

apps4carers Trainers Manual

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Trainers

Manual

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**Carers' characteristics
and support available
including the role
of ICT tools**

chapter 1

For most people, caring for others is a natural part of life, which implies health care, assistance or support provided due to illness, disability or old age (NBHWS, 2012). Approximately 80% of care across the European Union (EU) is provided by informal carers, and even in countries with a supply of formal long term care, informal carers is estimated to be at least twice as many as the formal cares (Eurocarers, 2017b). Approximately, there are more than 100 million carers in Europe today, which is a fifth of the total European population. The economic value of unpaid informal care in EU Member States, as a percentage of the overall cost of formal long-term care provision, ranges from 50% to 90% (Carretero et al., 2012). Informal carers can be defined as *“persons of all ages who provide unpaid care to someone with a chronic illness, disability or other long lasting health or care need, outside a professional or formal employment framework”* (Eurocarers, 2017b page 5). These people, who provide care, refer to family, friends, significant others or neighbors, i.e. anyone who provides emotional and practical help, support or care to people with a long-term illness, disability or age-related frailty (Carretero, et al., 2012). In this project, only adult and older carers who take care of other adults or older persons were considered, i.e. excluding the care of children, which is not the focus of this project.

1.1.1 Informal Carers in Cyprus and Greece

At the moment, in Greece and Cyprus there is no available estimation of the number of carers of older people with chronic diseases, even if there is information available on the prevalence of chronic diseases. Considering this, below statistics are made available regarding Greece and Cyprus for Dementia, Cardiovascular diseases, Cancer and Rheumatoid diseases.

Cyprus

In Cyprus in the year 2015, the total population was 848.000, with 14,6% of the population over the age 65 (OECD, 2017). According to Alzheimer Europe and prevalence of dementia in Europe, the estimated number of people with dementia in Cyprus in 2012 was 11.250, representing 1.07 of the total population (Alzheimer Europe, 2013). Cardiovascular diseases are the first cause of death in Cyprus, with 36% and 34% in women and men respectively (OECD report, 2017). According to the Cyprus Cancer registry (Pavlou & Dimitriou, 2016), for the years 1998 -2014, there are 43657 cancer cases and only in 2014, 3451 new cases. The age group 60-79 for men and 55-74 are the age groups with the higher incidence (new cases). Furthermore, according to the Cypriot national strategy for rheumatoid diseases by the Ministry of Health, there are no official data on this type of diseases, but based on the European Union data, Cypriot cancer cases are estimated to 200.000 (Constantinou, E et al, 2011)

Greece

Older people are 19% of the total population of Greece (Hellenic Statistical Authority, 2014).

According to Alzheimer Europe prevalence of dementia in Europe, the estimated number of people with dementia in Greece in 2012 was 201,766, representing 1.77% of the total population (Alzheimer Europe, 2013). The incidence of Cardiovascular diseases according to the longitudinal study (2002-2012) ATTICA was 19.7% in men and 11.7% in women, 317 people of the sample was over 65 years old (Panagiotakos et al, 2015). Cancer is the second cause of death after Cardiovascular disease in Greece (24.4% of deaths). The age group over 75 year old is the most vulnerable and has increased mortality due to different types of cancer. The three most common cancers in men are prostate, lung and bladder with prevalence: 19, 61%, 13,19%, 17,8% respectively and in women breast, large bowel and corpus uteri, with prevalence; 34,79%, 10,82%, 6.18% (Ferlay et al, 2013). According to the first epidemiological study in Greece for Rheumatoid diseases, the most frequent type of the disease is Rheumatoid arthritis, with prevalence, 6.7% in adults (Andrianakos et al, 2013).

Taking all the above into consideration and that almost 80% of the people with non-communicable diseases are cared for at home and that for every person with dementia three family members are involved in the care, we realize that carers play a core role in supporting the National Health Systems both in Greece and Cyprus. The most recent data of carers in Greece are provided by the Eurofamcare report (Triantafyllou, et al, 2006), no other study have been realized since then including carers of older people with chronic diseases. According to that report the majority of the sample (80,9%) was women, married (76,4%) and they cared for their parents (55.4%). In almost half of the sample (47,2%) carers were still working, providing care on average 51 hours per week and living in the same household as the cared for person (50.7%).

In Cyprus, Papastavrou et al (2012) presented high level of burden and depression among a sample of 410 carers of people with Alzheimer's disease, Cancer and Schizophrenia. The majority of carers were women (77% in Alzheimer's disease, 73.5% in Schizophrenia and 54.6% in cancer). In the case of carers of people with Alzheimer's disease, 41.3% cared for their spouse and 54% for their parents, in Schizophrenia, 44% cared for their child, 24% their spouse and 20% their parents. In Cancer cases, 48% cared for their spouse, and 48% for their parents.

Additional data is available for the carers of people with dementia both in Greece and Cyprus. In Cyprus, information for carers are derived by research on carers burden and social capital. Papastavrou et al, (2007), showed that 68.02% of the research sample was highly burdened and 65% reported depressive symptomatology. Caregiver's sex, income and level of education were related with the reported burden. In another study by Papastavrou et al (2011), positive coping adopted by carers was correlated with burden. Additionally, low social capital "norms and networks that facilitate collective action" may be related to the higher levels of burden (Papastavrou et al, 2015). In Cyprus there is also the Multidisciplinary Committee for patients with Alzheimer's disease which is under the umbrella of the Ministry of Health and consist of health care professionals and NGOs. The Committee has published the National Strategic Plan for Alzheimer's disease that includes the current situation of carers and a number of suggestions for supporting carers of patients with dementia in general and it has been submitted to the Minister of Health. The most recent data of carers of people with dementia are available in Greece by the Athens Association of Alzheimer's Disease and CMT prooptiki, providing information of a sample of 580 carers, 74% women, 61% married, 67% caring for their parents and 50% employed (Carers survey, 2017).

