



2017-1-IT02-KA204-036545

CARE4DEM

EVIDENCE REVIEW ON WEB-BASED MUTUAL AID GROUPS

Intellectual Input 1 of the Erasmus+ CARE4DEM project

INDEX

1. INTRODUCTION	10
2. METHODOLOGY	13
2.1. DESK RESEARCH	13
2.2. INTERVIEWS	14
2.3. COLLECTION OF GOOD POLICIES AND PRACTICES	14
TIMELINE, TASKS, AND ROLES	14
HOW WAS THE QUESTIONNAIRE DESIGNED AND USED?	16
CRITERIA AND METHODS TO GATHER DATA	17
THE USE OF LINESURVEY™	18
3. FINDINGS REPORT	19
3.1. KEY POINTS FROM THE LITERATURE SEARCH	19
3.2. KEY POINTS FROM THE INTERVIEWS	20
3.3. COLLECTION OF GOOD POLICIES/PRACTICES	21
DATA COLLECTION	21
ANALYSIS AND SUMMARY OF PRACTICES COLLECTED	23
4.-POLICIES AND PRACTICES GATHERED	25
Types of practices:	25
1. <i>(Online) peer support groups for informal carers</i>	25
ONLINE PEER SUPPORT GROUP FOR INFORMAL CARERS	25
THE CARERS' COMPANY: A SOCIAL NETWORK FOR INFORMAL CARERS AND VOLUNTEERS	28
A GOOD PLACE ("EN BRA PLATS"): INFORMATION AND PEER SUPPORT FOR CARERS THROUGH ICT	31
2. <i>Training opportunities for careers and professionals</i>	34
ELMI – ENHANCING LABOUR MARKET INTEGRATION OF ELDERLY FAMILY CARERS THROUGH SKILLS IMPROVING	34
EDUCA&CARE: EMPOWERING HEALTH CARE PROFESSIONALS TO WORK WITH INFORMAL CARERS	36
CUIDEM PROJECT: MUTUAL HELP GROUPS FOR INFORMAL CARERS	38
3. <i>Strategic interventions: this last group of selected interventions include one policy and a systemic intervention, both from Emilia Romagna Region, in Italy.</i>	41
LAW FOR THE RECOGNITION OF THE INFORMAL CARER (EMILIA ROMAGNA REGION)	41
BREAD AND INTERNET: A PROJECT FOR DIGITAL LITERACY OF SENIORS	43
TV-ASSISTDEM: A PLATFORM FOR PEOPLE WITH MILD DEMENTIA	48
5. CONCLUSIONS & KEY RECOMMENDATIONS	48

6. REFERENCES	58
7. ANNEX	61
1. QUESTIONNAIRE CARE 4 DEM	61
2. SUMARIZE POLICIES AND PRACTICES.....	77



This report has been coordinated by ISCIII, in close cooperation with the partners of the project Care4Dem.

For more information, contact Mayte Moreno at mmoreno@isciii.es

License and copyright

© Instituto de Salud Carlos III

May 2018, Madrid

The content of the dissemination and exploitation plan does not reflect the official opinion of the European Union. Responsibility for the information and views expressed in therein lies entirely with the authors.

ABSTRACT

This report gives an insight of the state of play regarding web-based peer support groups for informal carers of people with dementia in the EU.

It provides a baseline for the Erasmus+ project CARE4DEM, aimed to support the development of web-based support groups for informal caregivers of people with dementia, through the design and the piloting of an innovative model of web-based support group, as well as a competence profile and a blended training for facilitators.

The report is based on research including a literature review, a survey, as well as interviews. The report identifies the added value of web-based support group for carers, as well as the lack such supporting initiatives. It describes a series of relevant initiatives at local, regional, national and international levels.

The report confirms the relevance of the objectives and method of the project and points out the learning of existing initiatives and the challenges to be addressed.

EXECUTIVE SUMMARY

Dementia is the usual name of many different brain disorders which are degenerative, and produce a decrease of functional capacity and interactions in people who suffer from them. Due to its increase in this century, the *Organization for Economic Co-operation and Development (OECD)* has estimated 9.6 million people living with some kind of dementia in EU country and the *World Health Organization (WHO)* has established the higher costs come from dementia instead of cancer, heart diseases or depression.

This increase, obviously, has made the rise of the figure usually known as carer. Carers are inherent and indispensable part of this situation in fronts like provision, organization and sustainability of health, and care systems. However, caring can be a highly demanding task, sometimes even harder for the caregiver than for the person who has dementia. Beside that caring a loved person can produce a personal satisfaction, it can make at the same time a negative impact caregiver's physical, mental and social well-being. The most significant is related to carers who are on working age, and the difficulties they have to deal with to be

included in the labour market. As a consequence of this issue, there were created a lot of projects and initiatives that have tried to undertake it by intending to support informal carers who take care of a person with dementia, as well as recognising and increasing the skills acquired through caring experience.

Nevertheless, some initiatives aimed also prevention of physical and mental health problem in informal carers; support carers towards high quality care; avoidance of cases of causes of maltreatment and supporting development of community-based care; promotion of caregiver's inclusion in the labour market and social inclusion.

In order to get these aims, the European Commission (EC) has highlighted the benefits not only of supporting informal carers, but also training them for being able to face the challenges attached to their situation of family carers. Taking as a base this point of view, EC supports the European project CARE4DEM (2017-2020) through the programme Erasmus+.

The main difference of this project compared with other European project is not the usual use of mutual aid groups, it is the use of them by utilizing ICT, something that could promote social inclusion of caregivers who would be left out of these initiatives because of their burdens as carers. With this project, it is being tried to create an innovative model of web-based group for dementia carers by providing an insight of the state of playing regarding this particular type of support.

The chosen methodology to produce this project has been implemented by including desk research, the dissemination of a survey and interviews with relevant stakeholders. Nevertheless, this initiatives have developed in the projects countries, although it is referring also other projects that have been develop in other EU countries.

There were 38 practices and policies collected in through a Lime survey. However, after the in-depth analysis, there were only 9 that are suitable for this project. The classification of these practices is according to three types of intervention:

1) (Online) peer support groups for informal carers

- Gruppa Ama online, online peer support for informal carers, Italy
- The carers' company /La Compagnie des Aidants, France
<https://lacompaniedesaidants.org/>
- A good place (En Bra Plats), Sweden: <https://www.enbraplats.se/>

2) Training opportunities for carers and professionals

- ELMI Project, Romania, www.elmiproject.eu
- Educating professionals to enhance the quality of informal caregiving, Portugal
- Educa&care, Portugal (<http://educacare.web.ua.pt/>)

3) Strategic interventions

- Law for the recognition of the informal carer (Emilia Romagna Region) Italy,
<https://bit.ly/2HmxhRc>
- Bread and internet (Pane I internet), Italy,
<https://www.paneeinternet.it/public/pei-en>
- TV-ASSISTDEM, Spain, Italy, Switzerland, Romania, <http://www.tvassistdem-aal.eu/ion>:

Through the process of this part of the project, there were found some conclusions.

During the information gathering, there were a lot of lack of information in two main fields: in implementations, the initiatives regarding to training courses for informal carers and the little and insufficient information to take them into account.

The most highlighted difficulty happened when it was trying to find implemented good practices related to web-based support groups for informal carers, due to there were not

only very seldom implementations, but also the few ones that there were found were not all of them evaluated by practitioners and experts.

Regarding to the initiatives, it was too difficult to find training courses well-develop because of the lack of documentation, so it is very complex to build a facilitates' training guide with such a little piece of information.

In order to make this project more accessible, it is proposed to an inclusive practice for carers who don't have the necessary skills to access ICT training. If this issue is solved, the risk of isolation can be minimized. When carers have an adequate level of ICT, they can be part of the group. When they are in, they have the figure of facilitator, but just to assure that everybody is participating and understands how this website works. Sometimes, the facilitator could be a professional due to they have to value certain kind of knowledge about some practices or sometimes because of their experience, they can have motivation and soft skills that can be very useful for this kind of cases.

It is proposed to establish a recognition of carers in a legal level. On account of carers' situation, initiatives at local level could create alliances with the project CARE4DEM to offer interventions in the areas that have a real need of them. On the other side, it is also claimed to the public authorities to make some policies that allow caregivers to balance their labour and their care life in a long-term. The creation of a national framework is a real need currently, so governments should make sure this sustainability happen and they have granted a legal recognition, to which specific rights related to work-life balance, and financial support should be attached.

In a higher level, the European Union (EU) should play a decisive role in supporting and steering the efforts made by member states for supporting informal carers through the implementation the Pillar of Social Rights, including informal carers, and by funding initiatives and programmes that support informal carers and encouraging transnational research and mutual learning because that is the best way to support informal carers.

GLOSSARY

Dementia: the common name for many different brain disorders which are degenerative, including Alzheimer disease, causing a decrease in functional capacity and human interaction.

(Informal) carers: carers are persons of all ages who provide care (usually unpaid) to someone with a chronic illness, disability or other long-lasting health or care need, outside of a professional or formal employment framework. In the context of the Care4Dem project we do not include volunteers in the definition of “informal carers”, but only family members, friends, neighbours who have an emotional bond with the care recipient.

E-literacy relates to the skill set required to make efficient use of all of the materials, tools, and resources that are available online.

Psychoeducation refers to the education offered to individuals with a special mental health condition and their families to help empower them and deal with their condition in an optimal way.

Peer support interventions build on the capacity of individuals who have experienced a challenging situation to support adequately others dealing with a similar situation. By listening empathetically, sharing their experiences and offering suggestions based on their own experience, these people are particularly able to help others in a comparable situation.

1. INTRODUCTION

Background: the issues linked to informal caring in the case of dementia

Dementia is the common name for many different brain disorders which are degenerative, causing a decrease in functional capacity and human interaction. Dementia has become a high priority in the 21st century as Organisation for Economic Co-operation and Development (OECD) estimates 9.6 million people live with some type of dementia in EU countries and World Health Organization (WHO) reports the economic cost of dementia to be higher than the expenditure in cancer, heart diseases or depression (World Alzheimer Report 2015).

Obviously, carers are **an inherent as well as an indispensable part of the provision, organisation and sustainability of health and social care systems**. They will become even more important in view of the changing health and care needs, due to the ageing of society and the increasing prevalence of frailty, dementia and chronic disease. In our ageing societies, there is a clear need to move from a reactive policy-making to an increasingly proactive policy approach, building on innovation to develop efficient and cost-effective care provision (1).

The role of a caregiver is a highly demanding task, even more when the caretaker is a person with dementia. Whereas taking care of a loved one can bring some personal satisfaction, it can also impact negatively on the caregiver's physical, mental and social well-being. For carers of working age, these difficulties can compromise their inclusion in the labour market. Several projects and initiatives have been undertaken to address these issues, aimed at supporting informal carers of a person with dementia, recognising and increasing the skills acquired through informal and non-formal learning. Ultimately, these initiatives aim at:

- preventing physical and mental health problems among informal carers;
- supporting carers towards high quality care, respectful of Human Rights provisions avoiding cases of maltreatment and supporting the development of community-based care;

- fostering caregiver's inclusion on the labour market and social inclusion.

The CARE4DEM project: developing an innovative web-based model of mutual aid group for informal carers.

The European Commission (EC) has highlighted the advantages of supporting family carers, including via training, as a part of a range of strategies to face the challenges attached to long term care. Based on this acknowledgment, the EC supports the European project CARE4DEM through the programme Erasmus +. By doing so, the EC also pursues the objective of facilitating the inclusion in the labour market of the most disadvantaged, through the development of a partnership for adult education.

The CARE4DEM is a three-year project funded by Erasmus+ programme and led by Anziani e Non-Solo, which has established a partnership of six organisations, from Italy, Portugal, Belgium, Romania and Spain. CARE4DEM stands for creating opportunities for all caregivers to take part in interventions to help them on their role, by developing an innovative model of web-based mutual aid groups.

