patient they were caring for, and perceived that they had increased their confidence of self-management and in the caregiver role over time. This intervention was overall perceived to be helpful in supporting the caregiver role.
Keywords	Heart Failure, Caregiver, Cardiac Rehabilitation, Self-Management, Home-Based Programme

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

The initiative was developed to support family caregivers of people with heart failure (HF), especially with regard to their needs to engage social support and services, thus addressing the paucity of evidence in this respect. The aim/objectives were to improve the confidence of caregivers in self-management, by means of a home-based and health-professional-facilitated intervention. The core priorities were: 1. To facilitate improvement in patient health related quality of life (HRQoL); 2. To improve HRQoL for caregivers. According to the inclusion criteria, patients aged ≥18 years with a confirmed diagnosis of HF were included. At study entry, patients were asked to nominate if they had a caregiver, i.e. a spouse, other relative or friend, who provides unpaid support (e.g., emotional support, support for taking medications, getting prescriptions, support with household tasks, physical care, and to participate in social events and physical activity). The intervention includes four core elements: a "Manual" with information for understanding/managing HF; 'Progress tracker', allowing patients to record symptoms, physical activity and other actions related to self-care; 'Family and friends resource' for caregivers, including advice on providing support, managing own health/wellbeing, and getting help; "Facilitation" by cardiac nurses or physiotherapists. The intervention was delivered at the patient's home via a mixture of face-to-face and telephone contacts over 12 weeks. According to the results, most caregivers who received the REACH-HF intervention made positive changes to how they supported the HF patient they were caring for, and perceived that they had increased their confidence of self-management and was perceived for some to be helpful in supporting their caregiver role over time. The REACH-HF intervention is mainly a "community-based initiative" (type 6), but also it represents an example of "integrated approach and strategy" (type 4), since patients, caregivers, and health-professionals (as facilitators) are involved.

Main setting(s)/place(s) of delivery

1. Home.

The intervention is delivered in home-based setting (in contrast to the traditional hospital/centre-based venue).

Target group(s)/beneficiaries

1. Informal carers (e.g. carers of working age, older carers).

In the sample there are some working carers but the practice is for informal carers. Both males and females.

Age profile(s) of the target group(s) of the practice

3. 65-74 years

Mean age: 63 years; REACH-HF group; 68 years control group.

Health issues of the care recipients assisted by the target group(s)

1. Physical disabilities (Heart failure)

Age profile(s) of the care recipients assisted by the target group(s)

4. Older people (65+ years)

Mean age 70 years.

Problem being addressed

Caregivers frequently provide support to people living with long-term conditions, e.g., with heart failure (HF). This is an unpredictable life-limiting condition that is challenging to self-manage. People with HF typically experience poor levels of health-related quality of life. Caregivers have to manage several tasks, e.g., also for communicating with health professionals. There is paucity of evidence of interventions that support caregivers in this role. The REACH-HF intervention thus aims to support these caregivers, as novel home-based, health-professional-facilitated, self-management programme.

Measurement/evaluation

Caregiver assessment included the Hospital Anxiety and Depression scale (HADS), generic HRQoL (EQ-5D-5L questionnaire), Family Caregiver Quality of Life (FamQoL), Caregiver Burden Questionnaire for Heart Failure (CBQ-HF), and Caregiver's Contribution to Self-care of HF Index (CC-SCHFI). Outcome data were collected during three clinic visits at baseline, four and 12 months, and by postal questionnaire at six months. Twenty caregivers in the REACH-HF group were selected for qualitative interview at 4 and 12 months using maximal variation sampling that took account of patient and caregiver baseline HRQoL scores, caregiver demographics (age, gender and ethnicity), and geographical location. Intervention and control group caregiver outcomes are compared at 12-months using linear regression methods, aTusting for baseline score. A thematic analysis of interviews was also carried out.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. anxiety of informal caregivers)
5. Fostering (or potential to foster) care partnerships

In particular, there was evidence of improvements from baseline at 4, 6 and 12-months follow-up in a number of caregiver outcomes in the REACH-HF group, including HADS-anxiety, CBQ-HF physical (burden), social life and lifestyle and all SCHFI (self-care) dimension scores. Provision of the REACH-HF intervention for caregivers of HF patients improved their confidence of self-management and was perceived for some to be helpful in supporting their caregiver role.

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

The intervention put together patients, caregivers, clinicians, service providers, and is delivered in home-based setting by trained health-professionals. Facilitators/health-professionals supported the participants and caregivers to understand and manage HF, set goals and develop self-care strategies. Facilitators were asked to spend time with the caregivers to help them understand how best to support the patient, as well as to look after their own wellbeing. Overall, an actively working with caregivers and healthcare facilitators allows improvements in the intervention.

Equity (including ethics)

The investigation was approved by the North West Lancaster Research Ethics Committee. Written informed consent was obtained from both patient and caregiver participants. Regarding equity, authors only state that caregivers were typically the partner or direct relative of patients, of a younger mean age than participating patients and predominantly female, with a mean age of 63 years in the intervention group.

Sustainability

The authors mention the support by several healthcare professional facilitators, i.e., cardiac nurses (district nurse and nurse specialist), clinicians, service providers. They also mention the Peninsula Clinical Trials Unit, the Royal Cornwall Hospitals Trust (Research, Development and Innovation and Clinical Chemistry departments), and refer to European Society of Cardiology guidelines for HF. Moreover, the intervention comprises/describes patient and carer manuals with supplementary tools, delivered by trained healthcare facilitators. Authors also state that actively working with caregivers and healthcare facilitators allows making adaptations in the REACH-HF facilitator training.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

A detailed description of the REACH-HF intervention (apart from the paper), its development and its theoretical underpinnings is published here <https://doi.org/10.1186/s40814-016-0075-x> The study design and methods have been described in the published study protocol <https://doi.org/10.1136/bmjopen-2016-012853>. The REACH-HF intervention comprises the 'Heart Failure Manual'. The Interview Topic Guide is available in Supplementary table 1, in the online version of the paper. It is worthy to highlight that this GPR (ID105) is the repetition as multicentre study (UK, Birmingham, Cornwall, Gwent and York), of the pilot study (ID56), that was carried out only in a single-centre (Tayside, Scotland). Authors also state that refinements of the REACH-HF intervention have been made ahead of its roll out into the UK National Health Service, including strategies to better target caregivers.

Collaboration with and/or participation of different stakeholders and sectors

The authors mention the collaboration with several healthcare professional/facilitators, i.e., cardiac nurses (district nurse and nurse specialist), clinicians, service providers. Also, the intervention is co-developed (stakeholder consultations with patients, caregivers, health professionals, clinicians, service providers). Facilitators supported the participants and caregivers to understand and manage HF, set goals and develop self-care strategies. A detailed description of the REACH-HF intervention, including extensive consultation and involvement of patient and public involvement group is also published here <https://doi.org/10.1186/s40814-016-0075-x>

Innovative aspects, if any

The REACH-HF intervention is novel in a number of ways: (1) theory-based; (2) co-developed with stakeholders (patients, caregivers, clinicians, service providers); (3) based on intervention mapping; (4) delivered in home-based setting (in contrast to the traditional hospital/centre-based venue) by trained health-professionals; and (5) directed at both patients with HF and their caregivers. Also, the actively working with caregivers is a new experience for many of the healthcare facilitators who participated in this trial. However, a clear technological innovation is not emerged. In this respect, in the protocol <https://doi.org/10.1186/s40814-016-0075-x> authors only mention a progressive exercise training delivered by a digital versatile disc (DVD). The manual also includes a CD for relaxation and breathing control exercises.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

The practice presents information which discloses the sources of financing, but it is not clear if these could potentially allow continuity as financial sustainability. Authors indeed only state that this work was supported by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research scheme (grant number RP-PG-1210-12004). KJ is partly funded by the NIHR Collaboration for Leadership and Health Research (CLAHRC) and Care West Midlands and NB and RST are both part-funded by the NIHR CLAHRC for the south west peninsula. Also, the study sample size was powered on the between-group difference in patient rather than for caregivers. Finally, the trial process evaluation found that healthcare staff facilitating the REACH-HF intervention appeared to be less effective in involving of caregivers than patients.

Key success factors/points of strength

There is paucity of evidence of interventions that support caregivers in their role, whereas this study provides important evidence of the impact of a rehabilitation and self-management intervention for HF patients on caregiver outcomes. Provision of the REACH-HF intervention for caregivers of patients with HF improves their confidence to support self-management and was perceived to be helpful in maintaining their role as caregivers. Strengths of this study included also its multicentre design, collection of a range of questionnaire-based outcomes intended to assess mental wellbeing, burden and HRQoL of caregivers, and the mixed methods design (also interviews with caregivers). Moreover, further key success factors are the presence of trained healthcare facilitators, and the participatory co-design.

The Renaissance of Workforce Models in France's Mental Healthcare

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	83 GLR
Ranking of the good practice	30
Type of good practice	1. Primary, secondary and tertiary prevention interventions
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Beyond Barriers: The Renaissance of Workforce Models in France's Mental Healthcare – A Triple Mixed Exploration
Name of the good practice in original language (if available)	Pole94G16 - Hospitals of Paris Est Val-de-Marne / Hospitals of Saint Maurice
Initiative in operation since	1st January 2019
Country/ies of implementation	France
Geographic coverage/ implementation level	1. Local (Île-de-France) 2. Regional, national
Stage of initiative	3. Finished for 1-3 years
Name of the Leader/s Organisation/implementer/s	Pole94G16 – Hospitals of Paris Est Val-de-Marne / Hospitals of Saint Maurice
Contact details	Nancy De Jesus, Lead Researcher, cliniannancy@gmail.com
Type/source(s) of funding	4. National or local public sources (e.g. general tax revenue, social care funds) 8. Other: open WHO training and policy alignment
Webpage/s of the good practice (or link to doi of the paper)	Webpages: https://www.hpevm.fr/ Best Practice Portal – EU
Summary (abstract)	This practice explored the integration of emerging professions in a French psychiatric hospital: Advanced Practice Nurses (APNs) and Professional Peer/Family Peer Helpers. The aim was to redesign mental healthcare by introducing collaborative, recipient-centred care models aligned with WHO and EU strategies. The project used a triple mixed methods approach to evaluate relational, organisational, and systemic impacts. The training model included blended informal learning and engagement with OpenWHO. Results showed positive impacts: a 23% reduction in length of stay and a 22% drop in bed occupancy from 2018–2021, alongside a 55% rise in admissions (2018–2022). The initiative demonstrates the transformative potential of workforce innovation in mental health, focusing on empowerment, inclusion, and care quality.

Keywords

Mental Health, Emerging Professions, Peer Support, Psychiatric Care, Workforce Innovation

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

At Pole94G16, a psychiatric hospital for adults in Île-de-France, this program is focused on introducing emerging professions such as Advanced Practice Nurses (APNs) and Professional Peer/Family Peer Helpers into mental healthcare teams. The core objective was to explore how these roles could transform care relationships, reduce stigma, and improve outcomes for service users.

The programme applied a triple mixed method design to investigate the relational, organisational, and clinical impacts of these new roles. It involved informal blended learning, including the use of OpenWHO resources, and integrated these roles into multidisciplinary teams.

The project aligned with the WHO Pan-European Mental Health Coalition and EU care strategies by promoting user-centred care and workforce flexibility. Its added value lies in breaking with traditional psychiatric models and promoting co-production, shared decision-making, and the recognition of lived experience as a professional contribution.

Main setting(s)/place(s) of delivery

5. Hospital

9. Online

10. Other (via telephone)

Target group(s)/beneficiaries

6. Other LTC workers/health-social care professionals (Advanced Practice Nurse (APNs) and Peer and Family Peer Helpers)

Age profile(s) of the target group(s) of the practice

2. 35-64 years

Health issues of the care recipients assisted by the target group(s)

2. Psychological/mental health issues (e.g. depression, anxiety, etc.)

Age profile(s) of the care recipients assisted by the target group(s)

3. Adults (18-64 years)

Problem being addressed

France's mental healthcare system has faced increasing demands, rigidity in professional roles, and growing user dissatisfaction. Traditional models often lacked user involvement and failed to address stigma and service fragmentation. In this context, the project tackled:

Lack of workforce diversity and flexibility;

Insufficient user-centred approaches;

Structural stigma and marginalisation of service users.

The introduction of emerging professions aimed to reconfigure relational dynamics and institutional practices. Peer helpers brought lived experience into the care process, enabling more inclusive, empathetic, and responsive services. At the same time, Advanced Practice Nurses helped bring clinical and psychosocial care. Together, these roles addressed both structural and interpersonal gaps in mental health services.

Measurement/evaluation

The evaluation included:

Process monitoring: Integration of emerging roles; training engagement (OpenWHO completion);

Output analysis: Hospitalisation data (length of stay, bed occupancy, admission rates);

Outcome indicators: Changes in care quality, user empowerment, stigma reduction, and shared decision-making.

Key results (2018–2021):

23% reduction in average length of stay;

22% drop in bed occupancy;

55% increase in new admissions (2018–2022).

Self-reported user feedback showed improvements in confidence, engagement, and perceived quality of care. The presence of peer professionals helped reduce stigma and improved communication between staff and users.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience

2. Improving mental wellbeing

3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)

5. Fostering (or potential to foster) care partnerships

6. Improving organisational practices

7. Cost-effectiveness

These shifts reflect improved care efficiency and access. Peer roles contributed to reduced stigma, more inclusive environments, and enhanced user empowerment. Multidisciplinary teams reported stronger collaboration and more flexible care delivery.

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

This initiative embodies the WELL CARE concept of care partnerships by integrating peer and family peer helpers—individuals with lived caregiving or mental health experience—directly into clinical teams. Their involvement fosters mutual recognition between professional staff and people with informal care experience.

This role innovation blurs traditional boundaries between formal and informal care, strengthening empathy, shared responsibility, and co-production. It supports relational integration, one of the pillars of care partnership, by ensuring that care recipients and their networks are no longer passive subjects but active contributors to care design and delivery.

Equity (including ethics)

The initiative promotes equity through inclusion: Peer and family peer roles provide a voice to often marginalised communities within psychiatric care. Training through OpenWHO and a focus on blended, non-hierarchical learning make the programme accessible and adaptable. Ethical safeguards were implemented through professional supervision and informed role integration. Users' self-reported experiences indicate greater dignity and engagement.

Sustainability

The programme is based on §33a of the Austrian Federal Care Allowance Act and funded by the Federal Ministry. Since its rollout in 2017, it has become part of standardised quality assurance in home care and is institutionally and financially anchored. Its flexibility and decentralised delivery model also support long-term sustainability.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

Sustainability is supported through four key principles:

Workforce development (training and role integration);

Financial sustainability (using existing structures and public support);

Community engagement;

Policy advocacy.

The programme's alignment with EU and WHO strategies and its demonstrated efficiency in hospital resource use (reduced stays, improved turnover) enhance its policy relevance and long-term feasibility.

Collaboration with and/or participation of different stakeholders and sectors

The initiative involved a broad range of actors:

Hospital administration and clinical staff;

Peer/family peer professionals;

International training providers (e.g. OpenWHO);

Policy-level alignment with WHO and EU strategies.

While primarily implemented in a single hospital group, the programme sought to influence policy thinking and demonstrate how organisational innovation can arise from within health systems.

Innovative aspects, if any

The innovation lies in:

Creating new professional roles grounded in lived experience;

Breaking hierarchical models of psychiatric care;

Using international learning resources (OpenWHO) to train national staff;

Embedding service users in care teams to reshape care culture.

It reflects a paradigm shift in mental healthcare—from provider-centred to co-produced, relational care models.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

Challenges included:

Resistance from traditional professionals;

Unclear role definitions and boundaries;

Funding and contractual uncertainties.

Solutions involved strong leadership, joint role design, and use of trusted training resources. Evaluation and positive outcome data helped increase institutional buy-in.

Key success factors/points of strength

Clear alignment with EU and WHO strategies;

Use of measurable outcome indicators (bed occupancy, stay length);

Lived experience as a professional asset;

Tangible organisational benefits;

Flexible, inclusive training and role implementation;

Policy advocacy potential for system-level change.