1.1.2 Informal Carers in Italy

According to the most recent statistics available in Italy (Istat, 2017), the 14,9% of the population aged >15 (equal to over 7.2 million persons) provides care to a family member who is dependent because of age, disability or other diseases. This percentage is slightly above the European average of 12,7%. The majority of informal carers are spouses or children of the care-recipient (Vaccaro, n.d). The 56% of informal carers are women and the most represented age-group is that of 45-64 years old. However, it is worth mentioning that the 7.1% of informal carers is over 75 and that this is the cohort that bears the higher burden: the 48% of them (against an average of 25% for all age groups) cares for more than 20 hours per week.

The high incidence of older carers is relevant in relation to the potential impact of Information and Communication Technologies (ICT) tools to support them. Indeed, according to the Italian National Institute of Statistics only the 30% of persons between 65 and 74 years old has used internet in the past 12 months. A rather small percentage but a significant improvement compared to the previous survey in 2011 where the percentage was only of 13%. In spite of the high prevalence of informal carers, traditionally in Italy specific policies for family carers have never existed, since family care by other family members has always been taken for granted, as a sort of compulsory duty (Riedel & Kraus, 2011). For this reason the political and social recognition of informal carers is still low compared to other European countries.

1.1.3 Informal Carers in Portugal

Informal Portuguese carers are mainly woman, no younger than 50 years old, that normally take care of their parents and sometimes other close family members or friends. According to Eurofam-care (2004), the informal carers in Portugal are mainly family members of the person they care of, namely wife (around the age of 65) or daughter/daughter-in-law (between the age of 45 and 55). These carers normally live with the person they take care of and provide care for four or more hours a day. The majority of these carers are already retired and count with little help from external services for their daily duties as carers. In this case, they only count with the municipality cabinet help, which provides them with basic training in matters that are important for them to better perform at their role.

Within the carers' group that so far collaborated with Virtual Campus in the A4C scope, they have a low education level (often basic school education), with only a few cases in which the carers have secondary education. They also come from disadvantage backgrounds, either due to economic difficulties (low income) or due to weak family structure/support. The digital literacy level of the carers is low to medium. There are a few examples of carers that have good knowledge of how to use smartphones or tablets, but the majority has a low digital literacy level.

The majority of the carers takes care of old people with dementia and Alzheimer. The tasks performed by informal Portuguese caregivers range from the simplest (supervision) to the most complex (personal hygiene) and vary in frequency (daily, at weekends, etc.), and intensity (degree of dependence on who is cared for). The Portuguese informal caregivers face in their daily life physical challenges, especially related to tasks such as putting the person they take care of in bed, but also face emotional struggles. In this case, carers facing emotional problems are the ones with fragile family structures, since the ones who have strong family support end up managing their role as carer in a more balanced way.

1.1.4 Informal Carers in Sweden

In Sweden, approximately 20% over 18 years of age (1.3 million people) are informal carers; 900 000 of these are in paid employment (NBHWS, 2014). Caregiving is common in all ages, but most common in the age group 45-64 years of which the majority is caring for an aged parent. In the age group 30-44 years care is provided primarily to children, while people over the age of 65 care for a partner. In the age group 81 years and older, as many as 77% provide support, help or care to their partner (NBHWS, 2012), and this type of care relationship is in general more intensive than providing care to a parent, relative, friend or neighbor (NBHWS, 2016). Informal carers under the age of 65 receive more help from other family members or relatives in their caring responsibilities while those 65 years of age and older rarely have somebody who relieves them in their caring situation.

Both men and women are carers, but in general, it is more common for women to be carers (20%) than men (16%). However, women provide more personal care, supervision and coordinate contacts in health care while men provide more practical help and financial support. People with lower formal education provide family care to a greater extent, and one in four people born outside Europe cares for a close relative, compared to just under one fifth of the native Swedes (NBHWS, 2012).

Among those who provide regular care to a close relative in Sweden, 31% provide care on a daily basis, while 46% provide care at least once a week and 23% at least once a month. Over two thirds of the care provided consists of practical help, such as shopping, cleaning, laundry and cooking as well as social stimulation. Fifty percent of the informal carers provide help with getting in touch with healthcare and social services as well as supervision. Almost one third provides personal care, while 23% provide financial support. Sixty percent of all informal carers do not live together with the one who receives care; but in the age 81 years and older the proportion is reversed and 67% live with the person they provide care for (NBHWS, 2012).

By 2060, 30% of the total European population (i.e. 155 million Europeans), will be aged 65 years and older. It is estimated that 30% of these (about 45 million) will have at least one disability that disrupts activities of daily living. The need is even greater for the group aged 80 years and over, where long-term care is expected to increase by triplefold by 2060 (Eurocarers, 2017a). The economic value of informal carers work represents an indispensable part of the provision, organisation and sustainability of health and social care systems. In addition, because of the ageing societies and the increasing prevalence of frailty and chronic disease, informal carers' work will become even more important (Carretero et al, 2012).

Support services for informal carers vary considerably throughout Europe, and in many countries such services have not been a significant issue. In several Southern European countries, it has been viewed as a natural role of family members to provide care for older relatives, and in most Eastern European countries the caring responsibilities have been traditionally carried out by the family and mostly female members. Whereas in the Nordic countries, the assumption has been that the formal care has been sufficient to provide care for the older population and therefore there is no need for additional support for informal carers. In recent years, the issue has changed in several countries and the need for public support services for informal carers has moved onto the agenda of social policy. Besides, most countries offer some kind of financial benefit for informal carers providing long-term care. However, there is a broad variation, where a few countries provide financial support as a substitute for other paid employment, while some countries provide a more symbolic payment in value (Riedel & Kraus, 2011).

