

CARE4DEM - Dementia Caregivers Support
Intellectual Output O3/A3

The CARE4DEM facilitator's Competence Profile

Supporting professionals
and volunteers to facilitate
online Mutual Aid Groups
for **informal carers of**
people with Dementia

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Programme

CARE4DEM - Dementia Caregivers Support

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Abstract

This publication presents one of the outcomes of the project 'CARE4DEM', a Competence Profile, listing the Knowledges, Skills and Abilities that are desirable for professionals and volunteers willing to facilitate MAGs for informal carers of people with Dementia.

This outcome is part of a set of tools developed within the CARE4DEM project, aimed at developing an innovative model of web-based mutual aid group (MAG) for informal carers of people with Dementia. This project intends to address the acute needs of these carers, building on the potential of Information and Communication Technologies and the proven added value of Mutual Aid Groups.

The present publication presents the framework of the project and the different elements of the CARE4DEM model, before going into detail firstly about the methodology followed for drafting the Competence Profile, then concerning the outcomes of the desk research and consultation of experts, before presenting the Competence Profile itself.

This Outcome sheds light on the many competencies developed by informal carers through experience, which are overlapping to some extent with the competencies desirable for facilitating a MAG, and very much appreciated by peers. Hence it might be used, beyond the project itself, as a reference in the context of initiatives aimed at recognising and valuing informal carers' competences.

Executive Summary

How to build on the potentialities of Information and Communication Technologies (ICTs) to help informal carers of people with Dementia, a group facing a particular risk of isolation and social exclusion? How could professionals and volunteers be trained to provide online peer support in the form of Mutual Aid Groups (MAGs) for those whose caring responsibilities constitute an obstacle to participate in face-to-face support groups?

Indeed, there is clear evidence of the need for support of informal carers of people with Dementia, especially when care is provided on an intensive basis, which is often associated with negative impact on the physical and mental health. Mutual aid (or support) groups are being more and more used with Dementia caregivers to support them dealing with the disease and ease up their burden and stress. These interventions are associated with various benefits for participants.

The European project CARE4DEM (2017-2020), supported by the programme Erasmus+, stands for creating opportunities for all informal carers to take part in interventions specifically designed for them, by developing an innovative model of web-based MAG, and providing the concrete tools to implement it. The project's partnership is coordinated by Anziani e Non-Solo (Italy), and gathers five organisations from Italy, Portugal, Romania and Spain and a European umbrella organisation (Eurocarers).

Unlike other MAG practices observed in the field, CARE4DEM is deliberately focusing on the training of the facilitators, developing a specific set of tools to help potential facilitators develop the competencies desirable to facilitate the model of MAG developed through the project, namely: a Competence Profile (Intellectual Output O3/A3), an Online Self-evaluation Tool (O3/A3 bis) and a Blended Training Course for facilitators (Intellectual Output O4).

This publication presents the Competence Profile of online MAG's facilitators, providing a detailed list of the competencies which are desirable for facilitating online MAGs of informal carers of people with Dementia. The definition of a Competence Profile of online MAG's facilitators is considered helpful in many ways. It offers both volunteers and professionals the possibility to identify the competencies needed to facilitate such MAGs, assess their own competences with regards to the needs, and develop their skills accordingly, using the blended training provided by the project. It is meant for professionals in the health and care sector willing to assess and develop their competencies, enrich their practice, as well as understand better and involve more informal carers in the said practice. It is also meant for experienced informal carers, helping them to become more aware of the competencies they might



already have, and guide them- if they wish - on a path to reinforce and develop these competencies, in order to perform the meaningful role of MAG's facilitator. In this respect, the CARE4DEM project offers tools for empowering informal carers, recognising their contribution and valuing their competences and skills.

The first part of the present report presents the general context and objectives of the project, including the EU framework for competences development which constitutes its backdrop. The second part details the methodology followed for the drafting of the Competence Profile, which has been developed organically during the first phase of the project, and the third part presents the outcomes of the Desk Research and consultation of experts. Two versions of the Competence Profile (a comprehensive one and a shorter one) are presented in the last section, as well as included as Annexes.