The specific objectives of CARE4DEM are:

- To design and develop a new and innovative web-based model of mutual aid groups for informal caregivers of people with dementia, including learning materials for caregivers;
- To identify the suitable profile and competences to perform the facilitator role of mutual aid groups;
- To develop a multimedia training course to enhance the competences of mutual aid groups' facilitators;
- To pilot a web-based mutual aid group model;
- To create a network of professionals across Europe who work towards better support of informal caregivers of people with dementia.

Purpose and scope of the report

The use of mutual aid groups is being developed across Europe with several programs using this type of intervention to help dementia caregivers. There is evidence on the power of using ICT to promote social inclusion of caregivers who, otherwise, would be left out of these initiatives. Nevertheless, there is few information regarding the practices implemented, the methodologies applied or the most suitable competences and profile of the volunteers or professionals who facilitate these groups. This is the gap that the present report aims to address.

However, the objective of this report is not to provide readers with an exhaustive and detailed description of the best practices in web-based peer support groups across Europe, but rather to give an insight of the state of play regarding this particular type of support. As such, this publication aims to emphasise a series of **useful pointers for the development of an innovative web-based group support model as part of the CARE4DEM project.**

The methodology implemented included desk research, the dissemination of a survey and interviews with relevant stakeholders. It focuses mainly on initiatives developed in the projects countries, though referring also to projects developed in other EU countries.

This document includes:

- a presentation of the methodology followed;
- a presentation of the practices selected;
- analysis and recommendations with regards to the development of an innovative model of web-based support group for carers;
- recommendations for public policy in health care sector and on lifelong learning sector.

2. METHODOLOGY

2.1. DESK RESEARCH

Literature search

A search strategy was conducted by ISCII from September to October of 2017 through the following sources: PubMed, CINAHL (Cumulative Index to Nursing and Allied Health Literature), Cochrane Library, Embase and PsycINFO as well as Google Scholar

Firstly, strict criteria were applied and the search focused **on web-based interventions for mutual aid groups of dementia caregivers**. ISCII considered an intervention to be a group intervention of mutual aid if it explicitly focused on assisting informal caregivers through regularly group meeting with other caregivers. They were considered to be web-based if they had some kind of tool for online tracking, either through social networks, blogs, Skype or specifically developed tools. In addition to these criteria, ISCII specifically looked for interventions aimed at caregivers of patients with any type of dementia. Results of the search based on these strict criteria were very scarce. Consequently, it was extended to interventions aimed at **caregivers in general**, even not web-based, but likely to provide useful information regarding adequate moderator's profiles, success factors and difficulties attached to these interventions, as well as sustainability issues.

Search in a database of practices

Eurocarers searched the online repository of ICT based services for carers established through the European project CarICT (see: <http://www.eurocarers.org/carICT-Project>). This repository contains a series of initiatives which, although they don't match the search criteria, are illustrative of the variety of initiatives developed in the field aimed to address the needs of informal carers.

2.2. INTERVIEWS

The search also included interviews conducted by Eurocarers with 3 experts in the area of support for informal carers at the European level: Professor Elizabeth Hanson (Linnaeus University, Sweden), Dr. Giovanni Lamura (Head of Centre for Socio-Economic Research on Ageing in INRCA (National Institute of Health & Science on Ageing) and Benjamin Salzmann (Wir Pflegen, Germany). These interviews aimed at:

- Identifying relevant research, policies and practices outside the project countries;
- Discuss the main issues related to developing an innovative model of web-based support group for informal carers;
- Identifying relevant ongoing EU funded projects with which our partnership should exchange in the course of the project.

2.3. COLLECTION OF GOOD POLICIES AND PRACTICES

TIMELINE, TASKS, AND ROLES

The following template encapsulates the main categories of tasks and roles involved in the collection of good practices, which constitutes the main source of information for this study.

As leader of this project output, ISCII implemented most of the tasks involved, under the coordination of the project coordinator ANS.

Task	Preparation of a questionnaire
Objective	To design a strategy to collect relevant information To collect information on existing practices and policies related to caregivers of dementia patients and oriented towards online mutual help groups
Timeline	September 2017 – November 2017
Roles	Leader and main contributor: ISCII Review and contribution at all stages: all partners

	Note that ISCII also contacted external experts to review the questionnaire and included their comments: Carlos Hernández Salvador (Spanish Red Cross) and Jorgina Garrido Casas (Spanish federation of parents of children with cancer)
Task	Development of the online version of the questionnaire
Objectives	To select the most suitable online tool to implement the questionnaire and manage the outcome To develop the questionnaire in the format of Lime survey
Timeline	November 2017
Roles	Leader and main contributor: ISCII Review and contribution: all partners
Task	To gather information through the questionnaire about practices and policies.
Objectives	Identify relevant policies and practices according to predefined criteria Contact the organisation implementing the policy/survey to gather relevant information Populate the survey with information gathered on the policy/practice
Timeline	December 2017-February 2018
Roles	Each of the partners was in charge of collecting data about 2 policies and 3 practices in his country Eurocarers was in charge of finding information on policies/practices outside of the project countries, as well as gathering information on relevant EU policies and projects.
Task	To analyze the table of outcomes and to write the report
Aim	Accessing the database, analyzing the information and synthesize information in the report.
Timeline	March – May 2018

Roles	<p>Leader and main contributor: ISCIII, in charge of accessing the database, analyzing the information and merging it in the report.</p> <p>Co-leader: Eurocarers (contribution to the desk research, review and contribution to the draft drafting of a short version to be translated and used for validation workshops together with the coordinator ANS).</p> <p>Partners: review, discussion on the conclusions (Partners meeting #2 on 27/04/2018), ultimately translation and dissemination of a shorter version of the report.</p>
-------	--

HOW WAS THE QUESTIONNAIRE DESIGNED AND USED?

Is their strategy to gather relevant information, ISCIII built on a template designed for a similar objective in the CHRODIS EU Joint Action, which aimed at collecting good practices for chronic patients at European level.

This template was reviewed in accordance to CARE4DEMs' objectives and focused on practices aimed at caregivers, specifically those who had ICT as a facilitating tool to implement mutual aid groups. The modified template was reviewed twice by partners and their comments taken on board when relevant. At this stage the template was evaluated by external professionals in the field of ICT, with services for the chronically ill and / or with practices for caregivers, and their suggestions taken on board in the final version of the questionnaire. In addition, as suggested by ANS, more detailed questions were integrated in the questionnaire that concerned the way selected practices implemented web-based peer-support group (questions related to the recruitment, rhythm and facilitation of these groups...)

The final questionnaire (ANNEX 1) was disseminate among all partners under two forms:

- A word format document;
- A link to an online survey.

By doing so, ISCII made it possible for partners either to fill in the survey online directly (or ask an external organisation implementing a practice to fill it in) or to start by filling in a word

template with information gathered orally/on the internet, then have it checked and complemented by the organisation implementing the practice before transferring information into the online survey. This last approach proved useful to gather detailed and validated data in cooperation with external organisations. Information inserted in the survey was automatically added to a data collection table.

Each partner had to compile information regarding three practices and two policies in country (in countries outside the partnership and/or EU level initiatives when it came to Eurocarers).

CRITERIA AND METHODS TO GATHER DATA

The priority criteria applied to the collection of good practices had been first defined as follows:

- Aimed at informal carers;
- ICT based;
- Documented (objectives, target groups, approach, prerequisites for implementation, participants satisfaction and evaluation);
- Implementing a peer support group;
- Aimed at carers of people with dementia.

Though, it was clear after a few weeks that very few practices or policies met the whole list of criteria. In January, it was then decided to enlarge the search, and to prioritize the following criteria: '*informal carers*'/ '*ICT based*'/ '*documented*' over the other criteria, and to include training and learning opportunities for carers and professionals as well as more strategic interventions. It was also agreed that the partnership, alongside conducting the search for good practices according to this narrowed down set of criteria, could also seek inspiration from practices that did not meet these three criteria or are implemented outside the EU.

THE USE OF LINESURVEY™

Lime Survey was chosen for the purpose of the collection of best practices, because it is a free and open source on-line statistical survey web app. As a web server-based software it enables users to use a web interface to develop and publish on-line surveys, collect responses, create statistics, and export the resulting data to other applications such as Excel. It can be used for collecting data from different locations and different languages. Another reason to use LimeSurvey™ was that the survey can either be publicly accessible or strictly controlled. Additionally, participants can remain anonymous, or LimeSurvey™ can track IP addresses.

The number of questions in one single survey is not limited. Questions are organized through groups. Each page of the survey displays a group of questions. This survey app allows for a variety of question types that take many response formats, including multiple choice, text input, drop-down lists, numerical input, yes/no input, and upload files input. Some questions may depend on the results of other previous questions.

The responses table was shared with all partners through the administrator profile created for each of them. This access allows ISCIII to keep track of the information received from each country and to make the translations that were relevant, or ask to the respondents for complementary information.

3. FINDINGS REPORT

3.1. KEY POINTS FROM THE LITERATURE SEARCH

Globally, there is a rising number of elderly individuals who are suffering from dementia or Alzheimer's disease, that lead them to rely on family caregivers for assistance while living in the community. Informal caregivers tend to have poorer health and well-being than non-caregivers, however, caregiving-related declines can be off-set by the availability of support (e.g. information/education, emotional support). Caregivers underuse available help resources due to geographic and time constraints, leading social and health organizations to develop and research web-based interventions that can provide accessible support in an efficient and timely manner. Until now, the experience of caregivers with this type of intervention seems very positive, the burden of caregiver and depression usually improve positively in published studies (2,3). However, its use is still relatively low and decreases with time, which implies the need to adapt them to the different stages of the care process (4).

Mutual aid groups involve meeting with other people who share the same or similar circumstances or conditions to discuss and to share ways of coping and can be found in many areas such as physical disability, mental health, physical health conditions, groups for carers and addiction. Members usually meet at face-to-face meetings, but as use of the Internet increases, some groups hold 'virtual' meetings online. Sharing experiences enables them to give each other a unique quality of mutual support and to pool practical information and ways of coping. Groups are run by and for their members (5), this definition differentiates mutual aid groups from individual self-help and from a support group that is led by a professional.

Already in 2010, a study underlines the potential of multi-component interventions including group support to reduce both patient's symptoms and carer well-being and knowledge. (6)

We found published studies since then about web-based peer-supports for Dementia or Alzheimer's disease caregivers, the majority of them were conducted in United States, also

in Canada and Netherlands. These studies assess effectiveness of different interventions for these caregivers, most of them based on videoconferences, chat groups, forums, social networks, Facebook and LinkedIn groups, interactive videos and/or e-mail groups (6–34).

The complex interaction of a range of factors in providing support to carers with the help of technology has also been recognized in a review study (16). Findings were significant improvements in depression, burden and self-efficacy. These studies show that, while caregivers were satisfied with the online format of the interventions, their usage of the interventions was sporadic and declined over time. Usually because of reasons about time, economical or caring issues.

3.2. KEY POINTS FROM THE INTERVIEWS

In addition to sign post some relevant practices, interview with experts gave additional insights on the current state of play regarding online support for informal carers, as well as additional references to the literature. The main points arising from these exchanges can be summarized as follows:

- Peer support seems seldom proposed online in a structured way to carers, and is mostly offered face-to-face.
- Most online support for carers has been principally developed recently under the form of online advice and training, while peer support is happening informally notably through Facebook groups (especially between young carers).
- For some people, both ICT literacy and difficulties with regards to writing can constitute an obstacle, and tools such as video calls or Skype could prove useful to overcome these difficulties.
- It is difficult in general to get men involved in face-to-face peer support groups, but ICT might help addressing this issue.