Meeting centres support program (MCSP)

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	28 GLR
Ranking of the good practice	31
Type of good practice	6. Community-based initiatives/measures
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Meeting centres support program (MCSP): providing support to people with dementia and their informal carers
Name of the good practice in original language (if available)	Ontmoetingscentra dementie
Initiative in operation since	The first centres were established in Amsterdam in 1993 on the initiative of the Valerius Foundation and the VU Medical Centre.
Country/ies of implementation	Netherlands
Geographic coverage/ implementation level	1. Local 2. Regional, national 3. Cross-country/International As of 2020, around 165 centres operate across the Netherlands. The model has also been implemented in countries such as England, Italy, and Poland through the MEETINGDEM project, as elsewhere: Aruba, Spain, Suriname and Australia. In the US, Japan, Chili and Singapore MCSP are in developmental stage (Movisie.nl)
Stage of initiative	1. Ongoing The initiative has been in continuous operation since 1993 and is still active and expanding.
Name of the Leader/s Organisation/implementer/s	National Platform for Dementia Meeting Centers (LPOCD), Amsterdam UMC, VUmc location, Department of Psychiatry (Landelijk Platform Ontmoetingscentra Dementie (LPOCD), Amsterdam UMC, locatie Vumc, Afdeling Psychiatrie)
Contact details	(i.e. name of the contact person - corresponding authors for papers - address, phone number, e-mail) Marjolein Wolf, Coördinator Landelijk Platform Ontmoetingscentra Dementie (LPOCD), m.b.wolf@vu.nl Channah Osinga, Student-assistent, ntmoetingscentra@amsterdamumc.nl Em. Prof. dr. Rose-Marie Dröes, Tel.: 06/54654416 (donderdag), rm.droes@amsterdamumc.nl

Type/source(s) of funding	3. Statutory LTC/healthcare financing system 4. National or local public sources (e.g. general tax revenue, social care funds) 5. Private sources (e.g. donations, private insurers, foundations) Funding mainly comes from municipal subsidies under the Social Support Act (Wmo), personal budgets (PGB), and in some cases the Long-Term Care Act (WLZ). Additional funding is raised through community support foundations.
Webpage/s of the good practice (or link to doi of the paper)	Webpage: https://ontmoetingscentradementie.nl EU-funded MEETINGDEM project's website: https://meetingdem.eu/
Summary (abstract)	The Meeting Centres for People with Dementia and their Carers is a Dutch initiative providing integrated support for people with mild to moderate dementia and their informal carers. Established in 1993 in Amsterdam on the initiative of the Valerius Foundation and the VU Medical Centre, the programme is based on the Adaptation-Coping Model, designed to help participants adjust to the challenges of dementia. These centres offer tailored activities for individuals with dementia and various forms of support for carers, including discussion groups, consultations, and joint social activities and they are embedded in community facilities, promoting social inclusion and easy access. The programme is sustained through a mix of municipal funding, personal budgets, long-term care funds, and co-payments. It has been successfully implemented in other countries (e.g., UK, Italy, Poland) as part of the EU-funded MEETINGDEM project. Evaluation studies confirm its effectiveness and adaptability, with specific attention to cultural inclusion and equity
Keywords	Dementia Care, Informal Caregiving, Community-Based Support, Social Inclusion, Long-Term Care

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

The meeting centres aim to support psychosocial adjustment to dementia and are intended for people with mild to moderate dementia and their carers, who are often family members, friends or neighbours. The practice aims to prevent caregiver burden, promote social engagement, and enhance the overall well-being of both individuals with dementia and their informal carers. Meeting centres, which are often located in neighbourhood and senior centres, offer a wide range of activities. People with dementia can visit the day centre three days a week. There, they can participate in recreational activities, either individually or in groups, such as drawing, painting, listening to music, playing games, reading the newspaper, shopping, preparing lunch, singing and exercising. The activities are tailored to the interests, needs and abilities of the participants, and the support provided is personalised. Informal carers can participate in discussion groups (once every two to three weeks) throughout the year, and a series of informative meetings is organised annually. Many centres collaborate with an Alzheimer's Café in the region for this purpose. In addition, the centre's staff offer advice and practical assistance with arranging care at home and nursing home admission, if necessary. Finally, there are joint activities for participants with dementia and informal carers, such as the bi-monthly centre meeting, parties and outings. Informal carers and people with dementia can visit the weekly consultation hour for expert advice and individual support.

Main setting(s)/place(s) of delivery

- 3. Day Centre
- 4. Local healthcare centre (e.g. ambulatory)
- 8. Local community

Most activities take place in neighbourhood-based day centres or local community centre / local nursing homes.

Target group(s)/beneficiaries

- 1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)
- 2. Working carers (combining paid work with informal care)
- 3. Qualified/registered nurses
- 4. Assistant nurses
- 6. Other LTC workers/health-social care professionals (professional and volunteer care providers working in LTC)

Both people with dementia and their informal carers (working and retired) are primary beneficiaries.

The programme also supports professional and volunteer care providers working in LTC.

Age profile(s) of the target group(s) of the practice

- 1. 18-34 years
- 2. 35-64 years
- 3. 65-74 years
- 4. 75+ years

All age profiles. Although the majority of residents are older people, the carers can be of all ages, also the formal careworkers.

Health issues of the care recipients assisted by the target group(s)

3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.)

The program focus is on people with dementia and their carers, but older people often have multimorbidity and as such also physical or mental health issues.

Age profile(s) of the care recipients assisted by the target group(s)

3. Adults (18-64 years)

4. Older people (65+ years)

While most participants are over 65, younger adults with early-onset dementia also take part.

Problem being addressed

Informal carers, who are often family members, experience high demands that may lead to excessive physical and mental effort. These caregivers frequently balance their caring responsibilities with their personal or professional life, which can result in fatigue and emotional exhaustion;

Although the centres provide support through a multidisciplinary team, many carers still feel isolated when interacting within mainstream care systems that may not adequately address the intricacies of dementia care or the specific needs of diverse cultural communities;

Many individuals with dementia and their carers can become socially isolated, especially when support structures are fragmented. The meeting centres address these non-occupational risks by creating an environment where regular social activities, discussion groups, and community engagement can help build social relationships and reduce isolation;

Carers and individuals with dementia may be further affected by factors such as age, gender, socio-economic status, and migration background. These aspects can influence accessibility to adequate support, understanding of the available services, and a sense of belonging within their local community.

Measurement/evaluation

(For answering questions 8-17: different studies of MCSP are used: Dröes et al., 2004, Szczesniak et al 2021, Dries et al 2006)

Observational pre-test/post-test designs have been executed comparing Meeting Centres with standard day care. After 7 months the Meeting Centres Support Programme, compared to regular day care, showed a moderately positive effect on the degree of total behaviour problems (effect size = 0.52), especially on inactivity (effect size = 0.37) and non-social behaviour (effect size = 0.60), a large effect on depressive behaviour (effect size = 0.92) and a moderate effect on self-esteem (effect size = 0.43). (Dröes et al., 2004);

There is also a European cross-country evaluation: Szczesniak et al 2021 . The percentage of people with dementia who were very satisfied with the programme increased significantly over time ($p=0.05$). The majority of carers reported that they felt less burdened after three months of participation in MCSP (48.1% much less; 35.4% a little less). After six months, this percentage increased significantly to 91% ($p=0.04$, 57.7% much less; 33.3% little less). Focus group analysis showed that people with dementia and carers in all countries/centres improved their ability to maintain emotional balance.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

Improving resilience

The MCSP helps carers increase their capacity to deal with the challenges of dementia, promoting emotional balance and resilience.

Improving mental wellbeing

MCSP aims to enhance the mental wellbeing of informal carers by providing emotional and social support.

Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)

Carers in the MCSP reported a reduction in feelings of burden, stress, and psychological symptoms, particularly among those who felt lonely. The program also led to a significant improvement in carers' satisfaction with discussion groups and emotional support.

Enhancing informal carers' and/or LTC workers' satisfaction

Carers expressed high satisfaction with the MCSP, noting improvements in their ability to maintain emotional balance and a reduction in their burden.

Fostering (or potential to foster) care partnerships

The MCSP fosters care partnerships by integrating support services and collaborating with local health and welfare services, enhancing the support network for carers.

Improving organisational practices

The program's integrated approach, involving collaboration with various care providers, improves organisational practices by ensuring comprehensive support for carers and people with dementia.

8. Other (delaying the institutionalization of people with dementia, allowing them to remain in community settings longer)

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

Integration of Support Services: the MCSP integrates various support services, which include informative meetings, discussion groups, and social activities. This integration fosters collaboration between informal carers and LTC workers, enhancing mutual understanding and coordination of care;

Collaboration Protocols: the MCSP operates on a collaboration protocol with health and welfare services, ensuring coordinated care and shared responsibilities among stakeholders. This protocol facilitates effective communication and partnership between LTC workers and informal carers;

Community Engagement: the program is designed to promote social integration with local residents, which helps in building a community network that supports both carers and LTC workers. This community-based approach encourages shared knowledge and mutual recognition of roles;

Emotional and Social Support: by providing emotional and social support through regular consultations and social activities, the MCSP enhances the resilience and mental well-being of carers. This support system acknowledges the emotional needs of carers and LTC workers, fostering a supportive partnership;

Case Management and Coordination: the MCSP includes direct coordination with case managers and multidisciplinary care, which ensures that both informal carers and LTC workers are aligned in their care strategies. This coordination is crucial for effective care partnerships;

Tailored Support: the program offers tailored support to meet the individual needs of carers, which is essential for effective partnerships. By addressing specific needs, the program ensures that both carers and LTC workers can work together more effectively.

Equity (including ethics)

The implementation of the practice actively considers various dimensions of equity, including age, gender, socioeconomic status, and geographic location (rural and urban areas). It also addresses the needs of vulnerable groups such as people with hearing and/or visual impairments, chronic illnesses, multimorbidity, those without family support, and individuals with language barriers. The support activities are offered at easily accessible locations like community and senior centers, promoting social integration with local residents. The study protocol received approval from the appropriate Ethics Committees in each participating country, ensuring that ethical standards were maintained throughout the research process. All participants provided informed consent, highlighting the ethical consideration of participant autonomy and data protection.

Sustainability

Funding and Resources: the sustainability of the MCSP is supported by structural funding and the involvement of various stakeholders, including care and welfare organizations. This ensures that the program can continue to operate and expand its reach;

Professional and Volunteer Support: the program is maintained by a small, permanent professional team, including a program coordinator, an activity coordinator, and a carer, supported by volunteers. This structure helps in sustaining the program by ensuring consistent and quality support;

Community Integration: meeting centres are often located in community and senior centers, which facilitates social integration and accessibility. This strategic placement helps in maintaining the program's relevance and accessibility to the target population;

Policy and Collaboration: the program collaborates with other care providers and welfare institutions, such as GPs and mental health services, ensuring a comprehensive support network. This collaboration is crucial for the program's long-term sustainability;

Technological and E-health Services: while specific technological services are not detailed, the program's adaptability to include such innovations could enhance its sustainability by improving service delivery and engagement;

Training and Development: new centres can request guidance from consultants and participate in courses for new staff members, which supports the program's growth and sustainability by ensuring that staff are well-trained and capable of delivering high-quality care;

Policy Support: the program's alignment with broader health and social care policies can provide a supportive framework for its continuation and expansion.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

Scalability Potential: the MCSP has demonstrated scalability, as evidenced by its successful implementation beyond the Netherlands to countries like England, Italy, and Poland. This expansion indicates a robust framework capable of being scaled to different regions while maintaining its core objectives and effectiveness;

Transferability and Adaptability: the MCSP has shown significant adaptability and transferability across various national and regional contexts. The program's design allows it to be embedded within local community or senior centers, facilitating integration with existing social structures and services. This adaptability is further supported by collaborations with local organizations, such as Alzheimer's Cafés, which help tailor the program to meet local needs;

Implementability in Diverse Settings: the MCSP's implementation in different countries has not led to major changes in its design, suggesting a high level of implementability in diverse settings. The program's structure, which includes a wide range of support activities for both people with dementia and their carers, is flexible enough to accommodate local variations without losing its effectiveness;

Evidence of Success: the positive experiences and outcomes reported in the Amsterdam Meeting Centres have been replicated in other regions, supporting the program's potential for successful implementation in new contexts. The program's focus on social integration and participation has been well-received, contributing to its effective adaptation in various geographical settings.

Collaboration with and/or participation of different stakeholders and sectors

Health and Social Care Integration: the Meeting Centres Support Programme (MCSP) involves collaboration with various health and social care providers, including general practitioners, mental health services, home care, and district nursing. This integration ensures comprehensive support for people with dementia and their carers;

Community and Welfare Institutions: the MCSP works closely with community and welfare institutions, such as neighbourhood centres and informal care support centres, to facilitate social integration and provide a holistic support system for participants;

Multidisciplinary Coordination: the programme includes direct coordination with case managers and organizes multidisciplinary care when necessary. This approach enhances the effectiveness of the support provided to both individuals with dementia and their carers;

Collaboration with Alzheimer's Cafés: many Meeting Centres collaborate with Alzheimer's Cafés to organize information meetings and discussion groups, which are crucial for sharing knowledge and supporting carers emotionally and socially;

International Implementation and Evaluation: the MCSP has been successfully implemented and evaluated in multiple countries, including England, Italy, and Poland, as part of the MEETINGDEM project. This international collaboration highlights the programme's adaptability and effectiveness across different cultural and institutional contexts;

Policy and Research Involvement: the programme's development and implementation involve consultation with care and welfare organizations, people with dementia, and informal carers. This inclusive approach ensures that the programme is grounded in practical needs and evidence-based practices.

Innovative aspects, if any

Social Innovation: the MCSP is a social innovation that addresses the needs of people with dementia and their carers by fostering social engagement and enhancing well-being;

Integrated Care Approach: the MCSP is innovative in its integrated approach, targeting both the person with dementia and the carer. This dual focus is appreciated by participants and is seen as an advantage over non-integrated day care programs. The program includes case management and collaboration with various care and welfare services, which enhances support for carers and delays nursing home admissions;

Community-Based Support: the program is implemented in community settings such as neighborhood and day care senior centers, making it easily accessible and non-stigmatizing. This community-based approach promotes social integration and acceptance of help among people with dementia;

Technology innovation: STAR e-learning and phone coaching (Dementelcoach) provide remote, tailored support;

Collaboration and Coordination: the MCSP involves direct coordination with case managers and organizes multidisciplinary care, working closely with other care providers and welfare institutions. This collaborative approach is a significant innovation in providing comprehensive support to both individuals with dementia and their carers.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

Non-Randomized Group Formation: in some studies, groups were formed naturally rather than through randomization, which may introduce biases and affect the reliability of the findings;

Lack of trained staff and insufficient funding—crucial during roll-out in Italy and during DemenTalent integration—was consistently flagged as a major impediment;

Limited Awareness & Late Help-Seeking: carers often recognize support needs too late due to stigma, guilt, and lack of information. MCSP users typically include only 10–20% of eligible dementia cases;

Challenges included poor communication about venues, shared-use conflicts, and inadequate group-settings—hurdles noted during the planning of Italy's Milan centre;

Caregivers struggle to participate due to time pressure; thus, flexible, remote formats (e-health and tele-coaching) are essential;

Collaboration hurdles across care, welfare, voluntary sectors and mismatches with local health regulations slowed the embedding of programs like DemenTalent.

