2017-1-IT02-KA204-036545

CARE4DEM
Dementia Caregivers Support

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Care4Dem Facilitator's Competence Profile & Online Self-Assessment Tool

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USER'S GUIDE

I Programme

Care4Dem – Dementia Caregivers Support 2017-2020

I Partners

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I Publication date

June 2020

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Key information about the Care4Dem project

THE BACK DROP: INFORMAL CARERS OF PEOPLE WITH DEMENTIA NEED BETTER SUPPORT

Some support and care for people living with dementia is provided by services in the public and private health sectors, but also, for a number of these vulnerable persons, by their relatives. This is the case also for people affected by other chronic diseases or long-term conditions. Overall, informal carers provide over 80% of all care in Europe today, with women providing approximately two-thirds of care mainly as daughters (in law) and wives/partners. Although providing care to a loved one can give a sense of satisfaction and result in an increased self-esteem, informal caregivers, also called carers or family caregivers, face multiple disadvantages in our societies – including difficulties in balancing work and caring responsibilities, stress and risk of burn-out, drop-out from labour market, increased risk of poverty, isolation and social exclusion.

Therefore, there is a need for interventions to the benefit of informal caregivers, providing them with effective support. This support has been implemented over the years throughout training programmes, psychoeducational programmes, support groups and mutual aid groups (MAGs), information-technology based support or other formal approaches delivered by healthcare professionals. Though, it remains insufficient, and out of reach for carers who don't have the availability to attend face-to-face interventions, or live in an area where no support of this kind is provided.

THE CARE4DEM PROJECT (SEPT 2017 – AUGUST 2020)

The Care4Dem - Dementia Caregivers Support project is a three-year project funded by the Erasmus+ Programme of the European Union and implemented by a partnership of five national non-profit organisations from Italy, Portugal, Romania and Spain, and a European umbrella organisation.

This project aimed to develop a new and innovative model of Mutual Aid Group (MAG) which promotes caregivers' involvement by introducing web-based tools, in order to enhance caregivers' satisfaction with care and reduce burnout.

It also intended to expand the personal and professional development of MAGs' facilitators by offering a series of specific tools, enabling both, professionals in the health and care sector and experienced informal carers to take the role of the group's facilitator.

WHAT IS THE CARE4DEM MODEL OF AN ONLINE MAG FOR DEMENTIA CARERS?

The development of web-based MAGs for people providing care to a person with dementia is innovative. Nowadays, while MAGs are being more and more implemented, only a few introduce an ICT component and, in many cases, the purpose is solely for information repository and it does not allow for any interaction. As such, these initiatives fall short of contributing to the social inclusion of informal carers, a group which is often left out. Indeed, informal carers are often isolated, and more subject to stress and depression.

While general information regarding MAGs is available, it remains difficult to find guidelines or practical tips and recommendations to professionals on how to successfully implement it in their own context, without relying on external consultants. MAGs are a powerful mean of non-formal and adult learning, and they can have a very positive impact on caregivers' well-being. Nevertheless, professionals often don't feel secure enough to introduce non-formal methodologies such as MAGs in their practice.

Therefore, the Care4Dem project introduces a comprehensive model to implement a web-based MAG. This model has been carefully co-designed with informal carers and other relevant experts, and tested in three countries (Italy[1], Portugal[2], Romania[3]) with 42 informal carers in total. As a final result of the project, a package is made freely available on Care4Dem's website, comprising all information and tools enabling organisations and professionals to implement the model.

Distinct from the User's Guide devoted to the implementation of the MAG model, this User's Guide concerns the specific tools created for MAGs' facilitators. Indeed, the role of the facilitator is given particular importance within the Care4Dem model. Therefore, several tools have been developed specially to guide and support professionals and volunteers willing to engage in this role (see box below). This User's Guide presents specifically the Competence Profile and the Online Self-Assessment Tool.

Care4Dem tools for Facilitators

Competence Profile = an overview of the knowledges and competences that are useful to facilitate a Care4Dem MAG

Online Self-Assessment Tool = a tool designed to help you identify your strengths and weaknesses as a facilitator, and assess the skills you already have

Multimedia training course = a tool to strengthen your capacities as a MAGs facilitator

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1   12 Informal carers participated in three pilot groups
2   10 informal carers participated in two groups
3   20 informal carers participated in two groups

Introduction to the User's Guide for the Competence Profile & Online Self-Assessment Tool

ARE YOU CONSIDERING FACILITATING A CARE4DEM MAG?

This User's Guide is meant for you; it will guide you through the Competence Profile & Online Self-Assessment Tool. At first, the notions of Competence Profile and Assessment Tool might seem daunting and potentially discourage volunteer facilitators. On the contrary, these tools are here to help you to feel confident in this role, manage challenging situations and bring the MAG to its full potential.

Though the role of the facilitator is a crucial and somehow difficult one, **it is not out of your reach**. You might already have many of the skills required. The Competence Profile and the online Self-Assessment Tool will help you identify the competences you have already, and those you would need to develop. Indeed, you might have already acquired a number of the needed knowledges and skills through your experience as an informal carer or as a professional, without realising it: these tools will help you to be more aware of your capacities and to mobilise them while facilitating the MAG.

These tools will also help you realise that you may lack some of the knowledges and skills needed for facilitating a Care4Dem MAG. You might acquire them thanks to the Care4Dem training for Facilitators. The online Self-Assessment Tool will help you to make an efficient use of the flexible training resources provided in the Care4Dem model. By going through a selection of relevant training modules, you will be able to acquire most of the competences you need. The results of your Self-Assessment might also help you develop a complementary learning path, building on resources available from adult-learning providers in your local or national environment or on the internet.

The Care4Dem Competence Profile

WHAT IS IT?

A Competence Profile is simply a list of the competences needed to do a job well. It is often created and used in organisations to evaluate if a person is able to accomplish a given task or take on a specific position, but also to establish a personal developmental plan for staff or volunteers based on the competences required for a job.