Introduction: the CARE4DEM Project

The definition of this MAG facilitator's profile took place in the context of the CARE4DEM project (2017-2020) supported by the European Commission (EC) through the programme Erasmus+. Indeed, the EC has highlighted the advantages of supporting informal carers, including via training, as part of a range of strategies to face the challenges attached to long-term care. 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 adult education.

The project's partnership is coordinated by Anziani e Non Solo (Italy), and gathers five organisations from Italy, Portugal, Romania and Spain as well as an European umbrella organisation of carers organisations and research organisations on care and caring. CARE4DEM stands for creating opportunities for all caregivers to take part in interventions likely to help them in their role, by developing an innovative model of web-based mutual aid group (MAG).

The specific objectives of CARE4DEM are:

- To design and develop an innovative web-based model of MAG for informal caregivers of people with Dementia, including learning materials for caregivers;
- To identify the profile and competences that are the most suitable to the role of facilitator of such a group;
- To develop a multimedia training course to enhance the competences of MAGs' facilitators;
- To pilot a web-based MAG;
- To create a network of professionals across Europe who work towards better support of informal caregivers of people with Dementia.

1. The context of the definition of a Mutual Aid Group facilitator's Competence Profile

The need for supporting carers

The support and care for Dementia patients has been delivered by public and private health sectors, but there is also a great number of informal caregivers¹ who provide care informally – more than 15% of people aged 50 refers to have taken care of an older person. Although informal caregivers, also called carers or family caregivers, feel benefits from caring, such as increased self-esteem, society has not yet been able to tackle the multiple disadvantages attached to caregiving – 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. 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 MAGs, information-technology based support or other formal approaches delivered by healthcare professionals.

The untapped added value of Mutual Aid Groups and the need to train facilitators.

MAGs are being more and more used with Dementia caregivers to support them dealing with the disease and ease up their burden and stress. MAGs are commonly associated with several benefits, including mental and social well-being, by increasing self-confidence, resilience and knowledge. MAGs are a powerful opportunity for non-formal learning, as they help caregivers cope with difficulties, through the sharing of experience and knowledge, the interaction with peers, and the building of supportive relationships.

¹ Eurocarers defines informal carer as a person who provides care - usually unpaid - to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal framework.



The results from the baseline study undertaken by CARE4DEM partners showed that facilitation of groups requires not only experience, but a set of soft skills related to communication, empathy or sensitivity (CARE4DEM project, 2018). Although training of facilitators doesn't seem to be a pattern in the practices selected, the facilitation of a MAG and the requirements from the model proposed by CARE4DEM (IO2) imply the mobilization or the development of a series of competencies. Some informal carers have been acquiring such competencies through the experience of caring for someone with Dementia and possibly participating in face-to-face support group and forums. They might express the willingness to take a more active role towards their peers, and volunteer as facilitators for implementing the CARE4DEM model of MAG. Some professionals, aware of the needs of informal carers of people with Dementia, are also willing to set up MAGs for informal carers, in cooperation with them.

The opportunities provided by CARE4DEM

CARE4DEM offers both volunteers and professionals the possibility to identify the competencies desirable to facilitate MAGs for informal carers of people with Dementia, assess their own competencies with regards to the needs, and develop their skills. For this purpose, in addition to the MAG model itself (IO 02), the project has developed:

- A Mutual Aid Group facilitator's Competence Profile and Online Self-evaluation Tool (Intellectual Output 03)
- A Blended Training for the facilitators (Intellectual Output 04)

Besides supporting volunteers' commitment to help informal Dementia carers, the combination of the tools offered by CARE4DEM might help them strengthen their own capacities, and support them entering a pathway towards further training and employment, in case they are excluded from the labour market and willing to improve their situation. The same tools will support health and social care professionals developing their understanding of the situation and needs of informal carers, as well as their ability to work with them and support them.