- According to the literature, peer support is one of the most highly valued and most effective forms of support for informal carers, especially when combined with other services (e.g. appropriately designed respite care services) within the framework of community-based multi-components interventions (17).
- Experts confirm the overall lack of adequate support for informal carers of people with dementia across Europe, with support being either lacking, difficult to access to, or not relevant to the specific difficulties of the carer, as underlined by the Erasmus+ project TRACK (18). Though, a study exploring what constitutes good community-care for people with dementia pointed out the necessity to provide services to family carers, “referred to as the ‘invisible second patient’ because their own needs are often overlooked” (19).
- It seems that a series of relevant initiatives are being currently developed, which entail online peer to peer support (see for example in Germany: <http://www.wir-pflegen.net/projekte/oshi/>).

3.3. COLLECTION OF GOOD POLICIES/PRACTICES

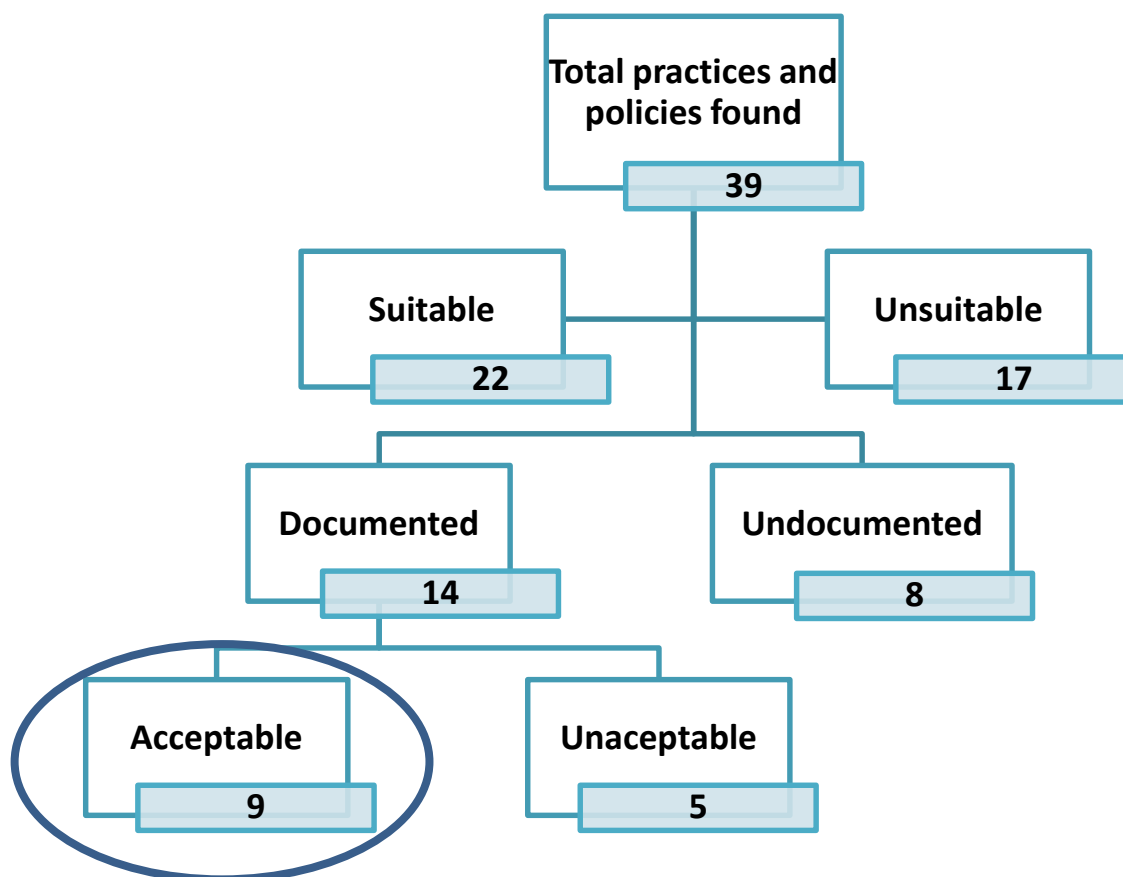
DATA COLLECTION

Data has been collected online. There are a total of **39** practices and policies collected through the questionnaire CARE4DEM. After having selected those who answered “yes” to the question “Does the intervention/practice/policy belong to the field of web-based support for caregivers”) we only had **22**. Among these twenty-two, only **14** answered “yes” to the question “Is the intervention documented, in a peer reviewed journal or grey literature?” Consequently, the other **8** have not been included in the review because they refer to interventions which are not documented either online, in a report that is easily accessible, in a peer reviewed journal or grey literature.

Nevertheless, two of them seem particularly relevant for the goal of the project, so we consider it worthy to briefly describe them:

- One of them is “a voluntary service created to fill in the lack of services aimed at the needs of sons of mentally ill parents” leaded by Association Novilunio (Italy). This has been created with the aim of reducing isolation and overcome the shame and fear of the social stigma they meet in talking about their personal experiences. Also for the possibility of having a space for sharing experiences, feelings, emotions, opinions and offering and receiving mutual support; sharing information regarding the caregiving of people with mental disorders; and working together to get out of invisibility and to focus public attention on the topic. In particular to make the institutions aware of the urgency to put the entire family at the centre of the course of treatment and to provide specific support to the sons of people with a mental disorder, especially if children. The intervention hasn’t been created to be an isolated practice but, on the contrary, as a way to demonstrate the existence of the problem and to focus the public attention on the children of mentally ill parents and their needs (supportive tools and policies). The intervention wants to bring these instances to the attention of the institutions, policy makers and professionals who work with families, in a preventive framework aimed to understand what to do to ensure that parenting and psychiatric illness could coexist. (See: <https://novilunio.net/about/>)
- The other is an online forum. It is one of the services offered to unpaid carers across the United Kingdom by *the NGO Carers UK*, *with the objectives of preventing the risk of isolation*, they are subject to; offering a space for mutual support, exchange of experience and information; improving their well-being and prevent stress and mental health problems; help them combine their caring responsibilities with their other employment or family related responsibilities; and finally allowing them to benefit from each other experience, in order to improve the way they are caring. This practice is part of Carers UK’s activity. (See: <https://www.carersuk.org/help-and-advice/get-support/carersuk-forum>)

Finally, from the **14** practices previously selected, **5** of them have not been take into consideration because of the lack of information, it is impossible to describe them accurately. **Therefore, the total number of selected practices and policies included in this report is 9.**



ANALYSIS AND SUMMARY OF PRACTICES COLLECTED

The main aims of these practices are:

Emotional support:

Caregivers experience emotional, physical, functional, psychological discomfort and isolation as a consequence of the continuous attention that must be made to his/her family member suffering from dementia. The interventions are therefore aimed to:

- Increase **personal skills to deal with emotional aspects**, feelings and behaviours that continuous attention can produce in caregivers.
- Creating a space for **listening and sharing** based on the principles of mutuality, respect and confidentiality.

Skills development:

To improve the lives of unpaid carers it is important to provide them with new knowledge, expert information and advice that's tailored to their own personnel situation, to support them in finding new ways to manage their situation. The interventions are therefore aimed to:

- Share **information** between caregivers, to help them with the difficulties of daily activities;
- Improve the **capacity** of the caregiver to manage the care of one or more dependent elderly people and reduce the intensity or burden that this causes on caregivers;
- Improve the **quality of care** in the accompaniment and care of the disabled patient by learning the skills needed by those relatives and volunteers with responsibility for direct care of patients and dependent people, attending to their needs.

Be more inclusive:

In this context, technologies can be helpful by:

- Giving the **possibility to participate** to the group to a group of people that, for various reasons, cannot access groups organized by local associations or structures.

The technologies piloted in the various interventions ICT-base are:

- Zoom (similar to Skype, that has a very clear interface and that guarantees a more stable connection);
- Blog, video for training, Apps for smartphones, Facebook, Twitter, Google+, Tumblr and Pinterest;
- Online forum, including the possibility of private messaging using phpBB platform.

4.-POLICIES AND PRACTICES GATHERED

Types of practices:

Among the selected practices, we can identify three main areas of intervention:

1. (Online) peer support groups for informal carers: this group of practices includes different experiences based on the concept of peer-support as a mean to relieve the emotional burden of informal carers. All these practices but one make use of ICT to deliver their services, with the goal to overcome geographical barriers.

From a technological point of view, these interventions are based on tools which are commonly used, such as Skype or Facebook. This is an attempt to overcome the main obstacle identified by respondents, i.e. the lack of ICT skills among users, which prevented some of them to fully benefit of the opportunities offered by the interventions.

<u>Practice Name</u>	ONLINE PEER SUPPORT GROUP FOR INFORMAL CARERS GRUPPO AMA ONLINE PER CAREGIVER FAMILIARI
<u>Country</u>	Italy
<u>Link</u>	-----

Objectives	The main aim is to fill a gap of expertise at local level, providing a support service which was unavailable in the community through a low-cost solution. A secondary goal is to initiate a professionally moderated peer-support group with the goal to encourage the transition towards a not-moderated peer support group.
What problem the practice example wants to tackle	The lack of expertise at local level concerning peer-support groups for informal carers.
Implementation	The programme was funded by "HOME CARE PREMIUM" a public initiative from the social security department aimed to support public employees who are carers through services and economic compensations. The funding is decentralised to municipalities who are free to decide how to implement the services within general guidelines approved at national level. The implementation is periodic.

Target groups	Informal carers
Technologies used	The group was moderated via Skype.
Challenges and difficulties	Participants are all together in the same room and it is always assured the presence of a facilitator with them to take care of ICT issues (turning the PC on, launching Skype, and checking the audio-video settings...). There are some challenges mainly due to connection problems/instability of the line that make the conversation not always fluent. Also, from the point of view of the moderator, it is a challenge not to have a perfectly clear vision of faces of participants (thus to see facial expressions, for example).
Include online peer-support:	YES.
Include ICT literacy support:	NO
Who implement the intervention	The intervention is implemented by the Italian NGO Anziani e non solo. The moderator is an individual with a psychosocial background and previous experience in the moderation of peer-support groups for informal carers. The team also includes an ICT facilitator in the place where participants gathered for the sessions. In one case it was a sociologist and in another case a social worker who already knew participants due to previous activities.
Activities implemented:	Recruitment of participants through local health care services; organization of a 1st face-to-face meeting to present the project and introduce the facilitator; submission of the Caregiver Burden Inventory (CBI) pre-intervention; organization of the sessions (the moderator had a list of topics to be suggested, but it wasn't strictly followed) and submission of the CBI post-intervention.
Best profile and skill for people implementing practice	The most important skill is the previous experience in the moderation of "traditional" peer support groups, in order to be able to propose some topics for discussion and anticipate some groups-dynamics. The moderator should also be aware of the challenges related with the use of ICT to prevent misunderstanding or frustrations (for example due to the frequent interruptions of the conversation). It is also important to have strong group-facilitation skills because due to the ICT constraints it is very important that discussions do not overlap and that everybody has the opportunity to talk.
Evaluation	The evaluation is carried out internally. The process evaluation is conducted through a final evaluation round (held during the last meeting) to collect

	<p>participants experiences, challenges, aspects to be improved etc. The impact is measured through the submission of the CBI questionnaire pre and post. Participants mentioned as results that participating to the group was empowering, energizing and that they learnt new things. Also, they mentioned that they felt supported and that they now have a stronger social network. Concerning the CBI, except for three persons (who had increased or stable results) we registered a reduction for at least one type of burden in all participants.</p>
--	---

<u>Practice Name</u>	THE CARERS' COMPANY: A SOCIAL NETWORK FOR INFORMAL CARERS AND VOLUNTEERS - LA COMPAGNIE DE AIDANTS
<u>Country</u>	France
<u>Link</u>	https://lacompaniedesaidants.org/qui-sommes-nous.html

Objectives	<p>Support informal carers based through enhanced local solidarity and exchange.</p> <p>Offer to informal carers a centralized point of access to the many kind of information they need.</p> <p>Support the social inclusion and the well-being of carers by breaking their isolation, reaching out to them and facilitate their self-recognition.</p> <p>Increase the visibility of informal carers in the society.</p>
What problem the practice example wants to tackle	<p>The need for information is widely cited by studies on the subject as a priority for carers. The main difficulty highlighted is to find one of the following structures and devices in place by the public authorities. This can notably result in a phenomenon of non-take-up.</p> <p>The second difficulty is to find the relevant information among all the information that are available on the Internet. The need for information doesn't necessarily mean the lack of sources of information but rather the need for carers to be able to filter and select the information that suits the specificity of their situations.</p> <p>Many studies also converge to highlight the isolation felt by informal carers. The help of a dependent person impacts social life and leisure; the psychological burden felt by caregivers can result in burn-out. Many caregivers express a need to be supported psychologically and to exchange on their situation.</p> <p>Finally, caregivers also face material needs. Accompanying dependents people can be expensive: even if aids exist to support the provision of care and the purchase of paramedical equipment, many families are facing difficulties. The possibility to exchange material or to buy services to service provider which has been selected by the Carers' Company for their reliability can help manage one's budget.</p>
Implementation	Continuous (embedded in the system).