Regarding the Care4Dem model, the facilitator's Competence Profile is the list of the competences needed to efficiently facilitate the Care4Dem model of MAG, in other terms to feel comfortable in this role, equipped to manage difficult situations in case they occur, and able to bring the group to its full potential.

In line with recommendations from the European Commission, who is encouraging the recognition and the transferability of competences across the EU, the Care4Dem's facilitators Competence Profile is structured as a combination of knowledges, skills and attitudes. The definition of each of the key competences lists the relevant knowledge, skills and attitudes. In the context of EU policies for Education and life-long learning, knowledges, skills and attitudes are defined as follows:

- Knowledge – facts and figures, concepts, ideas and theories which are already established and support the understanding of a certain area or subject;

- Skills – ability and capacity to carry out processes and use the existing knowledge to achieve results;

- Attitudes - disposition and mind-sets to act/ react to ideas, persons or situations also including values, thoughts and beliefs.

> *The document* *'The Care4Dem facilitator's Competence Profile'* *available on the Care4Dem website in the section entitled 'for Facilitators' gives you a detailed overview of methodology followed for the design of the Competence Profile, including the outcomes of the corresponding desk research and validation process with experts and users.*

WHY DEVELOPING A CARE4DEM COMPETENCE PROFILE?

Raising awareness on the competences involved in MAGs' facilitation

MAGs are being more and more used to support dementia caregivers, or people providing care to relatives facing other types of disease or disability, to help them deal with the disease and ease up their burden and stress. MAGs are commonly associated with several benefits, including mental and social well-being, as they tend to increase self-confidence, resilience and knowledge. MAGs are a powerful opportunity for non-formal learning, as they can help caregivers cope with difficulties through experience sharing and interaction with peers. Although MAGs are ideally led by groups' members themselves, the facilitators play a crucial role in particular in framing the discussion, managing the time, ensuring an enabling environment and making sure that the group's core rules are respected. However, little information is available concerning the competences associated with the facilitation of a MAG, and the facilitation aspect is often overlooked when setting up a MAG. **This is why the Care4Dem partnership considered that a MAG Facilitator's Competence Profile would contribute to:**

- a better recognition of this role;
- an increased awareness of competences involved;
- a better preparation of potential facilitators.

This in turn would support a wider implementation of the MAG's methodology to the benefit of informal carers.

Integrating the specificities of online moderation

When it comes to developing MAGs for carers, offering the possibility to participate online is of paramount importance if we want to involve those informal carers who are isolated and lack the availability to participate in face-to- face interventions. However, while online peer support is proved to provide effective support, it comes with an additional set of challenges for the facilitator. How to communicate effectively without relying on non-verbal communication? How to keep the group together and maintain an enabling environment when technical issues are likely to disrupt the conversation? How to keep participants involved in the discussion while some of them are struggling with ICTs? These are some of the questions you might be asking yourself when considering facilitation.

The Care4Dem Facilitator's Competence Profile is innovative in the sense that it includes competences that address these challenges and help the facilitator feel comfortable facilitating a MAG online, therefore supporting the development of peer support opportunities accessible to all informal carers.

Identifying the competences needed for co-facilitation

The Care4Dem model is based on co-facilitation, which means that, ideally, the MAG should be facilitated jointly by a professional from the healthcare or social sector, and an experienced carer. Indeed, it was considered that the knowledges and skills of both could create a positive synergy, benefiting the facilitation of the MAG. The active presence as facilitator of an informal carer who has gone through the caring experience is a powerful tool in allaying participants' fears and communicating information in relatable terms. On the other hand, the professional co-facilitator will prevent the risk of dissemination of potentially dangerous information among the group, and share relevant information as well as reliable sources of information. He/she might also sign post participants to relevant services available locally, should they wish to. Besides, the presence of a professional is likely to promote the implementation of

this kind of intervention that is still not well known among this public. In brief, co-facilitation allows the expertise of both peers and professionals to complement each other and creates an atmosphere of trust and collaboration.

Of course, depending whether you are a professional or an informal carer, your strengths and weaknesses with regards to the Care4Dem Competence Profile might be different. The Care4Dem model will help both professionals and experienced carers to share more knowledge and competences in common, though contributing to a smooth co-facilitation and, more generally, improved mutual understanding.

WHAT FOR? THE COMPETENCE PROFILE IS A TOOL AT THE SERVICE OF FACILITATORS' SELF-DEVELOPMENT

How to use the Competence Profile? First, the Competence Profile, complemented by the Online Self-Assessment Tool, gives you an insight of your strengths and weaknesses when it comes to facilitating a MAG for dementia carers, and helps you decide how you might want to prepare for this role.

Beyond the Care4Dem in itself, you might want to use it as a reference for your own self-development:

If you are a **PROFESSIONAL** willing to engage in support to informal carers, you might want to design a learning programme for your professional development, building on the Care4Dem training as well as on training opportunities in your environment. The Care4Dem Competence Profile might facilitate the recognition and valorisation of the competences involved in facilitation in your professional environment. If you have been caring for a dependent person, this Competence Profile can also help you identify the value of this experience, have it recognised in your professional environment, and build on it as you develop your skills.

If you are an **INFORMAL CARER**, the Competence Profile might help you realise the value of your experience, enabling you to effectively support other persons facing similar situations. Building on your experience, you might want to play an active role in supporting other carers in the community, contributing to the empowerment of your peers. Besides, being aware of your competences, potentially complemented through the Care4Dem training, may encourage you also to engage in professional development. Indeed, many of the skills listed in the Care4Dem Competence Profile are highly valued on the labour market, in particular those related to the use of Information and Communication Technologies (ICTs) and more generally the capacity to communicate efficiently. Their identification might be the starting point of the design of a self-development path, should you wish to go back to employment or progress in your career. Regarding that objective, you might get in contact with organisations providing life-long learning in your environment or on the internet.

HOW WAS THE COMPETENCE PROFILE DEVELOPED?

The development of the Care4Dem Competence Profile builds on the findings of the Care4Dem's baseline study (Evidence Review on mutual groups' available on Care4Dem website here), partners' expertise in the matter, and complementary research. Obviously, it was also developed in line with the Care4Dem model of online MAG.