Aims of the Competence Profile

In particular, the MAG facilitator's Competence Profile pursues the following aims:

- Supporting the recruitment of facilitators able to implement the CARE4DEM model of a MAG;
- Supporting the self-development of facilitators, giving them an insight of their assets and areas for improvement;
- Guiding them towards using the CARE4DEM Blended Training as well as other training resources at their disposal locally;
- Be part of a whole framework that organisations can use directly for implementing a MAG.

The EU policy framework regarding competences development

As an ESF+ funded project, the development of the CARE4DEM model, and in particular of the work package 03, is underpinned by the policy pursued at the European level for the development of competences across the EU. This policy can be described as a paradigm shift from knowledge to competence-oriented teaching and learning and related curricula reforms, aiming at facilitating transfer and adaptation of knowledge. This approach combines formal with non-formal and informal learning, and builds on collaboration with non-education stakeholders and local community (European Council, 2017), (European Council, 2018).

Against this backdrop, a competence is considered as a set of knowledge, skills and attitudes, defined as below. These definitions have been guiding the definition of the CARE4DEM facilitator's Competence Profile.

The competence-based approach, as defined by the EC (European Commission, 2018):

“In the early 2000s, more and more European countries made efforts to shift from knowledge solely to a broader competence approach in national curricula.”

“They are conceptualised as a combination of knowledge, skills and attitudes and the definition of each key competence states the knowledge, skills and attitudes relevant for it. This approach supported the definition of learning outcomes and its translation into curricula or learning programmes.

- 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 in the European Framework of Key Competences also including values, thoughts and beliefs.”

2. Methodology

The development of the Competence Profile took place principally between October 2018 and June 2019. A first version was finalised in June 2019, together with all the other tools part of the CARE4DEM model, before the testing phase of the CARE4DEM MAG model started in September 2019.

For developing this work package, the responsible partners (Eurocarers and EaSI) have been working in continuous coordination with other partners responsible for other work packages, so as to ensure the consistency of the project outcomes. Indeed, the content of the Competence Profile is closely interrelated with the development of the MAG model itself and of the Blended Training for the facilitators.

The method followed builds principally on the outcomes of the Baseline Study ('Evidence Review on mutual groups', IO 01) and the model of MAG intervention designed (IO 02), complemented with some desk research, as well as expert validation and testing, according to the timeline below.

The Competence Profile was developed in three stages.

Stage 1: The criteria for selecting relevant competencies have been agreed in October 2018. They were defined as follow (see box below).

Criteria for the Competence Profile:

- It should reflect accurately the outcomes of IO 1 and IO 2 in terms of competences needed to ensure a satisfying facilitation of the MAG model, from the point of view of the facilitators as well as the participants;
- The list should also build on existing knowledge and expertise regarding facilitation of MAGs outside the partnership;
- It should be consistent with the policies implemented at EU level in relation to competences and skills;
- It should mainly refer to competences acquired through experience, informal learning, 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 should not set over-demanding standards in terms of competencies required, to avoid discouraging potential facilitators. It should mainly aim at identifying and clarifying competences that experienced carers/ professionals willing to facilitate a mutual support group might have

acquired, and inviting them to update/ strengthen these competencies through the training offered;

- It should be concise, clear, concrete and accessible, again to avoid volunteers to be daunted.

Stage 2: The competences and the corresponding behavioural indicators have been developed according to these criteria between November 2018 and February 2019.

CARE4DEM partners, Eurocarers members as well as Experts engaged in the Validation Group at the EU level contributed to a large extent to the collection of relevant methodological and practical information. Ultimately, a **Comprehensive Competence Profile** was finalised, containing 53 behavioural indicators describing 7 competencies.

This comprehensive list was considered as a relevant reference for professionals and volunteers willing to implement the CARE4DEM MAG model, as it describes the knowledges, skills and attitudes which are desirable for facilitators and might guide the recognition of their own skills as well as their self-development trajectory.

Stage 3: Defining a shorter Competence Profile focusing on the core CARE4DEM competencies.