Target groups	Informal caregivers.
Technologies used	Built on the model of Facebook. Informal carers and volunteers registered in the directory can see each other's profile and exchange messages through a secured platform which respect their privacy.
Challenges and difficulties	No information provided.
Include online peer-support:	NO.
Include ICT literacy support:	Awareness raising to added value of ICT, as well as how to use the digital platform offered by the Carers' Company is introduced through a series of face-to-face and online activities: conference, training, online conferences...
Who implement the intervention	First launched by an individual, building on her experience in educational publishing.
Activities implemented:	Active communication has been developed around the activities of the Carers' Company, in order to make them known, though participation in conferences, public media, dissemination of leaflets, as well as in a contest on social innovation organised by a Foundation 'la France s'engage'. The Carers' Company is also engaged at EU level in a network of carer's organisations (Eurocarers) and was a partner of the European project TRACK.
Evaluation	<p>An external institution. The evaluation shows that the Carers' Company offers a social innovation in two ways: By leveraging the functionalities of digital platforms at the service of solidarities local; and by centralizing the initiatives developed around carers that they are supported by associations, companies or supported by public authorities.</p> <p>The evaluation explains the modalities of the change of scale undertaken by the project:</p> <ul style="list-style-type: none"> - The change of scale strategy was a hybrid one. If the main objective is to reach a larger number of beneficiaries by increasing the number of registered carers/volunteers on the platform (scale up), this was consolidated by a deepening of the offer and an improvement of its ergonomics (scale deep).

	<ul style="list-style-type: none">- The project team has diversified its active cities (scale out) by offering consultancy to companies, focusing on the issue of carers in the workplace.- These evolutions testify to the proximity of the Carers' Company project to the logic of associative start-ups namely: a pragmatic approach, a desire for rapid growth, a hybridization of entrepreneurial and associative values as well as the importance given to communication.- The project has developed an increasingly autonomous economic model, by relying on a diversity of customers, and by adapting its offer according to the type of actors.
--	--

<u>Practice Name</u>	A GOOD PLACE (“EN BRA PLATS”): INFORMATION AND PEER SUPPORT FOR CARERS THROUGH ICT
<u>Country</u>	Sweden
<u>Link</u>	https://www.enbraplats.se/

Objectives	<p>Implement legal-based support for informal carers; by making available to them information, and peer support through ICT.</p> <p>Prevent exclusion of informal carers from the information-based society;</p> <p>Overcome the lack of availability of carers due to caring responsibilities for face-to-face peer support meetings;</p> <p>Increase the ability of informal carers to provide quality care;</p> <p>Prevent health problems due to stress and overburden among informal carers.</p>
What problem the practice example wants to tackle	<p>Lack of support for informal carers, who are in need for information, advice, support and get often isolated. In addition, a number of informal carers combine their caring responsibilities with work, which makes it difficult to be available for information and support group meetings and reinforce their isolation. As a result, informal carers in Sweden, as in other countries, are subject to isolation, social exclusion, mental health problems, stress and difficulties at work.</p>
Implementation	<p>A law passed in 2009 states that local authorities have to provide support to informal carers. The service is therefore embedded in the system</p>
Target groups	<p>Informal carers older than 16 years</p>
Technologies used	<p>Social network, online forum available on mobile phone, tablets, laptops, stationary computers.</p>
Challenges and difficulties	<p>Lack of ICT abilities among older people and lack of understanding amongst professionals that some carers have needs for web-based solutions can create obstacles.</p>

Include online peer-support:	NO
Include ICT literacy support:	A written guide for the participants in order to demonstrate how to use the slack platform (particularly health and social professionals).
Who implement the intervention	Founders, Maria and Gustaf Cavalli, have an experience in informal caring and ICT. Maria has also worked as a manager in dementia care. The initiative was very much supported by a professional organisation of nurses dealing with dementia. The team consists of one programmer, one graphic designer/developer and one project manager in care improvement. In addition to that consultants are also involved in specific projects, for instance therapist and journalist.
Activities implemented:	Training session for professionals; manual for carers and professionals; Information material for carers and professionals and workshops for professionals.
Best profile and skill for people implementing practice:	An interest in improving the life of informal carers and an interest in working with ICT as a tool to do that; basic skills in ICT, being able to type, attach files, email; knowledge of how municipalities and healthcare works and how to guide the carer through the system and in this case also knowledge about dementia and how to guide the carer in specific situations.
Evaluation	The evaluation was carried out by an external institution, that highlighted that ICT mediated support provided working carers with the means to manage their caring situation, via the provision of information, e-learning and education, in addition to practical assistance and emotional and/or physical respite from caregiving. In this way, working carers felt empowered in their caring situation by feeling more competent and prepared in their caring role and by strengthening their self-efficacy and positive self-appraisal of their situation. Carers were provided channels to share their frustrations and burdens via forums for emotional and social support between working carers, caring professionals, and other peer carers. This led to working carers feeling less burdened by their caregiving role and it helped promote their well-being. Further, carers were helped in some instances to balance work and care. As a result, caregiving activities conflicting with work obligations were then lessened."

	<p>The need to provide ICT support in a timely and personalised fashion: “In contrast, when ICT mediated support was neither provided in a timely fashion nor in accordance with individual carers’ needs and preferences, then it was perceived by them to be unimportant. Cross-sectional data revealed that take-up of support services was low suggesting that unmet support needs maybe inflated by work-care conflicts.”</p> <p>The obstacle that can represent the low literacy of some carers. “For carers with lower digital skills, the additional time needed to learn to use ICTs was a further barrier.”</p>
--	---

2. Training opportunities for careers and professionals: the 2nd group of practices includes different interventions based on e-learning and the development of community of practices based on online forums for informal carers and professionals working with them.

In these cases, ICT was mainly used to overcome geographical barriers and also to improve cost-effectiveness. However, respondents mentioned again lack of ICT skills as the main challenge linked with the implementation of the practices.

<u>Practice Name</u>	ELMI – ENHANCING LABOUR MARKET INTEGRATION OF ELDERLY FAMILY CARERS THROUGH SKILLS IMPROVING
<u>Country</u>	Romania
<u>Link</u>	www.elmiproject.eu ; www.elmicourse.eu

Objectives	<p>Transfer to Romania of an e-learning based course for informal (family) carers already developed and used in Italy</p> <p>Development of a strategy to support transition from informal to formal care for former carers</p> <p>Support mobility of trained carers</p> <p>Analysis of the transferability of the on-line training tool and of the overall strategy to Poland and Czech Republic</p>
What problem the practice example wants to tackle	Labour market integration of informal carers who can work as formal carers, the need of care of older people, especially those with dementia
Implementation	Continuous (embedded in the system)
Target groups	Informal caregivers, low education people and unemployed.
Technologies used	E-learning platform, web-page; and web 2.0 forum
Challenges and difficulties	People not familiarized with ICT use.
Include online peer-support:	NO
Include ICT literacy support:	NO

Who implement the intervention	A consortium of partners from Romania, Italy, Czech Republic, Poland, and Austria; coordinating by the Asociatia Habilitas CRFP.
Activities implemented:	on-line training course for informal (family) carers of elderly, with special focus on the care of older persons with Alzheimer dementia; on-line platform of resources for the Romanian informal carers of elderly people, with focus on Alzheimer dementia; a handbook for the Romanian informal carers of elderly people referring to the care process, which will present also the advantages of the training program in order to obtain the professional re-insertion; and concept-paper for a strategy of integration on the labour market of former informal carers who want to become professional careers, strategy that will be presented to authorities during a round table.
Evaluation	Internal and external

<u>Practice Name</u>	EDUCA&CARE: EMPOWERING HEALTH CARE PROFESSIONALS TO WORK WITH INFORMAL CARERS
<u>Country</u>	Portugal
<u>Link</u>	http://educacare.web.ua.pt/

Objectives	<p>To promote health professionals' development to deal with informal caregivers of elderly people.</p> <p>To acknowledge the relevance of the professional development to be done in partnership with health institutions for elderly people.</p>
What problem the practice example wants to tackle	The lack of formation of health professionals, namely nurses, to deal with informal caregivers. This problem has been identified in several higher education institutions as well as in health community centres.
Implementation	<p>As mentioned above there is a lack of professionalism to deal with informal caregivers. The development of professionals for this task has had impact in local health service, namely with the creation of an "office to support informal caregivers".</p> <p>The local resources created by the research team are continuously implemented in local health services. However a more intensive work has been developed during financed projects.</p> <p>A webpage was created with several resources like publications, videos, good practices, a forum among others. Ultimately, the Educa&Care project culminates in the creation of a Practice Community for sharing knowledge, resources, practical procedures and other information, to enhance the quality of care among the formal and informal caregivers participating in this network.</p>
Target groups	High educated health students and Informal caregivers with emotional problems due to the lack of support in their task.
Technologies used	Web-page (http://educacare.web.ua.pt/), a forum (software phpBB)
Challenges and difficulties	People not familiarized with the participation in the web-page, namely in forums.
Include online peer-support:	NO

Include ICT literacy support:	In the web-page guidelines has been given to use it. Dissemination of the web-page in health local services.
Who implement the intervention	The intervention was implemented by a research team and health professionals with a post-graduation training in the field.
Activities implemented:	Classes and sessions with the Practice Community (CoP), face-to face services to informal caregivers in health local services. Dissemination activities (e. g. seminars, leaflets, books, articles).
Evaluation	The evaluation was carried out both internally and externally through questionnaires to students before and after the intervention; documental analysis of the students' works; questionnaires and interviews in community interventions and follow up of people who had participated in the interventions, through questionnaires and interviews.