Importantly, the partners wanted it to mainly refer to competences acquired through experience, informal learning, or non-formal education (as a carer, as a participant in a MAG, as a professional) as these are considered by practitioners as key to ensure the success of a MAG. It was considered also important that the Competence Profile shouldn't set over-demanding standards, and remain concise, clear, concrete and accessible.

The final result has been validated by a group of experts and tested during the piloting of the intervention. The methodology followed for developing the Competence Profile is presented in detail in the document 'Care4Dem Competence Profile: Supporting professionals and volunteers to facilitate online MAGs for informal carers of people with dementia', available here.

COMPREHENSIVE VERSION / SHORTER VERSION

You may wonder why the Care4Dem Competence Profile is available under two formats: **The Comprehensive Competence Profile and the Shorter Competence Profile.**

The Comprehensive Competence Profile contains in total 53 indicators describing 7 competences. It maps in detail the knowledges, skills and attitudes which are desirable for facilitators in the Care4Dem model.

The shorter version corresponds to the core set of competences, which are addressed in the Care4Dem training. Indeed, considering the limited scope of the project, and the fact that a number of online resources already exist which address transversal social competences identified in the Comprehensive Competence Profile, the project partners decided to focus in particular on a selection of 23 Knowledges, Skills and Attitudes which are:

- core to the role of facilitator in the Care4Dem model;
- reflecting its most innovative aspects (i.e. dementia caring, and e-moderation);
- less addressed by available training opportunities. The **online Self-Assessment Tool and the Blended Training have been designed to test and reinforce these particular competences.**

The Care4Dem Online Self-Assessment Tool

WHAT IS IT?

The online Self-Assessment tool was designed to help the facilitators gain a better understanding of their personal facilitation tendencies, which greatly affect their interaction with the mutual support group they facilitate. The items of the Self-Assessment were built in accordance with the Shorter Competence Profile, where the user, according to his/her knowledge and experience, needs to place him/herself between the two available options, by choosing the one that best suits him/her.

The main objectives of the assessment tool are:

- to offer guidance to those who want to improve their competences and get involved in the implementation of an online MAG;

- to identify the facilitators' strengths and weaknesses that can be further developed through the learning programme;

- to provide users with a hint on the competences that should be explored in order to deliver a high-quality online support group;

- to support the organisations and professionals willing to assess their competences and to bring professional development through the B-learning training course.

Regarding the structure of this Self-Assessment Tool, it is divided in two parts: the first part is the introduction, presenting the Care4Dem project and describing the assessment tool; and the second part is the Self-Assessment Tool itself, asking the facilitators to reflect on the 7 competences indicated in the shorter version of the competence profile, which focus on the 25 behavioural indicators corresponding to the content of the Blended Training.

Transversal social competences

Setting up and structuring the MAG | Knowledge [4], Skills [3], Attitudes [2]

Facilitating mutual emotional support | Knowledge [1], Skills [1], Attitudes [1]

Communicating efficiently (orally and in written) in the context of an online MAG | Skills [1]

Transversal ICT related competences

ICT Literacy: using the devices and software | Knowledge [2], Skills [1]

Ability to respect privacy and promote security online | Knowledge [1], Skills [1]

Competences related to dementia and support services

Being a resource person on dementia| Knowledge [2], Skills [1]

Being a resource person on Support services | Knowledge [2], Skills [2]

The estimated time to complete the assessment tool is 20 minutes.

WHAT IS IT FOR AND HOW TO USE IT?

This tool represents the first step of the learning path foreseen by the Care4Dem project which will offer a complete tailored learning programme on the main aspects that need to be addressed in order to successfully implement an online MAG.

The assessment tool will also allow to test the users' competences after having completed the learning programme in order to visualise the progress made.

The Care4Dem model foresees the intervention of two facilitators: a caregiver with experience and a health or social care professional, who will obviously have different training needs, to which the training will be adapted. After filling in the assessment tool, a report will be automatically generated and will help the users to identify their own strengths, as well as the competences that need to be improved.

In order to receive the report, the users will complete their email address at the end of the set of questions. For each of the competences assessed through the online Self-Assessment Tool, the report will give the reference (item – competence), the corresponding module and a short overview on its content. This way, during the training pathway, the users are invited to prioritise the training modules corresponding to the competences which have been identified as the weakest through the Self-Assessment Tool.

In terms of results, if the users are closer to the statement on the left (score 1) it is recommended that they go through all the provided modules. If they are closer to the statement on the right (score 5) then, the recommendation is to go through the modules that provide the needed resources to improve the competences with a low grade.

More specifically, if the users mainly select the statements on the left (1) it means that they have a basic knowledge, with a simple understanding of terminology and concepts. They do not have experience in the field but with befitting support they can manage an online support group.

If the users place themselves in the middle (3), we can say that they might have the knowledge and experience to carry out the activities required on facilitating an online support group. Still, it is likely they need to improve some of the assessed key competences.

In the end, if the users mainly choose the statements on the right (5) we can say that they have the essential knowledges and experiences to carry out the activities required for facilitating an online support group. They are aware of alternative options and approaches and can provide guidance, instruction and advice to others.

In case someone - an informal carer, a professional or an organization - wants to make use of the tool physically, they can request the support of the local organisation involved in the project (all the contacts are available on the project's website: https://eurocarers.org/Care4Dem/partners/.

