



Dem@entoring



DEM@ENTORING

Live and learn – Innovative
ICT based learning and
mentoring approaches for
Alzheimer's communities

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USER NEEDS' ANALYSIS

INTELLECTUAL OUTPUT 1 (IO1)

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Executive Summary

In the context of the Dem@entoring project, this report on the users' needs provides a profile of informal and formal caregivers of persons with dementia in five EU member states (Denmark, Greece, Italy, Poland, and Sweden) in order to contribute in the wider European endeavor to provide caregivers with the necessary support. It also presents the needs and concerns of persons with dementia and how e-training programmes can help their formal and informal carers increase the quality of the time spent with them.

Although the population is ageing and persons with dementia increasing, there is a lack of networking and capacity building opportunities for those who daily care for persons with dementia. As a result, the care given to the person with dementia is inefficient and the caregivers often neglect their own needs, leading them to emotional and physical exhaustion. Therefore, it is very important to properly train the carers of persons with dementia. In particular, e-learning modules can allow them to participate in training programmes without the need to leave their homes or working places.

The report portrays informal carers as women aged 45+ who are still working and devote more than 4 hours per day to the person they are caring for. According to the analysis, informal carers would like to be trained on practical issues in care management, including existing structures for caregivers' support and information on social management, legal and financial aspects. Being trained on ways to relieve them is also crucial for them.

Concerning formal carers, they are also mainly women, but younger (under 45). The most important overall topics to be covered in an online training program for them concern psychosocial interventions and practical issues for care management, including information on the existing structures for caregivers' support and good practice in the design of homes and living spaces for persons with dementia. Tips to relieve caregivers is also very much needed for them.

For both carers, online training needs to be short and flexible to fit into very busy days. On average both formal and informal carers could devote a few hours per week to such a training by using their laptops, tablets, smartphones and PCs. The e-mentor training and intervention is expected to have a positive effect on sense of competence, the perceived burden of care and health. Other positive aspects include receiving knowledge about dementia, gain new insights into the own situation and having their problems acknowledged. The possible risk of the online training could be the lack of face-to-face exchanges among caregivers, but this risk can be overcome by foreseeing online networking opportunities among trainees.

Concerning persons with dementia, the consortium reached out 11 men and 17 women with mild neurocognitive disorders through focus groups. Half of the participants was aged 75+. The main concerns of the reached persons with dementia were their health and loss of identity in the future. The change of the relationship with their carers was also a concern for them. Through the focus groups, participants also expressed the need to keep on carrying out as much as possible their daily activities and to make their own decisions, together with their loved ones.

Therefore, the trainings of the project will make sure that formal and informal carers take into account the needs that persons with dementia expressed, while also paying attention to their own wellbeing and needs.



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1. Introduction

The percentage of people aged 60+ is predicted to rise from 12% of the current population to 22% between 2015 and 2050. Rising life expectancy is associated with increased prevalence of chronic diseases like dementia. Dementia is not a specific disease. It's an overall term that describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities. Alzheimer's disease accounts for 60 to 80 percent of cases. There were an estimated 46.8 million people worldwide living with dementia in 2015 and this number will almost double every 20 years. These increases will have a marked impact on states' health care systems; and families and caregivers.

It is estimated that two caregivers are needed to take care of one person with dementia. Dementia challenges both the person diagnosed with dementia and the persons caring for them. This does not mean that there will no longer be times of joy, shared laughter, and companionship. Dementia often develops gradually, offering time to adjust to the diagnosis, plan ahead, and spend quality time together.

Dem@entoring will use an inclusive educational and training approach, addressing health, wellbeing and promotion of ICT activities to people with dementia and their formal and informal caregivers in order to understand their disease and to efficiently cope with the dementia symptoms, raise awareness, improve understanding and decrease the fear of stigmatization. By implementing this training in different EU countries, we will have the opportunity to respond to the growing numbers of people with dementia by upskilling formal and informal caregivers who wish to gain a greater understanding of the disease.

The project aims to create Mentoring Relationship Cycle & Mentoring Lifecycle for training and services creating multiplier eMentors and low-level interaction, addressing all involved target groups. The target group will, through the project's website be trained on issues related to the dementia, behavioral and psychiatric symptoms – non pharmacological interventions – caregivers burden etc. Experienced project partners will locate and motivate more users to attend. All training material will be OERs accessible as e&m-learning supporting ICT-based training, using a social learning approach and translated into partner languages and, accessible through the platform.

Objectives

The basic aim of this report is to identify the training needs of formal and informal carers of persons with dementia in 5 EU member states in the context of the Dem@entoring project (Denmark, Greece, Italy, Poland, and Sweden), aspiring to contribute to the European process of strengthening carers' capacity to care for persons with dementia. The report provides the evidence-base for project implementation and the theoretical framework of the Dem@entoring project. The scope of this report, which is the first intellectual output of the project, is to build the context for implementing the project's trainings. More specifically, the research questions that this report aims to provide answers to, are the following:

- What are the target groups' profiles and needs?
- How can carers be supported through online non-formal trainings? What inclusive training approaches can be used?



- What challenges need to be overcome to train carers of persons with dementia online?
- How can carers be helped by interacting online?

Based on the data gathered on this report, Dem@entoring will develop its training material that will contribute to decrease the social exclusion numbers among people with dementia in society, while providing them with new skills and tools to improve their wellbeing and lifestyle.

2. Methodology

The methodology of the report is based on a case study approach, as we use five case studies from the five countries that constitute the consortium of the Dem@entoring project. We carried out both desktop and field research on needs analysis and existing users' needs, training models and non-formal training, habits, mentoring, models used. To gather the users' needs, AAADRS also prepared questionnaires that have been largely disseminated online and through face-to-face meetings. A dedicated online page was created for each language version of the questionnaire. Instead of a workshop, as initially planned, each partner organized focus groups to gather extra information on the users' needs. Each country organized a focus group with formal caregivers, informal caregivers, and persons with dementia. Indeed, the focus group was considered more effective than a workshop to go deeper on the needs of the users. In particular, it was more effective to gather the feedback of persons with dementia who prefer to interact within very small groups. According to the findings of these five case studies, we developed the report's conclusions on the training needs of formal and informal carers.

In the context of the case study methodology, we used both a qualitative and a quantitative approach. In the desk research part, literature review at national level identified the main policies and legislation in support of formal and informal carers. In the field research, through online questionnaires, focus groups and interviews with caregivers of persons with dementia and persons with dementia themselves, Dem@entoring also gathered information about the barriers they are facing, the changes that would help them, and how an online training could support them. The meetings helped the project gather more thorough information and qualitative data that it was not possible to collect through online questionnaires.

In order to include other stakeholders in the needs' analysis, Anziani e Non Solo, in the framework of the Caregiver Day, also organized a workshop on 13 May 2019. The audience of the Caregiver Day included caregivers' themselves, CSOs, trade unions, policy makers, and citizens. The final Italian Multiplier Event of the project, organised on 25 February 2021, was finally used to gather a last users' feedback on the project and the capacity of the project to reply to caregivers' training needs. Based on the results in the five countries of the project and the workshop, the report contains conclusions on the profile of formal and informal carers of persons with dementia and guidelines on how e-trainings for them should be designed.



3. Dementia and caregiving: the state of play¹

According to the World Health Organization², most persons with dementia are aged 65 years or older. Dementia concerns around 50 million people worldwide. This number is due to triple by 2050, due to demographic change.

In 2018, the global societal cost of dementia was about US\$ 1 trillion, mainly within high-income countries (HIC)³. Out of this, around 80–85% were estimated to be associated with the costs of social care as well as informal care, including indirect costs for reduced quality of life and hours of work lost by informal caregivers⁴. Indeed, the majority of persons with dementia receive care and support from their family, friends or neighbours.

The WHO⁵ recommends that each country should have a specific action plan to improve “person-centred, gender-sensitive, culturally appropriate care” for persons with dementia and their caregivers. Indeed, dementia is a major public health concern affecting not only persons with dementia, but also their caregivers and the overall society and economy. In particular, informal caregivers may face various forms of physical, financial, social or psychological challenges, they are at higher risk of subjective caregiver burden⁶. Moreover, they have shown to be at higher risk of experiencing symptoms of depression and anxiety compared to caregivers of persons with other illnesses⁷.

As summarised in the research article ‘Self-reported symptoms of depression and anxiety among informal caregivers of persons with dementia: a cross-sectional comparative study between Sweden and Italy’⁸, specific factors increase the risk of symptoms of depression or anxiety among caregivers of persons with dementia. These factors include:

- caregivers being female;
- being the persons with dementia’s spouse;
- having unhealthy personality traits, like low confidence in the caregiver role;
- low-level education;
- poor physical health;

¹ This session has been developed in collaboration with the University of Lund to build on its recent researches on dementia and caregiving. In particular, the session builds on the recent research article ‘Self-reported symptoms of depression and anxiety among informal caregivers of persons with dementia: a cross-sectional comparative study between Sweden and Italy’, whose co-authors are also involved in the project.

² World Health Organization. Dementia: A Public Health Priority. Geneva: WHO Press; 2012.

³ Alzheimer’s Disease International. World Alzheimer Report 2018: The state of the art of dementia research: New frontiers. London: Alzheimer’s Disease International (ADI); 2018.

⁴ Alzheimer’s Disease International. World Alzheimer Report 2016: Improving healthcare for people with dementia. Coverage, quality and costs now and in the future [Internet]. London: Alzheimer’s Disease International; 2016. Available from: <https://www.researchgate.net/publication/310457795>

⁵ World Health Organization. Towards A Dementia Plan: A WHO Guide [Internet]. World Health Organization. Geneva: World Health Organisation; 2018. Available from: <http://www.who.int/iris/handle/10665/272642>.

⁶ Brodaty H, Donkin M. Family caregivers of people with dementia. Dialogues Clin Neurosci. 2009;11(2):217–28

⁷ Bin SA, Sayampanathan AA, Cuttilan A, Chun-man Ho R. Prevalence of mental health disorders among caregivers of patients with Alzheimer disease. J Am Med Dir Assoc. 2015;16(12):1034–41.

⁸ Wulff J, Fänge AM, Lethin C, Chiatti C. Self-reported symptoms of depression and anxiety among informal caregivers of persons with dementia: a cross-sectional comparative study between Sweden and Italy. BMC Health Serv Res. 2020 Dec 2;20(1):1114. doi: 10.1186/s12913-020-05964-2. PMID: 33267856; PMCID: PMC7709414



- history of psychiatric disease;
- a substantial number of hours of caregiving per day;
- professional commitments;
- lack of additional support;
- reduced time for leisure and social life;
- a poor quality of the relationship with the persons with dementia.

As summarised in the above mentioned article, if the persons with dementia show high dependency, inappropriate behaviours and increased severity and symptoms of dementia, a caregiver is also more likely to develop symptoms of depression and anxiety.