1.2.1 Informal carers and support services in Cyprus and Greece

Cyprus

In Cyprus, there are public and non profit association providing services to carers of people with chronic diseases. Cypriot carers who are recipients to the Guaranteed Minimum income and people with insufficient income may be eligible to apply for support under the scheme for the subsidization of care services and concerns long term care. The scheme may cover Home care, Institutional care, day care, respite care and community nursing (home nursing, community mental health nursing) Patients with medical cards are entitled to the public hospital service use with specific rates for their medical visits. People entitled to medical cards, they are obliged to pay 0.50 euros for every prescribed medicine and prescribed examination. The department of Social inclusion of people with disabilities is responsible to assess and certify disability level, social benefits to persons with disabilities, direct and indirect vocational rehabilitation and other support services and coordinate the implementation of the UN convention for the rights of people with disabilities and the national disability action plan. Other

services that could be of assistance to carers are Home nursing services, assisting people and their families to deal with the everyday activities and problems deriving from the illness and Community mental health nursing, that provides psychometric assessment, needs assessment, communication with psychiatrist, family support and counselling. Information on available non for profit association that could be of assistance for families could be found on the website of the Pancyprrian volunteerism coordinative council (www.volunteerism-cc.org.cy). Non – for profit associations links dealing with other diseases such as cardiovascular diseases, multiple sclerosis, rheumatoid diseases, cancer and dementia are available in this site. We present below few more detailed info on cancer and dementia.

Information of available services are derived by online sources:

- European Commission: Policies and Activites:
<http://ec.europa.eu/social/main.jsp?catId=1105&langId=en>
- Eurocarers association: Innovage platform (Cypriot version)
<http://eurocarers.org/informcare/carers-cy/support-by-the-state-cy/financial-aspects-cy/costs-of-caregiving-cy/?lang=cy>
- Pancyprrian Volunteerism Coordinative Council
www.volunteerism-cc.org.cy

Greece

Support service provision to carers are mainly provided by disease specific associations usually based in metropolitan cities. Only recently, an association devoted to carers of people with mental health problems and/or neurological diseases was established, Epioni (www.epioni.gr). Disease specific associations are usually responsible to provide information, counselling, psychoeducation to carers of people with chronic diseases. Not all associations operate in the same way. There are more and less active non-for profit associations. Legislation is differentiated according to disease, but there are benefits that the patient is eligible based on the disability level (over 67%). The families should address to the Centre of disability certification. Additionally, there are some tax cuts based on the patient's level disability, but the family needs to provide all related certificates provided by the Centre of Disability certification. Concerning the chronic diseases medication, there are 0% or 10% contribution by the patient with chronic disease. In the case of dementia, cardiovascular diseases, rheumatoid diseases and cancer, the Ministry of Health has developed national strategic plans. The main structures involved into the development of the policy to fight against chronic diseases are mainly non for profit associations, universities, day centres, medical associations and related ministries (ministry of Health and Education). Non- for profit association providing support to patients with cardiovascular disease, dementia, multiple sclerosis, cancer, rheumatoid diseases could be find in the ministry of health website: <http://www.moh.gov.gr/articles/citizen/c69-xrhsi-moi-syndesmoi/352-syllogoi-asthenwn>. Below we present more info on dementia available services:

Information on available services are derived by online sources:

- Eurocarers association: Innovage platform (Greek version)
<http://eurocarers.org/informcare/?lang=el>
- Greek Ministry of Health:
<http://www.moh.gov.gr/articles/health/domes-kai-draseis-gia-thn-ygeia/ethnika-sxe>

- Greek Ministry of Health:
<http://www.moh.gov.gr/articles/citizen/c69-xrhsimoi-syndesmoi/352-syllogoi-asthenwn>

1.2.2 Informal carers and support services in Italy

Informal care is an extremely important part of the Italian Long-Term Care system, which is largely based upon the assistance provided by families and friends to persons in need. Recently, thanks to the commitment of Interest Groups and Carers Advocacy Networks, a renewed attention to the role of carers has entered the public debate, paving the way to the formal recognition of this figure. A significant step in this direction has been made with the Budget Law for 2018 (Law No. 205, 2017), where a first definition of informal carer has been introduced and a Fund to support them has been instituted (for the years 2018-2020 the National Government allocated 20 million per year to the Fund). Furthermore, the same Law No. 205 has provided carers with additional social security rights, entitling them to retire in advance under certain conditions, i.e. age ≥ 63 years, at least 30 years of contribution, certified disability of the care recipient, at least 6 months of engagement in care provision. This measure, known as “APE Social”, acronym of **A**nticipo **P**ensionistico **S**ociale (Social Early Retirement), is managed by the National Institute of Social Security (INPS). These recent regulations represented a significant step forward the legal recognition of informal carers in Italy, and contributed to raise the awareness about the role of unpaid care work in our Long Term Care system.

Besides these measures, the Italian Welfare System mainly provides carers (and care recipients) with mostly indirect cash for care benefits instead of in-kind services. In particular the “attendance allowance” (Indennità di accompagnamento) provided by INPS, is the most widespread of these benefits, and is used by most recipients to hire care workers (in particular migrant care workers) helping them with everyday care (Barbabella, 2015; Lamura 2017). Moreover, among the measures aimed at helping carers to combine caring responsibilities with paid work, there is a rather well-developed care leave system, entitling employed carers to take periodical paid leave to care for severely dependent relatives (Law No.104/92 and Law 388/2000) (Socci, 2016).