The tool can be accessed in multiple languages (English, Portuguese, Romanian, Spanish and Italian) through the following link: https://cdn.jotfor.ms/easi.assistant/Care4Dem-self-assessment-tool.
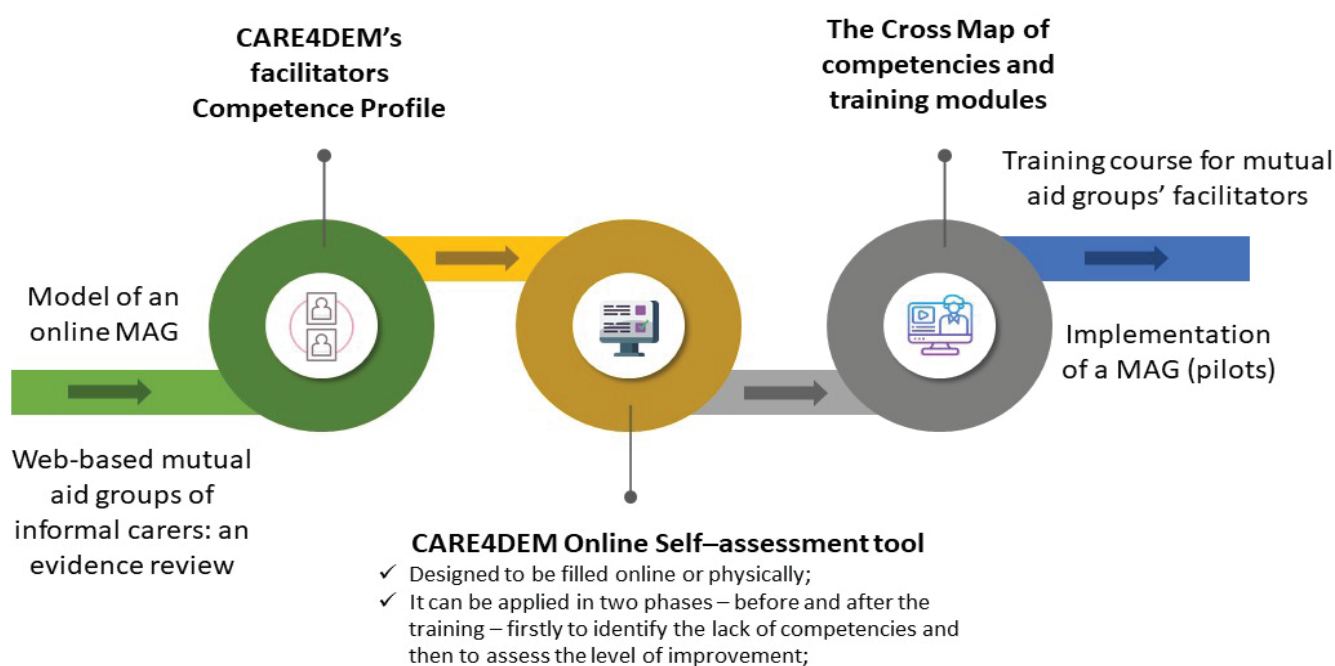
THE SELF-ASSESSMENT TOOL IS PART OF A PACKAGE OF 3 TOOLS THAT WILL HELP YOU ASSESS YOUR COMPETENCES

Three tools have been developed through the CARE4DEM project, forming a consistent pathway that you may want to follow to improve your facilitations skills.

- The Care4Dem's facilitators Competence Profile;

- The Care4Dem Self-Assessment Tool: the questionnaire for health and social professionals and experienced caregivers to reflect on their competences;

- The Cross Map of competences and training modules: it will guide you towards the most appropriate training module depending on the outcome of your self-assessment. It will be sent together with the self-assessment individual results. Being better aware of your skills, you will able to make the most of the CARE4DEM training for carers.

Graph 1
Assessing your competences as a facilitator in the Care4Dem project

CARE4DEM's facilitators Competence Profile

The Cross Map of competencies and training modules

Model of an online MAG

Training course for mutual aid groups' facilitators

Implementation of a MAG (pilots)

Web-based mutual aid groups of informal carers: an evidence review

CARE4DEM Online Self–assessment tool
✓ Designed to be filled online or physically;
✓ It can be applied in two phases – before and after the training – firstly to identify the lack of competencies and then to assess the level of improvement;

When & how to use the Competence Profile and the Online Self-Assessment Tool?

GUIDELINES FOR ORGANISATIONS WILLING TO DO A COMPREHENSIVE PILOTING OF THE MODEL

When preparing for the piloting of the MAG, the Competence Profile and the online Self-Assessment tools can be useful as references for the recruitment of facilitators, helping you to answer the following questions: Do the volunteers have the required competences? Are the competences they lack the most addressed in the Care4Dem training?
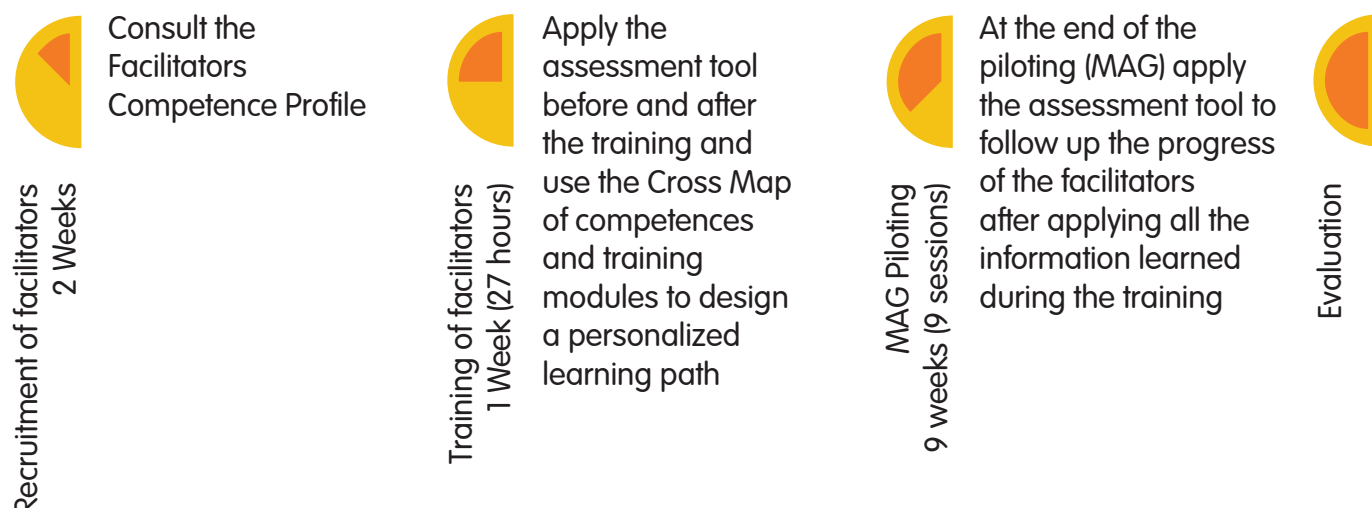
It is also important to introduce the Competence Profile during the face-to-face training for facilitators, explaining how it is underpinning the whole Care4Dem training programme. You might also want to indicate to participants other training opportunities that are complementary to the Care4Dem training.