4. National Report Denmark

4.1 Introduction – The national context

In Denmark the healthcare system operates on three political and administrative levels: the state (national), the regions (regional) and the municipalities (local). The state holds the overall regulatory and supervisory functions in health and elderly care. The five regions are primarily responsible for the hospitals, the general practitioners and for psychiatric care. The 98 municipalities are responsible for several primary healthcare services as well as for elderly care.

The Ministry of Health is responsible for the overall framework for the provision of health and elderly care. This includes legislation on the organization and provision of health and elderly care services.

All residents in Denmark have access to the public healthcare system, and most services are provided for free. National legislation ensures that diagnosis and treatment are provided within certain time limits and establishes a free choice of hospital for patients.

The Danish people are generally healthy and live longer than previous generations. It is expected that the number of people over 65 years will grow significantly, and it is estimated that by 2040 there will be twice as many people aged 80 or over than there is today.

The Danish Dementia Research Centre (DDRC) estimates, that the actual number of people with dementia in Denmark in 2019 is around 89.000. About 3.000 of these are under 30 years old. It is estimated that almost 400.000 people in Denmark have a close relative with dementia.

4.2 Legislative framework, policies and good practices

In 2017 the Danish Ministry of Health launched *National action plan on dementia 2025 – A safe and dignified life with dementia*.⁹ The action plan was developed through a broad and inclusive process that involved relevant actors in the field, citizens with dementia, their relatives and experts and health professionals, who expressed their ideas and priorities.

The action plan sets three national goals for the dementia efforts towards 2025:

- 1) All 98 municipalities in Denmark should be dementia friendly.

⁹ <https://www.sum.dk/English/-/media/Filer%20-%20dokumenter/Dementia-english/A-safe-and-dignified-life-with-dementia-jan2017.pdf>



- 2) More people with dementia must be detected and 80 percent must have a specific diagnosis.
- 3) Improving care and treatment reduce consumption of anti-psychotic medicines amongst people with dementia with 50 percent before 2025.

To reach the goals of the action plan 63 million euros have been allocated to implement 23 specific initiatives. One of the initiatives is the *Development and distribution of a national toolbox of courses for patients and relatives*.

The toolbox was published in January 2019.¹⁰ It contains presentations, movies, guidelines and other tools for carrying out courses and conversation groups for people with dementia and their relatives, so they can prepare themselves to handle the disease and the challenges it brings.

The toolbox is developed by DDRC and was tested in seven different municipalities before it was published. DDRC is also responsible for the dissemination and implementation of the toolbox. In various learning seminars around the country it is possible for healthcare professionals and other relevant target groups to learn about the toolbox and how to use it in practice in their own municipality.

The national toolbox focuses on tools for physical courses. However, DDRC has also developed a collection of online e-learning courses called *ABC Dementia*.¹¹ The courses are free and can be accessed by anyone, but they are targeted different groups of healthcare professionals, e.g. nurses and doctors, as well as social workers and students. It is used in many municipalities for training and improvement of qualifications. Some of the topics in the e-learning courses are: symptoms of dementia, prevention of behavioral disorders, cooperation with relatives and ethics and law. DDRC has also developed an app for smartphones and tablets called *Knowledge about dementia*.¹² The app provides some of the same information as the e-learning courses, but the content of the app is more easily accessible for caregivers in their daily working routine.

Another recent initiative, also part of the *National action plan on dementia 2025*, is the elaboration of three knowledge-based manuals.¹³ The manuals are published by the Danish Health Authority to strengthen the everyday practice of healthcare professionals. The content of the manuals is focused on areas where healthcare professionals themselves have requested more knowledge. The overall aim of the manuals is to increase the quality of the care in general, and to ensure a common and coherent approach across the country.

The municipalities in Denmark offers different programs to informal carers of people with dementia. One of the programs is the *Caregiver Self-Management Program*.¹⁴ It is a community-based course given in seven weekly 2.5-hour sessions in groups of 12-16 carers. Each course is facilitated by a pair of trained volunteer leaders, who are both caregivers themselves. The program is developed by the Danish Committee of Health Education and Center of Care and Rehabilitation in Copenhagen. The overall purpose of the course is to teach the participants to take better care of themselves in order to prevent

¹⁰ <http://www.videnscenterfordemens.dk/vaerktoejskassen/>

¹¹ <http://www.videnscenterfordemens.dk/abc/>

¹² <http://www.videnscenterfordemens.dk/app/>

¹³ <https://www.sst.dk/da/Viden/Demens/Anbefalinger-og-haandboeger/Haandboeger>

¹⁴ <http://patientuddannelse.info/3809.aspx>



them from becoming ill themselves. The course has shown positive result which has led to a grant from the Danish government to disseminate the program nationally. In the beginning of 2019, more than half of the 98 municipalities offers the program.

4.3 The training needs of informal caregivers in the country

Data about the training needs of informal caregivers was collected through an online questionnaire. The questionnaire was mainly distributed through Facebook. It was posted on pages for different health organizations and in different groups for relatives to people with dementia. 53 informal caregivers answered the questionnaire and most respondents were women (83%). Almost two-thirds of the respondents (62%) are older than 45 years. 50% of the respondents are still working, while 42% are retired. 8% are unemployed or students. The respondents of the survey are mainly the spouse (38%) or the child (43%) of the person suffering from dementia.

23% of the respondents lives together with the person with dementia and they are engaged in the caring on a 24-hour basis. Even though most respondents are not living with the person with dementia (77%) and are not engaged in the caring on a daily basis, most respondents (75%) feel they have been negatively affected by being a caregiver. A majority is affected on their mental health. Almost all respondents (91%) consider it to be important or very important to be trained on how to take care of their relatives suffering from dementia. However, only 25% have attended any kind of training.

Online training

Online training and e-learning is not yet widely used in Denmark, and less than a quarter of the respondents have ever attended an online course. If they were to attend an online training program 49% would prefer to use a PC. In Denmark almost 90% of the adult population uses a smartphone on regular basis¹⁵, and it is used for more and more everyday tasks. 42% of the respondent of the questionnaire would prefer to use a mobile device (smartphone or table) for online training, and this number is assumed to be even higher in the future.

Training needs of informal caregivers

According to our respondents, the most important overall topics to be covered in an online training program for informal caregivers are

- *practical issues in care management* (58%),
- *psychosocial interventions for people with dementia* (51%),
- *Updated news/latest development in dementia treatment* (49%), and
- *social management issues* (40%).

Among the topics concerning the role as an informal caregiver, the respondents find these topics most interesting:

¹⁵ Statistics Denmark, 2018



- *Ways to relieve the caregiver* (55%),
- *Information on the existing structures for caregivers' support* (49%), and
- *Information regarding legal/financial issues* (42%).

Most respondents would be able to devote 2 hours (42%) or 3 hours (25%) a week to attend an online training seminar on the topics they find most important.

4.4 The training needs of formal caregivers in the country

The online questionnaire for formal caregivers was distributed through the dementia units in four Danish municipalities. 44 employees answered the questionnaire and all respondents, except for one, are women. The respondents have different educational backgrounds. Around one third has an academical background, one third has an education as a home care worker and around one third has a vocational degree in nursing or as a physiotherapist or similar. Some of the respondents has later taken an education to become a dementia coordinator working in the municipality. In relation to age, the respondents are quite evenly distributed. However, the largest group of respondents are between 36 and 45 years old (32%). Only 16% of the respondents feel that their role as a formal caregiver has affected them in a negative way in terms of their mental health.

Online training

82% of the respondents participate in training activities on a regular basis, and only 5% have never participated in any training activities. More than half of the respondents have participated in online training activities. These numbers are supported by interviews with formal caregivers from different municipalities in Denmark. They have all participated in the e-learning program *ABC Dementia*, developed by Danish Dementia Research Center. In some municipalities the online courses are used as a formal part of the education to become a home care worker, in other municipalities it is used as a part of the ongoing training of different kinds of formal carers.

Both the majority of the respondents of the online questionnaire (64%) and the interviewees prefer to use a computer, desktop or laptop, for online training activities. Around one third of the respondents would prefer to use a mobile device for online training.

Training needs of formal caregivers

Almost all the respondents of the online questionnaire consider it to be very important to participate in training activities on how to take care of people with dementia. The main motivation for participating in training is to provide better service for the people with dementia they are caring (50%). But also the opportunity to upgrade qualifications is important for some of the respondents (25%).

The most important overall topics to be covered in an online training program for the formal caregivers are *psychosocial interventions* (80%). Some of the respondents would also be interested in the following topics:



- *Issues of the social management of the person with dementia* (67%),
- *Updated news/latest development in dementia treatment* (56%), and
- *Practical issues for care management* (47%).

Among the topics concerning the role as a formal caregiver, the respondents find these topics most interesting:

- *Ways to relieve the caregiver* (51%),
- and *Information on the existing structures for caregivers' support* (42%).

Most respondents would be able to devote 1 hour (33%) or 2 hours (27%) a week to attend online training. Interviews with formal caregivers have shown, that online training needs to be short and flexible to fit into a very busy working day.

4.5 The needs of persons with dementia in the country

In February 2019 a focus group with five persons with dementia was conducted in Copenhagen. Four of the participants were male, all 76 years old or older. One participant was female at the age of 66-75 years old. The focus group was conducted at the Center for Dementia, where all five participants attend cognitive training on weekly basis. All five participants of the focus group have dementia at an early stage and are still very active in their everyday life. They all like to spend time with friends and family and they are all trying to go for walks or biking on a regular basis.

Most of the participants are happy about their life, but at the same time they are worried about the future. They also find it very frustrating, that there seem to be no major progress in the research about dementia and the fact that their condition will only get worse. Two of the male participants have even volunteered for testing new methods of dementia treatment. They all wish that more people could have a greater knowledge about dementia and understand how it is to live with dementia. They also hope that the media in the future will talk more about dementia and teach the public about it.

4.6 Conclusions on the training needs

Most informal carers feel their mental health is affected by their role as a caregiver, and they think it is important to receive training on how to take care of the person with dementia they are caring. A new online training program should be accessible on both computer and mobile devices, and the most important topics are practical issues related to the care management and how the carers can get help and support themselves. If possible, the online program should be community-based with the opportunity to share problems and receive support from other caregivers to strengthen their sense of competence.

Informal caregivers often have very little time to participate in seminars or other training activities so an online program should be flexible to attend and contain short and optional modules. Many of the programs available for informal carers today, are offered through the local municipality. To reach the target group, a new online program should be rooted in and promoted through the municipalities and the content of the program should always reflect national and local guidelines and legislation.

Formal caregivers in Denmark are used to participate in training to upgrade or maintain their qualifications and many new initiatives are launched in these years as part of the *National action plan on dementia*



2025. A new online training program must be clearly distinct from other programs and should be possible to combine with other kinds of training. According to the online questionnaire the most important topics to cover in an online training program are psychosocial interventions and issues of the social management of the person with dementia. Interviews have shown that other topics of interest is the latest research on dementia and information regarding legal and financial issues. Some of the interviewees point out, that an easily understandable online module with information on legal issues would be of great interest of both formal and informal caregivers, because it is a very time-consuming issue to deal with.