However, it was clear that a number of behavioural indicators included in this Comprehensive Competence Profile were beyond the scope of the CARE4DEM project. Taking also into account the fact that a number of online resources already exist which address transversal social competencies identified in the Comprehensive Competence Profile², the partnership has decided to concentrate more on the specificities of the CARE4DEM model when developing the Online Validation Tool and the Blended Training. (i.e. dementia caring, and e-moderation). It was also considered that, in order for professionals and volunteers to engage more easily with the project, it was important to highlight the most important competencies in the framework of CARE4DEM, and allow them to develop them through the Online Validation Tool and the Blended Training to be offered within the CARE4DEM model.

Therefore, a **shorter version** of the Competence Profile was elaborated. In this objective, 23 behavioural indicators corresponding to the content of the Blended Training were selected from the Comprehensive Competence Profile in order to constitute the Shorter Competence Profile.

² See for example the Facilitation Competency framework developed by the National college for school leadership (National college for school leadership, 2012).

Complementary Desk Research

Within the limits of the CARE4DEM project, it was not possible to undertake a comprehensive desk research. However, it was possible to achieve a succinct mapping of relevant research and practices in the field, developed organically along with the successive versions. The desk research started with a literature search in the database EPALE, Google Scholar, Research gate, focusing on research publications. Since this first research yielded few results, it was extended to relevant grey literature, notably practical books or guidelines for MAGs' facilitators, searched on the internet or signposted by professionals, based on their practices. In one case, where a practice including a training for MAG's facilitators was implemented but not documented, information was collected through an interview (Aurélié Matignon, Association Française des Aidants, 8 January 2018).

Validation and Testing (see outcomes below).

The draft Competence Profile was discussed in parallel Expert Validation Workshops organised by partners in February 2019. It was also tested during the two Training Events aimed at training the trainers of the facilitators during the piloting phase (organised in February and June 2019).

3. Outcomes of the Desk Research and the consultation of experts

Outcome of the Desk Research

Little research has been published regarding the skills needed for facilitators of MAGs of informal carers, in particular carers of a person with Dementia. However, 14 publications, reference websites and practices were identified ultimately who could support the definition of the necessary competencies for facilitators against the backdrop of the CARE4DEM model. These publications arise from slightly diverse but connected areas of research (implementing online education, implementing patients' MAG in the area of cancer...), or emanate from to the grey literature (practical books, guidelines for facilitators...). Some are internal documents in use within organisations implementing online or face-to-face support (CarersUK, Alzheimer Society UK).

Naturally, taking into account the role of the facilitator as described in the CARE4DEM model of MAG, the Competence Profile includes competencies related to MAGs (basic knowledge on history and approach), moderation skills, emotional support, communication, ICT literacy, and knowledge about the challenges of caring for a person with Dementia and the support services available. The Desk Research was instrumental for **identifying complementary aspects**, and enrich the Comprehensive Competence Profile accordingly, taking into account the following take-aways.

- Some authors underline the **challenge of starting and sustaining quality focused dialogue**, (Collison, Elbaum, Haavind, & Tinker, 2000). A study on Friendsourcing Peer Support for Alzheimer’s Caregivers Using Facebook Social Media concluded that moderation is very important in order to facilitate peer dialogue through social media (Wilkerson, Brady, Yi, & Bateman, 2018) . Though the CARE4DEM model is based on a ‘light ‘moderation, letting the participants drive the discussion as much as possible, competences needed for maintaining the discussion have been included in the Comprehensive Competence Profile.
- Others insist on the **need to facilitate inter-participants relations and online socialisation** as a key step to a successful group intervention (Rovai, 2017) (Salmon, 2011).
- Many interventions implementing face-to-face and online support group require from the facilitator the **capacity to articulate clearly and enforce a series of rules** (Carers UK, 2018) (Alzheimer Society UK, 2018).
- Several references mention the cultural/ethnic **diversity as a potentially challenging aspect** for the facilitator, as it can, among others, implies a different approach to the mutual support group itself (Roman & Brandler, 2015) (Lavoie & Gidron, 2015). L’Association Française de Aidants observed that a diversity of approaches towards caring responsibility in a group can become challenging when implementing face-to-face MAGs (‘Café des Aidants’).
- The majority of authors pointed out **online facilitation as particularly challenging as compared to facilitation face-to-face (Owen, 2009)**, hence the need to emphasize communication skills, and to focus in particular on the competences needed to overcome online communication and group management shortcomings.
- Several publications also point out to **the risk for the facilitators in term of burden and the need to ensure he/she can manage emotionally**, which means that he/she should demonstrate self-care and self-awareness (Mental Health America, 2016). At the same time, there is clear evidence of the benefits for professionals of being involved in co-facilitation in terms of acquiring new skills, as observed in the area of cancer patient support (BC Cancer Agency, 2011).