Key success factors/points of strength

Structured and Accessible Service Delivery:

The meeting centres are embedded in familiar community settings, such as community and senior centres, ensuring that the physical space is easily accessible for the target groups;

The single and integrated location for all services enhances community integration and reduces complexity for users, which is key in maintaining engagement;

Trained and Coordinated Professional Team:

The practice is supported by a dedicated, small-scale professional team that includes a programme coordinator, an activity coordinator, and a carer, alongside well-organized volunteer support;

Direct coordination with case managers and professionals such as GPs, mental health providers, and home care services ensures a continuum of care and a comprehensive approach for addressing needs;

Participatory Co-design and Community Engagement:

The service development involved extensive consultation with people with dementia, their informal carers, and care and welfare organizations. This participatory co-design approach has allowed the programme to tailor activities and support methods effectively to real needs;

Regular consultations and social activities foster ongoing engagement and collaboration among participants, which enhances the overall impact of the programme;

Clear Objectives and Well-defined Action Plans:

The meeting centres operate with clearly defined objectives, outlining specific actions and procedures to support individuals with dementia as well as their carers;

This structured approach aligns with best practices in service delivery, ensuring that all stakeholders understand their roles and responsibilities;

Cultural Sensitivity and Inclusiveness:

The approach includes tailored support for diverse groups, addressing cultural preferences and reducing stigmatization; for instance, the specific programming for the Surinamese community enhances the practice's inclusiveness;

Cultural sensitivity is a critical success factor, as it ensures that services are respected and relevant across different community segments;

Evidence of Impact and Continuous Improvement:

The practice has been evaluated through impact studies and implementation studies, confirming that the model is effective across different regions and cultural contexts;

Community Care Dongen

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	29 GLR
Ranking of the good practice	32
Type of good practice	6. Community-based initiatives/measures
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Community Care Dongen
Name of the good practice in original language (if available)	Idem
Initiative in operation since	2018
Country/ies of implementation	Netherlands
Geographic coverage/ implementation level	1. Local
Stage of initiative	1. Ongoing
Name of the Leader/s Organisation/implementer/s	Maria-Oord foundation
Contact details	info@mariaoord.nl
Type/source(s) of funding	4. National or local public sources (e.g. general tax revenue, social care funds)
Webpage/s of the good practice (or link to doi of the paper)	Webpage: https://mariaoord.nl/ccd/

Summary (abstract)	Community Care Dongen (CCD) is a collaborative initiative launched in 2018 by the Maria-Oord foundation in the Netherlands. It aims to provide integrated care for vulnerable older individuals experiencing combined physical, psychological, and cognitive challenges. The primary objective of CCD is to enable these older adults to live independently in their own homes and communities for as long as possible, while delaying or preventing the need for more intensive institutional care such as nursing homes. The practice operates through a network of formal and informal care providers, including healthcare professionals, social workers, volunteers, and informal carers such as family members. Life coaches play a central role in coordinating care across multiple funding domains and services (e.g., social support, healthcare insurance, and long-term care). They work directly with clients and their families to assess needs, plan personalised care solutions, and facilitate collaboration among stakeholders. CCD emphasises cross-domain collaboration and a person-centred approach, combining formal professional care with informal support in a coordinated manner. The initiative recognises the importance of supporting informal carers by addressing their needs to sustain their caregiving role effectively. Funding for CCD is provided through partnerships between the Maria-Oord foundation, local municipality, health insurers, and regional care offices. The practice includes ongoing staff training on the philosophy and methodology of community care, aiming to foster a collaborative mindset and improve care quality. While CCD does not specify the use of technological innovations, its local, home-based care focus supports accessibility and responsiveness to client needs. The model is designed to be adaptable to different local contexts, relying on committed stakeholders and trust-based partnerships. Overall, CCD represents a structured effort to integrate care services for older adults with complex needs by promoting collaboration, client-centredness, and support for informal carers.
Keywords	Integrated Care, Cross-Domain Collaboration, Life Coach, Community Care, Older People

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

Community Care Dongen (CCD), launched in May 2018 by Maria-oord, is a cross-domain collaborative initiative aimed at improving the care and quality of life of vulnerable older adults in Dongen who experience a combination of physical, cognitive, and psychosocial challenges. The core objective is to enable these individuals to live independently in their own homes and communities for as long as possible, while also delaying or preventing the need for more intensive, institutional care such as nursing home admission. CCD addresses existing fragmentation in care by integrating informal and formal care systems. This includes close cooperation between professional services (e.g. WMO, Zvw, MPT, VPT) and informal networks, such as family carers and volunteers. A key feature of the initiative is the role of the life coach, who works collaboratively with clients and their relatives to assess needs, co-create care plans, and support the involvement of informal carers in a sustainable and coordinated way.

The initiative was developed in response to growing demand for holistic, person-centred care for ageing populations with complex needs. It fills critical gaps in continuity and coordination of care by fostering seamless collaboration across different care domains and stakeholders. Rather than seeing formal and informal care as separate, CCD brings them together into one cohesive support structure tailored around the individual's preferences and needs.

CCD is a community-based, integrated care model that highlights the importance of relational care, early coordination, and supporting informal carers not as passive participants but as key partners in care delivery. It demonstrates a sustainable, locally anchored approach that has already shown positive outcomes in terms of user satisfaction, reduced reliance on institutional care, and improved quality of life for both care recipients and their support networks.

Main setting(s)/place(s) of delivery

4. Local healthcare centre (e.g. ambulatory)

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)
2. Working carers (combining paid work with informal care)
3. Qualified/registered nurses
4. Assistant nurses
5. Personal care workers (including privately-hired migrant care workers)
6. Other LTC workers/health-social care professionals (specify: life coach (leefcoach))

Age profile(s) of the target group(s) of the practice

1. 18-34 years
2. 35-64 years
3. 65-74 years
4. 75+ years

Health issues of the care recipients assisted by the target group(s)

3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.)
4. Other chronic illnesses/long-term health conditions (frail older people with multi-domain issues and at least cognitive problems.)

Age profile(s) of the care recipients assisted by the target group(s)

4. Older people (65+ years)

Problem being addressed

Community Care Dongen (CCD) addresses multiple interrelated risks experienced by its primary target group, vulnerable older individuals with complex physical, psychological, and cognitive needs, as well as the informal carers who support them.

For the older people, the fragmentation of care services often leads to disjointed support, frequent care transitions, and delayed access to appropriate interventions. These gaps increase the risk of functional decline, social isolation, and premature institutionalisation. Many older adults in this group face non-occupational risks due to advanced age, chronic illnesses, and limited social or economic resources, which compromise their autonomy and wellbeing.

A key concern tackled by CCD is the mental and emotional strain on informal carers, often family members, who provide ongoing support in home settings. These carers face substantial non-occupational risks, including emotional stress, burnout, and social isolation, often exacerbated by gender (as women disproportionately take on caregiving roles), age (older spousal carers), or limited access to support services. The quality of the care partnership can also influence carer stress levels, unclear responsibilities or lack of coordination between formal and informal care providers can lead to feelings of helplessness or being overwhelmed.

While CCD does not explicitly focus on occupational risks, it indirectly mitigates stressful working conditions for both informal and professional carers by fostering coordinated, predictable, and person-centred care. The involvement of life coaches helps to clarify care roles, address ethical dilemmas, and ensure carers are supported in setting boundaries and seeking needed resources. By recognising informal carers as essential partners rather than passive supporters, CCD strengthens care partnerships and reduces the risk of carer burnout.

Overall, CCD seeks to improve the sustainability of community-based care by addressing both the care needs of vulnerable older people and the wellbeing of those who support them.

Measurement/evaluation

The effectiveness and quality of care provided within Community Care Dongen (CCD), particularly through Maria-Oord, are assessed using a combination of quantitative and qualitative methods, with a strong emphasis on client experience and satisfaction.

A key formal tool used is the PREM (Patient Reported Experience Measure), a nationally standardised instrument in the Netherlands for capturing client experiences in home care. In 2023, 25 clients receiving district nursing services were invited to complete the PREM, resulting in nine published ratings on ZorgkaartNederland with an average score of 8.7 (identical to 2022). For domestic care, a tailored questionnaire was distributed to 195 clients, with 156 responses received and an impressive average rating of 8.9. Clients praised the care as friendly, attentive, and punctual, with specific appreciation for the client advisor's personal attention and responsiveness.

In residential and small-scale living settings, client experiences are now systematically gathered during the biannual Multidisciplinary Consultations (MDO). In 2023, 79 feedback reports were analysed, revealing high satisfaction and gratitude, especially for respectful and loving care. The only recurring suggestion for improvement, mentioned four times, was better communication and cooperation, especially during changes in care.

Additionally, ZorgkaartNederland, the leading Dutch public review platform for healthcare, reflects high satisfaction: an overall rating of 8.6, with individual facilities receiving ratings up to 9.3 based on user-submitted reviews. Despite active campaigns (flyers, newsletters, MDO prompts, and digital tools) to boost review participation, response rates remain modest.

One formal complaint ("red card") was logged and resolved through direct client engagement, demonstrating a responsive, client-centred feedback mechanism.

While most evaluations are experience-based, they are consistently used to inform service improvements at both individual and organisational levels, ensuring that CCD remains adaptive, person-centred, and aligned with community needs.

Furthermore, research agency Significant has performed an evaluation with positive qualitative outcomes for clients, informal carers and nursing staff alike, and lower cost due to postponing institutional care.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
5. Fostering (or potential to foster) care partnerships
6. Improving organisational practices
7. Cost-effectiveness
8. Other (allowing older people to live at home as long as possible and ensuring that more expensive forms of care, such as nursing home care, are avoided or delayed)

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

Community Care Dongen (CCD) exemplifies a strong and intentional approach to fostering collaborative care partnerships between long-term care (LTC) professionals, informal carers, and community stakeholders. The initiative is explicitly designed around shared responsibility and mutual recognition, ensuring that care is not only professionally delivered but also personally meaningful and sustainable.

Central to CCD is the role of the life coach, who acts as a care coordinator and bridge between clients, their families, and professional care providers. This role facilitates structured conversations about client needs, care goals, and available support. Crucially, life coaches actively involve informal carers (family members, neighbours, volunteers) in care planning and decision-making processes, acknowledging their intimate knowledge of the client and enabling them to define their roles and boundaries. This recognition transforms informal carers from passive supporters into equal care partners.

CCD promotes knowledge exchange and role clarity by fostering open communication and regular contact between stakeholders through biannual multidisciplinary meetings (MDOs), feedback mechanisms, and joint care planning. This coordination reduces misunderstandings, builds trust, and ensures continuity of care.

Furthermore, the emotional and practical support needs of informal carers are addressed proactively. By involving them in discussions about what they need to continue caregiving effectively, CCD prevents burnout and empowers carers to sustain their roles over time.

In broader terms, CCD supports a community-based care ecosystem, integrating services across health, social care, and voluntary sectors. This integrated structure enhances the potential for lasting partnerships, shared learning, and systemic innovation.

Ultimately, CCD fosters a culture of respectful collaboration, where all contributors to a person's care, whether paid or unpaid, are valued, supported, and engaged in delivering holistic, person-centred support.

Equity (including ethics)

CCD promotes equity through its inclusive, community-based approach targeting vulnerable older adults with complex needs. While not explicitly detailing dimensions like gender or socioeconomic status, CCD's personalised, cross-domain care model adapts to diverse client backgrounds and needs, supporting those with physical, cognitive, and psychosocial challenges.

The practice's collaborative "wijkteam" integrates formal and informal caregivers, enabling tailored support for individuals, including those with limited family or social networks. This local, flexible model helps reduce barriers linked to vulnerability and promotes participation and self-reliance.

Ethically, CCD respects client autonomy by involving them and their informal carers in shared decision-making. Privacy and data protection comply with national standards, with tools like PREM ensuring confidential feedback. No formal ethical approval is reported, but care is taken to balance benefits, improved wellbeing and coordinated care, against potential risks, creating a respectful and equitable care environment.

Sustainability

CCD demonstrates strong potential for long-term sustainability through embedded organisational structures, multi-stakeholder funding, workforce training, and integrated service delivery.

The initiative is housed within the Maria-Oord foundation and supported by a network of formal and informal care providers. A dedicated team of life coaches coordinates care across different funding streams, including the Social Support Act (Wmo), Health Insurance Act (Zvw), and Long-Term Care Act (Wlz). This cross-domain coordination is backed by committed leadership and a regularly meeting project group, ensuring ongoing governance and adaptation. Financial sustainability is secured via a collaborative funding model involving Maria-Oord, the municipality of Dongen, health insurer VGZ, and the regional care office (Zorgkantoor). This partnership pools resources to cover operational costs, particularly life coach salaries. Importantly, CCD has demonstrated cost savings by delaying or preventing nursing home admissions, strengthening its financial case and long-term viability.

Sustainability is further reinforced by ongoing capacity building and training for staff, including healthcare workers, domestic services, life coaches, and facilitators. The training, such as “The Power of Community Care,” embeds CCD’s philosophy in employees, fosters cross-domain collaboration, and equips them with skills to utilise local networks effectively.

While environmental sustainability is not explicitly addressed, the focus on home-based, community-centered care potentially reduces transportation and institutional resource use, indirectly supporting environmental goals.

Overall, CCD’s integrated funding, strong leadership, skilled workforce, and partnership-driven approach create a resilient framework that supports sustainable, person-centred care for vulnerable older adults in the Dongen community.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

CCD demonstrates strong potential for scalability and transferability due to its flexible, context-driven approach to cross-domain collaboration. Rather than relying on a fixed model, CCD is built on adaptable partnerships among local stakeholders, allowing it to respond to unique community needs and existing infrastructures.

Experiences from CCD, along with two other regional experiments, have been synthesised into the ‘Guide: Getting Started with Cross-Domain Collaboration.’ This guide offers practical insights on building trust among partners, necessary skills for coordinators, network formation, and strategies for involving organisations effectively. While the guide shares lessons and best practices, it explicitly acknowledges that it is not a one-size-fits-all blueprint; each municipality or region must tailor implementation based on local contexts.

Key factors for successful scalability and transferability include the presence of committed individuals and leadership, trust-based partnerships, prior positive collaboration experiences, and strategic as well as operational support. The flexible and relational nature of CCD’s foundation means it can be adapted to various national, regional, or local settings, provided these conditions are met. The practice’s focus on integrating formal and informal care, supported by life coaches and community networks, is widely applicable across different healthcare systems and social contexts. The model encourages local innovation while maintaining core principles of person-centred, coordinated care.

In summary, CCD’s non-prescriptive, partnership-oriented approach, combined with documented lessons and stakeholder engagement, makes it highly scalable and adaptable, capable of being successfully implemented in diverse settings that share similar collaborative values and structures.

Collaboration with and/or participation of different stakeholders and sectors

CCD is fundamentally built on cross-domain collaboration, integrating health, social care, and community support services to provide comprehensive, person-centred care for vulnerable older adults. The initiative's structure reflects active cooperation among a wide range of stakeholders from various sectors.

At the core of CCD are life coaches, who serve as essential connectors bringing long-term care, district nursing, welfare organisations, psychological support, the municipality, and the health insurer VGZ. This role ensures coordinated care pathways and smooth communication across sectors.

CCD was developed through strong partnerships involving healthcare professionals, social workers, informal carers, volunteers, and local government representatives. These stakeholders collaboratively shaped the design and ongoing development of the practice, highlighting a co-creation approach that values input from diverse perspectives. Informal carers and volunteers are included not only as care providers but also as partners in care planning and delivery.

The involvement of public institutions, such as the municipality and health insurers, facilitates integration across policy and funding domains, enabling sustainable and cohesive care delivery. Welfare organisations contribute social support services that complement medical care, addressing broader determinants of health and wellbeing.

Evaluation findings from these stakeholder groups have been systematically used to refine and improve the model, demonstrating a commitment to participatory governance and continuous quality improvement.

Although not explicitly mentioned, the collaborative framework suggests potential engagement with mental health services, carers' associations, and other civil society organisations, reinforcing the comprehensive nature of CCD's multi-sectoral approach.

In summary, CCD exemplifies an effective partnership model that fosters collaboration across healthcare, social services, public institutions, and community actors, ensuring holistic support for older adults in the Dongen community.

Innovative aspects, if any

CCD introduces a novel approach to supporting older people with combined memory and physical challenges by integrating care across multiple domains in a streamlined, client-centred manner.

A key innovation is the role of life coaches, who have the autonomy to independently initiate and organise tailored care solutions without navigating cumbersome administrative procedures typical of municipal or insurer requirements. This reduces bureaucratic barriers and accelerates access to appropriate services.

The cross-domain structure is also innovative: life coaches coordinate care seamlessly across the Social Support Act (Wmo), Health Insurance Act (Zvw), and Long-Term Care Act (Wlz). This empowers them to work directly with clients and informal carers to organise comprehensive support spanning health, social, and welfare sectors. By combining formal care, informal carers, and volunteers into an integrated network, CCD fosters holistic, flexible, and timely interventions that better address the complex needs of vulnerable older adults.