An online training program for formal caregivers should be very flexible and preferably not more than one hour a week. Most formal caregivers prefer to use a desktop or laptop computer.



5. National Report Italy

5.1 Introduction – The national context

In Italy, healthcare is provided to all citizens and residents by a mixed public-private system. The public part is the national health service, Servizio Sanitario Nazionale (SSN), which is organised under the Ministry of Health and is administered on a regional basis. Family doctors are entirely paid by the SSN, while visits by specialist doctors or diagnostic tests are provided by the public hospitals, conventional private ones or private services. The Italian healthcare system looks cost-effective: public health expenditure, though rising, is below the European average. Unfortunately, interregional disparities in access to care persist and seem to be rising (European Commission Country Report Italy, 2017). According to the latest WHO data published in 2018 life expectancy in Italy is 80.5 for males and 84.9 for females. The total life expectancy, 82.8, gives Italy a World Life Expectancy ranking of 8, one of the highest ones in the EU.

According to the Alzheimer's Association, leading voluntary health organization in Alzheimer's care and research, in Italy more than 1 million people are living with dementia and it is estimated that more than 2 million people are taking care of them as formal or informal caregiver. According to ISTAT, informal caregivers are mainly women aged 45-64 and 2 out of 7 million are taking care of persons with dementia.

The support which is provided to those caring for persons with dementia is still limited in Italy. For example, there is not an Italian organisation representing their interest towards policy makers. However, there are several organisations dealing with specific diseases that take into account caregivers' needs (Boccaletti, et al., 2016). The services supporting caregivers are reaching no more than 5% of the total number of caregivers (Lamura & Chiatti, s.d.).

5.2 Legislative framework, policies and good practices

At the moment, there is not a national law on caregiving, but some regions have already developed laws on this topic. The first Italian region which did it is Emilia Romagna. The law proposal, whose first supporters were the regional MPs representing the majority at the government, was approved in March 2014 (Law nr. 2/2014) with the votes of the vast majority of the regional parliament. Based on the operational guidelines, a specific measure to support informal carers was included in the Social and Health Care Plan of Emilia Romagna for the years 2017-2019 and therefore included in the programmes of all the health-care Districts of the Region. Currently, a regional expert group is working to support the practical implementation of the law. The first steps have been: training of professionals, dissemination of the Carers Day experience across the Region, the definition of a common template for the identification of carers, the further implementation of respite care and protected hospital discharges. The main aims, in the framework of the Regional responsibilities, are: provide direct support to informal carers (through peer support groups, training, respite, emergency interventions...) and care services (strengthening the existing home care and protected hospital discharge services) using – as a tool to share the goals among the informal carer and the professionals – the Individual Care Plan. An important shared goal is to reach-out and support the informal carer right from the diagnosis / hospital admittance as these moments are identified as indicators of a change in the health-condition, requiring long-term care.



Upon an initiative of CARER (the Emilia Romagna Carers Association), a law proposal on informal carers was recently submitted to the national government too. Following to that, two more proposals have been submitted to the Labour Commission at the Senate. The parliamentary term that finished in 2018 included in the Budget Law a National Fund for the Support to informal carers, with a budget of 60 MLN euros for three-years (than increased to 75MLN in the current term) and the definition of the beneficiaries of the Fund (basically, informal carers of persons who had a formal recognition of disability according to the art. 3 of L.104/92 or who is a beneficiary of a disability allowance). The practical activation of the Fund, though, requires the approval of a dedicated law. Currently, seven proposals for this law have been submitted to the Parliamentary Commission. The Commission made the auditions and set up a restricted working group aiming to the definition of a single text.

5.3 The training needs of informal caregivers in the country

Data about the training needs of informal caregivers was collected through an online questionnaire and interviews. The questionnaire was mainly distributed through Facebook and the Caregiver Day, a series of awareness raising and knowledge sharing events organized during the month of May in Carpi by Anziani e Non Solo. It was also shared with health organizations and non-profit organisations for caregivers.

89 informal caregivers answered the questionnaire and 10 participated in an interview. Most respondents were women (80%). About 75% of the respondents are 45+. 60% of the respondents are still working, while 30% are unemployed. 2 of them are also students. The respondents of the survey are mainly the child (75%) of the person with dementia.

56% of the respondents lives together with the person with dementia and they spend at least 4 hours per day with the person with dementia. 83% of the respondents feel they have been negatively affected by being a caregiver, in particular from a mental point of view (50%). Almost all respondents (74%) consider it to be important or very important to be trained on how to take care of their relatives suffering from dementia. However, only 33% have attended any kind of trainings on these issues.

Training needs and preferences

Online training and e-learning is not yet widely used in Italy, and only 11% of the respondents have ever attended an online course. If they were to attend an online training program, they would prefer to use the smartphone (32%).

According to our respondents, the most important overall topics to be covered in an online training program for informal caregivers are:

- *practical issues in care management (69%),*
- *psychosocial interventions for people with dementia (40%),*
- *and updated news/latest development in dementia treatment (33%).*

Other relevant topics are linked to ways to:



- *relieve the caregiver (56%)*
- *manage anxiety (56%),*
- *contact the existing structures for caregivers' support (52%).*

Most respondents would be able to devote 2 hours (32%) a week to attend an online training seminar on these topics.

During the interviews, caregivers also expressed their interest in using the training as a way to open up with other people in the same situation, as well as to build new contacts. In particular, some of the interviewed participants are members of Gruppo di Auto Mutuo Aiuto, informal groups of caregivers, and they feel like the connection with others is as important as the knowledge on the disease. Finally, some interviewees also mentioned their difficulties in combining their working and caring responsibilities. They would find it useful to have some tips on these issues during a training for carers of persons with dementia.

5.4 The training needs of formal caregivers in the country

81 formal carers were also interviewed or reached out through the Dem@entoring online questionnaire. The online questionnaire was distributed through the network of Anziani e Non Solo and the Caregiver Day, as well as through social media. 77 employees answered the questionnaire and 87% of them are women. The respondents have different educational backgrounds. 33% has an academical background, 18% has an education as a home care worker and 30% has a vocational degree in nursing or a similar title. Moreover, 36% of the respondents said that they attend regular courses on dementia, 23% participated in a few-hour workshop on the topic, and 8% of them in a longer training course on this theme.

In relation to age, the respondents are quite young: the largest group of respondents are aged 36-55 (89%). 41% of the respondents do not feel that their role as a formal caregiver has affected them in a negative way. However 17% of them feel a negative impact of their role on their mental health.

Training needs and preferences

70% of the respondents have never participated in online training activities. However, respondents look interested in participating in online training using their laptop (32%). 44% of them see it as an opportunity to upgrade their professional profile, while 42% consider it a way to provide better service for the people with dementia they are caring.

According to the reached caregivers, the most important overall topics to be covered in an online training program for the formal caregivers are practical issues linked to:

- *the daily care management (61%),*
- *psycho-sociological interventions (59%),*
- *updated news/latest development in dementia treatment (44%).*

Among the topics concerning the role as a formal caregiver, the respondents find these topics most interesting:



- *Anxiety management (55%)*
- *Ways to relieve the caregiver (50%).*

During the interviews, it was also underlined the importance to get as much information as possible on the existing structures in support of carers, in particular for foreigners. They also said that the way they deal with persons with dementia is mainly based on their personal experience and the instructions of the family of their patients. Therefore, upgrading their knowledge and skills would be the main reason for them to attend such a training.

Most respondents would be able to devote between 2 to 4 hours a week to attend online training on this topic. Online training should be short and flexible to fit into the working day of formal carers.

5.5 The needs of persons with dementia in the country

Six people with Mild Neurocognitive Disorder were reached out by Anziani e Non Solo. Two of them were men and the other four ones were women over 76. Five out of six had less studied less than twelve years. Just two of them live with in the same house with their families.

During the interviews, persons with dementia looked primarily concerned by their health and the health of their families. In some cases, they fear not to be understood and not to be useful anymore. However, the majority of them feels that their family and/or formal carers support them and they are happy while thinking of their lives and their past.

Despite the health condition, the majority of the participants would like to keep on carrying out their usual daily activities and have control upon their lives. They also express the need to have their freedoms and moments for themselves. Last but not least, participants expressed the need to be listened and understood, as well as to spend time with their dear ones and for their passions.

5.6 Conclusions on the training needs

Both informal and formal carers feel the need to be trained in order to better take care of the person with dementia they care for and themselves. In particular, both formal and informal carers show to have little time to devote to these trainings and they would prefer short and flexible modules to be able to attend during a short break from their daily duties. The majority of the reached is not familiar with online trainings, but available to attend online courses through their laptops, phones, or tablets.

Concerning the content of the online courses, informal carers would like to be mainly trained on practical issues related to the care management, including information on existing structures providing support, and how the carers can get help and support themselves (anxiety management, ways to relieve themselves). If possible, the online program should give the opportunity to share problems and receive support from other caregivers to feel less lonely in their role and to acquire more competences with a



peer-to-peer approach. They also would like to share common negative feelings, such as tiredness and loneliness.

As for formal caregivers, they also would like to be trained on care management issues, even the more practical ones (e.g. relevant local structures in support of them, ways to better adapt the living environment to the needs of persons with dementia) and psychosocial interventions. There is also a lot of interest in ways to improve their wellbeing, as well as the wellbeing of the persons with dementia and their families (e.g. stress and anxiety management, meditation and other ways to relieve carers).



National Report Greece

6.1 Introduction – The Greek context

The Greek health care and social service system is a combination of the Bismarck and the Beveridge model. This means that the Beveridge health care system is exclusively financed by the state budget and offers comprehensive health care to all citizens. On the other hand, the Bismarck model is more reliant on social security and contributions from employees and employers, which is a percentage of wages. All employees, together with their families have social security and contribute to one or more social security institutions. Specifically, the Greek health care and social service system is funded by these contributions but the Greek Government is responsible for the management and apportionment of them. Furthermore, instead of many insurance funds, this model provides a single social security institution managed by the Government as well. What is more, Greek citizens have access to the health care system regardless their income and social status. There is also the private sector which sometimes cooperates with the public or works autonomously.

6.2 Legislative framework, policies and good practices

The responsibilities of the Department for the Protection of the Elderly of the Ministry of Labor, Social Security and Social Solidarity are the study and monitoring of the implementation of open and restricted programs for the elderly, the provision of all kinds of aid to the elderly, e.g. housing allowance etc., the setting of terms and conditions for the establishment and operation of profit or non-profit organizations providing open and closed care services for elderly people, implementation of programs for the establishment and development of social protection for third and fourth age groups. Within the framework of the Department's responsibilities, the following programs are provided:

- Housing assistance program
- Retirement of uninsured elders
- Home Help Program
- Camping program - clay therapy
- Open daily centers for older people (KIFI)
- Seniors' Closed Care Units
- Open Seniors' Recreation Centers (KAPI)

Regarding dementia there are currently 200,000 people living with dementia in Greece and 400,000 family carers looking after them. Although there is a National Action Plan for dementia and Alzheimer's disease in place and there are Memory Clinics and Day Care Centers for people with dementia in the large cities of Greece, compared to existing needs, services are woefully inadequate. Large areas of the country are not covered by any specialized facilities. Athens Alzheimer Association (AAA) in collaboration with the Greek National Network of Healthy Municipalities has developed a project called "Building Counselling Services network for Dementia within municipalities all over Greece" which aims to provide care to people with dementia and education and support to their carers in the local communities. [8] Greek Alzheimer's Associations (NGO) have committed to support the municipality with psychosocial programs for dementia with regular visits of experienced health professionals, printed material, seminars and events.