Practice Name **CUIDEM PROJECT: MUTUAL HELP GROUPS FOR INFORMAL CARERS**

Country Portugal

Link www.cuidem.pt

Objectives	<p>The main aim is to promote public and health professionals' awareness and informal caregiver's empowerment on the problematic of neurocognitive disorders, focusing on good practices, so as to improve the quality of care services provided to people with neurocognitive disorders and their caregivers in primary health contexts in the north of Portugal.</p> <p>The specific objectives are: train health professionals in promoting Mutual Help Groups (MHG) for informal caregivers of people with neurocognitive disorders; support the development of MHG for the empowerment of caregivers of people with neurocognitive disorders in primary health services; assess the impact of participating in MHG in the use of health services and resources; increase the awareness of health professionals about good practices in attending people with neurocognitive disorders and their informal caregivers; and increase awareness of civic society on neurocognitive disorders.</p>
What problem the practice example wants to tackle	<p>A research made in Portugal estimated that in 2013 the prevalence of dementia in the 60 plus group was of 5.91%, corresponding approximately to 160287 people with dementia. This type of disorder is more common in older ages, showing greater growth with the increase of age (Santana & col., 2015). Another study made in Portugal, analysing older people (65+) living in the community, showed in its preliminary results concerning part of the total sample, that approximately 35.0% of these subjects had some kind of mental impairment. Among those, 50% had mild problems, 31% with moderate difficulties and 18% with severe impairments. It was also possible to understand that for 31.5% of the cases, the care network was able to deal with the situation with effort, and 11% showed gaps in care, with difficulties at the informal care level.</p> <p>In particular, informal caregivers of people with dementia frequently experience burden and emotional distress, as well as negative consequences in their health.</p>

Implementation	Periodic
Target groups	Informal caregivers, Health professionals, people from ONG's and social workers.
Technologies used	web-page, Facebook, e-mail, Slack Platform.
Challenges and difficulties	<p>Difficulties in identifying informal caregivers for the mutual aid group: only few of all identified accept to participate in the group.</p> <p>Other health professionals (of the same organization) were not available and involved to identify the people who could benefit from the service (focused on their own work, not getting involved in parallel projects / activities).</p>
Include online peer-support:	NO
Include ICT literacy support:	Just a guideline for users using the Slack Platform, used for the discussion on the "Good Practices Guidebook".
Who implement the intervention	A team of professionals with different backgrounds (psychologists, gerontologists, occupational therapists, General Practitioner (GP). For the mutual aid groups, a network of health professionals from the public health network were involved (nurses, social workers, speech therapists, GP).
Activities implemented:	<p>Axis 1 – Capacitating primary health professionals: 2 training sessions on facilitating Mutual Aid Groups; 12 awareness sessions (6 for clinical and 6 for non-clinical professionals); 3 focus group (1- social and health professionals; 2- informal caregivers; 3- people with dementia); 1 web-based group for discussion and development of the good practices manuals; 2 good practices manuals (for clinic and non-clinic professionals);</p> <p>Axis 2 – Empowering informal caregivers: 6 Mutual Aid Groups; 6 health education actions for informal caregivers; macro dissemination of information (1 website, 4 leaflets);</p> <p>Axis 3 – Public awareness: 6 awareness sessions (for social professionals and others working with older people like policeman, graduation students, high school students); macro dissemination of information (1 website; 4 leaflets)</p> <p>Others- disseminations events: launching event, closing event, participation in congresses, seminars.</p>

Best profile and skill for people implementing practice:	To be a clinical health professional (nurse, GP, psychologist, social worker, speech therapist, among others) working in primary health public centres; to have knowledge about neurocognitive disorders and informal caregiving; to have knowledge about the development and dynamics of mutual help groups; and to have abilities on group management.
Evaluation	<p>The evaluation was carried out both by Internal and external parties</p> <p>The evaluation was focused on the impact/ benefit of participating in the mutual aid group (pre-test evaluation, 6 and 12 month after start to participate in the mutual aid group). Item measured:</p> <p>Informal carer: burden, anxiety, depression, time of care, self-perception of quality of life and health, coping profile, satisfaction with the participation</p> <p>People with dementia: level of cognitive impairment, dependency, use of health services.</p> <p>Other activities of the project were evaluated with questionnaires (at the end of the activity), like training facilitators sessions, seminars, awareness sessions.</p> <p>Main recommendations from the evaluation were the following: <u>before</u> enrolling in the training session, health professionals should have to compromise with the development of at least 1 mutual health group (MHG); in planning the MHG it should be predicted some possible difficulties that informal caregivers, like lack of transportation from IC, lack of substitute in care while attending MHG session. These difficulties can be addressed by establishing partnerships with municipalities, NGOs, others to provide transportation and volunteers.</p>

3. Strategic interventions: this last group of selected interventions include one policy and a systemic intervention, both from Emilia Romagna Region, in Italy.

The 1st one is a law establishing a service framework to support informal carers, which explicitly refers to the possibility for providers to offer ICT-based interventions. This is relevant as it acknowledges that ICT can respond to some specific needs of this target group but also because – from a public policy perspective – it encourages providers to experiment the use of new technologies in this field.

The 2nd one is an intervention aimed to offer, in a continuous and sustainable way, training opportunities to reduce the digital divide of seniors and other potentially excluded social groups, such as migrants and asylum seekers (among which many are employed as care workers). This intervention is particularly relevant as the lack of ICT skills was mentioned as a challenge for the successful implementation of all the above mentioned programmes and it is therefore a precondition for their further development.

<u>Policy Name</u>	LAW FOR THE RECOGNITION OF THE INFORMAL CARER (EMILIA ROMAGNA REGION) NORME PER IL RICONOSCIMENTO ED IL SOSTEGNO DEL CAREGIVER FAMILIARE (PERSONA CHE PRESTA VOLONTARIAMENTE CURA ED ASSISTENZA)
<u>Country</u>	Italy
<u>Link</u>	https://bit.ly/2HmxhRc

Objectives	The policy is a regional law aimed to support informal carers, listing responsibilities and options for different stakeholders to accomplish this goal. Among them, they explicitly mention the use of ICT as well as the implementation of peer-support groups.
------------	--

What problem the practice example wants to tackle	The policy lists the support interventions for caregivers that the Emilia Romagna Region commits to ensure to its citizens. The guidelines then specify how these supports should be provided and it is said that "opportunities offered by ICT should be included" and that among the Regional objectives there is the support to "mutual support groups" for informal carers.
Implementation	Continuous (embedded in the system).
Target groups	All informal carers above 18 y.o.
Technologies used	Not applicable
Challenges and difficulties	Since the law has been released recently, there is no information about specific challenges.
Role of ICT	the law explicitly mentions that training for informal carers has to be provided and it can be done via e-learning, however it only refers to training about care-related issues, empowerment of the informal carer and about how to access available services at local level. On the other hand, a Regional initiatives dedicated to digital literacy exists and it will be explained in another file.
The intervention include online peer-support group:	Not explicitly
Include activities to improve the digital knowledge and ICT learning	No
Who implement the intervention	According to the law, support services can be provided by public entities (social care and health care services) as well as by the non-profit sector).
Activities implemented:	Until now, the focus has been on disseminating information about the law via public events and working groups for professionals.
Evaluation	Internal

<u>Practice Name</u>	BREAD AND INTERNET: A PROJECT FOR DIGITAL LITERACY OF SENIORS - PANE E INTERNET
<u>Country</u>	Italy
<u>Link</u>	https://www.paneeinternet.it/public/pei-en

Objectives	<p>The strategic goal is to enhance citizens' digital competence and reduce digital exclusion among the project's target groups. This is done by promoting and supporting the establishment of so-called “Pane e Internet / PeI Points” by the largest municipalities and by Municipality Unions, with the involvement of their own resources and other local actors. A permanent and networked system of “PeI Points” across the whole region will cater for the citizens' digital needs. “PeI Points” promote citizens’ digital competence development in a life-long-learning perspective and their awareness and critical use of digital technologies and online services, in particular those offered by the public administration.</p>
What problem the practice example wants to tackle	<p>The strategic goal is to enhance citizens' digital competence and reduce digital exclusion among the project's target groups. This is done by promoting and supporting the establishment of so-called “PeI Points” by the largest municipalities and by Municipality Unions, with the involvement of their own resources and other local actors. A permanent and networked system of “PeI Points” across the whole region will cater for the citizens' digital needs. “PeI Points” promote citizens’ digital competence development in a life-long-learning perspective and their awareness and critical use of digital technologies and online services, in particular those offered by the public administration.</p> <p>Digital or e-facilitation means supporting a given citizen (occasionally a small group of people with the same problem) in using the Internet to meet his/her needs in everyday life: to communicate, find information, search for a job opportunity, learn something, and satisfy one’s interest and so on. Digital facilitation has two aims: to help a user with limited or no digital skills solving a specific problem by using the Internet (or other digital services and devices); to enhance the user’s autonomy by stimulating and enabling a continuous learning process.</p>

Implementation	<p>The implementation of the action is continuous and embedded in a broader action plan: It is part of Emilia Romagna's Digital Agenda axis/priority n.3 "Competences". The Competences axis addresses the development of digital competences for the following targets and domains: students and schools; workers, entrepreneurs and small-medium enterprises; civil servants; and through the PEI project all citizens, especially those at risk of digital and social exclusion.</p> <p>With the project, Region Emilia-Romagna contributes to the Italian coalition for digital competences. PEI has also witnessed one of the first Italian implementations of the European Digital Competence Framework for Citizens DigComp, developed by the European Commission.</p>
Target groups	<p>The following are Pane e Internet's main target groups: citizens in Emilia Romagna who are 45 to 74 years old and who have never used the Internet and online services. In absolute terms, they are about 760,000 people (in 2014) or 44% of the population in that age group. Considering the whole population, the share of the digitally excluded in Emilia Romagna is at 27%, whereas 93% of people above 74 years old have never used the Internet; immigrants and unemployed people with no or low digital competence; citizens who do not make a regular use of the Internet (about 35% of the whole population), any potential customer of digital facilitation services and also adults and young people interested in digital culture events.</p>
Technologies used	<p>Access to the community's online space is through the PEI website and is restricted to authorized users. On the platform, each user has a personalized dashboard, which reflects the user's role in the community and the interests and settings selected by the user. The dashboard provides a range of tools and resources organized into areas:</p> <ul style="list-style-type: none"> o Personal profile → where users post their photos, other personal information and make contact with other users chronological list of exchanges held with other users mutual help and o FAQ → where users ask for support on specific topics and/or give answers to other users' requests. Relevant content from this area is consolidated by the community moderators and fed into the FAQ o Section forum café → where users have informal exchanges about their activities and interests

	<ul style="list-style-type: none"> o News → where users find the news published on the PEI website and additional "internal" news from the PEI Service Centre and community moderators o Toolbox and questionnaires → where users find all the tools prepared by the Service Centre for the operation of the e-facilitation service (e.g. booking sessions with customers, gathering feedback from them etc.) and useful tools designed through peer-to-peer exchanges access to the e-facilitator section of the SELF e-learning platform where users join up to manage projects on topics of common interest access to the learning resources for e-facilitators in the SELF catalogue.
Challenges and difficulties	<p>A research performed among citizens who had benefitted from PEI's introductory digital literacy courses and digital facilitation services in 2011-14, showed that their needs go much beyond the initial digital literacy training and Internet access: 40% felt that they still had a limited mastery of Internet use 60% felt the need to get support (and had already requested it) in order to use the Internet as wished 78% were interested in further developing their competences to use the computer and the Internet. These findings led Regione Emilia-Romagna to design a second level of PEI courses and to develop a modular, flexible offer of additional training opportunities for specific target groups, such as unemployed people looking for a job and immigrants with low education and digital skills.</p>
Include online peer-support:	No
Include ICT literacy support:	Yes, this is the goal of the practice
Who implement the intervention	<p>The intervention is delivered by e-facilitators, which can be library staff or volunteers. They have been recruited through PEI's partners and other interested organizations; through specific promotion and recruitment events, PEI's web site and other means. An e-facilitator must be able to perform these and other common tasks. But she should also be able to listen to and make sense of customers' requests; to answer effectively with clear and simple explanations; to stimulate and support the customers' learning and autonomy. Free introductory course has been offered to e-facilitators.</p>
Activities implemented:	<p>The creation of the PEI Service Centre (PSC) is part of the move towards a more decentralized development of PEI activities, with the creation of local</p>