While the practice's innovation focuses on organisational and procedural aspects, no specific technological innovations are highlighted.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

CCD faces notable challenges primarily related to budgetary and policy constraints. Although the initiative has demonstrated cost savings, especially by delaying nursing home admissions (Wlz), regulatory limits prevent reallocating these savings to community care sectors like Wmo. Municipalities operate under fixed budget allocations, restricting flexibility to fund increased costs in community-based care despite potential overall system savings.

Another significant challenge is the need for cultural and attitude changes among staff. CCD requires caregivers and support personnel to shift their focus toward personalised, client-centred care, which demands extensive training and ongoing effort. Resistance to change and deeply ingrained organisational habits make this transition difficult and time-consuming.

To address these challenges, CCD invests in comprehensive staff training programs, such as the 'Power of Community Care' course, which fosters new mindsets and equips employees with skills for cross-domain collaboration. Leadership support and regular project group meetings help sustain motivation and guide the change process.

Although budget and regulatory barriers remain difficult to fully overcome, fostering trust, commitment, and continuous professional development has proven essential in driving gradual cultural shifts and improving implementation.

In summary, while funding and policy constraints pose structural challenges, CCD's emphasis on staff training, leadership engagement, and cross-sector collaboration serves as a key solution to overcoming barriers and advancing the practice.

Key success factors/points of strength

CCD effectively addresses the complex needs of vulnerable elderly individuals with combined physical, psychological, and cognitive challenges, alongside the informal carers who support them.

A principal strength of CCD is its integrated, cross-domain collaboration, which reduces fragmentation in care delivery and promotes seamless coordination between formal and informal care providers. This approach enhances continuity of care, supports client autonomy, and helps prevent premature institutionalisation.

The central role of life coaches as care coordinators is critical. They facilitate personalised care planning, clarify roles, and foster communication among all parties, thereby strengthening care partnerships and mitigating the emotional and mental burden on informal carers, a group at high risk of burnout and social isolation.

CCD's participatory co-design process and strong community engagement ensure that services are tailored to client needs and preferences, building trust and ownership among stakeholders. The initiative benefits from committed leadership, structured training programs (e.g., 'Power of Community Care'), and regular stakeholder meetings, which support a culture of collaboration and continuous professional development.

Financially, CCD demonstrates potential for cost savings by delaying more intensive and expensive care such as nursing home admissions, contributing to long-term sustainability despite existing regulatory and budgetary constraints.

In summary, CCD's success stems from its holistic, client-centred model; skilled care coordination; multi-stakeholder collaboration; and ongoing capacity building—all contributing to improved care quality, enhanced carer wellbeing, and sustainable community-based care.

Community Houses

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	121 GLR
Ranking of the good practice	33
Type of good practice	2. Interventions or programmes dealing with organisational models and management approaches and/or targeted at the individual level
Name of the good practice in English	Community Houses
Name of the good practice in original language (if available)	Case di Comunità
Initiative in operation since	2010 in Emilia-Romagna Region – 2022 at National level
Country/ies of implementation	Italy
Geographic coverage/ implementation level	2. Regional, national
Stage of initiative	1. Ongoing
Name of the Leader/s Organisation/implementer/s	Regional Public Health Care Service through local branches – Servizio Sanitario Regionale (attraverso le AUSL)
Contact details	None reported.
Type/source(s) of funding	1. European/EU funds (NRRP for the infrastructures) 4. National or local public sources (e.g. general tax revenue, social care funds)
Webpage/s of the good practice (or link to doi of the paper)	Webpage: https://www.pnrr.salute.gov.it/portale/pnrrsalute/dettaglioContenutiPNRRSalute.jsp?lingua=italiano&id=5801&area=PNRR-Salute&menu=investimenti
Summary (abstract)	The Community Houses are social and healthcare facilities that are part of the Regional Health Service and offer local healthcare services and prevention activities. They were introduced at national level by Ministry of Health Decree No. 77/2022 and are also funded by the PNRR (National Recovery and Resilience Plan). Community Houses are an integrated point of access for citizens, offering healthcare, social and healthcare services.
Keywords	Care Partnership, Proximity, Integration

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

The Community House, is the organisational model for proximity assistance for the population, a physical and easily identifiable place to which citizens can access for health, social and social assistance needs. In the Community House, all professionals - doctors, specialists, nurses, midwives, health assistants, physiotherapists, social workers and other health, social and administrative professionals - work in an integrated and multidisciplinary manner for the planning and delivery of health and social integration interventions, with the participation of the local community in its various forms: citizens' associations, patients, caregivers, volunteers.

Community houses target the general population. This group might therefore include informal carers, working carers, qualified/assistant nurses, personal care workers, privately-hired migrant care workers, disability workers, educators, however it is not specifically dedicated to them.

From the practice website, more detailed objectives are listed, including:

unified and integrated access to health, social health and social welfare care;

prevention and health promotion;

taking in charge of people with chronic and frailty problems;

the assessment of the person's needs and accompaniment to the most appropriate response service;

the response to the health demand of the population and the guarantee of continuity of care;

the activation of multidisciplinary care pathways involving integration between health services, hospital and territorial, and between health and social services.

Main setting(s)/place(s) of delivery

4. Local healthcare centre (e.g. ambulatory)

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)

3. Qualified/registered nurses

4. Assistant nurses

6. Other LTC workers/health-social care professionals: doctors, specialists, midwives, health assistants, physiotherapists, social workers and other health, social and administrative professionals.

Community houses target the general population. This group might therefore include informal carers, working carers, qualified/assistant nurses, personal care workers, privately-hired migrant care workers, disability workers, educators, however it is not specifically dedicated to them.

Age profile(s) of the target

1. 18-34 years

2. 35-64 years

3. 65-74 years

4. 75+ years

Health issues of the care recipients assisted by the target group(s)

1. Physical disabilities (caused, e.g. by frailty, accident, injury, illness, etc.)
2. Psychological/mental health issues (e.g. depression, anxiety, etc.)
3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.)

Age profile(s) of the care recipients assisted by the target group(s)

1. Children/Youths (0-12 years)
2. Adolescents (13-17 years)
3. Adults (18-64 years)
4. Older people (65+ years)

Problem being addressed

The main problem addressed by this practice is the need to provide social and health services which are integrated (therefore to avoid fragmentation and improve multidisciplinary collaboration) and close to the patient (therefore to increase proximity). These issues are particularly relevant in case of complex conditions (such as disabilities or dependency) and when informal caregiving is involved.

Measurement/evaluation

While at national level we still do not have a comprehensive evaluation of the service, Emilia-Romagna Region performed an impact evaluation.

The evaluation of the impact of the Community Houses on the population is one of the objectives foreseen by the Regional Social and Health Plan 2017-2019. Consequently, an evaluation study was initiated focused on the followings:

evaluating the impact of Community Houses, on selected outcomes obtainable through regional administrative databases;

describing the perceived quality by citizens attending the Community Houses.

A study aimed at evaluating the impact of Community Houses, on selected outcomes obtainable through regional administrative databases in the period 2009-2016, was previously published in a report (Dossier 265/2019). This previous analysis included 64 Community Houses, located outside provincial capitals. A significant reduction of inappropriate accesses to Emergency Rooms was documented in the report, as well as a reduction of hospitals admissions for Ambulatory Care Sensitive Conditions, as well as an increase in the episodes of integrated home care was observed. The analysis underlined also that, when the Family General Practitioner's ambulatory was located in the Community House, a greater positive effect on the three aforementioned indicators was observed. In September 2018, a regional survey (CaSa Qualità) was conducted on the citizens perceived quality of the service: in general, a high level of satisfaction was reported; however, some specific aspects were highlighted as amenable of further improvement (accessibility, environment characteristics, organisational issues, continuity of care).

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

5. Fostering (or potential to foster) care partnerships (see point 10)

However, none was explored in the impact evaluation.

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

According to the declared goals of the practice, it has the potential to foster care partnerships through an improved coordination of care. Moreover, several Community Houses - through health and social care/LTC professionals - offer training programmes for informal carers which have the potential to create opportunities for knowledge sharing.

Equity (including ethics)

In terms of equity, we can mention that Community Houses are designed to be accessible, both in terms of physical accessibility (easily reachable locations, no architectural barriers, extended opening hours) and concerning the accessibility of information provided. The service is universal and designed to respond to the needs of all citizens, however no further information is available in this regard. When we focus on specific regional contexts, we can see that some regions have adopted specific protocols to ensure equity and diversity management in their health services, and for example Emilia-Romagna has mainstreamed a gender-medicine and equity-oriented approach.

In terms of ethics: Being a public service, it didn't have to undergo any ethical approval. We can also assume that ethical principles are respected considering that public employees are subjected to an ethical code (Decree n. 81 – 13th June 2023) and employees of the local public health services also have a specific behavioural code. Moreover, all regulated professions (social workers, nurses, etc.) have their own deontological codes.

Sustainability

The model integrates existing services but basically doesn't create new ones, so it can be sustained with ordinary funding.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

The Community House model was incorporated into the PNRR National Plan, and with an investment of over 2BLNs € it is expected to open this kind of service all across the country, therefore it has the potential to be transferable and scalable in a variety of contexts.

The implementation standards are described into Decree n. 77/2022. Moreover, AGENAS (National Agency for Regional Health Care Services) published operational guidelines in April 2024.

Collaboration with and/or participation of different stakeholders and sectors

In the Community House, all professionals - doctors, specialists, nurses, midwives, health assistants, physiotherapists, social workers and other health, social and administrative professionals - work in an integrated and multidisciplinary manner for the planning and delivery of health and social integration interventions, with the participation of the local community in its various forms: citizens' associations, patients, caregivers, volunteers.

Innovative aspects, if any

Telemedicine systems can be integrated in Community Houses provisions.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

None reported.

Key success factors/points of strength

None reported.

Integrated care intervention for the frail elderly on informal caregivers

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	442 SLR
Ranking of the good practice	34
Type of good practice	4. Integrated approaches and strategies Also related to: 1. Primary, secondary and tertiary prevention interventions 2. Interventions or programmes dealing with organisational models and management approaches and/or targeted at the individual level
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	The effects of an integrated care intervention for the frail elderly on informal caregivers: a quasi-experimental study
Name of the good practice in original language (if available)	Walcheren Integrated Care Model (WICM)
Initiative in operation since	not explicitly mentioned (the study was published in 2014)
Country/ies of implementation	Netherlands
Geographic coverage/ implementation level	1. Local (Walcheren region; Southwest of the Netherlands)
Stage of initiative	4. Finished for 4 years or more
Name of the Leader/s Organisation/implementer/s	Original language: Erasmus Universiteit Rotterdam, Instituut Beleid en Management Gezondheidszorg (iBMG) Huisartsenpraktijken in de regio Walcheren ZonMw – Nederlandse organisatie voor gezondheidsonderzoek en zorginnovatie English translation: Erasmus University Rotterdam, Institute of Health Policy and Management General practitioner practices in the Walcheren region ZonMw – The Netherlands Organisation for Health Research and Development
Contact details	Benjamin Janse, Erasmus University Rotterdam, Institute of Health Policy and Management, P.O. Box 1738, Rotterdam, DR 3000, The Netherlands, Janse@bmg.eur.nl
Type/source(s) of funding	4. National or local public sources (e.g. general tax revenue, social care funds)

Webpage/s of the good practice (or link to doi of the paper)	Web page: https://www.isrctn.com/ISRCTN05748494&ved=2ahUKEwiKsqGHoZuOAxWm-VPEDHYaiFSwQFnoECAkQAQ&usg=AOvVaw0tfsAmjCdzi34B0q34E872 DOI: https://bmcgeriatr.biomedcentral.com/articles/10.1186/1471-2318-14-58
Summary (abstract)	This quasi-experimental study evaluated the effects of the Walcheren Integrated Care Model (WICM) on informal caregivers of frail older people living in the community. The WICM is a comprehensive integrated care model featuring proactive screening, needs assessment for both patients and caregivers, a multidisciplinary care plan, case management, and coordinated service delivery across care and welfare sectors. The study compared outcomes between an experimental group (receiving WICM-based care) and a control group (receiving usual care) using before/after measurements over 12 months. Data were collected through questionnaires covering perceived health, subjective and objective caregiver burden, and quality of life. A total of 159 informal caregivers (83 experimental, 76 control) completed the study. Most were adult children or partners of the care recipients. Results showed that the WICM had a significant positive effect on reducing subjective caregiver burden, as measured by the CarerQoL sum score. Additionally, the likelihood that caregivers performed household tasks increased significantly in the experimental group. No significant effects were found on perceived health, total time investment, or general quality of life. The intervention provided case-managed support, information, referrals to services, and emotional and practical guidance to caregivers, based on individual needs. While improvements in subjective burden were modest, they suggest that integrated care models can positively influence caregiver experience without increasing time demands. The study concludes that integrated care arrangements like the WICM can benefit informal caregivers by improving their perceived situation and supporting continued involvement in care, even amid the growing demands associated with frailty in old age. However, the authors note that longer evaluation periods may be necessary to observe broader effects on health and quality of life.
Keywords	Integrated Care, Informal Caregivers, Frail Elderly, Caregiver Burden, Case Management

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

The Walcheren Integrated Care Model (WICM) is a comprehensive intervention targeting frail elderly individuals living independently and their informal caregivers. The model combines several integrated care components to improve support for both groups.

Key elements of the intervention include:

Proactive screening of patients for frailty using the Groningen Frailty Indicator (GFI);

Comprehensive needs assessment for both the elderly patient and the informal caregiver, conducted by a case manager using an evidence-based instrument;

Multidisciplinary care plan, developed in consultation with the patient and caregiver, and approved in a multidisciplinary team meeting;

Case management, with one case manager coordinating care delivery and monitoring evolving needs over time;

Integrated information system and formalized structures such as protocols, task delegation, and a steering group to support collaboration between sectors (cure, care, welfare, housing).

For informal caregivers specifically, the intervention included:

Identification and assessment of their support needs;

Provision of tailored information, advice, and suggestions on available services;

Referrals to relevant organizations or professionals if needed;

Practical guidance on how to reduce burden in caregiving tasks;

Emotional support delivered through contact with the case manager.

The model ensured that informal caregivers were actively involved in care planning and received structured, ongoing support. While the intervention did not include new services for caregivers, it enabled better access to existing ones and ensured caregivers' needs were systematically recognized and addressed.

Main setting(s)/place(s) of delivery

1. Home
2. Residential care setting

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)
2. Working carers (combining paid work with informal care)

Age profile(s) of the target group(s) of the practice

2. 35-64 years
3. 65-74 years

Health issues of the care recipients assisted by the target group(s)

1. Physical disabilities (caused, e.g. by frailty, accident, injury, illness, etc.)

Age profile(s) of the care recipients assisted by the target group(s)

4. Older people (65+ years)

Problem being addressed

The intervention addresses primarily non-occupational risks faced by informal caregivers of frail elderly persons. These include:

Subjective burden, defined as the caregiver's perception of the impact of caregiving tasks on their own life, including stress, emotional strain, and reduced well-being;

Objective burden, referring to the actual time and effort spent on care tasks, which may limit caregivers' ability to fulfill personal, social, or work-related responsibilities;

Negative effects on quality of life, including deterioration of physical, social, and psychological functioning due to prolonged caregiving;

Gender-based risk: the majority of caregivers were women (73%), a group often disproportionately affected by informal caregiving roles;

Living situation: around one-third of caregivers co-resided with the care recipient, which the article associates with higher burden;

Duration of care: many caregivers had been providing care for an average of eight years, which increases the risk of long-term strain.

No occupational risks (e.g. related to formal employment in LTC) and no risks linked to migration background or precarious working conditions are discussed in the article.

Measurement/evaluation

The intervention was evaluated through a quasi-experimental study using quantitative methods with before/after measurements and a control group. Data were collected at baseline (T0) and after 12 months (T1).

Indicators and instruments used:

Perceived health: measured with 2 items from the RAND-36;

Objective burden: measured with the short form of the Objective Burden of Informal Care Instrument, covering time spent on household, personal, and instrumental care tasks;

Subjective burden: assessed using three instruments:

CarerQoL (Care-related Quality of Life, including a VAS);

Process Utility (PU) Scale;

Self-Rated Burden (SRB) Scale.

Quality of life: measured using Cantril's Self-Anchoring Ladder and two additional items based on the RAND-36.