Considering the services for carers available at local level, there are some differences among the 20 Italian Regions, depending on the organizational model of each of them. Broadly speaking, all the regions provide care recipients and carers with home health services managed by Local Health Units (the so-called Integrated Care) and social services provided by Local Municipalities (i.e. domestic and personal help provided at home). In addition, quite widespread are also Day care and Community Care Services where the ill person can spend some hours each day, while Respite Services specifically targeting carers needs keep being less available. These differences among regions are partly due to regional policies on carers adopted by each region. While there are regions such as Emilia Romagna that has already provided legal status to carers since 2014 (Emilia Romagna, Regional Law No.2, 2014), this process is still ongoing in other areas of the Country. The provision of a National Framework Law on carers, as wished for by most stakeholders, would contribute to solve this issue by setting up a minimum level of services to be granted to them throughout the country.

1.2.3 Informal carers and support services in Portugal

In Portugal, there is no informal caregiver legal statute, at the moment. However, the Portuguese

government and the national parliament recently began a discussion on this topic. The working group created to develop the statute suggests creating benefits to reduce the risk of informal caregiver poverty and providing support that addresses the decrease in income when the caregiver has to opt for part-time work. Among the deliberated measures, the possibility of these people having the option of emergency permits is being discussed. A matter that will have to be dealt with in social agreement to agree on the number of leave days to be allocated to help the informal caregiver manage emergency situations of the person in need of care. The social partners are also involved in the discussions on solutions to reconcile work and care without negative impacts and prevent discrimination, particularly with regard to women, while safeguarding gender equality. The working group further notes that the measures to be taken should be independent of the age of the person being cared for and the informal caregiver should be covered by a support plan also defined by health professionals with the facilitation of specialist consultations.

Thus, with no legal statute yet, what one may find in Portugal are household and municipal social responses that address caregiver's respite, counselling support and self-help groups. Locally, (in Porto district), there are various types (yet not too many) of organizations that address the informal carers' problematic. Alzheimer Portugal is one of those cases. In spite of mainly dealing with people suffering from Alzheimer and other dementias on a daily basis, this association actively promotes the training and support of informal carers. They held initiatives such as support groups for sharing experiences and mutual support, and foster training sessions for basic informal carers' needs. Besides, the Municipality of Gondomar has a project directed at informal carers which aims to ensure training for all informal caregivers and also contribute to the network development of interventions aimed at promoting the physical and psychological well-being of caregivers. Within this project, they organize a training programme for all the informal caregivers living in the municipality. After the caregiver has finished the training, they are then part of the municipality caregivers network and are invited to all the support group sessions that take place every month, and also participate in other initiatives held by the municipality. The Carers Association from Porto is a non-profit association whose mission is to support all those who care for family and friends in an unpaid way. The association provides both training, information and advice to informal carers through workshops and capacity building actions; they held support groups and psychology consultations. In Portugal, there are also some institutions that provide medical assistant at home, such as Cruz Vermelha. Usually, the household services are paid. However, some municipality's and some non-profit organizations also provide free household services that include to go to the carers house twice a week to help them give a bath/shower to the patient, among other services.

1.2.4 Informal carers and support services in Sweden

According to the Swedish Health Care Act, informal carers' caring responsibilities are of a voluntary nature and the carers themselves decide how much caring responsibility they want to take on (SFS, 2001:453). Further, since the change in the Social Services Act in 2009, municipalities in Sweden are obliged to offer support to carers (SFS, 2001:453). The same responsibility does not exist in the Health Care Act. Instead, this law stipulates that health care professionals shall take into account children as next of kin and their needs for information, advice and support (SFS, 2017:30). However, the Social Services Act does not stipulate what the support should actually consist of, and in reality the voluntariness in informal care, if carers want to take on a caring responsibility and how much, is not always recognised.

Sweden has a devolved government and the range and extent of carer support services varies

considerably from one, of Sweden's 290 municipalities, to another. Coordination of carer support services are carried out at the level of the individual municipality (NBHW, 2016). There are different types of support for informal carers. Direct support, which means that the carer applies for support such as education about disabilities, practical help in the home, parental support and social support via a needs assessor in the municipality. It could also be indirect support whereas the care receiver applies for support via a needs assessor, concerning for example respite care, home care or short term care which can also mean that the carer gets some respite from his/her caring situation. There are also general services offered by the municipalities, for example individual counselling or group counselling, information about illness or disability, different kinds of assistive devices, and support from a municipal family carer advocate or advisor (NBHWS, 2016).

Employees have legal entitlements to go on emergency leave, longer temporary leave for long-term care, and the possibility to reduce working hours, and collective agreements sometimes go beyond the legal entitlements (Eurofound, 2015). Informal carers can also get some financial support, but the rates are based on the amount of caring hours, and rates also differ between the municipalities. Some municipalities have Carers Allowance, mostly targeted at carers who are caring for an older person at home. In some municipalities, informal carers can be employed to take care of a relative, if there are special reasons why their needs cannot be met from ordinary home care professionals (Riedel & Kraus, 2011). If a person is severely ill, with a life-threatening illness/ end of life care needs, relatives can get 80% of their salary for 100 days while caring for a sick close relative (Eurofound, 2015).

Counselling services for carers are usually provided by family carer advisors/advocates 'anhörig-konsulenter' who are employed by the municipality and exist in nearly 80% of the 290 municipalities in Sweden. Their role is to provide support to carers at the point of need and guide them to sources of local support available. The support can consist of emotional support on an individual or group basis, lectures/education about relevant topics concerning the caring situation etc. Some family carer advocates also provide strategic direction for the development of carer support services at municipality level (Winqvist, 2014). A few carers can get free counselling service such as emotional support, either individually or in group sessions, that are provided by a certified psychologist. In addition, professionally-led, psycho-educational carer groups sometimes are offered in different health care regions (Riedel & Kraus, 2011).