Validation workshops

In February 2019, a series of Validation Workshops were organised in each of the countries of the project, during which experts commented on the draft short version of the Short Competence Profile. Globally, experts found the Competence Profile useful and relevant. Their comments have been taken into account. In particular they helped:

- To select those competences from the comprehensive version of the Competence Profile that should be kept in the Shorter Version (notably their comments lead to keep in the short version the following competency 'Knowledge of the mental health issues associated with caring for a person with dementia' and Skill 'the time management skill');
- To enrich the description of some competencies (for example 'Co-facilitation' should include 'preparation and debriefing by the chair before and after the session'; 'Positive attitude towards diversity' should also refer to difference of 'religions');
- To clarify the wording and the structure of the competencies where it was unclear, or where some competencies were overlapping;
- To prepare for the piloting phase, with regard to the recruitment process and to the articulation between the Competence Profile and the other tools developed in the project.

Testing

During the training event, the tool was generally well received by trainees, and their comments allowed for some improvements and simplification aimed at making the Competence Profile easier to use.

4. Presentation of the Competence Profile

The comprehensive Competence Profile

The Competence Profile includes seven competencies, each of them composed of a set of Knowledges (K), Skills (S) and Attitudes (A).

Transversal social competencies:

- 'Setting the group in motion' (4 Knowledges, 5 Skills, 3 Attitudes)
- 'Emotional support' (1 Knowledges, 4 Skills, 3 Attitudes)
- 'Communication' (3 Knowledges, 4 Skills, 3 Attitudes)

Transversal ICT related competencies

- 'ICT devices and software' (2 Knowledges, 2 Skills, 3 Attitudes)
- 'Online security' (2 Knowledges, 2 Skills, 2 Attitudes)

Specific competencies related to dementia and support services

- 'Being a resource person on dementia' (2 Knowledges, 3 Skills, 1 Attitudes)
- 'Being a resource person on support services' (2 Knowledges, 2 Skills, 1 Attitudes)

All together, these 7 competences described through **53 behavioural indicators** constitutes what the partnership agreed to consider as the ideal profile of the facilitator of the CARE4DEM MAG model. The complete Competence Profile is presented in Annex 1, including a description of each behavioural indicator.

The Shorter Competence Profile

The shorter version is organised around the same competences, but limited to **23 behavioural indicators**.

Transversal social competencies:

- 'Setting the group in motion' (4 K ,2 S,2 A)
- 'Emotional support' (1 S,1 A)
- 'Communication' (3 S)

Transversal ICT related competencies

- 'ICT devices and software' (2 K,1 S)
- 'Online security' (1 K,1 S)

Specific competencies related to Dementia and support services

- 'Being a resource person on dementia' (2 K,1 S)
- 'Being a resource person on support services' (2K,2S)

This shorter version will serve as a basis for developing the blended training for facilitators.

Conclusions

While the CARE4DEM MAG's facilitator Competence Profile is primarily meant to be used in the context of the CARE4DEM model of an online MAG for informal carers of people with Dementia, it is hoped that it will also be used beyond this particular project. Indeed, as it describes – extensively in the case of the Comprehensive Competence Profile, the Knowledges, Skills and Attitudes involved in the facilitation of a MAG, it can be used as a reference in many other contexts, by organisations willing to develop online MAGs for carers. Indeed, many initiatives in the field aimed at supporting carers are integrating online peer-support in various forms. The present Competence Profile brings specific added value as it focuses in particular on the competencies needed for online facilitation, as well as co-facilitation. We believe these two aspects are key if we want to offer informal carers adequate opportunities of online peer support, and strengthen a much-needed mutual understanding and cooperation between professionals and informal carers.