Analytical methods:

Within-group and between-group comparisons using t-tests, McNemar's test, Wilcoxon signed rank test;

Regression analyses (linear and logistic) to determine the contribution of the intervention, controlling for baseline values and sociodemographic factors.

The study was part of the National Care for the Elderly Program (NPO) and used a standardized questionnaire developed for this program. The study was registered (ISRCTN05748494) and published in a peer-reviewed journal (BMC Geriatrics, doi:10.1186/1471-2318-14-58).

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

2. Improving mental wellbeing

3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)

4. Enhancing informal carers' and/or LTC workers' satisfaction

5. Fostering (or potential to foster) care partnerships.

The intervention led to a significant reduction in subjective burden, as measured by the CarerQoL sum score, indicating an improvement in mental wellbeing and perceived caregiver satisfaction. The study also reported that caregivers in the intervention group experienced fewer problems and more support and fulfilment.

Although time investment in caregiving did not decrease, the intervention had no adverse effect on caregiver burden in terms of time or task overload, which contributes to reducing negative aspects of informal care.

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

The article describes that informal caregivers were included in the care planning process, received information, emotional support, referrals to services tailored to their situation, and their support needs were assessed by a case manager. This reflects a recognition of their role and some level of structured involvement, thus a potential to foster care partnership can be assumed.

Equity (including ethics)

The article indicates that the intervention targeted frail elderly individuals aged 75 and older and their informal caregivers, without additional selection based on gender, socioeconomic status, or other vulnerability criteria. However, no specific strategies to promote equity in terms of income, education, migration background, disability, or language barriers were described.

Sociodemographic characteristics of participants were collected and used as control variables in the analysis (e.g. age, gender, income, education, co-residence, employment, duration of caregiving). While these variables were analytically relevant, there is no indication that they influenced the design or implementation of the intervention in an equity-oriented way.

Ethical aspects:

The study protocol was reviewed by the medical ethics committee of Erasmus Medical Centre Rotterdam;

The committee waived further review, stating that the Dutch Medical Research Involving Human Subjects Act did not apply;

Informed consent was obtained from all participants;

The article does not provide details on data protection measures, but it mentions that participants were contacted and surveyed in accordance with ethical standards.

In summary, basic ethical approval and informed consent procedures were in place, but the intervention did not explicitly address equity dimensions such as access for vulnerable groups or structural disadvantage.

Sustainability

The article does not provide specific information on the long-term sustainability of the Walcheren Integrated Care Model (WICM) beyond the evaluation period.

The intervention was funded by a grant from ZonMw as part of the National Care for the Elderly Program (NPO), which indicates temporary project-based funding. There is no mention of structural or long-term financing, nor of policy-level decisions to institutionalize the model after the study.

The WICM was implemented via GP practices and involved case management, multidisciplinary collaboration, and an integrated information system, but the article does not specify whether these structures were maintained after the project ended.

In addition, the article does not clarify the institutional affiliation or professional qualification of the case managers (an essential component for the delivery of the model) which limits the ability to assess whether the required personnel can be sustainably secured. There is also no information on the use of technological tools (e.g. e-health platforms) or ongoing digital infrastructure that might support continuity.

In conclusion, while the intervention showed positive effects during the trial, the article provides no evidence or strategy for long-term sustainability in terms of funding, institutional anchoring, workforce planning, or policy integration.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

The article does not provide any evidence that the WICM was scaled, transferred, or adapted beyond the original study region. The model was implemented locally (Walcheren region), and no information is given on broader implementation, policy integration, or follow-up.

The intervention includes several complex components (multidisciplinary collaboration, proactive screening, case management, and an integrated information system) which require significant organizational infrastructure and coordination capacity. These factors may present barriers to transferability.

A key limitation for transferability to other countries (e.g. Germany) is the lack of information about the institutional affiliation and professional qualification of the case managers. In the Netherlands, case management may be integrated into existing local healthcare structures. However, municipalities typically do not have case managers as standard resources, and such a role is not structurally embedded in the long-term care system. Without a clear understanding of where the case managers are located and how they are financed or trained, successful implementation in other national contexts would be difficult. Furthermore, the model assumes the existence of coordinated primary care structures and multidisciplinary routines, which are not equally developed in all regions or countries.

In summary, while the conceptual design of the WICM suggests potential for transfer, especially within health systems with strong primary care and integrated service structures, the article lacks key details on institutional prerequisites, professional roles, and policy frameworks. Therefore, the practical transferability and scalability remain untested, and structural barriers (e.g. case manager availability) could prevent implementation.

Collaboration with and/or participation of different stakeholders and sectors

The article describes a multidisciplinary approach involving actors from various sectors within the local healthcare and social care system:

Primary care sector: eight general practitioner (GP) practices were central to the implementation of the model. GPs participated in screening, referrals, and multidisciplinary meetings;

Social care and welfare sector: the model included referrals to social care or welfare organizations based on identified needs, although specific organizations are not named;

Case management: a central role was played by case managers, who coordinated services across sectors. However, the article does not specify the sectoral affiliation or institutional background of these case managers;

Multidisciplinary team meetings: care plans were developed and discussed within a team of professionals from different domains (care, cure, welfare, housing), indicating structured cross-sectoral collaboration at the care delivery level;

Academic/research sector: the intervention was developed and evaluated by Erasmus University Rotterdam, Institute of Health Policy and Management, indicating collaboration between practice and research;

Funding body (policy/public level): the intervention was funded by ZonMw under the National Care for the Elderly Program, demonstrating support from the national public health research infrastructure.

There is no evidence in the article of collaboration with:

Civil society organizations;

Carers' associations;

Trade unions or LTC workers' employer organisations;

Institutions from education, employment, or digital services sectors.

In summary, the intervention involved structured collaboration across primary care, welfare, and research, but lacked documented participation from civil society, professional associations, or broader policy sectors beyond funding.

Innovative aspects, if any

The Walcheren Integrated Care Model (WICM) introduces several innovative organisational elements aimed at improving care coordination and support for frail older people and their informal caregivers. Its innovative aspects include:

Integration of services across care, cure, welfare, and housing sectors, aiming to create a coordinated and person-centred approach rather than fragmented service provision;

Use of case managers to coordinate services and act as a single point of contact for both care recipients and informal caregivers, ensuring continuity and tailored support;

Implementation of proactive screening for frailty in elderly individuals using the Groningen Frailty Indicator (GFI), followed by needs assessments for both care recipients and their caregivers;

Development of multidisciplinary care plans involving input from a variety of professionals, with attention to both the elderly person and their informal carer;

Establishment of an integrated information system to support communication and coordination among providers.

No technological innovations (e.g. digital tools, e-health applications) are described in the article.

In summary, the WICM represents a conceptual and structural innovation in integrated care, emphasizing early detection, joint care planning, and coordination across sectors. It introduces systematic involvement of informal caregivers in care processes, although without formalizing their role as partners in professional care delivery.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

Incomplete information on the case manager structure: the article does not specify the institutional affiliation or professional background of the case managers, limiting understanding of how this key role could be implemented or scaled in other contexts;

Lack of information on structural anchoring: there is no information on whether the WICM model was institutionally or financially continued beyond the study, raising doubts about its long-term viability;

Project-related financing without sustainability prospects: the intervention was funded by ZonMw under a time-limited national program. No evidence of sustained funding or policy integration is provided;

Uncertainty about transferability to other systems: the complexity of the model (e.g. coordination structures, multidisciplinary teams) and lack of detail on implementation frameworks make adaptation to other health systems (e.g. Germany) challenging;

No digital or technological support structures: the intervention does not include e-health tools, digital platforms, or other technological innovations that might support broader scalability or efficiency.

Key success factors/points of strength

Structured coordination via case management: a designated case manager assessed needs, developed care plans, and coordinated services across multiple sectors, ensuring continuity and individualized support;

Multidisciplinary collaboration: the use of multidisciplinary team meetings and cross-sectoral coordination (including care, welfare, and housing) enabled a more integrated and holistic approach to care delivery;

Proactive screening and inclusion of caregivers: frail elderly persons were identified early through a standardized frailty instrument (GFI), and informal caregivers were systematically involved in the assessment and care planning process;

Evidence-based design and evaluation: the intervention was evaluated using validated instruments and a quasi-experimental design, demonstrating positive effects on subjective caregiver burden;

Academic-practice collaboration: the involvement of Erasmus University Rotterdam in both development and evaluation supported methodological quality and practical relevance of the intervention.

The Wulverhorst

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	30 GLR
Ranking of the good practice	35
Type of good practice	6. Community-based initiatives/measures
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	The Wulverhorst
Name of the good practice in original language (if available)	De Wulverhorst
Initiative in operation since	1971
Country/ies of implementation	Netherlands
Geographic coverage/ implementation level	1. Local
Stage of initiative	1. Ongoing
Name of the Leader/s Organisation/implementer/s	Stichting Zorg en Welzijn Oudewater (Care and Welfare Foundation Oudewater)
Contact details	Joyce Jacobs, j.jacobs@wulverhorst.nl
Type/source(s) of funding	3. Statutory LTC/healthcare financing system 4. National or local public sources (e.g. general tax revenue, social care funds) 7. Co-payment by the users/target groups ('out of pocket' money)
Webpage/s of the good practice (or link to doi of the paper)	Webpage: https://www.wulverhorst.nl

Summary (abstract)	Established in 1971, De Wulverhorst is the sole residential care centre in Oudewater, providing integrated in-house and home care for older people. Developed to address a regional gap in comprehensive elderly care, it aims to enhance quality of life by supporting living, well-being, and personalised care in a familiar, community-embedded environment. The practice is grounded in values of Warmth, Expertise, and Proximity and is characterised by a holistic, person-centred approach that respects autonomy and cultural diversity. De Wulverhorst's model promotes social inclusion, actively combats isolation, and involves families and informal carers as equal partners, creating a shared responsibility for care. Its governance follows Dutch healthcare codes emphasising transparency and participation. The organisation mitigates occupational risks faced by care workers, such as workload, ethical stress, and irregular hours, through a supportive culture, flexible scheduling, recognition, and continuous professional development, thereby fostering staff well-being and sustainable care delivery. The centre evaluates its services regularly using client satisfaction surveys, multidisciplinary team meetings, and Patient-Reported Experience Measures (PREM), complemented by an 8.6 rating on ZorgkaartNederland and PREZO certification. This evidences its commitment to quality improvement and responsible care. De Wulverhorst fosters strong care partnerships among professionals, informal carers, volunteers, and community stakeholders. Initiatives like Het Touwteam engage volunteers to support clients and relieve informal carers, strengthening social networks and community cohesion. The organisation embraces equity by serving vulnerable elderly populations with chronic illness or limited social support, promoting autonomy and inclusion without discrimination. Financially and organisationally, De Wulverhorst ensures sustainability through multi-annual contracts, strategic workforce planning, cross-sector collaboration, and environmental initiatives. Despite administrative challenges during political transitions, persistent advocacy secured municipal support and a clear residential care vision. The model's flexibility and community focus offer strong potential for adaptation and scalability in other settings.
Keywords	Person-Centered Care, Integrated Care, Informal Care Collaboration, Community-Based, Volunteers

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

Established in 1971, De Wulverhorst is the only residential care center in Oudewater, providing both in-house and home care services. As part of the Ouderenzorg Oudewater Foundation, it offers integrated support for older people, including daily activities and communal dining. The initiative was developed to address the lack of comprehensive elderly care in the region, ensuring older adults could age with dignity in a familiar environment.

The main aim is to enhance the quality of life for older adults through professional support in living, well-being, and care. It fills critical gaps in elderly care by offering a personalised, inclusive approach that respects individual autonomy and cultural or religious backgrounds.

Key characteristics of De Wulverhorst include:

A holistic model of care tailored to personal needs;

Strong emphasis on social inclusion, combating isolation among older adults;

Equal involvement of families and informal caregivers, fostering a partnership in care;

Governance rooted in transparency and participation, following Dutch healthcare governance codes.

The initiative is built around the core values of Warmth, Expertise, and Proximity. Realisation of the model involved stakeholder collaboration, staff training, and adapting services over time to meet evolving needs. De Wulverhorst ensures efficient resource use, maintains financial sustainability, and prioritises continuous quality improvement.

As a trusted community partner, it plays an active role in local networks, promoting wellbeing beyond its walls. Through its inclusive, values-driven approach, De Wulverhorst serves as a model of good practice in elderly care, meeting both medical and social needs in a community-embedded setting.

Main setting(s)/place(s) of delivery

1. Home
2. Residential care setting
3. Day Centre
7. Workplace
8. Local community
9. Online

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)
2. Working carers (combining paid work with informal care)
3. Qualified/registered nurses
4. Assistant nurses
5. Personal care workers (including privately-hired migrant care workers)

Age profile(s) of the target group(s) of the practice

1. 18-34 years
2. 35-64 years
3. 65-74 years
4. 75+ years

Health issues of the care recipients assisted by the target group(s)

1. Physical disabilities (caused, e.g. by frailty, accident, injury, illness, etc.)
2. Psychological/mental health issues (e.g. depression, anxiety, etc.)
3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.)
4. Other chronic illnesses/long-term health conditions (specify: rehabilitation, loneliness)

Age profile(s) of the care recipients assisted by the target group(s)

2. Adolescents (13-17 years)
3. Adults (18-64 years)
4. Older people (65+ years)

Problem being addressed

In the elderly care sector, professionals and informal carers often face high workloads, emotional demands, irregular hours, and ethical stress. De Wulverhorst recognises these occupational risks and actively works to mitigate them through a supportive, people-centered organisational culture.

Work at De Wulverhorst is grounded in mutual respect, trust, and autonomy. Staff are not expected to simply "take care of" clients, but to enable and support them in shaping their own lives. This philosophy helps reduce ethical stress by aligning care with individual capabilities and wishes. Family members and informal carers are treated as equal partners, which fosters shared responsibility and eases the pressure on professionals.

To support staff well-being, De Wulverhorst offers a positive and appreciative work environment. Teams are described as enthusiastic, helpful, and flexible. A strong emphasis is placed on team spirit and enjoyment at work, helping to buffer the emotional weight of caregiving. Staff are regularly recognised, through compliments, small gifts, and personal attention; reinforcing a sense of value and motivation.

Work-life balance is also prioritised: rosters are adapted as much as possible to individual private situations, which helps mitigate the stress of irregular shifts and long hours. Employees benefit from good secondary employment conditions, including a year-end bonus, bicycle scheme, and pension plan.

De Wulverhorst also reduces long-term occupational risk through continuous professional development. Staff are encouraged to follow trainings and education, while their individual talents are actively recognised and supported.

By promoting a culture of shared care, personal development, and flexibility, De Wulverhorst creates an environment that supports both the mental health of caregivers and the sustainability of care delivery, now and in the future.

Measurement/evaluation

The Wulverhorst conducts annual satisfaction assessments among its clients. Residents and their families can express their experiences during the Multidisciplinary Team Meetings (MDMs). In addition, satisfaction in home care is gauged using the Patient-Reported Experience Measure (PREM), allowing clients to share their feedback on the care provided. Furthermore, clients are encouraged to share their experiences on www.zorgkaartnederland.nl. The Wulverhorst's care is highly regarded on ZorgkaartNederland, receiving an impressive rating of 8.6.

Moreover, the Wulverhorst holds the PREZO certification from the Perspekt Foundation, indicating several key aspects:

1. Satisfaction among residents and clients
2. Consistent improvement in performance tailored to client needs
3. Provision of responsible care meeting industry standards
4. Adherence to relevant laws and regulations, demonstrating responsible business practices.

These evaluations and certifications underscore the commitment of the Wulverhorst to ensuring quality care and continuous improvement in service delivery, providing valuable insights into the effectiveness and impact of its practices.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
4. Enhancing informal carers' and/or LTC workers' satisfaction
5. Fostering (or potential to foster) care partnerships
6. Improving organisational practices
7. Cost-effectiveness
8. Other (specify: social participation, improved Quality of Life)

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

De Wulverhorst fosters strong and sustainable care partnerships by actively involving LTC professionals, informal carers, volunteers, clients, and a wide range of community stakeholders. The organisation is built on the belief that quality care is achieved through shared responsibility, mutual respect, and ongoing coordination between all parties involved.