6.3 The training needs of informal caregivers

Through the online questionnaire for informal caregivers in Greece, Dem@entoring reached 204 persons, mostly women (90%). Their education level is 12 years and more (23.04% have less than 12 years of education) and their age is 46-55 (37.75%) as well as 36-45 and 56-75 (20.10% each). More than half of them are the children of those who have dementia (55.88%) that are still working and live very close to them (58.82% live in the same house). 37.75% of the reached persons take care of the person who has dementia on a 24 hour basis and 29.41% on a daily basis for up to 4 hours. They claim that the care they provide has adversely affected their mental health (67.65%) and their social life (13.73%). They consider training on how to take care of people with dementia very important, but 66.67% have not participated in any seminars or followed an online course (83.33%). The devices they prefer to use for the online course are mostly smartphones, PCs and laptops. Furthermore, practical issues for care management (78.92%) and psychosocial interventions (45.59%) are the most wanted topics for the online training as well as updated news on the disease and latest developments (39.22%). They would also like to include anxiety management techniques, ways to relieve the caregivers and information regarding legal/financial issues. Considering all the above, a large percentage can devote only 2 hours a week for the online training (31.86%) or 3 hours a week (20.59%).

Data from Greece were also gathered through focus groups. Ten informal caregivers participated in one focus group. Half of them (50%) are children of persons with dementia disease. They are mainly women whose age is between 56-65 and their educational level is the highest, more than 16 years. Most of the members of this participated group are retirees except two who are employees. Their parents with Alzheimer disease continue to live on their own. It is often difficult to decide when a person is at too much risk to continue living alone. On the other hand, the second group of participants consists of spouses of people with AD. Eighty percent (80%) of the spouses are women. Their age is between 66-75 and their educational level is high (12-16 years). All of them are retirees and live in the same house with their husbands or wives. They did not follow an online course. They do not use devices for an online training. Only one participant would prefer to use laptop or smartphone for this training.

Two groups of caregivers were identified based on how they described their experience; a negative group and a positive group. The first group refers that caregiving affects their daily life as it takes them a lot of time and energy. Also, even though they occasionally live with the persons with dementia, they are often worried about them. Caregiving is very difficult for them and prevents them from realizing their personal dreams. It also creates negative emotions for their future life. They have great anxiety and uncertainty about the progress of the disease. It causes them great sorrow and feelings of fatigue. The second group feels more optimistic for their relatives with dementia disease. They feel pleasure for having the opportunity to spend time with them. Caregiving is very difficult but they accept it positively. Twenty percent (20%) of these participants live in another city from their relatives with dementia. Seeing in hindsight, most of the participants would like to have more knowledge about dementia. More specifically, they must be informed about dementia disease, in order to avoid anxiety about what to expect as the disease progresses and concern about their ability to support the person living with dementia.

Regarding taking care of themselves, caregivers mentioned that they participate in activities (pilates, yoga, books, seminars) that enhance their sense of well-being and may help them reduce their stress level. They also spend time with friends and family, eat well and engage in physical activity. Moreover, they gave some tips to other caregivers : 1) Read and be informed about dementia, do not postpone the



search for help and support and prepare for an experience that is both difficult and highly rewarding, 2) Have love, patience, and awareness of the responsibility of the care work, 3) Ask for and accept help, 4) Accept the situation as quickly as possible. Do not be surprised by new symptoms of the disease. Most of the participants act according to a plan. They try to work together to find what helps persons with dementia relax. Many of them get their relatives in touch either by phone or by living with old friends. Additionally, they suggest that tours and various events must be held. Others emphasize the importance of routine and psychosocial interventions (Do easy tasks like dish washing in order to feel useful. The caregiver plays her/his favorite music). Most of the caregivers try to have a plan but due to other health problems that arise for people with dementia disease, it is violated. All caregivers want to educate themselves about the disease and the way to solve problems as the disease progresses. The sources that helped them are: Day Care Centers, Alzheimer's Association, seminars, books about dementia, internet and specialized health professionals.

6.4 The training needs of formal caregivers

101 formal caregivers took part in the online questionnaire. Most of the participants were women (approximately 74%). The educational level of the majority is up to 16 years: half of them has a nursing degree and their age is less than 35 years (50.5%). Opinions differ on how their life was affected by providing care to people who have dementia, as 32.67% of them believe that their mental health was affected by anxiety, sorrow or anger but 29% of them were not affected at all. Furthermore, most of them have attended seminars regarding dementia but not an online course and therefore they consider training very important, as they want to provide better services for people with dementia and improve their skills and qualifications. Half of them would prefer to use their smartphones and Pcs as a device for the online training. What is more, practical issues for care management of the person with dementia is the main topic that the majority wants to be covered by the training (66.34%) as well as psychosocial interventions (52.48%). There is also a 48.51% that want to be updated about news on the disease or latest developments. With reference to topics of the training, 52.48% would like to be informed about anxiety management techniques of the caregiver as well as issues of configuration and organization of caregivers' daily program (43.56%). In addition, ways to relieve the caregiver is one of the most wanted topic (39.6%). On the whole, almost 29% of the participants could be able to devote 4 hours a week to attend the training. The rest can devote less than 2 hours a week.

Eight formal caregivers also participated in the focus group. Five of them are foreigners and they do not have the ability to speak the local language fluently. All of them are women aged 46-55 and their educational level above 12 years. Most members of the group work on a daily basis with people having dementia and half of them live with them in the same house, six days a week. There is no one who has ever followed an online course. However, they said they would prefer to use smartphones or tablet for an online training. Furthermore, most of them have been working as caregivers for over five years and they believe that their former knowledge and experience helped them to cope with the needs of the people who are caring and their families.

Regarding the caring of people with dementia, they all agreed that is very challenging. First of all, they have to deal with their emotional burden. Anxiety and sorrow are the main emotions and the relationship that is establishing with the person they take care of makes it even more difficult for them to be optimists for the future as they see how the disease progresses. Additionally, they claim to feel physically exhausted



at the end of the day and sometimes they suffer from insomnia due to tenseness and worry for the people with dementia who usually wanders around during the night time. It is important to emphasize that for those who cannot speak the native language fluently, the communication barriers make the caring even more challenging.

Moreover, most of the caregivers have no particular training about caring for people with dementia. They mostly rely on their personal experience and work according to the instructions of the family. Some of them have asked for advice and guidance from the Alzheimer's Association and others have basic nursing knowledge. Only one of them was a professional nurse who has retired. Owing the fact that they find it difficult to deal with the requirements of such care, they are more than willing to attend an online course with the purpose of improving their knowledge and upgrading their skills. According to their preferences, the course should be brief and understandable, emphasizing to practical issues of managing the care of a person with dementia as well as to psychosocial interventions. Moreover, the foreign caregivers express the need for the lesson to be translated in their language in order to be more understandable and sufficient. On the whole, they are able to spend two hours a week for the online course in average.

Persons with Mild Neurocognitive Disorder The point of view of persons with Mild Neurocognitive Disorder was also gathered through a focus group which involved five persons in this situation. Three of them were men and the other two were women between the age of 66-75 years old. The educational level of the most is 12-14 years and one of them has more than 16 years. In addition, all of them live in the same house with their families and the caregivers are their spouses and their children.

It is a fact that people with Mild Neurocognitive Disorder need more information about the disease and how to face it. Since they are at the early stage of dementia, the more they know the better their family and themselves will be prepared. The truth is that they worry about the future and that makes them anxious and frustrated as most of them express their worries about their children and how the relationship between the family members is going to change. Needless to say, that the financial burden seems to be on top of all as the expenses will increase in the future. Despite the imminent health deterioration, people with Mild Neurocognitive Disorder strongly believe that is essential for them to be able to make their own decisions and have control upon their lives. In other words, they need advocacy and empowerment. Actually, this means recognizing the ability of people with dementia to take part in decision-making with or without the mediation of advocacy actions. On the other hand, the concept of empowerment emphasizes the need to recognize and strengthen the rights of people with dementia and, more specifically, to support their abilities for the longest possible time. Last but not least, the need of Dementia Friendly Communities is something they are looking forward as a way to reduce stigma and improve their quality of life.

6.5 The needs of persons with dementia

Five people with Mild Neurocognitive Disorder participated in the focus group. Three of them were men and the other two were women between the age of 66-75 years old. The educational level of the most is 12-14 years and one of them has more than 16 years. In addition, all of them live with in the same house with their families and the caregivers are their spouses and their children for those who are widowed. They attend the groups at the Day Care Centre for people with Dementia in Maroussi on a weekly bases for cognitive training through psychosocial interventions.



It is a fact that people with Mild Neurocognitive Disorder need more information about the disease and how to face it. Since they are at the early stage of dementia, the more they know the better their family and themselves will be prepared. It is also true that they worry about the future and that makes them anxious and frustrated as most of them express their worries about their children and how the relationship between the family members is going to change. Needless to say, that the financial burden seems to be on top of all as the expenses will increase in the future.

Despite the imminent health deterioration, people with Mild Neurocognitive Disorder strongly believe that is essential for them to be able to make their own decisions and have control upon their lives. In other words, they need advocacy and empowerment. Actually, this means recognizing the ability of people with dementia to take part in decision-making with or without the mediation of advocacy actions. On the other hand, the concept of empowerment emphasizes the need to recognize and strengthen the rights of people with dementia and, more specifically, to support their abilities for the longest possible time. Last but not least, the need of Dementia Friendly Communities is something they are looking forward as the inclusion of people with dementia in the community and their active participation will reduce stigma and improve the quality of their lives.

6.6 Conclusions on the training needs

In conclusion, all Greek participants express their preference for online courses, as they will be able to have access from everywhere. In addition, they claim that they want the course to be between 2- 4 hours, twice a week. Some of them expressed the need to be more than two times during the week but they finally came to the conclusion that this will not be feasible for those whose everyday program is more demanding. They also suggested that laptops and tablets are more suitable for the online training. The training program should contain practical issues for care management of the person with dementia, psychosocial interventions for people with dementia and ways to relieve the caregiver.

The burden of caregivers of people with dementia is one of the most important issues in approaching the disease. The psychological, practical and financial burden is usually borne either by the relatives of those who suffer or by the working caregivers. The demands of such care are extremely high and people who take on this role often experience negative emotions that affect their mental health as well as their social lives. That's the reason why it is so important to them to be properly trained by the guidance of people who have the same experiences and more information and knowledge to communicate.