During the piloting, these tools can also serve as a reference to facilitators when they evaluate jointly the MAG sessions. They might realise during the piloting itself that they lack one or the other competence and go back to the corresponding module in the online training.

After the piloting, facilitators might find it useful to use the Competence Profile and the Online Self-Assessment Tool to assess the progress made during the piloting itself. They might want to build on this experience to engage in a more ambitious self-development plan.

Graph 2
When to use the Competence Profile, Self-Assessment tool and Cross Map during the piloting of the Care4Dem model

Consult the Facilitators Competence Profile

Recruitment of facilitators 2 Weeks

Apply the assessment tool before and after the training and use the Cross Map of competences and training modules to design a personalized learning path

Training of facilitators 1 Week (27 hours)

At the end of the piloting (MAG) apply the assessment tool to follow up the progress of the facilitators after applying all the information learned during the training

MAG Piloting 9 weeks (9 sessions)

Evaluation

GUIDELINES FOR USING CARE4DEM FACILITATION TOOLS INDEPENDENTLY IN OTHER CONTEXTS

Even if the Care4Dem model is a comprehensive package of tools meant to be implemented all together, each of them can be used independently, as it is the case of the Competence Profile and the Online Self–Assessment Tool.

Below, you will find some examples of situations where the Care4Dem Competence Profile and online Self–Assessment tool can be useful.

- You are a professional willing to develop MAGs online for informal carers confronted with a particular disease or disability: since the Care4Dm model is **not disease specific**, you can easily identify the competences and the training modules that concern dementia, and replace them with elements of information or training that are relevant to your target audience. It also gives an insight of the competences that professionals and informal carers can respectively bring to an intervention meant to support carers, and facilitate mutual understanding between the two.

- You are a professional with experience in developing online interventions based on peer-support: the Competence Profile and the Online Self-Assessment Tool give you insight on assets and areas for improvement. It can help you **to strengthen your facilitation skills, and have them valued in your professional environment.**

- You are an experienced informal carer already active as a facilitator on an online forum for informal carers: the Competence Profile and the Online Self-Assessment Tool can help you **identify the competences you are putting in practice** in this role. Taking the time to explore the Care4Dem model might help you think about the possibilities to reinforce your competences, and valorise them. Some of **these competences are transferable**, in particular those in relation to communication and ICTs, in other contexts: **volunteering in the community, progressing in your career….**

- You are an experienced informal carer and you are wondering how to help other people in a comparable situation: the Competence Profile sheds light on the great variety of knowledges, skills and attitudes that people taking care of a person with Dementia tend to develop through their experience, which are greatly appreciated by their peers in the context of MAGs, and **make them able to support them efficiently**.

FEED-BACK, TESTIMONIES, TIPS FROM THE PILOTING OF THE CARE4DEM MODEL

Tips

The Self-Assessment tool for facilitators can be used to evaluate the improvement of competences addressed in the training: in Italy the post training assessment showed an average improvement of 0,90 points. (IT)

All the potential facilitators should follow at least some basic modules available within the Care4Dem learning program, regardless of their results received from the validation tool. (RO)

The assessment tool is an important tool to have a general idea of the set of competences that you already have, but it is important to go through the modules developed for the training. (PT)

The profile guides you on the relevant skills you need to mobilize or improve as a facilitator also, during the online sessions, while completing the session report, as facilitator you need to reflect on the skills used and it helps you to prepare the next session. (PT)

Feedback

It is interesting to notice that in the post-training test the score can also decrease compared to the pre-test, possibly because of the improved awareness on the real meaning and implications of a skill. (IT)

The assessment tool was well received by the participants of the Care4Dem piloting and appreciated for being simple to use and clear. (RO)

The most useful competences in facilitating the MAGs were the ones related with having basic knowledge about dementia and MAGs; also those related with light e-facilitation and co-facilitation, since it allowed to know what was expected from the facilitators during the MAGs; and empathy and emotional self-control, in the sense that is crucial to have a non-judgmental attitude, to listen actively while avoiding to participate actively. (PT)

Glossary

Blended-learning is an approach to education that combines online educational materials and opportunities for interaction online with traditional place-based classroom methods.

Competence Profile: A list of the competences needed to do a job well. A competency profile (sometimes referred to as skills profile) is often created and used in organizations to evaluate candidates for a specific job but also to establish a developmental plan for employees based on the needs required for a position.

Dementia is an overall term for diseases and conditions characterized by a decline in memory, language, problem-solving and other thinking skills that affect a person's ability to perform everyday activities. Memory loss is an example. Alzheimer's is the most common cause of dementia.

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

Facilitation The definition of facilitate is "to make easy" or "ease a process." What a facilitator does is plan, guide and manage a group event to ensure that the group's objectives are met effectively, in a supporting environment, with good participation and full buy-in from everyone who is involved

Health literacy is the ability to obtain, read, understand, and use healthcare information in order to make appropriate health decisions and follow instructions for treatment.

Informal 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 a professional or formal employment framework.

Mutual Aid Group (MAGs) 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, this definition differentiates mutual aid groups from individual self-help and from a support group that is led by a professional.

Peer Support: Peer-support can be defined as the process of giving and receiving nonprofessional, nonclinical assistance from individuals with similar conditions or circumstances. A peer support group (or mutual-aid group – MAG) happens when people experiencing similar conditions, voluntarily gather together to receive support and provide support by sharing knowledge, experiences, coping strategies, and offering understanding. There is evidence that participating in a MAG has positive impact in mood, self-efficacy, and burden... (Tracy, 2016).