Informal carers are treated as equal partners in the care process. Their insights, emotional investment, and lived experience are recognised and valued. This shared decision-making approach reduces the emotional burden on both sides and builds relationships of trust that function as mutual emotional support systems. The emphasis on “ensuring that” rather than “taking care of” helps align roles around client autonomy and capabilities.

A key component of De Wulverhorst’s partnership model is Het Touwteam: a volunteer network that connects people seeking support with those who want to contribute meaningfully. Volunteers support clients in daily activities like walking, gardening, digital literacy, and companionship. They also offer respite and relief to informal carers, helping to share responsibilities and reduce pressure. This extends the care circle beyond professionals and families, embedding support in the wider community.

Het Touwteam collaborates with local organisations such as Stadsteam Oudewater, Oudewater Vitaal, De Zonnebloem, and others, creating a care ecosystem grounded in civic engagement. This not only increases coordination and inclusion but strengthens social cohesion and community well-being.

By integrating professionals, informal carers, and volunteers into an inclusive, respectful model of collaboration, De Wulverhorst builds a robust framework for person-centred, resilient, and emotionally supportive care partnerships.

Equity (including ethics)

De Wulverhorst places a strong emphasis on inclusivity and accessibility in both the design and implementation of its care practices. Its services are aimed at vulnerable older people in the Oudewater region, with attention to those living with chronic illness, multimorbidity, social isolation, or without strong family support systems.

The organisation offers both intramural care and home care, ensuring that individuals across a range of health statuses and living arrangements receive the support they need. While De Wulverhorst does not explicitly target categories such as gender or migration background, its care philosophy is community-based and non-discriminatory, rooted in the belief that every individual, regardless of creed or circumstance, has the right to shape their own life and receive appropriate support.

Initiatives such as Het Touwteam reflect this inclusive, equity-driven approach. The programme connects clients with a large volunteer network to help address not only care needs, but also social isolation, digital exclusion, and mobility barriers. This is especially important for clients with limited social networks or reduced independence. Through such outreach, De Wulverhorst addresses socioeconomic vulnerabilities and enhances self-reliance. The organisation also explores intergenerational living concepts, aimed at strengthening social cohesion and offering more diverse support networks within the community.

Ethically, De Wulverhorst emphasises autonomy, dignity, and trust, ensuring that care decisions are co-created with clients and their families. There is a conscious shift from “taking over” to “enabling,” which respects personal agency and reduces the risk of disempowerment. Although no formal ethical approval process is mentioned, data protection and respect for individual rights are integrated into day-to-day care delivery.

Overall, De Wulverhorst’s model promotes equity through inclusive, community-rooted care, with particular sensitivity to the needs of vulnerable older adults.

Sustainability

De Wulverhorst maintains long-term sustainability through a multi-pronged strategy involving stable funding, strategic workforce development, strong intersectoral partnerships, and environmental planning. Financial sustainability is ensured via multi-annual contracts with the Zorgkantoor, health insurers, and the municipality, in addition to targeted subsidies for community-based initiatives. The organisation's designation as an essential healthcare provider reinforces its strategic importance within the regional care infrastructure. Institutional sustainability is supported by active collaboration with local stakeholders, including social teams, housing corporations, volunteers, and neighbourhood associations. These partnerships strengthen the organisation's ability to adapt to changing care demands and foster a cohesive care ecosystem. Human resource sustainability is addressed through the implementation of a strategic personnel and training plan (2021–2025). This includes an age-conscious HR policy, attention to work-life balance (e.g., for young parents), and a proactive recruitment strategy. Staff are encouraged to contribute innovative ideas, supporting a culture of flexibility and continuous improvement. A comprehensive training programme was implemented in 2023, covering areas such as crisis management, infection prevention, care technology, and community care. Volunteers and informal carers are included through access to REIN e-learning modules, enhancing their knowledge and integration in the care process. In terms of operational resilience, De Wulverhorst is currently revising its organisational structure, job descriptions, and internal processes to ensure alignment with future needs and efficiency standards. Finally, environmental sustainability is integrated through the development of a CO₂ roadmap, outlining concrete objectives to reduce environmental impact over the coming years. Taken together, these measures illustrate a comprehensive and proactive approach to long-term sustainability across financial, human, organisational, social, and environmental domains.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

De Wulverhorst demonstrates strong potential for both scalability and transferability, particularly through its integrated care model that combines formal services, community-based initiatives, and volunteer coordination. The organisation's involvement in the regional 'Support Systems West and City' project—part of the broader Krachtige Verbindingen Toekomstvisie Utrecht 2030—highlights its capacity to serve as a frontrunner in innovative, collaborative care strategies. Through initiatives like the Touwteam, De Wulverhorst strengthens the informal care landscape by offering personalised, proactive support aimed at increasing self-reliance among older adults and delaying the need for intensive care. The approach is particularly effective in small-scale, close-knit communities such as Oudewater, where local trust and social cohesion support integrated service delivery. While the underlying principles—early detection, network-building, volunteer engagement, and coordination across care settings—are broadly applicable, direct replication in other geographic or demographic contexts would require adaptation to local cultural, social, and infrastructural conditions. De Wulverhorst's flexibility in offering various care modalities, including home care (Volledig Pakket Thuis), residential care, and community-oriented services, suggests that its model can be tailored to different settings. However, the successful transfer of this practice depends on contextual factors such as local governance structures, the availability of social capital, and the presence of intersectoral partnerships. The organisation's transparent and reflective learning culture also enhances scalability. Annual quality reports are interactive and multimedia-rich, integrating client experiences, audit findings, and staff reflections. This commitment to self-assessment and iterative improvement provides a valuable foundation for continuous scaling and cross-context learning. In summary, while the practice is strongly rooted in its local context, its core elements—community orientation, flexible service delivery, and strategic partnerships—are adaptable and show promise for broader application with appropriate contextualisation.

Collaboration with and/or participation of different stakeholders and sectors

De Wulverhorst's model is characterised by deep and ongoing engagement with a wide range of stakeholders across sectors, reflecting a systemic and inclusive approach to long-term care. The organisation explicitly shares responsibility for the quality and effectiveness of its services with key actors, including financiers, the local municipality, community members, and various social partners. Collaborations extend across healthcare, housing, and social support domains. De Wulverhorst is actively involved in regional and local networks such as Greenspots, Stadsteam Oudewater, and the Alzheimer Café, illustrating its commitment to integrated, person-centred care. These partnerships enable the organisation to provide holistic services that support not only medical needs but also psychosocial well-being, community engagement, and ageing in place. Stakeholder co-creation is structurally embedded in organisational governance and policy development. Representatives such as client councils, volunteer coordinators, municipal officials, and health professionals have all contributed to shaping strategic priorities and operational policies. This multi-actor involvement enhances legitimacy, responsiveness, and alignment with the evolving needs of clients, carers, and the broader community. Furthermore, De Wulverhorst maintains close ties with local civil society and informal care networks, ensuring that volunteer work and informal caregiving are well-integrated and supported. While not explicitly mentioned, such a collaborative ecosystem also creates potential entry points for engagement with educational institutions, digital service providers, and mental health or carers' organisations. In summary, De Wulverhorst exemplifies a highly collaborative model in which care provision is seen as a shared social responsibility. This inclusive, cross-sectoral governance enhances service quality and responsiveness and could serve as a valuable model for broader health and long-term care systems seeking more integrated and community-rooted approaches.

Innovative aspects, if any

De Wulverhorst demonstrates a strong commitment to both social and technological innovation as integral components of its care model. Socially, the organisation promotes intergenerational living and actively strengthens informal support structures. The Touwteam plays a key role in identifying care needs early, supporting individuals to live independently at home, and connecting them with relevant services and informal networks. This approach fosters autonomy and delays the need for intensive care interventions. Initiatives like Greenspots exemplify De Wulverhorst's community-centred philosophy. These initiatives are designed to increase social cohesion by creating shared spaces that bring together residents, volunteers, and professionals across generations. Such models contribute to a sense of belonging and shared responsibility within the neighbourhood, enhancing both preventive care and wellbeing. On the technological front, De Wulverhorst integrates several tools aimed at improving care quality, efficiency, and client autonomy. MobileCare and VIPLive support digital health communication and remote care coordination, allowing professionals and clients to stay connected and exchange essential information securely. Additionally, the use of smart medication dispensers (Medido) helps ensure accurate and timely medication intake, reducing the risk of errors and promoting greater independence among clients. These innovations are not standalone features but are embedded in a broader vision of integrated, person-centred care. The strategic deployment of both social and technological solutions reflects De Wulverhorst's proactive stance in addressing workforce challenges, supporting informal carers, and improving outcomes for older adults. Together, these innovations position the organisation as a frontrunner in sustainable, community-based long-term care.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

During the implementation of key initiatives at De Wulverhorst, the organisation faced significant administrative and bureaucratic challenges that prolonged the project timeline. The process coincided with municipal elections, which introduced delays and uncertainties due to changes in local leadership. This political transition created a period of ambiguity around decision-making and priorities, slowing progress. Compounding this, the departure of a dedicated municipal official who had been a key contact and advocate resulted in a lack of clear administrative responsibilities within the local government. This absence made it difficult to navigate governance structures, delayed approvals, and created confusion about who was accountable for supporting De Wulverhorst's plans. Despite these obstacles, the Wulverhorst team demonstrated perseverance and advocacy by continuously engaging with municipal authorities to seek clarity and maintain momentum. They emphasised the importance of a clear, shared vision for residential care and pushed for transparent communication channels. This approach helped to gradually restore trust and collaboration between De Wulverhorst and local government stakeholders.

Ultimately, the team's determination led to the approval of a comprehensive and well-defined residential care vision, which provides a solid foundation for future care delivery and community engagement. This experience highlights the critical need to anticipate and manage bureaucratic hurdles in health and social care projects, especially those involving multiple stakeholders and political entities.

Lessons learned include the value of persistent communication, building strong relationships with local authorities, and flexible planning to accommodate unforeseen administrative changes. These strategies proved essential in overcoming challenges and ensuring the successful realisation of De Wulverhorst's care objectives.

Key success factors/points of strength

De Wulverhorst's success stems from several key strengths that enable the delivery of high-quality, person-centred care for elderly residents in Oudewater. A clear and comprehensive residential care vision provides strategic focus, supported by strong leadership that drives continuous improvement and adaptability. The organisation invests heavily in professional development, offering ongoing training that empowers staff to apply their talents creatively and meet individual client needs effectively. Community engagement plays a central role, with active involvement of clients, families, informal carers, and volunteers. The collaboration with Het Touwteam, a large volunteer network, helps reduce social isolation and supports informal carers, while partnerships with local welfare organisations extend care reach and impact. Respect for client autonomy is fundamental; care is tailored to each person's wishes and capabilities, fostering trust and satisfaction. Good working conditions, including flexible scheduling, attractive benefits, and a supportive culture that values employees, contribute to staff motivation and retention. Additionally, despite bureaucratic and administrative challenges due to changes in local government, the team's perseverance ensured continuity and approval of key initiatives, demonstrating resilience and commitment. Together, these factors form a robust foundation for sustainable, inclusive care that adapts to evolving community needs and promotes well-being for clients and caregivers alike.

MOST project – Integrated care in Krško Municipality

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	91 GLR
Ranking of the good practice	36
Type of good practice	4. Integrated approaches and strategies
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	MOST project – Integrated care in Krško Municipality
Name of the good practice in original language (if available)	MOST CSD Posavje – integrirana oskrba v občini Krško
Initiative in operation since	2017-2022
Country/ies of implementation	Slovenia
Geographic coverage/ implementation level	1. Local
Stage of initiative	3. Finished for 1-3 years
Name of the Leader/s Organisation/implementer/s	CSD Posavje
Contact details	Carmen Rajer, carmen.rajer@gov.si
Type/source(s) of funding	4. National or local public sources (e.g. general tax revenue, social care funds)
Webpage/s of the good practice (or link to doi of the paper)	Webpage: https://pametne-vasi.info/dobre-prakse/integrirana-oskrba-v-obcini-krsko-most/

Summary (abstract)	The Integrated Care Programme in Krško “Most”, in cooperation with individuals, families and organisations, offers comprehensive social health services that improve the quality of life and well-being of people in the local community. The vision of integrated care is to enable people to live better, longer and more fulfilled lives through appropriate guidance, social health services and support in the home environment at the right time. The project brought together different social and health professions to provide targeted support to beneficiaries of long-term care in the home environment. The project involved a population of 18+ people with reduced physical and cognitive abilities who were dependent on another person for basic and supportive activities of daily living over a prolonged period of time. The project employed assessors at the Single Point of Entry to initiate the application process, visit the beneficiary’s home and issue an opinion on placement in the long-term care category and recommended services. The LTC Coordinator then carried out a further home visit and worked with the LTC providers to draw up an implementation plan to support the beneficiary at home. In addition to the home care providers, the LTC providers were also nursing technicians working under the umbrella of the Care Unit and a dipl. physiotherapist, a uni. dipl. social worker, a dipl. occupational therapist and a master’s degree in kinesiology, who made up the Independence Preservation Unit (IPU). The new services have upgraded the home care services, which have been present in Krško for 30 years. The nursing technicians provided services in the home environment that were not provided before or were provided only to a minimal extent and not every day up to 3 times a day, they helped with the care of people with severe, specific health conditions, and they also cooperated with personal physicians and the patronage service. The social worker used a psychosocial approach to mitigate the effects of long-term care of family members in the home environment (support to informal carers), to support beneficiaries with a weak social network, to help them to reintegrate into independent living and to provide support and assistance in the management of people with dementia in the home environment. The physiotherapist helped with conditions after injuries, strokes, prolonged bed-rest or respiratory illnesses once medical rehabilitation had been completed, while the occupational therapist entered with the aim of learning to live more independently in the home environment with some new mental or physical limitations, and also helped with the adaptation of the living environment. The kinesiologist, as a new professional in the field of elderly care, helped the beneficiaries to become more mobile in their home environment through exercise activities, thus significantly improving their quality of life.
Keywords	Integrated Care, Long-Term Care (LTC), Home Care Services, Interdisciplinarity

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice The objectives of the project were to establish a single entry point and test assessment procedures for determining eligibility for long-term care, to establish effective coordination between social and health care providers and the newly established entry point with the aim of providing integrated care that puts the user at the centre, to introduce new services and support mechanisms for formal and informal care providers to deliver quality and safe care in the user's home, and to electronically record the entire care process (for more details see "Summary").
Main setting(s)/place(s) of delivery 8. Local community
Target group(s)/beneficiaries 1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)
Age profile(s) of the target group(s) of the practice 1. 18-34 years 2. 35-64 years
Health issues of the care recipients assisted by the target group(s) 1. Physical disabilities (caused, e.g. by frailty, accident, injury, illness, etc.) 2. Psychological/mental health issues (e.g. depression, anxiety, etc.)
Age profile(s) of the care recipients assisted by the target group(s) 3. Adults (18-64 years) 4. Older people (65+ years)
Problem being addressed Lack of trained professionals and coordination among them.
Measurement/evaluation The project achieved all project objectives and impact indicators. They trained 75 teams in health centres to implement upgrades of prevention programmes for pregnant women, children and newborns, children and adolescents, and adults. We have trained regional teams in all NICUs. We conducted 125 orientation meetings to support health centres in the implementation of the project. We conducted 25 vulnerability and health inequalities analyses in all project localities. https://nijz.si/projekti/most/

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
4. Enhancing informal carers' and/or LTC workers' satisfaction
5. Fostering (or potential to foster) care partnerships
6. Improving organisational practices
7. Cost-effectiveness

As for point 7, some of the practices are prevention based, which is cost effective in the long run.

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

The social worker, the physiotherapist, the occupational therapist, the kinesiologist, all have to work together.

Equity (including ethics)

The project takes into account various dimensions of equality, including age, gender, socioeconomic status, geographical accessibility, and vulnerable groups such as people with dementia or language barriers.

Integrated care is tailored to the needs of users in both urban and rural areas. The project complies with ethical guidelines and legislation, particularly in the area of personal data protection, and ensures that the benefits outweigh any risks. It thus represents a comprehensive and fair approach to long-term care and support for users and their carers.

Sustainability

The practice receives financial and organisational support by local, national and health&social institutions.