6. National Report from Poland

7.1 Introduction – The national context

In Poland, care for people with dementia is provided by different structures, subordinate to the Ministry of Health and the Ministry of Social Welfare. There are care services for the elderly, but there is a lack of services specific to people with dementia. The care of dementia patients is provided in: family homes, nursing and healthcare facilities, nursing and care centres, social welfare homes, daily psycho-geriatric units, 24-hour psycho-geriatric wards, community welfare centres, social welfare homes, and private care and residential homes. It is possible to hire a personal caregiver for the sufferer at home. Counselling centres and Alzheimer's associations as well as support groups can also assist in the care of patients with dementia.

Data from the Central Statistical Office show that in Poland the population of people over 65 years of age is currently about 14.7%, in 2035 it will increase to 24.5%, and in 2050 it will reach over 30%. Alzheimer's disease, which mainly affects the elderly, already concerns almost 400'000 people in our country today. This is a huge number, and it should be underlined that the disease involves at least the same number of people who act as carers for the sick. By 2050, the number suffering from the condition will have tripled to almost one million.

7.2 Legislative framework, policies and good practices

The Ministry of Health gives priority to the health of the elderly, including Alzheimer's patients. This is indicated, among others, by the inclusion of dementia issues in the National Health Programme for 2016-2020. Dementia is indicated in the Regulation of the Minister of Health of 27 February 2018 on health priorities (Journal of Laws of 2018, item 469; §1 points 5 and 10): increasing the coordination of care along with prevention, treatment and rehabilitation of Alzheimer's patients. Recognising the problems of carers of people with Alzheimer's disease, the Ministry of Health has announced a procedure for awarding targeted grants to non-public sector entities, including associations and foundations, for the task entitled 'Information and education programme on Alzheimer's disease for people with dementia and their caregivers' (<https://www.gov.pl/web/zdrowie/ngo2017>). Two NGOs were selected to carry out this task.

According to the official Statement of 13 February 2018 issued by The Committee on Family, Senior Citizenship and Social Policy of Senate of the Republic of Poland the government should take immediate measures to introduce a strategic National Alzheimer's Programme established previously in 2011 by the Alzheimer's Coalition on the initiative of the Polish Alliance of Alzheimer's Organisations following European Parliament resolution of 19 January 2011. This requires the adoption and implementation of systemic state action plans of educational, scientific, organisational, medical, social and welfare character. It is also necessary for the state to develop standards of care for patients, their families and patient carers that correspond to the challenges and scale of the phenomenon. Unfortunately, it has never been actioned for 2019 by the current government.

The Association "Polish Local and Regional Television" in Elbląg (<http://www.telewizjelokalne.org.pl>) developed a dedicated TV program. A cycle of 5 episodes was produced under the slogan '**Let's not forget about those who have forgotten**'. The following topics were included in the programme:



- *Don't forget* – in this episode you will find an overview of the disease, its causes and stages of development. The importance of early diagnosis and the role of pharmacotherapy were emphasized. The issue of prophylaxis is also discussed and the sources of reliable information on diet, drugs and help provided to families and patients are indicated;
- *First of all, peace* – in this episode the expert discussed various forms of therapy affecting the alleviation of disease symptoms, as well as the scheme of functioning of the Alzheimer's Centre in Olsztyn;
- *Let's talk* – in this episode the role of communication with a person suffering from Alzheimer's disease is discussed. The problems with verbal and non-verbal communication are also pointed out; On the other hand, this episode presents the day of the carer of a person suffering from Alzheimer's disease and discusses the features and qualifications of an ideal carer;
- *Almost like at home* – in this section the role of Community Self-help Home was discussed and the scheme of functioning of such a centre in Elbląg was approximated.

In total, 7500 broadcasts in 125 cities were transmitted in the common interregional channels network.

Wielkopolska Alzheimer's Association in Poznań (<http://www.alzheimer-poznan.pl>) delivered a series of thematic lectures. They conducted workshops with specialists (psychiatrists, psychologists, social workers) for people suffering from Alzheimer's disease and their carers. The project was carried out under the slogan 'Alzheimer's Information and Education Centre'. As part of the assignment, the Association conducted 39 workshops with social workers, 39 workshops with psychologists, 40 workshops with psychiatrists. The workshops with the social worker included issues related to Alzheimer's disease, information on existing support centres, information on how to cope with difficult situations while caring for the patient, motivating people with dementia to participate in classes, communication exercises and elements of reminiscence therapy. During workshops with a psychologist, cognitive functions were studied, cognitive therapy was presented along with ways how to engage and motivate participants in various activities. The doctor diagnosed dementia disorders, ordered additional tests and analysed the results of cognitive function tests. Moreover, the Association organized lectures for families and carers of elderly people under the slogan "Understanding Alzheimer's".

7.3 The training needs of informal caregivers in Poland

In Poland, the Dem@entoring on-line questionnaire reached 81 informal caregivers (60 female, 21 male). The majority of them (59,26%) followed higher education path (more than 16 years of schooling), almost one third (28,40%) graduated at secondary level (12-16 years of schooling) while the minority (12,35%) claimed less than 12 years of schooling. The biggest group (almost 40 persons) is in the age ranging from 46 to 65 years old. 14 persons are from mid-thirties to mid-forties. The younger group (less than 25 years old) is almost equally represented as the caregivers in the age of 66-75 (10/ 11 persons respectively). Almost half of the interviewees are professionally active (48,15%), 22,22% are unemployed, 17,28% are retired and the minority (12,35%) are still studying. Children are the main informal caregivers (51,85%), spouses and grandchildren are equally represented (20,99%). The same number of family caregivers live with the person they take care of and live independently (40/41 persons). Nevertheless, among those who live separately, the majority stay in the close neighbourhood (77,59%). There are three equally represented groups (27,16% each) providing care 24/7, 4 hours per day and 2 days a week for care giving. 32,10% of responders claim that caring for a person with dementia has not affected them negatively. However, among those who noticed negative aspects, mental health (sadness,



anger, stress) is indicated on the first instance (23,46%). Training on how to take care of person with dementia is perceived as important by most of interviewees (very much: 32,10%, enough: 29,63%, a little: 20,99%). Majority of informal caregivers has never participated in any training (48,15%), 29,63% of them took part in short seminars while only 22,22% have attended a full training course. More people participated previously on an on-line course (55,56%) but those who didn't still constitute a large number (44,44%). The most preferred device indicated for e-learning is laptop (28,40%), then tablet (25,93%) and finally smartphone (22,22%).

Among the three most desirable topics for on-line training there are:

- *updated news on the disease/ latest developments in dementia treatment (59,26%),*
- *psychosocial intervention for people with dementia (51,85%),and*
- *practical issues for care management (48,15%).*
- *ways to relieve caregiver (56,79%),*
- *information on the existing structures for caregivers support (56,79%)*
- *anxiety management techniques (46,91%).*

Finally, the maximum number of hours per week declared by the family carers to allocate for on-line course is two (37,04%), three (22,22%) or four (17,28%).

Focus groups provided the opportunity to touch issues that are not measurable but equally important for the family care givers. One of the predominate emotions mentioned they cannot cope with is **feeling guilty**. It is often caused by frustration and tiredness of the caregiver, as well as conflicts among the closest ones, relatives – because sooner or later the issue of care puts the relations of the whole family of the patient to the test. Many spheres of life remain in the **area of neglect**: own family, professional work, health, hobbies, friends. There may appear a **sense of lost life**.

Within the same focus group sessions we talked with people with mild dementia (light initial stage of the illness). One of the biggest fears of elderly people is total memory loss, which leads to **loss of identity**. Another very important concern is the **relationship with the caregiver**. Common testimonials and worries expressed were: "So that I am not a burden to you". This anxiety leads to blaming oneself for bringing the caregiver's difficulties. On the other hand, what gives them hope is contact with other people, **avoiding isolation** at home.

7.4 The training needs of formal caregivers in Poland

Through the on-line questionnaire, 72 Polish formal caregivers were reached (50 female, 22 male). The majority of them (59,72%) followed higher education path (more than 16 years of schooling), 31,94% graduated at secondary level (12-16 years of schooling) while the minority (8,33%) claimed less than 12 years of schooling. Most of them (40,28%) have an academic degree in nursing or vocational degree in nursing (20,83%) while 15,28% attended VET training as a home care worker. The biggest group (44,44%) is in the age ranging from 36 to 45 years old. 29,17% are less than 35 years old while 16,67% are care givers in their mid-forties till mid-fifties.



58,33% of responders claim that caring for a person with dementia has not affected them negatively. However, among those who noticed negative aspects, financial situation is indicated as the first place (13,89%). Training on how to take care of person with dementia is perceived as important by most of interviewees (enough: 38,89%; very much and little: 27,78%). A considerable number of formal caregivers do not tend to participate in any training activity (26,39%), 31,94% attend training on the topic on regular basis while 29,17% participate in few hour seminar/course.

More people participated within an on-line course (66,67%) but those who did not still constitute a large group (33,33%). The most preferred device indicated for e-learning is smartphone (30,56%), then laptop (26,39%) and finally PCs (19,44%). In order to attend professional training formal caregivers are motivated the most by: providing better service for people with dementia (34,72%), upgrading qualifications (25,00%) and improving professional status (19,44%).

Among the three most desirable topics for on-line training there are:

- *updated news on the disease/ latest developments in dementia treatment (indicated by 63,89% persons),*
- *issues of the social management (56,94%)*
- *psychosocial intervention for people with dementia (55,56%).*
- *existing structures for caregivers support (52,78%),*
- *anxiety management techniques (51,39%)*
- *ways to relieve caregiver (38,89%).*

Finally, the maximum number of hours per week declared by the formal carers to allocate for on-line courses is two (29,17%) or three (37,5%) hours.

Formal caregivers who participated in focus groups presented their perspective and personal perception on the training available in Poland. Even though they are already well qualified within formal educational system, they feel the need to improve their competences and up-date the knowledge and gain new skills. There are several general on-line and face-to-face courses caregivers, but the topic of dementia is not so widely discussed. It is very seldom to find training dedicated only to Alzheimer's disease, therefore Dem@enting project fulfils the identified gap. As already underlined, the state system requires improvement at many levels. In the same time the bottom-up initiatives are very much appreciated like self-supporting groups, networking and mutual cooperation of all the key-players in the field. One of the aspects mentioned during research carried out is the financial situation of the carers. This profession is not sufficiently profitable in Poland to invest in further professional development, hence the available training offered is usually on a commercial basis. As a consequence carers are depending on free courses. From a technical point of view, user-friendly on-line solutions accessible on all possible devices and less time-consuming are the most desired.

7.5 The needs of persons with dementia

groups in Poland with people with mild dementia (light initial stage of the illness) were organised in Spring 2019 with a considerable support of ŁTA – Łódzkie Towarzystwo Alzheimerowskie (Lodz Alzheimer Association). We reached directly 5 persons, 2 male and 3 female, all of them in their mid sixties up to mid-seventies. The majority declared high educational level (more than 16 years). They receive informal caregiving by family members on one hand and day care provided by ŁTA, on the other.