1.3

Informal Carers' support needs and support outcomes

Caring for a significant other can be highly rewarding, but also demanding and it can cause for example both physical and psychological exhaustion, social isolation, and difficulties in reconciliation of work and care responsibilities (Carretero et al., 2012). The combination of various demographic and socioeconomic developments, such as lower birth rates (leading to smaller families), increasing mobility (relatives live further apart), women working outside the home to a greater extent and a prolonged working life due to delayed retirement, is causing a pressured situation (Eurocarers, 2016e; 2017b). Caring is still carried out mostly by women, nearly two-thirds of informal carers aged over 50 year are women. The mean age among carers is 55 years, ranging between 45-68 years old (Carretero et al., 2012). More than 50% of informal carers combine care with employment, 11% of female workers and 7% of male workers are providing care regularly (daily or several days per week), and this is more common among older workers (14% of female workers and 10% for men aged 50-64 year) (Eurofound, 2015). In addition, nearly half of non-working carers (42%) have the lowest income, twice as many compared to non-carers (Eurocarers, 2017a). The caring duties not only include personal care (bathing, feeding, dressing etc.), they also include specific medical care (such as administering medication, monitoring of blood and insulin levels, dialyses, management of oxygen/nebulisers and tracheotomy patient care etc.) (Eurocarers, 2016a). The development of medical care also mean that informal carers have to deliver more and more advanced levels of medical care, with very little training and minimal support (Eurocarers, 2016e).

All of the above facts highlight the importance for actions aimed at building and strengthening carers' resilience and putting support in place that enables those carers who wish to continue caring to be able to do so (Eurocarers, 2016e). Support services and fair working conditions are important and according to the work life balance, in the European Pillar of Social Rights, it is stated that, *"people with caring responsibilities have the right to suitable leave, flexible working arrangements and access to care services. Women and men shall have equal access to special leaves of absence in order to fulfil their caring responsibilities and be encouraged to sue them in a balanced way"* (European Commission, 2018, chapter II, principle 9).

A crucial first step in the support of carers is to enable better recognition of carers' invaluable role within our society. In particular, among decision makers and policy makers at local, regional, national and EU level (Eurocarers Strategy, 2018). With the increasing importance of people-centred, integrated care systems in Europe there is also a growing recognition of seeing and valuing families and informal carers of people with chronic conditions as partners in care. This means not only involving carers in the treatment decision making of their frail older relative (with the relative's permission) but also enabling and facilitating their participation within the co-design of health and long term care policies that directly affect them and their frail older relative. As well, to enable carers to be involved in the co-design of innovative technologies and practices which aim to make informal caregiving and their everyday lives easier. Health and care professionals need to recognized carers and offer them appropriate tailored education and training that meets the needs and preferences of individual

carers (Eurocarers, 2016d). Furthermore, health and care professionals can engage in a range of key strategies to help support carers, such as:

- “Acknowledge carers, what they do, and the problems they have.
- Flag the notes of informal carers to be aware of their circumstances in any consultation
- Treat carers as team members and listen to their opinions.
- Include them in discussions about the person they care for.
- Give carers a choice about which tasks they are prepared to take upon themselves.
- Enquire about the health and wellbeing of the carer as well as the patient.
- Provide information about the condition the «caree» suffers from.
- Provide information about being a carer and support available.
- Provide information about benefits available.
- Provide information about local services available for both the caree and the carer.
- Be an advocate for the carer to ensure services and equipment appropriate to the circumstances are provided.
- Liaise with other services.
- Ensure staff are informed about the needs and problems of informal carers.
- Respond quickly and sympathetically to crisis situations.” (Eurocarers, 2016e, page 3-4).

Valuing and strengthening informal carers’ skills may counter their social exclusion and improve their chances to maintain an active life, and possibilities to enter or re-enter the labour market. Training can effectively help informal carers to break their isolation and pay attention to their own well-being and life satisfaction. Informal carers can become more aware of their skills, to gain motivation and self-confidence, and also to improve their caring experience and to enter professional training pathways likely to support their social inclusion and their integration on the labour market. Training gives an increased competence and has a positive impact on informal carers’ quality of life, skills and self-reported burden, as well as on their ability to cope and resilience to depression (Carretero et al., 2012; Eurocarers, 2016a). Carers combining paid work and caregiving responsibilities can effectively be helped by the availability of Carer leave and flexible working arrangements allowing carers to adapt their working hours or place to their needs; prevent them from dropping out from the labor market particularly during an intensive period of care. Which in turn, leads to maintaining the economy and social inclusion (Carretero et al., 2012; Eurcarers, 2016c).

1.4

Support to informal carers via Information and Communication Technologies (ICT)

ICT products and services can be useful in managing informal care, and have the potential to decrease the care burden, to increase emotional condition, physical and mental health, personal support and social integration, and provide a degree of relief from grief following the loss of a family member/significant other. ICT-based services for informal carers can also improve the quality of life and increase the independence of the persons cared for (Carretero, Stewart & Centeno, 2015).