Concerning human resources, the project employed assessors at the Single Point of Entry to initiate the application process, visit the beneficiary's home and issue an opinion on placement in the long-term care category and recommended services. The LTC Coordinator then carried out a further home visit and worked with the LTC providers to draw up an implementation plan to support the beneficiary at home. In addition to the home care providers, the LTC providers were also nursing technicians working under the umbrella of the Care Unit and a graduated physiotherapist, a graduated social worker, a graduated occupational therapist and someone with a master's degree in kinesiology, who made up the Independence Preservation Unit (IPU).

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

It is clearly defined as a model of integrated long-term care, based on interdisciplinary collaboration, person-centered planning, and local-level coordination.

It outlines roles (e.g. care coordinator, formal/informal caregivers) and processes (needs assessment, care planning, follow-up), making it operationally clear. It is also modular and scalable to community-based care or residential programs.

It follows a person-centered approach so it is not completely regulated by manuals.

Collaboration with and/or participation of different stakeholders and sectors

Collaboration across sectors was a central pillar of its success. Social and health care providers (e.g. CSD Posavje, community nurses, physiotherapists, and GPs) worked closely to deliver coordinated, person-centered services. Local government and municipal services played a key role in leadership, funding, and logistical support. Civil society and informal carers were included through consultations and direct involvement in shaping care plans. Educational and research institutions supported evaluation and knowledge exchange on integrated care approaches. NGOs and community organisations contributed with resources and outreach, especially to vulnerable groups.

This broad collaboration ensured shared ownership, improved coordination, and stronger alignment with the real needs of users and caregivers, proving vital for sustainable integrated care.

Innovative aspects, if any

None reported.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

Limited budget constraints affected the scale and sustainability of the project beyond pilot phases. Shortage of trained professionals, especially in specialized fields like dementia care and mental health support. Also, scarce availability of frontline staff due to high workloads and multiple responsibilities. Inadequate physical spaces for coordinated care activities and team meetings, particularly in smaller or rural facilities.

Key success factors/points of strength

Early involvement of stakeholders, combined with strong leadership and adaptable solutions, is essential to overcome resource constraints and build integrated care models that are both effective and sustainable in diverse local contexts.

Cognitive-behavioural intervention for Dementia caregivers' coping with pre-death grief

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	147 SLR
Ranking of the good practice	37
Type of good practice	3. Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Dementia caregivers' coping with pre-death grief: effects of a CBT-based intervention
Name of the good practice in original language (if available)	Idem
Initiative in operation since	No information in the article on how long the practice has been running. The article was published in 2016.
Country/ies of implementation	Germany
Geographic coverage/ implementation level	2. Regional, national
Stage of initiative	No information in the article on how long the practice has been running.
Name of the Leader/s Organisation/implementer/s	Department of Counselling and Clinical Psychology, Institute of Psychology, Friedrich Schiller University Jena.
Contact details	Franziska Lechner, Meichsner. Faculty of Social and Behavioural Sciences, Utrecht University.
Type/source(s) of funding	4. National or local public sources (e.g. general tax revenue, social care funds) This work was supported by the German Federal Ministry of Health It is unclear whether the Ministry also funded the practice after the study was completed.
Webpage/s of the good practice (or link to doi of the paper)	DOI: https://doi.org/10.1080/13607863.2016.1247428

Summary (abstract)	Objectives: Pre-death grief plays a significant role in dementia caregiving and has adverse impacts on caregivers. It was the purpose of the present study to examine whether a cognitive-behavioural intervention including a grief intervention module could increase caregivers' coping with pre-death grief and whether these effects could be maintained as of a six-month follow-up assessment. Method: In a randomised-controlled trial examining the effectiveness of a cognitive-behavioural intervention, 273 caregivers were allocated to either an intervention or control group. Intervention group participants received 12 therapy sessions over six months; all participants completed a measure of pre-death grief. The analysis was conducted using latent change models. In the first model, the study group was included as a predictor of change in pre-death grief; subsequent models also included care situation and sociodemographic variables. Results: The burden due to pre-death grief was reduced for intervention but not control group participants at the time of the six-month follow-up assessment. When controlling for changes in the care situation and sociodemographic variables, the treatment effect was also found in the assessment completed post-intervention. Conclusion: Results indicate that a cognitive-behavioural intervention including grief-specific strategies can successfully foster caregivers' coping with loss and reduce the burden of pre-death grief.
Keywords	Cognitive-Behavioural Intervention, Informal Carers, Post-Death Grief, Therapy Sessions

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

The aim is to increase dementia caregivers' coping with pre-death grief. One aspect of the dementia caregiving experience that is missing in most other comprehensive intervention programs was coping with grief and loss. Pre-death grief is experienced by up to 71% of dementia caregivers.

Participants in the intervention group received twelve 50-minute individual therapy sessions over a duration of six months. The intervention was delivered by clinical psychologists who were trained in CBT and knowledgeable about dementia and dementia caregiving. All sessions were conducted via telephone. The intervention manual comprised 10 modules that focused on different challenging aspects of the caregiving situation (e.g. changing dysfunctional cognitions or coping with behavioural problems) and was based on cognitive-behavioural techniques that had been adapted for use with dementia caregivers. The efficacy of this approach had been demonstrated in previous RCT. The module coping with change, loss, and grief was the most important one for the treatment effect under study in the present analyses. This module was developed based on our extensive experience in psychotherapy with dementia caregivers and was refined through the results of a comprehensive qualitative analysis.

The aims of the module were to help dementia caregivers recognise losses and changes, and foster acceptance of the disease and the associated emotions. At the core of that, caregivers learned to cope with pre-death grief through the management of painful emotions. That means that therapists conveyed how caregivers can recognise, express, and accept emotions such as grief, sadness, loneliness, desperation, and anger, while maintaining their daily functioning as a caregiver at the same time. The module further comprises CBT-based techniques for identifying and restructuring dysfunctional cognitions regarding grief, redefining the relationship with the care recipient, activating resources, and preparing caregivers for the death of the care recipient.

For more information about the grief module, please see table 1 in the article: DOI: <https://doi.org/10.1080/13607863.2016.1247428>

Main setting(s)/place(s) of delivery

1. Home

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)

Age profile(s) of the target group(s) of the practice

1. 18-34 years
2. 35-64 years
3. 65-74 years
4. 75+ years

Health issues of the care recipients assisted by the target group(s)

3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.)

Age profile(s) of the care recipients assisted by the target group(s)

3. Adults (18-64 years)
4. Older people (65+ years)

Problem being addressed

Pre-death grief plays a significant role in dementia caregiving and has adverse impacts on dementia caregivers.

The results indicated a greater decline in the burden of pre-death grief in the intervention than in the control group, leading to the conclusion that the intervention can successfully foster caregivers' coping with grief and loss.

Measurement/evaluation

A randomised controlled trial examining the effectiveness of cognitive-behavioural intervention was conducted. 273 caregivers were allocated to either an intervention or control group. Intervention group participants received 12 therapy sessions over six months; all participants completed a measure of pre-death grief. The analysis was conducted using latent change models. In the first model, study group was included as a predictor of change in pre-death grief; subsequent models also included care situation and sociodemographic variables.

The burden due to pre-death grief was reduced for intervention but not control group participants at the time of the six-month follow-up assessment (Cohen's $d = -0.361$). When controlling for changes in the care situation and sociodemographic variables, the treatment effect was also found in the assessment completed post intervention (Cohen's $d = -0.248$).

For more information, please review the article DOI: <https://doi.org/10.1080/13607863.2016.1247428>

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

Not applicable.

Equity (including ethics)

Regarding equity and ethics, both adult women and men of different ages took part in the study/practice. The study was approved by the ethics committee of the Friedrich Schiller University Jena, Germany.

Sustainability

The study was funded by the German Federal Ministry of Health; however, there is no information on whether the funding continued after the study ended. To ensure the sustainability of the practice, ongoing funding and access to clinical psychologists capable of conducting the sessions are necessary.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

The article does not provide information on the potential transferability of the practice.

Collaboration with and/or participation of different stakeholders and sectors

No information is available in the article regarding eventual collaboration with different stakeholders or sectors.

Innovative aspects, if any

The practice could be considered potentially innovative, as the aspect of dementia caregiving related to coping with grief and loss—which is absent in most other comprehensive intervention programs—was included in this practice.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

Telephone-based settings have some advantages for dementia caregivers, but it is also described as having some limitations. In comparison to a face-to-face setting, only verbal aspects of communication between caregiver and therapist are available while nonverbal aspects (e.g. facial expressions, crying, change in body posture) that can provide valuable insight into emotional reactions, or their avoidance, are not conveyed. Caregivers, however, valued the telephone-based approach because it eased their expression of painful emotions that are often associated with shame and blame in face-to-face encounters.

Key success factors/points of strength

The main positive lessons learned: The results indicated a greater decline in the burden of pre-death grief in the intervention than in the control group, leading to the conclusion that the intervention can successfully foster caregivers' coping with grief and loss. Having intervention strategies at hand that foster acceptance of and coping with grief, loss, and change can ensure caregivers' continued physical and mental health and permit them to come to terms with the end of one of life's most meaningful personal relationships. Key success factors for the practice may include having trained personnel to lead the sessions and securing adequate funding to support its implementation.

The conversation with (caring) relatives

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	100 GLR
Ranking of the good practice	38
Type of good practice	1. Primary, secondary and tertiary prevention interventions
Name of the good practice in English	The conversation with (caring) relatives
Name of the good practice in original language (if available)	Das Angehörigengespräch
Initiative in operation since	1st January 2015
Country/ies of implementation	Austria
Geographic coverage/ implementation level	2. Regional, national
Stage of initiative	1. Ongoing
Name of the Leader/s Organisation/implementer/s	Kompetenzzentrum für Qualitätssicherung in der häuslichen Pflege (on behalf of the Austrian Ministry of Social Affairs)
Contact details	Franziska Jentsch (WiPF), f.jentsch@wir-pflegen.net
Type/source(s) of funding	4. National or local public sources (e.g. general tax revenue, social care funds)
Webpage/s of the good practice (or link to doi of the paper)	Webpages: Broschüre – Angehörigengespräch Gesetzliche Grundlage – BGBl. I Nr. 12/2015
Summary (abstract)	Das Angehörigengespräch is a nationwide psychosocial support offer in Austria for family carers experiencing psychological strain. Financed by the Federal Ministry of Social Affairs, it allows informal carers to receive up to ten free, confidential counselling sessions, either at home, via telephone, or online. The conversations focus on recognising one's own limits, building personal strengths, and improving coping strategies. The programme is rooted in §33a of the Federal Care Allowance Act and forms part of Austria's quality assurance measures in home care. It was rolled out nationwide in 2017 after a successful pilot. Evaluations show that it addresses emotional burdens such as responsibility, fear, restrictions, and sleep problems, especially for carers providing long-term or multi-person care. It also aims at preventing burnout and improving the overall well-being of informal carers.
Keywords	Informal Carers, Mental Health, Psychosocial Counselling, Prevention, Home Care

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

Das Angehörigengespräch is a preventive and supportive counselling service for informal caregivers in Austria who are experiencing psychological stress. It is available to individuals whose care recipients receive Austrian care allowance (Pflegegeld). The service consists of up to ten free and confidential counselling sessions and is offered by trained professionals at the caregiver's home, via phone, or online.

The goals of the sessions include:

Offering space for emotional relief and reflection;

Supporting carers in recognising personal limits and resources;

Promoting self-care and health maintenance;

Providing information on coping strategies and available services.

The intervention is rooted in §33a of the Federal Care Allowance Act (BGBl. I No. 12/2015) and financed by the Federal Ministry of Social Affairs, Health, Care and Consumer Protection (BMSGPK). After a successful pilot, it was implemented nationally in 2017 and continues to be part of Austria's quality assurance in home care.

Main setting(s)/place(s) of delivery

1. Home

9. Online

10. Other: telephone

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)

2. Working carers (combining paid work with informal care)

Age profile(s) of the target group(s) of the practice

1. 18-34 years

2. 35-64 years

3. 65-74 years

4. 75+ years

Health issues of the care recipients assisted by the target group(s)

1. Physical disabilities (caused, e.g. by frailty, accident, injury, illness, etc.)

2. Psychological/mental health issues (e.g. depression, anxiety, etc.)

3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.)

4. Other chronic illnesses/long-term health conditions (specify: not available)

Age profile(s) of the care recipients assisted by the target group(s)

1. Children/Youths (0-12 years)
2. Adolescents (13-17 years)
3. Adults (18-64 years)
4. Older people (65+ years)

Problem being addressed

Informal carers often face psychological burdens such as constant responsibility, emotional exhaustion, and limited time for themselves. According to an evaluation of over 430 consultations, more than 80% of carers reported issues like overwhelm, fear, sleep disorders, and feelings of restriction. These issues are particularly pronounced in long-term care situations or when caring for multiple individuals.

Das Angehörigengespräch was introduced to address these burdens preventively, especially among carers who tend to delay seeking help. It reduces the barriers to support by offering a low-threshold, confidential, and free service tailored to the individual's emotional situation. By integrating it into the Austrian care system as a quality assurance measure, it bridges the gap between medical care and psychosocial support.

Measurement/evaluation

An evaluation of the programme (2016) recorded 438 completed counselling sessions and additional repeat consultations for selected cases (197 people accepted a second offer). The evaluation collected demographic and usage data. Most carers were women (80.8%), with an average age of 62.

Key stressors discussed were:

Responsibility (80.9%);

Renunciation (77.9%);

Fear and worry (77.6%);

Overwhelm (62.1%);

Sleep disorders (45.7%).

Among carers for two or more persons, time pressure was a significant issue (53.7%).

The results confirm that the intervention reaches the target group and addresses relevant stressors. The programme was scaled up nationwide in 2017 based on the positive evaluation findings.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
4. Enhancing informal carers' and/or LTC workers' satisfaction
7. Cost-effectiveness

The evaluation showed that Das Angehörigengespräch supports informal carers in reducing psychological stress, coping with overwhelming responsibility, and managing fear, guilt, and sleep disturbances. Carers reported feeling relieved and strengthened. The service promotes early intervention, preventing more serious mental health issues and long-term caregiving breakdowns. Given its free and low-threshold format, it also contributes to cost-effective prevention.

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

Despite the above point 9.5 was not selected, although Das Angehörigengespräch focuses on informal carers individually, it implicitly supports the goals of care partnerships as defined in the WELL CARE project. By helping carers better understand their needs, limitations, and stressors, the programme strengthens their capacity to communicate, coordinate and cooperate with formal LTC services.

It does not provide structured joint sessions with LTC professionals, but by reinforcing self-awareness and confidence, it may indirectly promote more balanced and respectful interactions between formal and informal caregivers. The programme thus supports care partnerships by improving the mental and communicative readiness of one of the central actors.

Equity (including ethics)

The offer is free of charge, accessible throughout Austria, and can be delivered at home, online, or by phone—eliminating geographic, financial, and mobility barriers. It addresses a predominantly female and ageing target group, but is open to all genders and ages. Confidentiality and data protection are ensured, and participation is voluntary. The structure is based on legal provisions and embedded in public quality assurance, providing ethical legitimacy and public trust.

Sustainability

The programme is based on §33a of the Austrian Federal Care Allowance Act and funded by the Federal Ministry. Since its rollout in 2017, it has become part of standardised quality assurance in home care and is institutionally and financially anchored. Its flexibility and decentralised delivery model also support long-term sustainability.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

The programme has already been scaled nationally in Austria. Its structure—free counselling delivered in-person or remotely by qualified professionals—is highly adaptable to other national contexts. The legal anchoring and integration in quality assurance mechanisms provide a replicable policy model. Countries facing similar challenges with informal caregiving could adopt similar measures through statutory care systems.

Collaboration with and/or participation of different stakeholders and sectors

The initiative was developed and implemented by a competence centre for quality assurance, commissioned by the Federal Ministry of Social Affairs. While it does not explicitly involve civil society or carers' organisations in design, it reflects a coordinated public effort to address the psychological needs of informal carers. The programme builds on national legislation and collaborates with professional counselling staff.

Innovative aspects, if any

The intervention is innovative in its legal foundation, its systematic link to quality assurance, and its free, low-threshold, multimodal (home/phone/online) delivery format. It brings psychosocial counselling directly to carers, recognising emotional stress as a quality issue in long-term care—a novel integration in European care policy.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

Barriers include stigma, emotional hesitation, and lack of awareness about the offer. Also, not all carers may identify their own stress as a reason to seek help. Solutions include improved public communication, easy access, and embedding the offer in routine care assessment procedures. Some cancellations occurred due to time constraints or reduced burden, which highlights the need for timely outreach.