In general, the interviewees seemed happy and satisfied. They eagerly participate in activities proposed by their formal and non-formal caregivers.

However, they also underlined some worries that bother them. One of the biggest fears of elderly people is total memory loss, which leads to loss of identity. Another very important concern is the relationship with the caregiver. Common testimonials and worries expressed were: "So that I am not a burden to you". This anxiety leads to blaming oneself for bringing the caregiver's difficulties.

On the other hand, what gives them hope is contact with other people, avoiding isolation at home. They look forward to various activities proposed by the centre like art or musical classes and last but not least all physical-wise training. However, among the aspects the most appreciated there are homely atmosphere, kindness and acceptance of others and strong feeling of belonging to the community that guarantees security.

7.6 Conclusions on the training needs

Desk research revealed that there is still plenty to develop in Poland from structural point of view. The government has never implemented the National Alzheimer's Programme established previously in 2011 by the Alzheimer's Coalition on the initiative of the Polish Alliance of Alzheimer's Organisations following European Parliament Resolution of 19 January 2011. On the other hand, there are other measures undertaken at the state level to improve the situation of people with dementia and their caregivers. Third Sector and numerous initiatives carried out by NGOs play a crucial role in this process with a considerable support of such initiatives as Dem@entoring project.

Apparently both the formal and informal caregivers have similar expectation towards e-learning. The maximum hours per week they are capable to allocate for on-line course is four with the biggest preference of two or three hours per week. The course should be available on and compatible with all devices: laptop, tablet, smartphone and PC. Among the most desirable topics for on-line training there are: updated news on the disease/ latest developments in dementia treatment, issues of the social management, psychosocial intervention for people with dementia and practical issues for care management. Additionally, most beneficiaries would like to gain information on the existing structures for caregivers support, be skilled in anxiety management techniques and learn the ways to relieve caregiver.

Importance of networking, bottom-up initiatives, and support groups has been underlined several times as the most essential in empowering Alzheimer communities. Local and national channels can be easily used for dissemination of the Dem@entoring platform to be created. It was also emphasised to use social media to reach the caregivers in the most efficient way. All beneficiaries reached are very positive towards project results to be developed. Everybody believes in positive impact of the implementation planned that should make a real difference in life of persons with dementia and the caregivers.



7. National Report Sweden

8.1 Introduction – The Swedish context

The Swedish health care and social service system is primarily tax funded. A progressive tax system is applied, where taxes are paid in relation to income. However, the use of the health care and social service system is used based on the person's needs. Thus, health care and social services consumption should have no relation to the person's income or his/her financial situation. People are taxed according to their income and on three levels; the governmental level, the regional or county council level (21 councils) and the municipal level (290 municipalities). This system is built up to ensure a democratic situation and politicians who steer the health care system in a certain area are elected at each level among people living within this geographic area. Each of these levels independently decide about the level of taxation to be applied and also the services they will provide, although the government have a quality monitoring control function.

Health care and social services are a public responsibility and there are no obligations for family members to provide care and service to their next of kin. Married couples have a responsibility to be financially responsible for each other but not in the case of care and service. Health care is regulated by the Health and Medical Services Act (SFS2017:30) and the county councils are responsible for health and medical care, i.e. assessment and treatment, in hospitals, outpatient clinics and primary care. The municipalities are responsible for home care and services, day care and nursing homes. Care for people aged 65 years and older and living at home, is granted after needs assessment regulated by the Swedish Social Services Act (SFS2001:453).

Ten million people are living in Sweden, and 130 000 - 150 000 people are living with a dementia disease, and approximately 25 000 of those are younger than 65 years of age. Every year, 20 000 – 25 000 are diagnosed with dementia and the number is expected to double by 2050 (The National Board of Health and Welfare [NBHW], 2018). It is estimated that 92 000 are living in ordinary housing, and approximately 75% of those are cared for by informal caregivers, most often a spouse or an adult child (NBHW, 2014).

8.2 Legislative framework, policies and good practices

Relatives (informal caregivers) in Sweden is defined as persons who care or support relatives. The social welfare committee shall offer support to make it easier for people who care for a close relative who is elderly, long-term ill or has a disability according to the Social Services Act (SFS 2001:453). Support for informal caregivers shall cover all the activities of social services. Examples of persons covered by the provision of support to relatives are relatives of persons with mental or physical disabilities, long-term mental or physical illness, and relatives of persons with addiction or addiction problems. The provision applies to parents of children or adults who fit into one of these and also of their possible adult children. The purpose of the support is to reduce the relatives' mental and physical strain. For some people, the support comprises efforts related to the person's needs, for others information or education about the disease or disorder is most important. The municipality's responsibility includes setting up intervention and provision plans, to inform the local residents about the possibility of obtaining support if one cares for a relative, to allocate money for relatives' support and to follow up and evaluate. Furthermore, individual calls and group conversations, education, technical devices, home help or in a sheltered accommodation,



relief in various forms as well as economic compensation. Children sometimes provide extensive help and support to parents or siblings. The health care services has a statutory responsibility to consider the needs of these children (SFS2017:30). Also the social services have, through their responsibility for ensuring that children have a safe upbringing and to work preventively, an important task in both detecting and supporting children as relatives when parents have abuse/ dependence, mental illness or other serious difficulties that can affect parenting and children's health and development.

For formal caregivers the employer is responsible for ensuring that the healthcare personnel (formal caregivers) have the skills and knowledge required to meet patients safely. It includes, among other things, ensuring that the employee has the competence and necessary language skills to practice the profession. The website Kunskapsguiden.se (eng. The Knowledge Guide) [NBHW, 2019] is a national platform that gathers knowledge in evidence-based practice, mental illness, the elderly, addiction and addiction, children and young people, and disabilities. The Knowledge Guide shall provide staff working with health, care and services, the best available knowledge as well as support and guidance within the current areas. In the elderly area there is information about various knowledge support, courses and education. In 2019, the NBHW launched a framework for a standardized course of action in dementia which is a model for multi-professional collaboration for person-centered care and services in dementia. The incitement for the standardized course of action, is that a person with a dementia disease, and their informal caregivers, can live many years with the disease with a good quality of life, if they have good knowledge of the disease and different types of care and support, and are offered the right interventions in the form of health care and social services in the right stage of the disease course.

8.3 The training needs of informal caregivers in the country

We reached five informal caregivers for the survey regarding training needs. No responses or demographic data are available. For the focus group interview, five informal caregivers participated, of which three were men and two were women. The caregivers were between 72-85 years of age and retired, and all of them were living with their spouses. They had been caring for their spouses between less than one, and up to five years, and their educational training were elementary school (four) or short-cycle tertiary education (one). One of the caregivers were using a computer to search for information about the disease, and none of them expressed that they wanted to use a computer, iPad or mobile phone to educate themselves. Four of the caregivers had participated in education about cognitive diseases, available care and support from the municipality.

Caring for a relative with a cognitive disease was experienced as demanding, and especially if the person did not admit that they had a cognitive disease and memory loss. The informal caregivers expressed that they tried to live in the presence, taking one day at a time, adjusting and learning how to deal with each situation on the way. They were grateful for available pharmacological treatment which was helpful to some persons with dementia. They perceived day care as a meaningful activity for their relative, as well as a relief for themselves. One man was caring for his wife alone, without any support from formal care services. Even though he wanted to manage on his own and keeping his independence, he expressed a wish to have some relief to be able to do things on his own. In addition, despite the strenuous daily life situation there were also times with good laughs when caring for a spouse with dementia.

Four of the informal caregivers experienced that they were well informed about the dementia disease, and available care and support from both healthcare and social services. One man expressed that he



missed general information about the disease, available care and support and who to turn to when in need of help or advice. All of the caregivers emphasized the importance of having their own time and doing things on their own. They expressed that in reality, they prioritized their relatives' needs and set their own needs aside. One man expressed that he had had to learn new things that he couldn't manage before, like cooking and washing. He became so skilled and efficient that his wife complained because she felt set aside. For this caregiver, this was a real challenge, to find the balance of his caring and keeping his wife active and involved in their daily activities. To get information about the disease, four of the participants phoned the specialized Memory Clinic, the specialized nurse in dementia in the municipality or the elder care services.

8.4 The training needs of formal caregivers in the country

We reached 40 formal caregivers for the survey regarding training needs. The majority of the respondents were female (95%), and 5% were male. They were aged 35 years or younger (26%), 36-45 years and 46-55 years (21% respectively) or 56 years and older (32%). No focus groups have so far been conducted due to the late clearance from the ethical authority. Focus groups are planned to middle of June.

The majority of the formal caregivers had an education background of 16 years (40%), less than 12 years (34%) and 26% between 12-16 years. All education started at seven years of age. Almost half of the formal caregivers had a bachelor's or master's degree in healthcare (50%) and 40% had a short-cycle tertiary (vocational) education in healthcare. One caregiver (3%) had upper secondary (vocational), two (5%) had no education and three (8%) stated other education such as a PhD degree or body therapist.

The majority of the caregivers did not consider themselves being affected by caring for a person with dementia (82%), 10% considered that their physical or psychological health (5%) or economic situation (3%) was affected. Having a formal training in dementia care was considered very important by 82%, important (11%) and rather important by 8%. 42% of them were regularly attending education in dementia care, 32% had longer training, 21% had taken a course for a couple of hours and 5% had no training at all. Internet/online training was valid for 55% of the formal caregivers.

The most preferred media for online courses was laptop (50%) followed by smartphone/stationary computer (18% respectively) and iPad (13%). The personal motivation to attend any education consisted of being able to deliver appropriate care for persons with dementia (80%), to get further education, increase the status of the profession (5%) or for personal interest (3%).

When it comes to the content of an online course 74% preferred to include practical issues for care management of the person with dementia, updated news on the disease/latest developments (48%), different psychosocial interventions for people with dementia (63%), and issues of social management of the person with dementia (16%). Furthermore, good practice in the design of homes and living spaces for people with dementia (61%), technical devices for monitoring people with dementia (11%). Also other issues such as person-centered care (3% was suggested to be included. Beyond this, the formal caregivers asked for anxiety management techniques (63%), ways to support and relieve the informal caregiver (18%), information about existing structures for caregiver support (34%) and information regarding legal/financial issues (34%) was considered important to include. Management and organization of caregivers' daily schedule (53%), possibilities and ways of social networking among informal caregivers (32%), exercises and physical training and relaxation of the informal caregiver (21%) were mentioned together with depression in dementia and social aspects of people with dementia in the



society. The formal caregivers were willing to use between 2 and 20 hours weekly for online training, with the majority of 2 (32%) to 3 hours (24%).

In the focus group interview, nine formal caregivers participated. All were working in a nursing home for people with dementia with long experience in dementia care, in average 6.3 years (5-20 years). They represented all age groups, with a majority (66%) between 46 years and older than 55 years of age. Eight of the participants had between 12 and 16 years of education, and one participant had more than 16 years. Regarding tools for web based education, most of the formal caregivers would prefer iPad (38%), followed by laptop (29%), smartphone (19%), and stationary computer (14%).