	<p>PEI Points and the involvement of other local actors. This made it necessary to set up a regional service centre that could support in various ways all these actors and stimulate their horizontal collaboration, and that could design and promote common operational procedures and quality standards in PEI services delivery (training, digital facilitation etc.). Along with existing and new PEI Points, the PSC offers a range of tools and services also to other Municipalities, public libraries and any local non-profit organizations wishing to implement autonomously some of the typical PEI activities such as digital literacy courses, digital facilitation and digital culture events. This offer comprises: learning materials published on the PEI Catalogue procedures and tools for use in training and digital facilitation activities (e.g. the free-phone booking service, the course register, the attendance certificate and others) standard and customizable promotional materials (leaflets, posters etc.); information on funding opportunities from regional, national and European sources, also thanks to PEI's membership in All Digital on-demand advice and consulting for the effective implementation of digital competence and inclusion initiatives. The above PSC's services are given for free to the PEI Points and the other actors, with the aim to lower their operational costs, increase the sustainability and promote a more homogenous quality of their initiatives.</p>
Best profile and skill for people implementing practice	<p>An e-facilitator must be able to perform these and other common tasks. But she should also be able to listen to and make sense of customers' requests; to answer effectively with clear and simple explanations; to stimulate and support the customers' learning and autonomy. Methodological competences adapting one's support activities depending on the type of customer and context becoming aware of what a citizen service is and how it works codifying one's tacit knowledge to be able to "transfer" it to others. Relational competences listening to and receiving a customer's needs communicating effectively by adapting communication to customers' characteristics team work organizational competences managing the e-facilitation service's operational processes according to PEI project's rules: collecting customers' registration, organizing an e-facilitation session, optimizing time use with the customer and so on.</p>
Evaluation	<p>The evaluation was done internally and it focused on: satisfaction of participants to the facilitation / training sessions through a questionnaire (over 6.000 collected).</p>

	<p>Main results/conclusions/recommendations from the evaluation: 58% evaluated the training as "excellent", 32% as "fair", 9% "sufficient", 1% "insufficient". A research performed among citizens who had benefitted from Pel's introductory digital literacy courses and digital facilitation services in 2011-14, showed that their needs go much beyond the initial digital literacy training and Internet access: 40% felt that they still had a limited mastery of Internet use 60% felt the need to get support (and had already requested it) in order to use the Internet as wished 78% were interested in further developing their competences to use the computer and the Internet.</p>
--	--

<u>Practice Name</u>	TV-ASSISTDEM: A PLATFORM FOR PEOPLE WITH MILD DEMENTIA
<u>Country</u>	Spain, Italy, Switzerland, Romania
<u>Link</u>	http://www.tvassistdem-aal.eu/

Objectives	<p>The main purpose of TV-ASSISTDEM is to evaluate an assisted and integrated solution system of home care, based on ICT for a challenging clinical domain (i.e. mild dementia) and show how it will provide benefits to patients, carers and the healthcare systems.</p> <p>The project objectives are:</p> <p>To design a new platform that can be comfortably and reliably used by patients with Mild Dementia (MD), validated by at least 80% approval rate in focus groups and small scale patient trials.</p> <p>To show the medical benefits of using the platform by increasing treatment compliance by MD patients from 50% to 60%; reduce functional decline of patients during the first 24 months from diagnosis by 10%; monitor and improve the quality of life for MD patients, measured using the Johns Hopkins Alzheimer's Disease Related Quality of Life (ADRQL); monitor the mental well-being of carers through the internationally validated quality of life scales Short Form 12 (SF-12).</p> <p>To show the economic and financial benefits of using the TV-ASSISTDEM platform: Reduce costs wasted on unused medicine by 50%; reduce costs associated with patients failing to attend appointments by 75%; reduce costs associated with readmission of patients to hospital (for resurgent conditions due to lack of treatment adherence) by 30%; provide overall efficiency savings to the healthcare system of 10% of dementia budget.</p> <p>To develop sustainable business models for large-scale commercial roll-out of the TV-ASSISTDEM platform in different scenarios and regions. Include financial models for investment, based on risk sharing between relevant stakeholders and provide projections for each stakeholder's return on investment to complete the economic argument.</p>
What problem the practice example wants to tackle	TV-ASSISTDEM aims to improve the quality of life of both, patients and their carers. Patients will benefit from improved adherence to their treatment (for MD or other conditions), which will slow down their physical or mental

	deterioration. Carers will benefit from easier communication with doctors, allowing the carers to draw on support to avoid mental and emotional exhaustion.
Implementation	Periodic
Target groups	Older people
Technologies used	<p>Support platform based on their own Home TV device (or STB, Set Top Box) designed with android and digital TV for older people with healthcare necessities, and more specifically, for older people with dementia.</p> <p>This Home TV device or STB include several hardware and software features that allow the project to develop the services in order to reach the project goals of high functionality and low cost expected. This specific design of the platform solution is the key differentiation from consumer devices like Apple TV, Amazon fire TV, Google Chromecast or Smart TV product like Samsung Smart TV or LG Smart TV. This commercial platform does not have the complete set of functionalities that services for older people with dementia require, and most important, they don't allow the service provider to control and managing the system at complete level (like install or remove applications/contents remotely from service provider servers).</p>
Challenges and difficulties	<p>Patients have a very special set of requirements, due to the nature of the condition. TV-ASSISTDEM will need to be adapted such that MD patients and, where necessary, carers can comfortably and reliably use it. To be successful this adaptation must be heavily informed by patients, with additional input from carers and healthcare professionals.</p> <p>Most of research on assistive technologies, led by computer scientists, is remarkably thin on clinical detail. Because of this, it tends to generate superficially plausible solutions that may prove unusable in practice because their design fails to take account of how multiple medical conditions affect a person's ability to understand and operate a technical device – or of variation in how people may want to use the device and, indeed, what they may want to use it for.</p> <p>The medical benefits of the adapted application must be objectively proven through a dedicated large scale pilot with MD patients and their carers. For</p>

	credibility, the pilot should include a second group of patients / carers as controls, to isolate the effect of TV-ASSISTDEM from general treatment. The pilot's results must be published in high-quality peer-reviewed journals, both to validate them and to increase their visibility to potential adopters.
Include online peer-support:	<p>YES</p> <p>Patient-support tool TV-ASSISTDEM could help patients with dementia to keep control over their lives, increasing patients' independence. The improved communication between patients and their (formal and informal) carers reduces the social isolation and social exclusion of patients. Through TV-based transmission of data and video-interactivity, carers, patients and professional have the opportunity to communicate and share their experiences. Across this communication path, all participants create stronger communication links between not only with their respective roles, but also between healthcare professionals, something that allow better support for the latter, improving careers' quality of life by reducing the negative impacts of care. Ultimately, TV-ASSISTDEM could reduce the need for emergency and/or institutionalised care for patients and carers, reducing the costs of healthcare systems and increasing the healthcare systems' sustainability in the face of the ageing population. The end user could be involved from the beginning through patient's associations and health system involvement in the adaptation and personalization of platform to patients with dementia.</p>
Include ICT literacy support:	No.
Who implement the intervention	<p>A consortium that include:</p> <p>Health Research Institute of Malaga (IBIMA; www.ibima.eu) is a multidisciplinary public institution dedicated to biomedical research around the Servicio Andaluz de Salud in Malaga (Regional University Hospitals and Hospital Virgen de la Victoria and primary care centres) and biotech groups at the University of Malaga. The IBIMA integrates 47 research groups at the University of Malaga and Andalusian Health Centres.</p> <p>MEDEA an European leading consultancy SME working to promote innovation policies and strategies in the following areas:</p> <p>Connected Health and Active Ageing • Smart Living & Ageing Society • Inclusive Society</p>

	<p>The Italian National Research Council (CNR - www.cnr.it) is the main public research organization in Italy. It participates in this project with CNR-ISTC, the CNR Institute for Cognitive Science and Technology (istc.cnr.it), and more specifically with the Planning and Scheduling Technology Lab (PSTlab–istc.cnr.it/group/pst) which conducts research in Artificial Intelligence (AI) since 1997 and in Ambient Assisted Living (AAL) since 2002.</p> <p>MSD is a statistical consulting company working for national and international companies and academic institutions. It has a large experience in the assessment of scientific projects, in data analysis and scientific communication. MSD will be mainly responsible for the data analysis part of the project and it will get involved from the beginning of the project as the experience shows that early involvement of the statistical analysis (clinical set up, data types, sampling rates, etc.) is crucial for the success of a research project.</p> <p>Home care LTD.(INGRIJIRI LA DOMICILIU SRL), is a Romanian home care company founded in 2008. AIA provides social and medical care at home for over 800 people, most of them elderly, temporarily or permanently incapacitated and unable to take care of themselves. From wound care to treatment administration and physical recovery, AIA provides its services in a large region in Romania, having a team of approx. 25 people (doctors, medical nurses, kinetotherapists).</p>
Activities implemented:	Requirements identification and analysis; designing the methodology for all partners to use during the pilot; defining the best practices for patients recruitment; acquiring ethics approval in the countries of our pilot and training of clinicians.
Evaluation	<p>Who did the evaluation: Internal and external parties.</p> <p>The evaluation was focused on the potential Impact of the Proposed Solution on Quality of Life.</p> <p>IMPROVING QUALITY OF LIFE FOR END-USERS: The quality of patients life and also of carers will be measured throughout the project, using the ADRQL scale for patients and the Mental Component Summary of the SF-12 questionnaire for carers.</p> <p>The difference in average QoL scores between intervention and control group will be reported at least annually. MSD will lead the data analysis and will determinate the main indicators related with quality of life.</p>

	<p>THE AIMED SERVICE MODELS: IMSD will calculate the financial savings for the healthcare system in each country, based on reduced emergency / repeat admissions to hospital, reduced expenditure on unused medication and on time of healthcare professionals.</p> <p>SOCIAL AND ETHICAL IMPACT: The main societal benefit of ICT based solutions for cognitive impairments is that sufferers participate in society longer, driving by a reduced rate of cognitive decline. During the life time of project we will show how the system reduces the rate of cognitive decline at the end of MD. As we will maintain the platform post-project we will be able to show directly that TV-ASSISTDEM delays patients' entry into full-time care. Furthermore, slowing the pace of cognitive decline directly reduces the stress placed upon carers and improves the carers' quality of life.</p>
--	--

5. CONCLUSIONS & KEY RECOMMENDATIONS

The data gathered through the literature review, interviews and good practices review lead the partnership to **some general conclusions**.

- The difficulties encountered when trying to identify good practices in relation to web-based support groups for informal carers illustrate the fact that such support is **very seldom implemented**, despite being valued by experts and practitioners. This is an acute illustration of the lack of recognition of the needs of informal carers, and of the lack of development of relevant supporting services.
- More initiatives were identified that relate to **training for informal carers of people with dementia**, which content could be usefully used in the development of training for facilitators of web-based support groups for informal carers, as well as signed posted to carers likely to be interested. However, guarantees regarding the positive evaluation, the regular update and the accessibility in the long term of the training material are often lacking.
- A series of relevant initiatives were identified, though not selected because of a **lack of documentation**, which made them difficult to transfer. Indeed, a number of relevant initiatives are developed within a tight budget, and face sustainability issues. Such financial limitations prevent these initiatives to benefit from robust evaluation and extensive dissemination. This illustrates also the lack of transnational research on how to better support carers, likely to focus on these promising initiatives.
- This is all the more regrettable that, as shown in this study, initiatives developing web-based support groups for carers share a series of common challenges, and **the development of this promising tool would benefit from evaluation and cross-country analysis**.

Though, based on the outcomes of our research, we can identify some **key-recommendations** that could inform the next steps of the Care4Dem project:

Digital skills are a precondition for the success of ICT-based programs, but they shouldn't be given for granted: it is clear that no ICT-based intervention can be effective if the target users do not have the necessary skills to access and use them. Therefore, while adopting ICT tools can be an inclusive practice towards carers who have reconciliation issues or who live isolated, it can on the other hand contribute to exclude those who are not familiar with new technologies or who do not have the necessary devices. In order to avoid this risk, some precautions should be taken:

1. **Make sure that target users can access ICT training opportunities:** these could either be embedded in the project or make use of opportunities offered at local level by other organizations. In this latter case, available courses should be mapped and synergies seek with “local intermediaries” such as associations, unions, municipalities, local communities or others. High school students can be involved in delivering smartphone digital literacy to citizens through School internships.
2. **Promote the “Bring your own device approach”:** in either cases, it is a good practice to allow trainees to attend the training using their own devices. Indeed, if people are able to use their devices it is more likely that they will continue learning activities and internet usage after the course.
3. **Build on applications and software that are largely used:** it seems wise to implement interventions using tools which the public is likely to know, such as for example Whatsapp / Messenger – Facebook – Skype etc. Users might be more encouraged to use something they already know instead of a new tool that they have to learn from scratch.