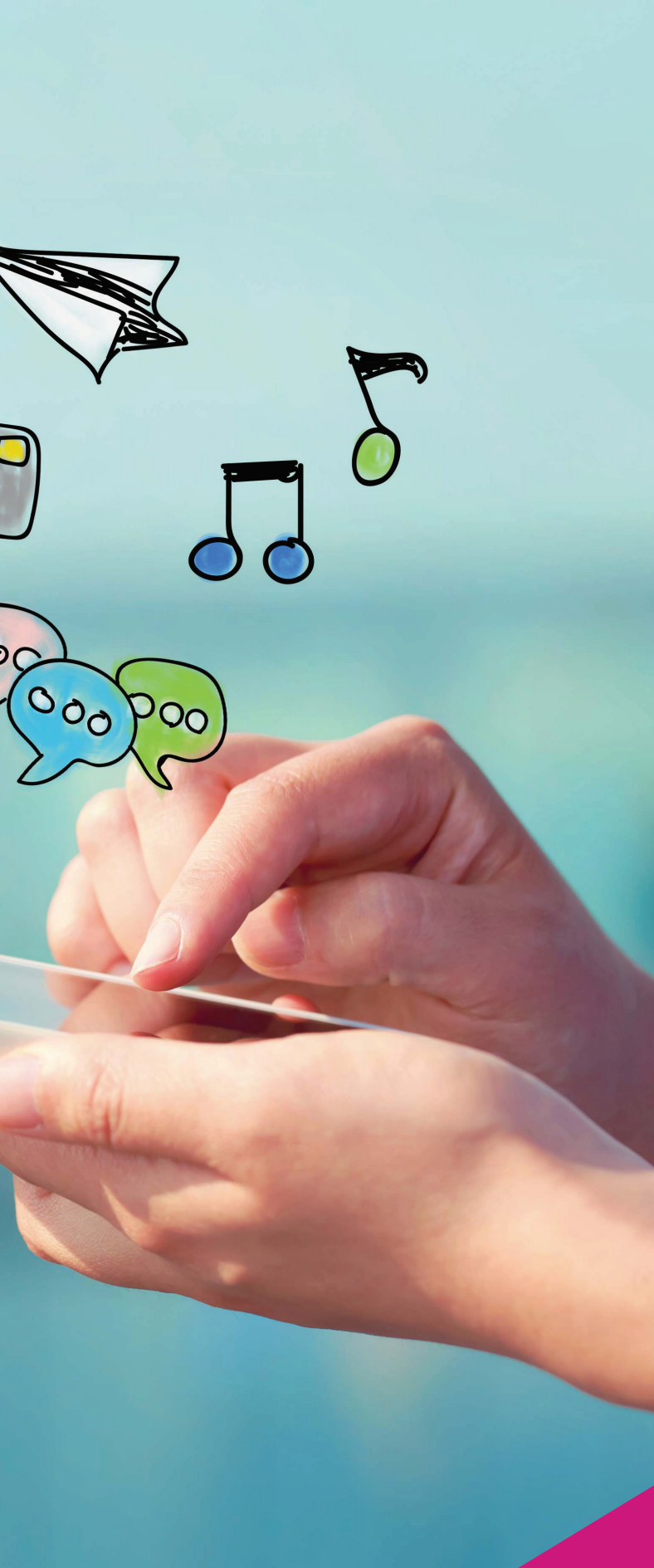
ICT potentially could contribute to a higher quality of life, by increasing social integration, provide informal carers with social, emotional and peer support and connecting them to life outside the home. Online networks, are an effective way to obtain and exchange information and to help to decrease the feeling of isolation experienced by many informal carers. Online tools can also prove effective for sharing information and coordinating care tasks from professional, informal and family-employed carers. By providing accessible information from peers and professionals, education (for example online self-training through e-learning platforms) and support, ICT tools can help and prepare carers directly in their caring situation; providing better caregiving skills, self-confidence and self-mastery, which in turn can improve the quality of informal care provided by the informal carer. Furthermore, ICT can facilitate flexible working arrangements and tools to remotely monitor the safety and well-being, of the care receivers, during working hours; helping informal carers to find work-care balance and successfully fulfil their caregiving tasks while remaining active and productive (Carretero, Stewart & Centeno, 2015; Eurocarers, 2016b).

According to Eurocarers, ICT-based services for informal carers can positively impact on:

- The quality of life of the informal carers, helping them to reconcile care and work, and improving their social lives and health conditions.
- The quality of life of care recipients, improving their health-related quality of life and their social lives.
- The quality of care provided by informal carers and privately-paid assistants, improving their knowledge of care, skills and competences.
- The cost of care for end-users, generating savings compared with ordinary services.
- The acceptability and accessibility of ICTs, in terms of people's greater willingness to use ICT and their satisfaction with it, their acquisition of digital competences, and their wider use of ICT materials" (Eurocarers, 2016b, page 3).

Mobile devices, in particular, can be of great advantage for carers as they are highly widespread and normally easier to use compared to desktop PCs (also for persons who are not very digitally-literate). Additionally, they allow a very handy access to internet-based applications. Nowadays, there is a wide range of applications already available on the market that can be extremely useful for carers at any time and in any context (Handel, 2011), for example: to support scheduling and sharing of caring

tasks and information; to have access to useful information, including micro-training opportunities; to remember tasks and deadlines; to involve the care recipient in simple recreational or even rehabilitation activities (for example for persons with cognitive impairments); to communicate remotely with other family members and professionals involved in the caring activities; to access services useful to save time and support reconciliation, such as on-line payments; to book medical appointments etc. In brief, carers could benefit significantly of many free applications already offered in the market, but most of the time they are not aware of them, or they do not know how to install or use them from their mobile devices, or they have not realized the potential benefits they could get out of their use.



Digital Skills and style of ICT- mediated support

chapter 2

Digital skills have been marked as an important factor in explaining differences in individual's Internet use (Mossberger et al., 2003; Van Dijk, 2005). These skills are relatively novel with regard to the digital divide debate and there has been little work on the online abilities of the Internet user (Hargittai & Hinnant, 2008). Existing empirical investigations point towards large differences in skill levels between segments of the population.

Digital Competence can be broadly defined as the confident, critical and creative use of Information and Communication Technology (ICT) to achieve goals related to work, employability, learning, leisure, inclusion and/or participation in society. Digital competence is a transversal key competence which, as such, enables us to acquire other key competences (e.g. language, mathematics, learning to learn, cultural awareness) (Ferrari, 2013).

Ferrari (2012) considers digital competence as a combination of:

- Information skills (identify, locate, retrieve, store, organise and analyse digital information, judging its relevance and purpose),
- Communication skills (communicate in digital environments, share resources through online tools, link with others and collaborate through digital tools, interact with and participate in communities and networks, cross-cultural awareness),
- Content Creation skills (Create and edit new content (from word processing to images and video); integrate and re-elaborate previous knowledge and content; produce creative expressions, media outputs and programming; deal with and apply intellectual property rights and licences),
- Safety skills (personal protection, data protection, digital identity protection, security measures, safe and sustainable use), and
- Problem Solving skills (identify digital needs and resources, make informed decisions as to which are the most appropriate digital tools according to the purpose or need, solve conceptual problems through digital means, creatively use technologies, solve technical problems, update one's own and others' competences).