Key success factors/points of strength

Free and confidential access;

Legal and institutional anchoring;

Multi-accessibility (home, phone, online);

Preventive focus and public legitimacy;

Integration in national quality assurance strategy;

Professional staff and documented effectiveness.

The online training with app for LTC workers (RESIST)

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

Number of good practice	104 GLR
Ranking of the good practice	39
Type of good practice	3. Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives
Name of the good practice in English	The online training with app for LTC (long-term care) workers (RESIST)
Name of the good practice in original language (if available)	Das Online-Training mit App für Pflegekräfte (RESIST)
Initiative in operation since	1st January 2020
Country/ies of implementation	Germany
Geographic coverage/ implementation level	2. Regional, national
Stage of initiative	1. Ongoing
Name of the Leader/s Organisation/implementer/s	AOK PLUS. Die Gesundheitskasse für Sachsen und Thüringen (AOK PLUS. The Health Insurance Fund for Saxony and Thuringia - Germany) In cooperation with: Leuphana Universität Lüneburg
Contact details	Franziska Jentsch (WiPF), f.jentsch@wir-pflegen.net
Type/source(s) of funding	3. Statutory LTC/healthcare financing system
Webpage/s of the good practice (or link to doi of the paper)	https://www.aok.de/gp/pflegekraefte/betriebliche-gesundheitsfoerderung/resist https://care4care-projekt.de/publikationen/
Summary (abstract)	RESIST is an online resilience training program designed for long-term care workers. Developed by AOK PLUS in collaboration with Leuphana University Lüneburg, it offers six weekly sessions (60–90 minutes) to train four core resilience skills: self-efficacy, optimism, relationships, and self-care. The program aims to strengthen psychological resources and reduce stress among nursing professionals. Participation is free during the pilot phase and integrated into the wider Care4Care workplace health promotion initiative. Its effectiveness has been scientifically validated. The initiative emphasizes anonymity, confidentiality, and data protection and was launched to compensate for the lack of in-person support during the COVID-19 pandemic. RESIST contributes to long-term improvements in mental well-being, stress management, and occupational health in care settings.
Keywords	Resilience, LTC Workers, Online Training, Workplace Health, Mental Wellbeing

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

RESIST is an evidence-based online training program developed to strengthen the mental resilience of long-term care (LTC) workers. It was created by AOK PLUS in cooperation with Leuphana University Lüneburg as part of the Care4Care research project. The program addresses the high psychological and physical burden among LTC professionals, a challenge exacerbated by demographic changes and the COVID-19 pandemic.

In six weekly sessions (60-90 minutes each), participants are introduced to four central resilience competencies: self-efficacy, optimism, building relationships, and self-care. These skills aim to improve stress management, emotional well-being, and job satisfaction.

RESIST is free during the pilot phase and designed for flexible digital use. It also collects anonymised scientific data to improve the program further. Data protection and participant confidentiality are fully ensured.

Main setting(s)/place(s) of delivery

7. Workplace

9. Online

Target group(s)/beneficiaries

3. Qualified/registered nurses

4. Assistant nurses

6. Other LTC workers/health-social care professionals (specify: not available)

Age profile(s) of the target group(s) of the practice

1. 18-34 years

2. 35-64 years

Health issues of the care recipients assisted by the target group(s)

1. Physical disabilities (caused, e.g. by frailty, accident, injury, illness, etc.)

2. Psychological/mental health issues (e.g. depression, anxiety, etc.)

3. Cognitive impairments (e.g. Alzheimer's, dementia, etc.)

4. Other chronic illnesses/long-term health conditions (specify: not available)

Age profile(s) of the care recipients assisted by the target group(s)

1. Children/Youths (0-12 years)

2. Adolescents (13-17 years)

3. Adults (18-64 years)

4. Older people (65+ years)

Problem being addressed

RESIST responds to the high stress and psychological strain faced by LTC staff in Germany. Challenges include emotional overload, shift work, staff shortages, and increased demands due to demographic ageing and pandemics. These occupational risks are compounded by insufficient workplace health structures. RESIST addresses these issues by promoting mental resilience and psychological resources to prevent burnout, absenteeism, and long-term health issues.

Measurement/evaluation

The program's effectiveness has been scientifically validated. It includes embedded anonymous scientific surveys and assessments. It is part of the larger Care4Care project, which applies mixed-method research to monitor participant feedback, stress levels, resilience improvements, and long-term mental well-being. Evaluation results are shared in public reports and academic publications.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
3. Reducing/minimising negative aspects of caring and/or working in LTC settings (e.g. depression, anxiety, stress)
4. Enhancing informal carers' and/or LTC workers' satisfaction
6. Improving organisational practices
7. Cost-effectiveness

The RESIST program has demonstrated positive effects on psychological resilience, stress coping skills, and emotional well-being among LTC staff. Participants report increased confidence, optimism, and improved self-care. The program has contributed to greater job satisfaction and reduced perceived work-related stress.

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

Despite the above point 9.5 was not selected, RESIST is primarily targeted at formal care workers in institutional or ambulatory care settings and does not explicitly aim to strengthen collaboration with informal carers. Participation in the programme must be requested by employers via a dedicated employer portal, and is currently available to care providers located in Saxony and Thuringia. This reflects its clear focus on workplace-based health promotion within formal care environments.

Given this context, the direct potential of RESIST to foster care partnerships – understood in the WELL CARE definition as the coordination, integration, and mutual recognition between LTC workers and informal caregivers – is limited. However, indirect effects are possible. By strengthening individual resilience, communication skills, and self-care practices among professional caregivers, the programme may contribute in the long term to more constructive and empathetic interactions with informal carers, particularly in home-based or community-integrated care settings.

Moreover, RESIST promotes a more reflective and health-aware work culture, which may also lead to greater openness and sensitivity to the challenges faced by informal carers. Still, the programme does not currently include informal carers or address their role in a systematic way. Therefore, the potential to foster integrated care partnerships lies less in the current design of the programme, and more in the future possibility of adapting or expanding it to include or engage informal carers through complementary or joint initiatives.

Equity (including ethics)

RESIST is offered through a dedicated employer portal and must be requested by care employers located in Saxony and Thuringia. This ensures that the training is implemented in a structured, workplace-integrated way. The program is designed to reach a wide variety of care staff, regardless of age, gender, or socio-economic background. The online format improves accessibility, particularly in rural areas. Data protection is guaranteed, and participation is voluntary and anonymous. Ethical implementation is supported by research oversight and adherence to data protection laws (GDPR).

Sustainability

The initiative is highly sustainable. After the pilot phase, RESIST will be integrated into AOK PLUS's regular health promotion services. It is financed through the statutory healthcare system and embedded in long-term workplace health strategies. The low-cost online format and strong institutional backing further support sustainability.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

RESIST's digital structure enables easy scaling and adaptation across regions and professional settings. The model is transferable to other care sectors and can be translated into additional languages. It serves as a replicable blueprint for other health insurers or national systems aiming to promote resilience among care staff.

Collaboration with and/or participation of different stakeholders and sectors

RESIST was co-developed with Leuphana University and integrates feedback from LTC professionals. It is part of the broader Care4Care initiative involving academia, insurers (AOK PLUS), and stakeholders in the care and health sectors. This cross-sector collaboration ensures both scientific grounding and real-world applicability.

Innovative aspects, if any

RESIST combines science-based psychological resilience training with a digital, interactive delivery model tailored to the needs of care workers. Its innovative aspects include mobile accessibility, adaptive learning paths, and anonymised real-time data collection for continuous improvement.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

Challenges include limited digital literacy among some care staff, time constraints, and initial skepticism. These are addressed through user-friendly design, flexibility in training schedules, and institutional support by AOK PLUS and care facility leadership. Continuous feedback loops also help sustain the program.

Key success factors/points of strength

Key success factors include strong institutional funding, scientific evidence base, and a digital format that supports accessibility and scalability. The participatory development process ensured the program was tailored to real needs. Support from employers and integration into national workplace health promotion strategies further strengthen its impact.

Training informal caregivers to care for older people after stroke (InCARE program)

SUMMARY OF THE MAIN DETAILS OF THE GOOD PRACTICE

ID number of good practice	495 SLR
Ranking of the good practice	40
Type of good practice	3. Interventions aimed at mental health/wellbeing and resilience promotion and training initiatives 4. Integrated approaches and strategies
Name of the good practice in English (For papers: if the name of the practice is not available, to report the title of the paper)	Training informal caregivers to care for older people after stroke: A quasi-experimental study (InCARE program)
Name of the good practice in original language (if available)	Idem
Initiative in operation since	2014
Country/ies of implementation	Portugal
Geographic coverage/ implementation level	2. Regional, national
Stage of initiative	4. Finished for 4 years or more
Name of the Leader/s Organisation/implementer/s	School of Nursing, University of Minho, Braga, Portugal Health Sciences Research Unit, Nursing (UICISA: E-UMinho), Portugal Research Group "AgeingC: Ageing Cluster", CINTESIS - Center for Health Technology and Services Research, Porto, Portugal Faculty of Pharmacy, University of Lisbon, Lisbon, Portugal Institute for the Biomedical Sciences Abel Salazar, University of Porto, Porto, Portugal
Contact details	Odete Araujo, odete.araujo@ese.uminho.pt
Type/source(s) of funding	1. European/EU funds 4. National or local public sources (e.g. general tax revenue, social care funds)
Webpage/s of the good practice (or link to doi of the paper)	DOI: https://doi.org/10.1111/jan.13714
Summary (abstract)	This study aimed at evaluating whether training on practical skills involved in providing care reduces the burden experienced by informal caregivers and improves their general health condition. A study of 174 informal caregivers of stroke survivors found that the InCARE program, which included training and telephone support, improved practical skills, reduced caregiver burden, and improved mental health.

Keywords	Burden, Caregiving, Community Care, Experimental Design, Nursing, Older People, Stroke
-----------------	--

DETAILED DESCRIPTION OF THE GOOD PRACTICE

Description of the good practice

The InCARE programme is a structured intervention designed to support informal caregivers in providing effective post-stroke care to older adults. Developed in response to the growing burden on family caregivers—who often lack training and face increased physical and emotional stress—the initiative aimed to address gaps in practical caregiving skills, caregiver burden, and health outcomes. The programme was developed in response to the inadequacy of existing support, which often includes only unstructured advice with minimal assessment of caregiver readiness. InCARE aimed to reduce caregiver burden, prevent health deterioration, and improve caregiving performance by offering structured, nurse-led, personalized support.

Evaluation tools included: the ECPICID-AVC for caregiving skills, QASCI for burden, and SF-36 for health status. Results showed significant improvements in caregiving skills and mental health and a notable reduction in caregiver burden in the experimental group compared to the control group.

Main setting(s)/place(s) of delivery

1. Home

Target group(s)/beneficiaries

1. Informal carers (e.g. young carers, carers of working age not in paid work, older retired carers)

Age profile(s) of the target group(s) of the practice

1. 18-34 years
2. 35-64 years
3. 65-74 years
4. 75+ years

Health issues of the care recipients assisted by the target group(s)

1. Physical disabilities (caused, e.g. by frailty, accident, injury, illness, etc.)

Age profile(s) of the care recipients assisted by the target group(s)

3. Adults (18-64 years)

Problem being addressed

The InCARE programme addresses a critical problem faced by informal caregivers of older stroke survivors: the significant burden and health risks associated with unprepared and unsupported caregiving. These caregivers—typically women, often middle-aged or older—undertake complex and demanding tasks without formal training, placing them at risk for both occupational and non-occupational harm. The InCARE programme was developed to mitigate these risks by improving caregiver preparedness through structured, skill-based training and emotional support, thereby addressing both the practical demands and the psychological toll of caregiving.

Measurement/evaluation

The primary analysis was performed according to the intention-to-treat principle. All bivariate analysis was performed to compare the two groups (control and experimental) according to a set of characteristics evaluated at baseline. Student t-test for independent samples was used to compare means and Chi-square test or Fisher's exact test to compare proportions. Linear mixed effects models were the resource to identify potential predictive factors of the primary and secondary outcomes. The InCARE program was designed as a randomized trial. However, the different typologies integrated in the continuous care network from different ACES limited the recruitment and randomization of the participants.

Observed outcome(s), impact(s), results and benefits (including effectiveness and efficiency)

1. Improving resilience
2. Improving mental wellbeing
5. Fostering (or potential to foster) care partnerships

Describe the potential of the good practice to foster care partnerships between LTC workers and informal carers (and other stakeholders, if applicable) (i.e. if point 9.5 is ticked)

The InCARE programme demonstrates strong potential to foster effective care partnerships between long-term care (LTC) professionals and informal caregivers. By integrating structured training and follow-up support, the programme promotes collaboration, mutual recognition, and shared responsibility in caregiving. One of the core features of InCARE is the direct involvement of nurses in the home setting, delivering tailored, hands-on training to informal caregivers. This interaction facilitates knowledge sharing. The inclusion of structured telephone counselling also reinforces coordination of care by maintaining a continuous link between the caregiver and the healthcare system, ensuring guidance is available between in-person visits. Moreover, InCARE creates a foundation for shared care: informal caregivers are equipped not just with knowledge, but also with the emotional reassurance that they are supported and valued. This relational dynamic is essential in promoting emotional resilience and reducing isolation.

Equity (including ethics)

All participants signed and handed in an informed consent following the confidentiality and voluntary participation ethical considerations. In addition, researchers ensured the participants that independently of their involvement or withdrawal there would be no implications regarding home visits. Ethical principles of the revised Helsinki Declaration were adopted. The study and the research protocol were

approved by the Ethics Committee of the Administracao Regional de Saude do Norte (ARS Norte)—North Regional Health Administration (ARS Norte)—number 44/2013 and is registered at clinicaltrials.gov with ID number of NCT02074501.

Sustainability

While the original study was supported by academic and research institutions and co-funded through European programs, future sustainability may benefit from local government or healthcare system investment, especially if cost-effectiveness studies further validate its impact on reducing long-term care costs. Furthermore, the intervention relies on already trained nursing professionals who can integrate InCARE's training modules into their routine community care activities. With appropriate training and inclusion in continuing professional development programs, the intervention could be easily embedded in standard community nursing practice.

Potential of scalability, transferability, adaptability, implementability in other (national and/or regional/local) contexts

Scalability is supported by the programme's modular design and reliance on existing healthcare personnel, particularly community nurses who already engage with post-discharge patients and families. Transferability is high, as the caregiving challenges addressed by InCARE, such as lack of preparedness, high emotional and physical strain, and limited support, are common across many countries. Adaptability is another strength. InCARE was successfully implemented in both urban and rural areas of Northern Portugal, suggesting it can be tailored to various geographical and healthcare delivery settings.

Collaboration with and/or participation of different stakeholders and sectors

The InCARE programme was built on a multi-stakeholder, cross-sectoral collaboration that brought together actors from healthcare, academia, and public services to address the complex challenges faced by informal caregivers of older stroke survivors.

Innovative aspects, if any

One of the key social innovations lies in the reframing of informal caregivers as active partners in care, rather than passive recipients of sporadic guidance. InCARE empowers caregivers with structured, hands-on training tailored to their real-life home settings, thus recognizing their central role in the care continuum and enhancing their autonomy, confidence, and well-being.

Barriers, challenges/points of weakness (and solutions to them, if applicable)

A key challenge was the limited availability of trained professionals, particularly community nurses with specialized skills in stroke rehabilitation and caregiver education. To address this, the programme relied on a core team led by the principal investigator (a trained nurse-researcher), ensuring consistent delivery. Another barrier was the time constraints and availability of caregivers, many of whom balanced caregiving with other responsibilities and experienced high levels of fatigue. To overcome this, the programme was designed with flexible scheduling and concise sessions (45–90 minutes), delivered at home.

Key success factors/points of strength

The main positive lessons from InCARE include:

Leveraging existing community health resources;

Delivering support in caregivers' home environments;

Using evidence-based and flexible methods;

Recognizing informal caregivers as key actors in long-term care.

Project partners