> All the materials produced during the Care4Dem project are available on the project's website: https://eurocarers.org/Care4Dem/

Annex 1 - Comprehensive Competence Profile

COMPETENCE #1
SETTING UP AND STRUCTURING THE MUTUAL AID GROUP (MAG)

Set of knowledges, skills and attitudes which make the facilitators able to ensure that the group is functioning well as a MAG.

KNOWLEDGES

1K1 Basic knowledge about MAGs

Knowing key information and concepts about MAG's origins, principles and aims. Knowledge of the role of the facilitator, full understanding of his/her own role in the group.

1K2 Basic knowledge about group management.

Key concepts of group management: different roles in the group, leadership styles or how to keep the group motivated.

1K3 Knowledge of main objectives and techniques of light e-moderation

Being aware of how to facilitate a discussion **online** while leaving participants drive the conversation. Being aware of strategies to foster participants' engagement. Being aware of the need to adapt one's level of moderation to the needs of the group, from triggering the discussion to let the group go on their own. Being aware of how to provide a well-structured exchange and sharing, which facilitates navigation on the online software and promotes active participation. Knowledge about **online socialisation** being a key step for a successful MAG. Being aware of **different frameworks of e-moderation**, such as forums, chats....

1K4 Knowledge about the core rules to be set for a well-functioning MAG

Knowledge about a basic set of rules to be applied to the discussion, such as mutual respect, confidentiality, equal participation, democratic decision making....

Knowledge about the role of the facilitator in case these rules are not respected by a participant.

Knowing in which cases a situation shared within the group must be referred to social and health care professionals, in line with the national legal framework.

SKILLS

1S1 Conflict management

Being able to manage effectively cases of conflict or infringement of the rules, building on awareness of the possible causes of conflict within a MAG, as well as on the capacity to identify feelings and emotions involved in a conflict, while focusing on factual information.

Being able to help other people solve a situation of conflict.

1S2 Ensuring a conversation content that respects the needs of all

In case this is not happening spontaneously, being able to start the conversation and keeping it going, building on topics brought by participants or introduced in the conversation directly by the facilitator. While the content should be triggered by participants themselves, the facilitator might ensure that the conversation addresses the diversity of participants' expectations, needs and interests; the facilitator should aim at including all participants in the discussion and foster interaction between them if necessary.

1S3 Ensuring an enabling environment

Being able to develop and sustain an environment based on respect, objectivity, non judgment, active listening, equality between the members of the group and democracy. Create a comfortable environment where participants feel free to express opinions and feelings.

Being able to stand back from the discussion and let the participants run the group by themselves when needed.

1S4	**Co-facilitation**

Implementing adequate co-facilitation by clarifying mutual commitment and consensus on tasks and roles of each facilitators in the MAG, including preparation before and debriefing after the sessions.

1S5	**Time management**

Ability to manage each participant's turn, to control the amount of resources shared, so participants don't get «overfilled» and have time to discuss with each other, and ability to close the topics if necessary, so that the discussion can move on.

ATTITUDES

1A1	**Assertivity**

Communicate firmly and clearly without becoming aggressive or disrespectful to participants or co-facilitator, even in case of disagreement.

1A2	**Positive attitude towards social, religious and cultural diversity**

Being curious and promote openness regarding the diversity of the participants, in terms of social and cultural origins, religion, as well as different arrangements and attitudes regarding caring for a person with Dementia.

1A3	**Enthusiasm and motivation**

Positive attitude towards MAGs, reflecting the conviction that they can be of very much added value for carers of people with dementia in particular, and that developing these tools online will even strengthen the support offered.

COMPETENCE #2
FACILITATING MUTUAL EMOTIONAL SUPPORT

Set of knowledges, skills and attitudes which make the facilitators able to ensure that participants can exchange experience and feelings and provide emotional support to each other.

KNOWLEDGES

2K1 Knowledge of the mental health issues associated with caring for a person with dementia (especially when on an intensive basis).

Knowing the variety of feelings likely to be experienced by people caring for someone with dementia, the mental health risks occurred by these carers and the added value of peer support in addressing them.

SKILLS

2S1 Ensuring that every participant feels comfortable enough within the group to share her/his feelings.

Being aware whether every participant feels comfortable enough within the group to share her/his feelings. The facilitator is able to identify if the participants are able/willing to talk freely and express difficulties and frustration without being judged at any point of the session. Being available in case a participant needs support or feedback (only in acute situations) and when the group is not able to address this need.

2S2 Being able to facilitate empathic exchange between members of the group

Ability to encourage the group to respond empathically to the experiences shared by a participant, for example by facilitating the linking of similar experiences lived by different group members.

2S3 Emotional self-control

Capacity to stay composed and positive in challenging, emotional and stressful situations.

2S4 Perceptiveness regarding the limits of the support one can expect from a MAG

Ability to not overcome the limits of one's role as a facilitator, which may imply to reformulate the expectations of the participants towards the MAG and the support expected from the facilitator.

In situations where the expectations (or needs) of a participant are not consistent with the aims and principles of the MAG, where a participant's needs are beyond the group 's supporting capacities, and in case the group is not able to identify their limits, the facilitator may intervene and possibly refer the participant to professionals outside the MAG.

ATTITUDES

2A1 Trust and confidence

The facilitator must guarantee a trustworthy environment, by assuming a non-judgmental posture.

2A2 Empathy

The facilitator should listen, understand and respect the various perspectives and emotions of participants (positive or negative). Without intervening directly in the conversation unless necessary, he/she might communicate through his/her attitude that he/she is listening actively to participants and understanding their various perspectives and emotions.

2A3 Sensitivity

High level of perceptiveness and sensitivity regarding participants' needs, problems and feelings.