In this focus group they expressed that working with people with dementia was a growing interest, often coming with age. The participants were trained prior to working with people with dementia, at a post-secondary non-tertiary vocational level, in some cases with a specialization in dementia care. One participant was a registered Silvia nurse, i.e. she had a master's level degree. The formal caregivers resonated about their work with people with dementia from a person-centered approach. They expressed the need to see the person with dementia and their needs, and always figure out how to best approach them in a specific situation. As staff it was crucial to be present in mind, be aware of the person's state of mind and focus on signals and how to best respond to them. Their challenge was how to reach to the person in specific situations, and they pinpointed the importance of teamwork. It was important to bond, build trusting relationships and create the good feeling for the person with dementia. Every day was filled with joy and hugs, and when the person with dementia was happy, the staff was happy.

At present, the participants used their smartphones in their daily work, something they also encouraged the informal caregivers to do. The application "0-vision" is a tool where they can find some information about dementia diseases, physical restraints (voluntary and involuntary) etc. On the stationary computer they used "Senior alert", a national quality register for preventive health care and social services, and the BPSD-register, a national quality register and tool to reduce the incidence and severity of behavioral and psychological symptoms of dementia (BPSD). The participants requested educational tools such as applications for smartphones that contained information about the different stages of the dementia disease and end of life stage, different forms of restraints, how to approach persons with dementia and BPSD, sexuality when living with dementia, e.g homosexuality, bisexuality, transgender people and queer people (HBTQ), how to manage social issues, and also in different languages.

8.5 The needs of persons with dementia

The participants in the focus group with persons with dementia were all woman (seven), between 68-80 years of age and diagnosed with Alzheimer disease. Two of the participants were participating in day care, while the others did not use this service. One woman was living with her husband, the remaining six women all lived on their own. Three of the persons with dementia were educated in elementary school, four had short-cycle tertiary educational training and one had short-cycle vocational tertiary educational training.

For the people with dementia, social contacts and having people they could trust around them was the most important issue. To them, it was very important to be met with dignity and respect, and to be counted



on. They strived to remain independent as long as possible, and they appreciated the social and physical activities provided by the municipalities. It encouraged them to get along, despite the difficulties they were facing from time to time. In particular they missed being able to drive a car or go by bike. The fears they had were related to family and close friends, not their own life situation. They more or less lived very much in the present, not anticipating so much in the future. They all used smartphones, but only for keeping in touch with family and friends, not to search for information.

8.6 Conclusions on the training needs

The majority of formal caregivers in the Swedish survey would prefer online courses on laptop and the course to be between 2 and 3 hours.

The training program should contain:

- Practical issues for care management of the person with dementia, psychosocial interventions for people with dementia;
- Good practice in the design of homes and living spaces for people with dementia.
- Personal motivation to attend any education were most important to see to that the person is able to deliver appropriate care for persons with dementia.

The e-mentor training and intervention is expected to have a positive effect on sense of competence, the perceived burden of care and health complaints among the informal caregivers to people with dementia.

The training should provide an atmosphere where the mentee has the opportunities to open up about problems, without feeling judged, as well as receiving emotional support and positive feedback. Other positive aspects include receiving knowledge about dementia, gain new insights into the own situation and having their problems acknowledged. Less positive aspects of online training and coaching include the lack of possibilities of a personal meeting, difficulties to make appointments if the caregiver works fulltime (van Mierlo et al, 2012).

One potential risk or negative aspect of online mentoring could be the lack of integration with other interventions directed towards the caregiver as well as the person with dementia. Multicomponent interventions involving both the informal caregivers and the person with dementia has proved to be more successful than single ones. Also, the older population of caregivers are less comfortable with technology than e.g. adult child caregivers, thus indicating that this kind of mentoring approach could be problematic for some target groups (Span et al, 2013).



9. Conclusion

The analysis allowed the Dem@enting consortium to get a better picture of the target groups of the project, as well as a more comprehensive idea of the content of the upcoming Dem@enting trainings and how they should be delivered to formal and informal carers.

Formal carers

The analysis allowed the project to get a better picture of formal carers. The majority of the formal carers participating in the survey were women under 45 years of age. Their education level varied, as well as their level of knowledge in dementia. However, the majority was positive about the idea to attend e-learning training on dementia. In particular, there was a special interest in the following topics:

- psychosocial interventions
- issues of the social management of the person with dementia
- updated news/latest development in dementia treatment
- practical issues for care management
- ways to relieve the caregiver
- information on the existing structures for caregivers' support
- Good practice in the design of homes and living spaces for people with dementia.
- Personal motivation to attend any education were most important to see to that the person is able to deliver appropriate care for persons with dementia.

Informal carers

The majority of the informal carers participating in the survey were women aged 45+ and were still working.

The analysis portrayed informal carers as women aged 45+ who were still working and devoted more than four hours per day to the person they were caring for. According to the analysis, informal carers would like to be trained in:

- practical issues in care management
- psychosocial interventions for people with dementia
- updated news/latest development in dementia treatment
- social management issues
- ways to relieve the caregiver
- information on the existing structures for caregivers' support
- information regarding legal/financial issues

Furthermore, informal carers expressed interest in having networking opportunities in order to share the negative emotions they sometimes cope with. Among them, they reported the fact of feeling guilty, frustrated, tired, and lonely.



Training needs

Apparently, both the formal and informal caregivers have similar expectations towards e-learning and they both feel that being trained on dementia is very important. The maximum hours per week they are capable to allocate for on-line courses are two or three hours per week. The course should be compatible with all devices (laptop, tablet, smartphone and PC) and be organised in short and optional modules to allow caregivers to attend them according to their needs. Importance of networking, bottom-up initiatives, and support groups has been underlined several times as the most essential in empowering caregivers. The training should provide participants with opportunities to open up about problems, without feeling judged, as well as receiving emotional support and positive feedback.

The e-mentor training and intervention is expected to have a positive effect on sense of competence, the perceived burden of care and health complaints among the informal caregivers to people with dementia. However, one potential risk or negative aspect of online mentoring could be the lack of integration with other interventions directed towards the caregiver as well as the person with dementia.

To reach the target group, a new online program should be rooted in and promoted through the municipalities. Social media are also considered a powerful tool to reach out isolated informal carers.



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Appendix: Guidelines for the project's partner to gather inputs on the users' needs.

The steps associated with Output 1 were the following:

1. Each partner conducted desk and field research regarding the national context for formal and informal caregivers, as well as persons with dementia. Sources of information of the desk research can be:
 - Official reports
 - Governmental and nongovernmental organizations
 - Official press releases and data
 - International scientific literature
 - Research papers from local universities or research centers
2. Each partner organized focus groups (instead of a workshop as initially planned) with persons with dementia, formal caregivers, and informal caregivers to explore the training needs of formal and informal carers (see below). Interviews will also be carried out by each partner.

The interviews took place in the respective language of each partner to ensure participants' comprehension. Each partner, translated the interviews to their respective language.

Participants were recruited through:

- The network of contacts of the partners
- Communication channels of the partners/ the project
- The involvement of local stakeholders that are in contact with the target groups of the focus groups/ interviews

During the focus groups/interviews, participants signed the consent form (see below).

3. Each partner used the project's online questionnaires (see below) to reach out formal and informal caregivers
4. Each partner translated the questionnaires to their respective language and sent it to the consortium so that it could be uploaded on SurveyMonkey, the platform that was used for this activity.
5. Each country filled in the 'National Report template' (Annex I) with the gathered information and submitted it to ANS.
6. ANS summarised the information provided in the national reports in an executive summary that highlighted the key outcomes for each country in a cross-national analysis and came up with recommendations for the next outputs of the project.



National Report Template

a. Formative and Layout guidelines:

For Headlines: Font: Arial, size 12, Bold.

For main text: Font: Arial, size 10

b. Structure:

1. Introduction – The national context (200-300 words)

Provide the basic characteristics of welfare/healthcare system in your country.

2. Legislative framework, policies and good practices (300-600 words)

Identify any relevant national/regional legislative framework or initiative in support of formal and informal caregivers in your country. In addition, present at least 2 good practices aiming at supporting caregivers in your country. These initiatives can be led by from public authorities, companies, and NGOs aiming to support caregivers. Add links where readers can find more details on what you present in this part of the report.

3. The training needs of informal caregivers in the country (400-600 words)

Start with some demographic data on the informal caregivers you reached out through the online questionnaire and the focus groups (gender, age, education, relationship with the person with dementia, etc)

Develop the main findings of the online questionnaire for informal caregivers and the relevant focus groups. In particular, please focus on the gathered training needs of informal carers and the current challenges they face to take care of persons with dementia. Thank you for specifying informal caregivers' familiarity with e-trainings (e.g. what device do they prefer to use? How much time would they devote to an online training?).

4. The training needs of formal caregivers in the country (400-600 words)

Start with some demographic data on the formal caregivers you reached through the online questionnaire and the focus group (gender, age, education, background, etc.).

Develop the main findings of the online questionnaire for informal caregivers and the relevant focus groups. In particular, please focus on the gathered training needs of formal carers and the current challenges they face to take care of persons with dementia. Thank you for specifying formal caregivers' familiarity with e-trainings (e.g. what device do they prefer to use? How much time would they devote to an online training?).



5. The needs of persons with dementia in the country (max 400 words)

Start with some demographic data on the persons you reached through the the focus group (gender, age, education, background, etc.).

Develop the main findings of the focus group.

6. Conclusions on the training needs (300 - 400 words)

Develop a conclusion with the main findings from desk research and the focus groups/interviews.

Identify 3 main recommendations for the upcoming project's training for informal carers:

- How to deliver an online training? What device would you use? How long should the training be?
- What topics should the training present?
- Why should participants participate? How should the training be promoted to reach out the target group?
- Explain the risks and threats and the expected positive impact that the trainig can have.

Identify 3 main recommendations for the upcoming project's training for formal carers:

- How to deliver an online training? What device would you use? How long should the training be?
- What topics should the training present?
- Why should participants participate? How should the training be promoted to reach out the target group?

Explain the risks and threats and the expected positive impact that the trainig can have.