Peer-support groups are proven to be effective for informal carers, but the participation should be fostered in different ways and from different points of view: there are evidences that peer-support groups are an effective tool to support informal carers and relieve their burden. However, it is important to take into consideration some issues, concerning the recruitment and retention of participants:

1. Participation to the group should not be perceived as an extra-task for the carer: although ICT should help to control this risk, it is important to recognize the difficulties of the informal caregiver to participate in the mutual aid group and to acknowledge that there might be drop-outs or inconstant participation.
2. Recruitment strategies should take into account the specificities of informal carers: special attention should be taken to reach the target population living in more isolated/not urban areas. For this target population it would be important to identify dedicated promotion channels, in order to make sure that information reach also those people.
3. Virtual vs. Physical: although ICT is meant to overcome geographical distances, this might not necessarily mean that the all process should be virtual. For example, it could be envisaged that while the process will primarily be delivered online, some meetings are foreseen. Indeed, being all together in the same room might contribute to create a sense of belonging and of being “a group” for participants. Also, in case participants come from different geographical areas it might be advisable for the facilitators to make sure he/she knows to whom the carer can be referred to at local level, and which services he/she can access locally in case of need.
4. Web-based support groups should be embedded in an integrated set of supporting services for informal carers, offering recognition, information, respite care, counselling ...

Moderation: experience and soft skills are highly recommended

1. In most of the practices analysed, the moderation of online discussion is relatively light, contributions do not need to be approved before publication, and the priority is put on facilitating the participation of all. Therefore, the role of the facilitator is not prominent.
2. For four practices, facilitators are required to have followed a training (either a generic training or an ad hoc training regarding this particular support group): providing a training to facilitators is not a common pattern.
3. Some practices require that the facilitator is a professional (care or social worker, psychologist...) and value to a certain degree of knowledge about the issues (from a

medical and administrative point of view). However, experience (in caring and in participating to support groups), motivation, and soft skills (communication, empathy, and sensitivity) seem to be of paramount importance in most of the cases.

Local policies recognizing carers and their needs constitute the necessary background for an effective intervention: interventions are never delivered in a vacuum. The local context makes the difference in terms of potential impact of the intervention:

1. **Raise awareness:** Promote the increasing awareness of the issues faced by informal carers in the context of the demographic change within public opinion and public authorities at local level. This will have positive consequences on the capacity of reaching out carers and in creating synergies between the Care4Dem and other interventions offered at local level.
2. **Foster commitment:** the commitment of public authorities towards informal carers should be fostered, for example by lobbying for the explicit inclusion of informal carers as target group of interventions dealing with ICT-literacy, or build partnerships with the promoters of initiatives at local level, allowing them to scale-up and reach a wider group of informal carers;
3. **Introduce web-based support groups:** local policies aimed at developing dementia friendly societies and community care for people with dementia should, building on existing initiatives, introduce web-based support groups within the set of tools implemented.

Policy background at national level

Main competencies in relation to health and long-term care lay at national level; governments should ensure the sustainability of long-term care for people with dementia through an adequate combination of appropriate quality care services and support for their carers. Such a national framework is needed to back the development of relevant support at local and regional level.

1. Informal carers should be granted **legal recognition**, to which specific rights in relation to work-life balance, and financial support should be attached.
2. The provision across the whole territory of **adequate integrated social, health and long term care services** should ensure that the long-term care of people with dementia is not left to the sole responsibility of informal carers, that they can rely on services on general interest to alleviate the most intensive aspect of care, and concentrate on contributing to the well-being and quality of life of people with dementia, and preserve their own health status.
3. **Adequate funding** should be devoted to the development of initiatives supporting informal carers at national level, in cooperation with organisations representing informal carers.

The European Union should play a decisive role in supporting and steering the efforts made by member states for supporting informal carers, notably through:

1. **Implementing the Pillar of Social Rights**, including for informal carers (including adopting and implementing the 'Work-Life Balance Directive currently discussed, which allows specific rights to carers.
2. **Ensure European funding is available** for initiatives that support informal carers.
3. **Support transnational research and mutual learning** on how to best support informal carers.

6. REFERENCES

1. **European Commission, 2014.** *The social protection for long-term care needs in an ageing society. Report jointly prepared by the Social Protection Committee and the European Commission.* Brussels : European Commission, 2014.
2. Ploeg J, Markle-Reid M, Valaitis R, McAiney C, Duggleby W, Bartholomew A, et al. Web-Based Interventions to Improve Mental Health, General Caregiving Outcomes, and General Health for Informal Caregivers of Adults With Chronic Conditions Living in the Community: Rapid Evidence Review. *J Med Internet Res* [Internet]. 2017 Jul 28 [cited 2018 Apr 17];19(7):e263. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/28754652>
3. Andersson S. Information and Communication Technology-mediated support for working carers of older people. [cited 2018 Apr 17]; Available from: <http://www.diva-portal.org/smash/get/diva2:1108889/FULLTEXT01.pdf>
4. Wasilewski MB, Stinson JN, Cameron JI. Web-based health interventions for family caregivers of elderly individuals: A Scoping Review. *Int J Med Inform* [Internet]. Ireland: Elsevier; 2017 Jul;103(April):109–38. Available from: <http://dx.doi.org/10.1016/j.ijmedinf.2017.04.009>
5. Self Help U.K. What is a self help group? | Self Help UK [Internet]. [cited 2018 Mar 14]. Available from: <https://www.selfhelp.org.uk/about/what-is-a-self-help-group>
6. Primary care and dementia: long-term care at home: psychosocial interventions, information provision, carer support and case management, Louise Robinson Steve Iliffe, Carol Brayne, Claire Goodman, Greta Rait, Jill Manthorpe, Peter Ashley, Esme Moniz-Cook, and the DeNDRoN Primary Care Clinical Studies Group, in *International Journal of Geriatric Psychiatry* 2010; 25 : 657–664 Available from: <https://www.ncbi.nlm.nih.gov/pubmed/19946862>
7. Higgins JPT, Altman DG, Gøtzsche PC, Jüni P, Moher D, Oxman AD, et al. The Cochrane Collaboration’s tool for assessing risk of bias in randomised trials. *BMJ*. 2011;343(7829):1–9.
8. Flatley Brennan P, M. Moore S, A. Smyth K. Brennan PF, Moore SM, Smyth KA. The effects of a special computer network on caregivers of persons with Alzheimer’s disease. *Nurs Res*. 44(3):166-172. Vol. 44, Nursing research. 1995. 166-172 p.
9. Austrom MG, Geros KN, Hemmerlein K, McGuire SM, Gao S, Brown SA, et al. Use of a multiparty web based videoconference support group for family caregivers: Innovative practice. *Dementia* [Internet]. NIH Public Access; 2015 Sep [cited 2018 Mar 14];14(5):682–90. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/25062788>
10. Boots LM, de Vugt ME, Withagen HE, Kempen GI, Verhey FR. Development and Initial Evaluation of the Web-Based Self-Management Program “Partner in Balance” for Family Caregivers of People With Early Stage Dementia: An Exploratory Mixed-Methods Study. *JMIR Res Protoc*. Canada; 2016 Mar;5(1):e33.

11. Glueckauf RL, Ketterson TU, Loomis JS, Dages P. Online Support and Education for Dementia Caregivers: Overview, Utilization, and Initial Program Evaluation. *Telemed J e-Health* [Internet]. 2004 Jun [cited 2018 Mar 14];10(2):223–32. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/15319052>
12. Serafini JD, Damianakis T, Marziali E. Clinical Practice Standards and Ethical Issues Applied to a Virtual Group Intervention for Spousal Caregivers of People with Alzheimer's. *Soc Work Health Care* [Internet]. Taylor & Francis Group ; 2007 Apr 5 [cited 2018 Mar 14];44(3):225–43. Available from: http://www.tandfonline.com/doi/abs/10.1300/J010v44n03_07
13. Smyth KA, Rose JH, McClendon MJ, Lambrix MA. Relationships Among Caregivers' Demographic Characteristics, Social Support Ratings, and Expectations of Computer-Mediated Support Groups. *J Appl Gerontol* [Internet]. Sage PublicationsSage CA: Thousand Oaks, CA; 2007 Feb [cited 2018 Mar 14];26(1):58–77. Available from: <http://journals.sagepub.com/doi/10.1177/0733464806296144>
14. O'Connell ME, Crossley M, Cammer A, Morgan D, Allingham W, Cheavins B, et al. Development and evaluation of a telehealth videoconferenced support group for rural spouses of individuals diagnosed with atypical early-onset dementias. *Dementia* [Internet]. SAGE PublicationsSage UK: London, England; 2014 May 4 [cited 2018 Mar 14];13(3):382–95. Available from: <http://journals.sagepub.com/doi/10.1177/1471301212474143>
15. Bank AL, Argüelles S, Rubert M, Eisdorfer C, Czaja SJ. The value of telephone support groups among ethnically diverse caregivers of persons with dementia. *Gerontologist* [Internet]. 2006 Feb [cited 2018 Mar 14];46(1):134–8. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/16452294>
16. McKechnie V, Barker C, Stott J. Effectiveness of computer-mediated interventions for informal carers of people with dementia—a systematic review. *Int Psychogeriatrics* [Internet]. 2014 Oct 3 [cited 2018 Mar 14];26(10):1619–37. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/24989249>
17. S. Andersson (2017) Information and Communication Technology-mediated support for working carers of older people, Doctoral dissertation, Department of Health and Caring Sciences, Linnaeus University, Kalmar, Sweden. Available from: <http://www.diva-portal.org/smash/get/diva2:1108889/FULLTEXT01.pdf>
18. Schulmann, K., Ilinca, S. & Leichsenring, K. (2017) Community care for people with dementia: A handbook for policymakers, EURO.CENTRE.REPORT no. 10, European Centre, Vienna. Available from: <http://www.euro.centre.org/publications/detail/424>
19. Eurocarers. Informal caregiving and learning opportunities: an overview of EU countries [Internet]. Brussels; 2017 [cited 2018 Apr 17]. Available from: http://eurocarers.org/userfiles/files/track/TRACK Baseline Report_ APRIL 2016_for external publication.pdf

*The European Commission support for the production of this publication
does not constitute an endorsement of the contents
which reflects the views only of the authors,
and the Commission cannot be held responsible for any use which
may be made of the information contained therein.*

7. ANNEX

1. QUESTIONNAIRE CARE 4 DEM

Dear Partners in O1,

During this task all participating member states will have to identify three promising practices in the field of Dementia Caregivers in their countries. The identified promising practice examples will then be reviewed and their summaries will be published in our platform.

What are we looking for?

Interventions, practices, strategies and policies that develop web-based support groups for dementia caregivers.

Policies and web-based strategies which aim is to reduce the absenteeism and dropout in current dementia carers support programmes through web-based mutual aid groups for dementia caregivers.

What is beyond the scope of our task and cannot be included?

Interventions, practices, strategies and policies that address to dementia patients, without their caregivers.

Please do not hesitate to double check with us in case you are insecure if your promising practice example matches the above mentioned areas.

Please identify three promising practice interventions and two policies in your country to develop web-based mutual groups for dementia caregivers.

We would appreciate if you could identify and send us your promising practice examples until the **31th of January 2018**.

Please coordinate your selection with the partner organization(s) from your country.

Please feel free to contact us for any additional information.



Acknowledgement: This template has been developed on the basis of the RARHA Joint Action's best practice documentation framework (www.rarha.eu/) and on CHRODIS Joint Action (<http://chrodis.eu/>).

Before starting to fill in the questionnaire, please read carefully the following questions representing the basic requirements for inclusion of examples of promising practices.