COMPETENCE #3
COMMUNICATING EFFICIENTLY (ORALLY AND IN WRITTEN) IN THE CONTEXT OF AN ONLINE MAG

Set of knowledge, Skills and Attitudes that make the facilitator able to ensure efficient communication online within the MAG

KNOWLEDGES

3K1 **Good mastery of the group's language (oral and written) allowing for clear and precise communications**

3K2 **Knowledge about the general principles of communication and effective communication in particular**

Importance of verbal and non-verbal communication, barriers to communication and how to overcome them...

3K3 **Knowledge about challenges of communication online and how to overcome them**

SKILLS

3S1 **Ability to adapt the level of language used**

Being able to adapt the level of language used to the characteristics of the group.

3S2 **Active listening**

Being able to listen actively to the participants (i.e. listener fully concentrates, shows he/she understands….), and to intervene only when relevant.

3S3 **Ability to adapt one's oral and written communication style to online interaction**

When communicating with participants on the forum, the facilitator should adapt to the medium (be concise, to the point, clear, clearly indicate to whom the message is meant…). He/ she needs to be explicit to overcome the impediments of online communication.

3S4 **Ability to structure the discussion**

Although the conversation should be mainly driven by participants, the facilitator should be able when necessary to close a discussion, to summarise the conversation, to provide the opportunity to open a new one or to wrap up contributions. As well, being able to highlight commonalities across situations and concerns, by pulling discussions or contributions together might be useful if participants do not do it spontaneously.

3S5 **Written reporting**

Being able to write a short report of a discussion and present it during the following session.

ATTITUDES

3A1 **Welcoming diverse communication skills among participants**

Demonstrate a non-judgmental attitude regarding the level of oral and written language used by participants.

COMPETENCE #4
LITERACY: USING THE DEVICES AND SOFTWARE

Set of knowledges, skills and attitude equipping the facilitator in order to manage the technical aspects of the use of ICT for the MAG

KNOWLEDGES

4K1 Knowledge about the digital divide challenge and the lack of ICT literacy

Some knowledge about the digital divide challenge and the types of difficulties participants may face during their participation in the MAG.

4K2 Awareness of the diversity of tools geared to supporting carers available online

Some knowledge about the range of tools likely to support informal carers that are available on line, likely to be shared with participants if relevant.

SKILLS

4S1 Use of the devices

Being able to use the effectively devices used by participants (PC, smart phone, tablet) as well as the software used for the MAG synchronous activities (Skype - including specific features such as sharing screen, sharing documents - emails, application to download documents) and asynchronous activities (Online forum).

4S2 Light technical support for the use of their devices and software by participants

Being able to help remotely participants to overcome minor issues when using their device as well as the platform, and being able to advice participants regarding the use of devices and software.

ATTITUDES

4A1 Positive attitude

Positive attitude towards ICT considered as promising for better supporting informal carers.

4A2 Confidence

Express confidence in the capacity of participants to overcome minor difficulties when using their devices.

4A3 Patience

Ability to leave to the participants the time they need to get acquainted to the technical aspects of the MAG and to solve minor difficulties.

COMPETENCE #5
ABILITY TO RESPECT PRIVACY AND PROMOTE SECURITY ONLINE

Set of knowledges, skills and attitude equipping the facilitator to ensure privacy and security online within the MAG

KNOWLEDGES

5K1 Knowing the risks

Knowing about the risks of using online devices for individuals, and the challenges attached to data collection and processing notably in relation to data privacy, knowledge about the General Data Protection Regulation.

5K2 Prevention

Knowing the most important measures to take to prevent such risks.

SKILLS

5S1 Promoting secure behaviour online

Being able to explain clearly the risks and the preventative measures to take to participants, make sure they understand and are ready to implement them.

5S2 Detecting and address unsecure use of ICT

Ability to notice when a participant is putting his/her/another participant's privacy and online security at risk in the context of the MAG (for example: sharing 'dodgy' documents on the forum) and interact with the participant in order to explain the risks and the need to avoid such practice.

ATTITUDES

5A1 Adequate level of precaution without discouraging participants to use online tools

The attitude of the facilitator should be reasonably cautious regarding the risks attached to online support.

5A2 Confidence and trust

The facilitator should be confident in the capacities of participants to manage the risks attached to ICT based solutions.

COMPETENCE #6
BEING A RESOURCE PERSON ON DEMENTIA

Ability to ensure the reliability and relevance of information on dementia shared within the MAG

KNOWLEDGES

6K1 Basic knowledge about dementia

Knowing basic facts about the disease, including the fact that each experience of the disease is different, knowing basic facts about treatment as well as relevant reliable informative websites.

6K2 Basic knowledge about (e)health literacy

Knowing the basics about the notion of (e)health literacy and the challenges posed by the lack of (e)health literacy in general.

SKILLS

6S1 Basic health literacy

Being able to access, understand and effectively use health-related information, in order to promote and maintain good health.

6S2 Assessing participants' knowledge about dementia

Ability to assess the level of knowledge of participants about dementia, in order to understand the extent to which they can be used as a source of information for the rest of the group.

6S3 Supervising information

Ability to supervise the information about dementia exchanged within the group, and to react when it is not reliable and/or potentially dangerous.

ATTITUDES

6A1 Positive attitude

Being positive and confident in the capacity of participants to provide information on dementia to each other that can reveal helpful.

6A2 Initiative

Ability to initiate relevant action based on one's own interpretation or understanding of a situation (for example intervene when irrelevant information is disseminated).

COMPETENCE #7
BEING A RESOURCE PERSON ON SUPPORT SERVICES

Ability to ensure the reliability and relevance of information on Informal caring and support available shared within the MAG

KNOWLEDGES

7K1   Awareness of the challenges faced by informal carers in general

Basic knowledge of the risks occurred by carers (regarding their physical and mental health, social inclusion…) and their difficulty to access adequate support.

7K2   Basic knowledge about support available in the area for carers of people with dementia

Being aware of the level and type of support provided at the local level by public services and NGOs to carers of people with dementia.

SKILLS

7S1   Ability to sign post information source in response to the demand expressed by participants

Being able to respond to need for information expressed by participants by searching online or referring participants to relevant information source.