Questions for the focus groups and the interviews

Questions for the focus groups with:

a. Informal caregivers:

- How would you describe having a relative with a dementia disease?
- How does it affect your daily life?
- Given the experiences you have, what do you wish that someone had told you before?
- Can you tell us a little bit about how you take care of yourself? Do you have any tips for others?
- Do you act according to a plan or strategy; if so, would you like to describe it? How did you come to choose the specific strategy (-ies) you use?
- What sources do you use to search for information about dementia and its consequences? How should the information sources be designed in order to fit your needs?

b. Formal caregivers:

- How would you describe caring for people with dementia?
- What are the main challenges in the caring situations?
- Can you please describe the training you had to care for people with dementia?
- Do you use any online education tool for the moment? If so, what does it comprise?
- If you were to design an online education tool for dementia care, what would it include?
- Do you use online education tools for learning? (all types). Can you recommend any?

c. People with dementia

- Tell us something about what makes you happy and satisfied
- Tell us something about what worries you
- Let us know something about what you look forward to

Demographic questions (to be gathered with an anonymous form) for

a. Informal caregivers:

1. Gender

- Female
- Male
- Decline to answer

2. Educational level in years

- Less than 12
- 12-16
- More than 16

3. Age in years

- Less than 25



- 25-35
- 36-45
- 46-55
- 56-65
- 66-75
- More than 76

4. Are currently working?

- Yes
- No, I am studying
- No, I am retired
- No, I am unemployed

5. What is your relationship with the person having a dementia disease?

- Spouse
- Children
- Grandchildren
- Other relatives/related persons

6. Are you living with the person you care for?

- In the same house
- In close distance (less than 20 km)
- In another area or another city/ country (more than 20 km)

7. Have you ever followed an online course?

- Yes
- No

8. What kind of devices would you prefer to use for an online training

- Smartphones
- Tablets
- Pcs
- Laptop
- None

b. Formal caregivers:

1. Gender identity

- Female
- Male
- Decline to answer

2. Educational level in years

- Less than 12
- 12-16
- More than 16

3. Age in years

- Less than 25



- 25-35
- 36-45
- 46-55
- More than 56

4. How would you assess your knowledge on dementia?

- Elementary
- Lower
- Intermediate
- Advanced

5. What kind of devices would you prefer to use for an online training

- Smartphones
- Tablets
- Pcs
- Laptop
- None

c) people with dementia participating in the focus groups

1. Gender identity

- Female
- Male
- Other
- Decline to answer

2. Educational level in years

- Less than 12
- 12-16
- More than 16

3. Age in years

- Less than 25
- 25-35
- 36-45
- 46-55
- 56-65
- 66-75
- More than 76

4. What kind of care do you receive today?

- Informal caregiving (spouse, child, friend)
- Day care
- Healthcare
- Home help care
- Respite care
- Other:.....



In particular, the interviews will serve to extract valuable input related to:

- a) non-formal training
- b) Target group profiles & needs
- c) Existing use of technology
- d) Inclusive training approaches used
- e) Efficiency of models proposed
- f) Issues and obstacles faced and how to overcome them
- g) Possible use of project results
- h) Application of models
- i) Considerations to take into account i.e. how users will interact online (anonymous, avatar use, real profiles, habits of communication, tools commonly used, avoidance of stereotypes, age groups etc.).

As for the focus groups:

- **Moderator:** The focus groups were moderated by the partners of the project
- **Agenda:** After a short introduction on the project, the moderator asked the agreed questions (see above) to the target groups. At the end, the moderator summarised the main conclusions of the focus group and discussed them with the participants.
- **Reporting:** The findings of the focus groups were summarised in the national report each partner prepared
- **Social media:** Each partner used social media to promote the project, as well as the aims and the results of the IO1



Questions of the online questionnaires

Online questionnaire for informal caregivers

Cover page

Dear respondent,

we would like to inform you that the data we will collect through the survey will be anonymous and therefore it won't be possible for us to link them to your identity. We also confirm you that we will not track and store identifiable respondent information in survey results.

Data will be accessible by the members of the consortium delivering the Erasmus+ Project De@mentoring (see: www.dementia@mentoring.eu)

Data will be managed and stored using a platform named SurveyMonkey. To check their privacy policy, including the use of Cookies, you can read: <https://www.surveymonkey.com/mp/legal/privacy-policy/>

By responding to the survey you confirm that you have read, understood and accepted these information.

Evaluation of the training needs of caregivers for people with dementia

The study aims to explore issues related to the educational needs of caregivers of people with dementia, so that through developed training programs, they will acquire knowledge and skills that will contribute both to the better management of the caregivers and to their personal burden relief.

➤ ***To which gender do you belong to?***

- Female
- Male
- I prefer not to answer

➤ ***Years of schooling***

- <12
- 12-16
- >16

➤ ***Age***

- Up to 25
- 25-35
- 36-45
- 46-55



- 56-65
- 66-75
- More than 76

➤ ***Are you currently in paid employment?***

- Yes, I am still working
- No, I am studying
- No, I am unemployed
- No, I have been retired

➤ ***What is your relationship with the person suffering from dementia?***

- Spouse
- Children
- Grand-children
- Other relatives/related persons

➤ ***Are you living with the person you care?***

- Yes
- No

If the answer is Yes please select one the below choices

- In the same house
- In close distance (up to 20 km)
- Far away (more than 20 km)

➤ ***How much are you engaged in your caring role for the person with the dementia disease***

- On a 24-hour basis
- Daily, up to 4 hours
- Up to 2 days a week
- Up to 4 days a month
- Occasionally, whenever I am needed
- Other (please specify)



- ***Would you say that your care for the person with dementia has negatively affected:***
 - Your Mental health (you feel sad/angry/ stressed)
 - Your Social health (you feel excluded from society, lonely)
 - Your Physical health (you feel tired, unhealthy)
 - Your Financial situation (you are concerned about your financial situation)
 - None of the above: I don't think that caring for a person with dementia has negatively affected me

- ***Would you say that your care for the person with dementia has positively affected:***
 - Your Mental health (you feel sad/angry/ stressed)
 - Your Social health (you feel excluded from society, lonely)
 - Your Physical health (you feel tired, unhealthy)
 - Your Financial situation (you are concerned about your financial situation)
 - None of the above: I don't think that caring for a person with dementia has positively affected me

- ***How important do you consider it is to be trained on how to take care of people with dementia?***
 - Very much
 - Enough
 - A little
 - Not at all

- ***Have you ever attended some kind of training about the care of people with dementia?***
 - Yes, I have participated in educational seminars
 - Yes, I have attended a full training course
 - No, I have not participated in any training activities

- ***Have you ever followed an online course?***
 - Yes
 - No



- ***What kind of devices would you prefer to use for an online training program?***
 - Smartphones
 - Tablets
 - Pcs
 - Laptop
 - None

 - ***What topics would you like to cover in an online training for caregivers of people with dementia?***
 - Practical issues for care management of the person with dementia
 - Updated news on the disease/latest developments in dementia treatment
 - Psychosocial interventions for people with dementia
 - Social management issues
 - Good practice in the design of homes and living spaces for people with dementia
 - Assistive devices for people with dementia
 - Technology for monitoring
 - Other

 - ***Apart from the previous thematic units, which of the following topics will you be interested to learn in a training program for caregivers of people with dementia?***
 - Anxiety management techniques of the caregiver
 - Ways to relieve the caregiver
 - Information on the existing structures for caregivers' support
 - Information regarding legal/financial issues
 - Issues of configuration and organization of caregivers' daily program
 - Possibilities and ways of social networking of caregivers
 - Exercises of physical training and relaxation of the caregiver
 - Other

 - ***You personally, how many hours a week, could you be able to devote to attend the training seminar on the modules you are interested in?***
-



Online questionnaire for formal caregivers

Cover page

Dear respondent,

we would like to inform you that the data we will collect through the survey will be anonymous and therefore it won't be possible for us to link them to your identity. We also confirm you that we will not track and store identifiable respondent information in survey results.

Data will be accessible by the members of the consortium delivering the Erasmus+ Project De@mentoring (see: www.dementoring.eu)

Data will be managed and stored using a platform named SurveyMonkey. To check their privacy policy, including the use of Cookies, you can read: <https://www.surveymonkey.com/mp/legal/privacy-policy/>

By responding to the survey you confirm that you have read, understood and accepted these information.

Online questionnaire for formal caregivers

Evaluation of the training needs of caregivers for people with dementia

The study aims to explore issues related to the educational needs of caregivers of people with dementia, so that through developed training programs, they will acquire knowledge and skills that will contribute both to the better management of the caregivers and to their personal burden relief.

➤ ***To which gender you belong to?***

- Female
- Male
- I prefer not to answer

➤ ***Years of schooling***

- <12
- 12-16
- >16

➤ ***What is your educational background?***

- Academic Degree in Nursing (professional nurse)
- Vocational Degree in Nursing (assistant / practical nurse)
- VET training as home care worker
- Other: please clarify
- I do not have an educational background in nursing / caring

➤ ***Age***

- Less than 35



- 36-45
- 46-55
- 56-65
- More than 66

➤ ***Would you say that your care for the person with dementia has adversely affected:***

- Your Mental health (you feel sad/ angry/ stressed)
- You Social health (you feel lonely)
- Your Physical health (you feel tired, unhealthy)
- You Financial situation (you are concerned about your financial situation)
- None of the above: I don't think that caring for a person with dementia has adversely affected me

➤ ***How important do you consider to be trained on how to take care of people with dementia?***

- Very much
- Enough
- A little
- Not at all

➤ ***Have you ever attended some kind of training about the care of people with dementia?***

- Yes, I have participated in educational seminars
- Yes, I have attended a full training course
- No, I have not participated in any training activities

➤ ***If the answer in the previous question is Yes, please select one the below choices:***

- Training on a regular basis
- A longer training course
- A few hours course

➤ ***Have you ever followed an online course?***

- Yes
- No



- ***What kind of devices would you prefer to use for an online training?***
 - Smartphones
 - Tablets
 - Pcs
 - Laptop
 - None

- ***What would be your personal motivation for participating in a training program on taking care of persons with dementia?***
 - Upgrading qualifications
 - Better services for people with dementia
 - Personal interest
 - Improving professional status
 - Other:.....

- ***What topics would you like to cover in an online training for caregivers of people with dementia?***
 - Practical issues for care management of the person with dementia
 - Updated news on the disease/latest developments
 - Psychosocial interventions for people with dementia
 - Issues of the social management of the person with dementia
 - Good practice in the design of homes and living spaces for people with dementia
 - Devices for detecting people with dementia
 - Other

- ***Apart from the previous thematic units, which of the following topics will you be interested to learn in a training seminar for caregivers of people with dementia?***
 - Anxiety management techniques of the caregiver
 - Ways to relieve the caregiver
 - Information on the existing structures for caregivers' support
 - Information regarding legal/financial issues
 - Issues of configuration and organization of caregivers' daily program



- Possibilities and ways of social networking of caregivers
- Exercises of physical training and relaxation of the caregiver
- Other



You personally, how many hours a week, could you be able to devote to attend the training seminar on the modules you are interested in?.....



Consent Form

I, _____, hereby declare that:

(name)

1. I have been informed about the De@mentoring project and I have understood what the project is about and what it aims to achieve.
2. I have accepted to take part in this research as my personal experience will contribute much to the understanding of issues under study.
3. I may choose not to answer anyone or more of the questions that I will be asked and may stop participating in the session at any time I wish. During the focus group/interview, or at its end, I can ask to modify or remove some of my remarks.
4. My name will not be published or communicated to anyone outside of the research team. Only the researchers will be able to identify me in relation to the number code and will keep my name and code confidential.
5. Reference to my participation will be made only by a number code. When quoted or cited, information and data provided during the focus group/interview will be referenced with this number code.
6. The information I will provide will only be used for this study.
7. My participation is entirely voluntary and I can withdraw from the study at any time.

I consent to participate in this study.

Place and date: _____ Signature: _____