Besides, this Competence Profile is shedding 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. We hope that this Competence Profile will also be used to identify and raise awareness of the competencies often developed by informal carers -including among carers themselves-. Together with training opportunities, the Competence Profile can be a stepping stone for informal carers willing to see their experience recognised and valued in the context of a training pathway toward new professional opportunities, or meaningful involvement in the community. However, such developments are possible only if pathways for the validation of informal and non-formal learning are available and accessible for carers, as well as the relevant training opportunities needed to complement these competencies, in order to improve their situation on the labour market and in society in general.

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Annexes

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	<p>Basic knowledge about MAGs</p> <p>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.</p>
	1K2	<p>Basic knowledge about group management.</p> <p>Key concepts of group management: different roles in the group, leadership styles or how to keep the group motivated.</p>
	1K3	<p>Knowledge of main objectives and techniques of light e-moderation</p> <p>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....</p>
	1K4	<p>Knowledge about the core rules to be set for a well-functioning MAG</p> <p>Knowledge about a basic set of rules to be applied to the discussion, such as mutual respect, confidentiality, equal participation, democratic decision making....</p> <p>Knowledge about the role of the facilitator in case these rules are not respected by a participant.</p> <p>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.</p>
Skills	1S1	<p>Conflict management</p> <p>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.</p> <p>Being able to help other people solve a situation of conflict.</p>

	1S2	<p>Ensuring a conversation content that respects the needs of all</p> <p>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.</p>
	1S3	<p>Ensuring an enabling environment</p> <p>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.</p>
	1S4	<p>Co-facilitation</p> <p>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.</p>
	1S5	<p>Time management</p> <p>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.</p>
Attitudes	1A1	<p>Assertivity</p> <p>Communicate firmly and clearly without becoming aggressive or disrespectful to participants or co-facilitator, even in case of disagreement.</p>
	1A2	<p>Positive attitude towards social, religious and cultural diversity</p> <p>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.</p>
	1A3	<p>Enthusiasm and motivation</p> <p>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.</p>

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.

Knowledge	2K1	<p>Knowledge of the mental health issues associated with caring for a person with dementia (especially when on an intensive basis).</p> <p>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.</p>
Skills	2S1	<p>Ensuring that every participant feels comfortable enough within the group to share her/his feelings.</p> <p>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.</p>
	2S2	<p>Being able to facilitate empathic exchange between members of the group</p> <p>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.</p>
	2S3	<p>Emotional self-control</p> <p>Capacity to stay composed and positive in challenging, emotional and stressful situations.</p>
	2S4	<p>Perceptiveness regarding the limits of the support one can expect from a MAG</p> <p>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.</p>
Attitudes	2A1	<p>Trust and confidence</p> <p>The facilitator must guarantee a trustworthy environment, by assuming a non-judgmental posture.</p>

	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

Knowledge	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.

* “Active listening is a technique that is used in counselling, training, and solving disputes or conflicts. It requires that the listener fully concentrate, understand, respond and then remember what is being said.”

Competence #4 ICT 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

Knowledge	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

Knowledge	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.

Knowledge	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.

Knowledge	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	<p>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.</p>
	1K2	<p>Basic knowledge about group management. Key concepts of group management: different roles in the group, leadership styles or how to keep the group motivated.</p>
	1K3	<p>Knowledge of main objectives and techniques of light e-facilitation 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....</p>
	1K4	<p>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.</p>
Skills	1S1	<p>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</p>

	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.

Knowledge	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.
Skill	2S3	Emotional self-control Capacity to stay composed and positive in challenging, emotional and stressful situations.
Attitude	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

Skill	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.
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* "Active listening is a technique that is used in counselling, training, and solving disputes or conflicts. It requires that the listener fully concentrate, understand, respond and then remember what is being said."

Competence #4 ICT 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

Knowledge	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.
Skill	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).

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

Knowledge	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.
Skill	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.

Competence #6 Being a resource person on Dementia

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

Knowledge	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.
Skill	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.

Knowledge	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.