7S2   Supervising information exchange

Ability to supervise the information about services available at local level exchanged within the group, and to react when it is not reliable and/or potentially dangerous.

ATTITUDES

7A1   Positive attitude

Being positive and confident in the capacity of participants to provide each other information on informal caring and support available that can reveal helpful.

7A2   Initiative

Ability to initiate relevant action based on one's own interpretation or understanding of a situation (for example intervene when irrelevant information is disseminated)

Annex 2 - Shorter version of the Competence Profile

COMPETENCE #1
SETTING UP AND STRUCTURING THE MUTUAL AID GROUP (MAG)

Set of knowledges, skills and attitudes which make the facilitators able to ensure that the group is functioning well as a MAG

KNOWLEDGES

1K1   Basic knowledge about MAGs

Knowing key information and concepts about MAG's origins, principles and aims. Knowledge of the role of the facilitator, full understanding of his/her own role in the group.

1K2   Basic knowledge about group management.

Key concepts of group management: different roles in the group, leadership styles or how to keep the group motivated.

1K3   Knowledge of main objectives and techniques of light e-moderation

Being aware of how to facilitate a discussion online while leaving participants drive the conversation. Being aware of strategies to foster participants' engagement. Being aware of the need to adapt one's level of moderation to the needs of the group, from triggering the discussion to let the group go on their own. Being aware of how to provide a well-structured exchange and sharing, which facilitates navigation on the online software and promotes active participation. Knowledge about **online socialisation** being a key step for a successful MAG. Being aware of **different frameworks of e-moderation**, such as forums, chats....

1K4   Knowledge about the core rules to be set for a well-functioning MAG

Knowledge about a basic set of rules to be applied to the discussion, such as mutual respect, confidentiality, equal participation, democratic decision making....

Knowledge about the role of the facilitator in case these rules are not respected by a participant.

Knowing in which cases a situation shared within the group must be referred to social and health care professionals, in line with the national legal framework.

SKILLS

1S1   Conflict management

Being able to manage effectively cases of conflict or infringement of the rules, building on awareness of the possible causes of conflict within a MAG, as well as on the capacity to identify feelings and emotions involved in a conflict, while focusing on factual information.

Being able to help other people solve a conflict situation.

1S4   Co-facilitation

Implementing adequate co-facilitation by clarifying mutual commitment and consensus on tasks and roles of each facilitators in the MAG, including preparation before and debriefing after the sessions.

1S5   Time management

Ability to manage each participant's turn, to control the amount of resources shared, so participants don't get «overfilled» and have time to discuss with each other, and ability to close the topics if necessary, so that the discussion can move on.

ATTITUDES

1A1 Assertivity

Communicate firmly and clearly without becoming aggressive or disrespectful to participants or co-facilitator, even in case of disagreement.

1A2 Positive attitude towards social, religious and cultural diversity

Being curious and promote openness regarding the diversity of the participants, in terms of social and cultural origins, religion, as well as different arrangements and attitudes regarding caring for a person with Dementia.

COMPETENCE #2
FACILITATING MUTUAL EMOTIONAL SUPPORT

Set of knowledges, skills and attitudes which make the facilitators able to ensure that participants can exchange experience and feelings and provide emotional support to each other

KNOWLEDGES

2K1 Knowledge of the mental health issues associated with caring for a person with dementia (especially when on an intensive basis)

Knowing the variety of feelings likely to be experienced by people caring for someone with dementia, the mental health risks occurred by these carers and the added value of peer support in addressing them.

SKILLS

2S3 Emotional self-control

Capacity to stay composed and positive in challenging, emotional and stressful situations.

ATTITUDES

2A2 Empathy

The facilitator should listen, understand and respect the various perspectives and emotions of participants (positive or negative). Without intervening directly in the conversation unless necessary, he/she might communicate through his/her attitude that he/she is listening actively to participants and understanding their various perspectives and emotions.

COMPETENCE #3
COMMUNICATING EFFICIENTLY (ORALLY AND IN WRITTEN) IN THE CONTEXT OF AN ONLINE MAG

Set of knowledge, Skills and Attitudes that make the facilitator able to ensure efficient communication online within the MAG

SKILLS

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LITERACY: USING THE DEVICES AND SOFTWARE

Set of knowledges, skills and attitude equipping the facilitator in order to manage the technical aspects of the use of ICT for the MAG

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Some knowledge about the range of tools likely to support informal carers that are available on line, likely to be shared with participants if relevant.

SKILLS

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ABILITY TO RESPECT PRIVACY AND PROMOTE SECURITY ONLINE

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KNOWLEDGES

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SKILLS

5S2 Detecting and address unsecure use of ICT

Ability to notice when a participant is putting his/her/another participant's privacy and online security at risk in the context of the MAG (for example: sharing 'dodgy' documents on the forum) and interact with the participant in order to explain the risks and the need to avoid such practice.

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BEING A RESOURCE PERSON ON DEMENTIA

Ability to ensure the reliability and relevance of information on dementia shared within the MAG

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6K2   Basic knowledge about (e)health literacy

Knowing the basics about the notion of (e)health literacy and the challenges posed by the lack of (e)health literacy in general.

SKILLS

6S3   Supervising information

Ability to supervise the information about dementia exchanged within the group, and to react when it is not reliable and/or potentially dangerous.

COMPETENCE #7
BEING A RESOURCE PERSON ON SUPPORT SERVICES

Ability to ensure the reliability and relevance of information on Informal caring and support available shared within the MAG

KNOWLEDGES

7K1   Awareness of the challenges faced by informal carers in general

Basic knowledge of the risks occurred by carers (regarding their physical and mental health, social inclusion…) and their difficulty to access adequate support.

7K2   Basic knowledge about support available in the area for carers of people with dementia

Being aware of the level and type of support provided at the local level by public services and NGOs to carers of people with dementia.

SKILLS

7S1   Ability to sign post information source in response to the demand expressed by participants

Being able to respond to need for information expressed by participants by searching online or referring participants to relevant information source.

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Ability to supervise the information about services available at local level exchanged within the group, and to react when it is not reliable and/or potentially dangerous.

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