Her Operationalization of Communication skills, however, is technically oriented; based on the number of devices used for online communication. Content Creation is considered as the skill to produce content in different formats, platforms, and environments.

Helsper and Eynon (2013) defined four broad skill categories:

- Technical (the skills to use mobile-devices and applications to accomplish practical tasks and recognize specific online environment to navigate and maintain orientation),
- Social, Critical (the skills to use to make informed judgments and choices about obtained information and communication using reflective reasoning and sufficient evidence to support the claims), and Creative skills (the skills to use ICT to generate new or previously unknown ideas or treat familiar ideas in a new way and transform such ideas into a product, service or process that is recognized

as novel within a particular domain). This classification is based on media literacy research which suggests that skills should be measured beyond the basic technical level and in relation to the ability to work with communication technologies for social purposes.

Van Deursen and Van Dijk (2009a, 2009b, 2010) measured Internet skill using the following domains: Operational, 'the skills to operate digital media' (*are the basic skills for using Internet technology*); Formal, 'the skills to handle the special structures of digital media such as menus and hyperlinks'; (*These relate to the hypermedia structure of the internet which requires the skills of navigation and orientation*). Information, 'the skills to search, select and evaluate information in digital media'; and Strategic, 'the skills to employ the information contained in digital media as a means to reach a particular personal or professional goal; and for the general goal of improving one's position in society. The emphasis lies on the procedure through which decision-makers can reach an optimal solution as efficiently as possible.

Recently, Van Dijk and Van Deursen (2014) completed this framework by adding both Communication and Content creation skills. They defined Communication Internet skills as the ability to encode and decode messages to construct, understand, and exchange meaning with other humans using message systems such as e-mail, chat boxes, or instant messaging. This entails searching, selecting, evaluating, and acting upon contacts online, encoding, decoding, and exchanging messages online, attracting attention online, profiling, the capacity of online experimentation for better decision-making, the social ability to pool knowledge and exchange meaning with others in peer-to-peer networking and the ability to exchange meaning to reach decisions and realize transactions while understanding the meanings of others/partners.

The concept generally matches with the elaborate concept of Communication skills proposed by Spitzberg (2006), who considered coordination, attentiveness, expressiveness, composure, selectivity, appropriateness, effectiveness, clarity, satisfaction, attractiveness, efficiency/productivity and general usage/experience.

Van Dijk and Van Deursen (2014) consider Content creation skills to be the skills to create content of acceptable quality to be published on the Internet. It is about textual, music and video, photo or image, multimedia and remixed content. Derived from the framework of Van Dijk and Van Deursen (2014), and adjusted in correspondence with findings of several of the mentioned studies, we propose a framework consisting of five different types of Internet skills.

2.2

Digital skill and style of ICT use per country

In this section, Appsfor carers partners provide available information in internet use and carers or older people

2.2.1 Greece and Cyprus

According to Piirto et al (2015) between 2009 to 2014, household internet access has been increased by 28 percentage points in Greece and by almost 20 points in Cyprus. The proportion of daily users ranged 45% in Greece and 56% in Cyprus.

According to the press release on the usage of ICT made in the end of 2015 by the Hellenic Statistical authority, 7 out of 10 households have access to Internet and own a Personal Computer. During the period 2010 to 2015 there is an increase of 46% in internet use at home. Interestingly, city of Athens has the higher percentage of use in comparison with central Greece. In Central Greece, Aegean Islands and Crete, there is a decrease in internet use between 2014 to 2015. Main reason for not accessing the internet at home is the lack of skills (60.7%). The largest increase in use compared with 2014 was recorded in age group: 45-54 years old. In age groups 65-74 years old and 55-64 y.o people use internet in daily basis (77% and 76% respectively). Seven out of ten people access internet through a mobile device.

Most common internet activities include: reading news, finding information, sending/receiving emails, participating in social networks, seeking health related info, telephone with the use of internet, looking for a job, downloading software. Participation in social networks is lower as older the person is.

According to Kondilis et al (2012), 1000 people have been interviewed, with average age 46 years, 55% of the sample reports excellent and sufficient health literacy, 74% easily can find information on illnesses, 81% is able to make health decisions, 87% understand what doctor says, 93% understand instructions, 85% understand health warnings. On the other hand, 45% has difficulty to assess information from media.

In Cyprus, all most all Cypriots have internet access in 2014 based on World Internet Report: The Internet in Cyprus (2016), with Greek-Cypriots have internet access in 94,3% and Turkish-Cypriots 96.6% (4). Eurostat provides slightly lower percentage (71%). Main reasons for not accessing the internet are the lack of interest and lack of skills. In age group 55-64, an increase is observed in 2014 in relation to 2012. This is not the case for Greek-Cypriots in comparison with Turkish Cypriot for the same period. In Greek-Cypriot age group 65-74, there is a decrease from 17,6% in 2012 to 11,1% in 2014 and in age group, 75-99, from 12,7% in 2012 to 6,4% in 2014. Only 9,6% searches the internet for health information in a weekly basis and 43% has never searched the internet for health topics (4).

2.2.2 Italy

According to the 14th CENSIS report on the use of mass media and communication in Italy, Internet penetration in this country grew steadily in recent years. In 2017, 75.2% of the population had access to internet, with a growth of 1.5% in comparison to 2016 (and a growth of 29.9% in comparison to 2007) (CENSIS, 2017).

We don't have information about the use of ICT among carers, however we know the incidence of informal carers in the older population, which is the following:

- 29% of the population 55-64 is a carer;
- 13,7% of the population 65-74 is a carer.