Does the intervention/practice/policy belong to the field of web-based support for caregivers?

(This support could be based on training programmes, psychoeducational programmes, support groups, mutual aid groups, information technology based support and/or other formal approaches delivered by social and/or healthcare professionals).

Yes

No

Is the intervention documented (e.g. online, in a report that is easily accessible, in a peer reviewed journal or grey literature? (e.g., implementation procedures, resources, manuals, measurement of outcomes and processes)

Yes

No

ONLY IF YOU ANSWERED ONE OUT OF THESE QUESTIONS WITH 'YES', PLEASE PROCEED WITH THE COMPLETION OF THIS QUESTIONNAIRE.

If you selected NOT both questions, but you have a practice / policy in some way related, please attach the document containing the detailed explanation

Are all of the following elements described in such detail that the approach and methodology are comprehensive, transferable, and also allow for some estimate of effectiveness?

	YES	NO
Objectives		
Target group		
Approach		
Prerequisites for implementation (e.g. description of ICT infrastructure)		
Participants' satisfaction		
Evaluation		

DESCRIPTION OF THE INTERVENTION OR POLICY

Name of the intervention in English and in original language:

Short description of the intervention (abstract): WHO, WHAT, WHERE, WHEN, HOW (Please give a short description (less than 600 words) of the aim of the intervention, the target group and the design/ method - sequence of activities, frequency, intensity, duration, recruitment method):

To which type of interventions does your example of policy / promising practice belong to (*it is possible to mark more than one answer*)?

- Group Intervention
- Pilot intervention
- European or international project (i.e. implemented in several countries)
- Policy/strategy/ service
- Other. (Please specify)

How is this example of policy / promising practice funded? (*it is possible to mark more than one answer*)

- National/regional/local government
- Institution of education, public health and/or research
- Non-governmental organization
- Private sector company/organization
- Other resources. (Please specify)

What is/was the level of implementation of your example of policy / promising practice ()?

- National
- Regional
- Local (municipality level)
- Other. (Please specify)

What are the main aim and the main objectives of your example of policy / promising practice?.

(Less than 300 words)

Please give a briefly description (less than 300 words) of the problem the policy / promising practice example wants to tackle (nature, size, spread and possible consequences of the problem):

Is your example of policy / promising practice embedded in a broader national/regional/ local policy / action plan?

- Yes (please, describe in less than 300 words)

- No

Implementation of your example of policy / promising practice is/was:

- Continuous (integrated in the system)
- Periodic (Please specify):

- Single - How long did it last?
 - Less than one year
 - One year
 - From one to two years
 - More than two years

- If you have already finished the intervention, please answer these questions

Date of the last time it was carried out:

Are you planning to repeat it?

Profile of target groups (it is possible to mark more than one target group):

- General population
- Young adults
- Adults
- Older population
- Women
- Men
- Other. (Please specify)

Are you including one of these vulnerable social groups (*it is possible to mark more than one answer*):

- Ethnic minorities
- Migrants
- Disabled people
- Low income groups
- Low education groups
- Unemployed
- Uninsured groups
- Homeless
- Isolated older people
- Other. (Please specify)

What kind of technologies are used/ have been used (i.e. social network, email, web 2.0 forums, web-page, blogs, chat messages, Apps,...) in order to achieve the objectives of the policy/promising practice?. (Less than 300 words)

What are the challenges and difficulties you had in introducing the use of ICT? (Less than 300 words)

Does your policy/promising practice include activities to improve the digital knowledge and ICT learning of caregivers who is addressed (i.e. manuals, face-to-face training, e-learning, etc.)? Please describe them briefly (Less than 300 words)

Who implements/implemented the intervention (an individual or a team or an organization or a network of organisations, describe professional background of the team, etc.)? (Less than 300 words)

What core activities are/have been implemented (i.e. the activities that have been implemented in order to achieve the objectives of the intervention, such as for example training sessions, dissemination events, material published)? (Less than 300 words)

What is the best profile and skill for people implementing the policy/promising practice? (Less than 300 words)

In case of Mutual Aid Groups, What is the best profile for moderator? (Less than 300 words)

EVALUATION

Who did the evaluation?

- An external institution
- An internal institution (representatives of the intervention, own organisation)
- Both – internal and external parties

What has been measured / evaluated?

- Process evaluation (respondents, method, participants satisfaction) (please describe)

- Evaluation of the impacts/effects/outcome (please describe the design)

- Other (please add and describe, less than 300 words)

What are the main results/conclusions/recommendations from the evaluation (please describe, less than 600 words)?

Is the evaluation report available, preferably in English or at least in Your country language summary? (if yes, please provide link/reference/document)

Was there a follow-up (describe how) or is any follow-up evaluation planned in the future?. (Less than 300 words)

What were, in your opinion, the pre-conditions for success? Were there any facilitating factors?. (Less than 300 words)

What are the main lessons to be learned?. (Less than 300 words)

What are the main challenges and difficulties have you found?. (Less than 300 words)

Recommendations, based on your experience, to improve the sustainability of promising practice. (Less than 600 words)

ADDITIONAL INFORMATION

Web page related to the intervention

References (with possible links) to the most important articles or reports on the intervention

Other relevant documents (implementation manuals, training manuals, posters, videos or other tools available for use or adaptation, etc.):

Contact details of person who may be contacted for further information

ONLINE PEER SUPPORT

Answer following questions only if your practice / policy include online peer support.

Please, provide us with the following information concerning the organization of the online peer-support group presented in your practice.

QUESTIONS FOR SYNCHRONOUS GROUPS (MEETING VIA TELECONFERENCE BASED TECHNOLOGIES)

1. **Recruitment:** how do you recruit participants for the group?

- ☐ Self-referral
- ☐ Sign-post by other organizations
- ☐ Other (specify):

2. **Organization of the group:** is the group

- ☐ Open (new participants can join at any times)
- ☐ Close (new participants can only join on fixed terms)
- ☐ Other (specify):

3. **Frequency:** how often does the group meet?

- ☐ Weekly
- ☐ Every 15 days
- ☐ Monthly
- ☐ Other (specify):

4. **Time schedule:** at what time of the day does the group meet?

- ☐ Morning
- ☐ Afternoon
- ☐ Evening
- ☐ Night

5. **Participants:** how many participants does an average session have?

- ☐ Up to 5
- ☐ 5-10
- ☐ More than 10
- ☐ Other (specify):

6. **Moderation:** the group is moderated by

- ☐ Professionals
- ☐ Peers
- ☐ Other (specify):

7. **Promotion:** how do you promote your group, in order to get new participants?

- ☐ Word-of-mouth
- ☐ Social networks / web
- ☐ Local advertisements
- ☐ Other (specify):

8. **Geographical location:** your participants:

- ☐ All live in the same geographical area (city / district)
- ☐ Live in different cities around the country
- ☐ Live in different countries
- ☐ Other (specify):

QUESTIONS FOR ASYNCHRONOUS GROUPS (MEETING VIA TELECONFERENCE BASED TECHNOLOGIES)

1. **Recruitment:** how do you recruit participants for the group?

- ☐ Self-referral
- ☐ Sign-post by other organizations
- ☐ Other (specify):

2. **Organization of the group:** is the group

- ☐ Open (new participants can join at any times)
- ☐ Close (new participants can only join on fixed terms)
- ☐ Other (specify):

3. **Frequency:** in average, how frequent are new posts / discussions?

- ☐ Several times during the day
- ☐ Daily
- ☐ Weekly
- ☐ Every 15 days
- ☐ Other (specify):

4. **Participants:** how many participants does your group have?

- ☐ Up to 5
- ☐ 5-10
- ☐ More than 10
- ☐ More than 20
- ☐ Other (specify):

5. **Participants:** Among them, how many can be considered as active members?

- ☐ 10%
- ☐ Up to 30%
- ☐ Up to 50%
- ☐ Up to 75%
- ☐ Up to 100%
- ☐ Other (specify):

6. **Moderation:** the group is moderated by

- ☐ Professionals
- ☐ Peers
- ☐ There is no moderation
- ☐ Other (specify):

6b. **Moderation:** in case the group is moderated, are the posts subjected to approval by moderator before being published?

- ☐ Yes
- ☐ No
- ☐ Other (specify):

7. **Promotion:** how do you promote your group, in order to get new participants?

- ☐ Word-of-mouth
- ☐ Social networks / web
- ☐ Local advertisements
- ☐ Other (specify):

8. Geographical location: your participants:

- ☐ All live in the same geographical area (city / district)
- ☐ Live in different cities around the country
- ☐ Live in different countries
- ☐ Other (specify):

2. SUMARIZE POLICIES AND PRACTICES

NAME OF PRACTICE/POLICY	TARGET GROUPS	TECHNOLOGIES USED	ACTIVITIES IMPLEMENTED
<u>POLICY 1:</u> <i>NORME PER IL RICONOSCIMENTO ED IL SOSTEGNO DEL CAREGIVER FAMILIARE (PERSONA CHE PRESTA VOLONTARIAMENTE CURA ED ASSISTENZA)</i>	Young, older and informal caregivers	Not able to get information	Training for informal careers by e-learning refer to care-related issues, empowerment of the informal career and how to access available services at local level
<u>PRACTICE 1:</u> <i>PANE E INTERNET</i>	Older, ethnic minorities and migrants	Website PEI with an online space which include personal profile, FAQ, section forum café and toolbox and questionnaire	Creation of the PEI Service Centre (PSC) which include learning material; tools for use in training and digital facilitation activities and standard; customizable promotional material
<u>PRACTICE 2:</u> <i>ONLINE PEER SUPPORT GROUP FOR INFORMAL CARERS – GRUPPO AMA ONLINE PER CAREGIVER FAMILIARI</i>	Informal caregivers and other vulnerable groups	Skype	Virtual and face-to-face meeting in order to provide a support service
<u>PRACTICE 3:</u> <i>STIMULAREA INTEGRARII PE PIATA MUNCII A INGRIJITORILOR FAMILIALI AI PERSOANELOR VARSTNICE PRIN IMBUNATATIREA COMPETENTELOR – ELMİ</i>	Informal caregivers, low education people and unemployed.	e-learning platform, web-page and web 2.0 forum	On-line training course, on-line line platform of resources, a handbook for informal careers of elderly
<u>PRACTICE 4:</u> <i>LA COMPAGNIE DE AIDANTS</i>	Informal caregivers	Built on the model of Facebook. Informal carers and volunteers registered in the directory can see each other's profile and exchange messages through a secured platform, which respect their privacy	Active communication with conferences, public media, dissemination of leaflets and contest

<u>PRACTICE 5:</u> <i>EDUCA&CARE</i>	Educated health students and Informal caregivers with emotional problems	web-page (http://educacare.web.ua.pt/)	Classes and sessions; Face-to face services to informal caregivers in health local services; Dissemination activities (e.g. seminars, leaflets, books, articles).
<u>PRACTICE 6:</u> <i>CUIDEM PROJECT</i>	Informal caregivers, Health professionals, people from ONG's and social workers.	web-page, Facebook, e-mail	For health professional: training sessions, awareness sessions focus group, web-based group and good practices manuals. For informal caregivers: mutual Aid groups, health education and dissemination of information (website, leaflets). Others disseminations events: launching event, closing event, participation in congresses, seminars.
<u>PRACTICE 7:</u> <i>EN BRA PLATS</i>	People older than 16 years coming for all groups	Social network, online forum available on mobile phone, tablets, laptops, stationary computers	Training session for professionals; manual for carers and professionals; Information material for carers and professionals and workshops for professionals.
<u>PRACTICE 8:</u> <i>TV-ASSISTDEM</i>	Older people	Support platform based on their own Home TV device (or STB, Set Top Box) designed with android and digital TV	Requirements identification and analysis; designing the methodology for all partners to use during the pilot; defining the best practices for patients recruitment; acquiring ethics approval in the countries of our pilot and training of clinicians