Among this target population, the use of ICT is growing, although the generational gap is visible. Indeed: among the population 60-64 the 56% has used internet in the past 12 months (30% in the age group 65-74 years old). There is a significant improvement (in 2011 it was respectively 28% and 13%) even if there is still a significant generational gap with 90.5% of Italians under 30 going online compared to 38.3% among those over 65.

Among those aged 65-80 years, one out of 4 (27.6%) has a smartphone. Almost all smartphone owners use WhatsApp, or other social networks such as Facebook (19%), YouTube (16.5%) and Twitter (3.2%) underlining the growing interest of this age group for online networks.

2.2.3 Portugal

Evidence from 2011 shows that the Intensity of ICT usage is directly related to the educational attainment level and inversely related to age. In Portugal, around 2 million people are over 65 years old and a low education attainment level (19% of the population). This group is quite vulnerable in what concerns digital literacy, a problem that inclusion policies have attempted to soften over the last 15 years, concentrating on Informal training actions and learning activities developed and adapted specifically for this population group. (1)

As it has been evidenced by national and international researchers, working with the elderly seems to first require the recasting of common sense representations about the elderly as “unable” to learn how to use ICT or “uninterested” by these matters. This work requires a prior preparation for adaptation of content and of technological learning purposes targeting the concrete needs of the elderly. (1)

In Portugal, much of the efforts for the digital inclusion of the elderly have been achieved through the means of municipal telecentres, public libraries, civil parishes programmes, local development associations and Social Assistance (Misericórdias) and through Senior Universities, spread over the country, who play a key role in the process of qualifying the elderly for ICT usage. (1)

Data shows that by 2014, the Internet was used by 65% of the Portuguese population, but still had a share of 30% of the population that never used it. From the sociodemographic profile of these two samples of the Portuguese population it was noticed that two characteristics stand out and differentiate the use of Internet: age and education. (2)

“In the younger age groups, the Internet is used by an overwhelming majority: 98% of the population aged between 16 and 24 years. A similarly high figure is registered in the population with higher education: 97% use the Internet. At the other end of the spectrum, there are those who have never used the Internet: 76% of the population between 55 and 74 years of age and with a low level of education (most have basic education) and 73% of the population aged 65-74 years” (2).

TABLE 1 OF INDICATORS FOR INTERNET USAGE DIMENSION

INDICATORS	PORTUGAL		EU
	Value	Ranking	Value
Social Networks -% of citizens (16-74 years who have used the Internet in the last 3 months)	72%**	2º	58%**
News -% of citizens (16-74 years who have used the Internet in the last 3 months)	74%**	15º	67%**
Music, videos and games -% of citizens (16-74 years who have used the Internet in the last 3 months)	49%**	16º	49**
Banking -% of citizens (16-74 years who have used the Internet in the last 3 months)	39%**	23º	57%**
Purchases -% of citizens (16-74 years who have used the Internet in the past 3 months)	39%**	23º	63%**

** 2014

If among all Internet users in Portugal Social Networks are highlighted, together with the search / reading of news (2nd and 15th position, respectively), the same does not occur with uses that require greater digital skills, or trust in such use - online shopping and online banking. (2)

Information retrieved from:

1. UISEL Report on “Senior Learning and ICT usage” (<http://uisel.eu>).
2. “Estratégia Nacional para a Inclusão e Literacia Digitais (2015 – 2020)” (<http://www.ticsociedade.pt/enild#n02>)

2.2.4 Sweden

In Sweden, almost everyone has access to the Internet in their home (SCB 2017) and 90 percent of the population using the internet regularly (European commission, 2017). Sweden has a high score for both the basic and advanced ICT skills (European commission, 2017). Among those who are between 16–54 years of age, virtually everybody (98%) uses the Internet (SCB 2017), and then up to 75 years old, nine out of ten are connected (Internetstiftelsen i Sverige, 2017). Even a majority (61%) of the oldest age group, those between 75–85 years and older, use the Internet; and 43% uses the Internet daily (SCB 2017). A more detailed description of the Internet usage among elderly people can be seen in Table 2.

**TABLE 2.
PEOPLE OVER 65 YEARS OLD, IN SWEDEN, USED THE INTERNET FOR THE FOLLOWING (SCB 2017),**

	AGE 65-74 (%)	AGE >75 (%)
to send / receive e-mail	75	45
for phone and / or video calls	29	19
for social networks	39	17
to upload / share their own created content (such as images)	23	12
to read news sites / e-newspapers	71	45
to search for health information	41	26
to use internet banking	71	45
to book travel, accommodation and / or other travel-related services	41	23

to retrieve information from government websites / apps	52	26
to search information about goods / services	63	34
to sell goods or services (eg Tradera, Ebay)	10	7
to purchase or order goods / services via the internet	35	18

Moreover, on average, there are 1.2 tablets in Swedish households. Among those aged 75-85 years, only 20 % have used a smartphone to connect to the internet outside the home, compared with 84 percent for those aged 16-74 years (SCB 2017). Nevertheless, there are still a half million Swedes who do not use the Internet at all; most of them are over 66 years old. Some ask others for help, but many in this group cannot use or get access to online services on a regular basis. In addition to high age, those who do not use the internet are more often women, widows/widowers, they have low levels of education and low economy (Internetstiftelsen i Sverige, 2017).

One important way of taking advantage of the Internet and the power of tablets and smartphones is to download and use mobile applications or “apps”. In the age group up to 55 years, most people know how to install mobile apps. But among 56-65 years 8 percent do not know how to install apps, while the number for 66-75 years is 12 percent; and in the group 76 years and over as much as 50 percent do not know how to install apps. Among those who do not use the Internet on their mobile phones, 46 percent say that it is because it is not possible with the current phone, 25 percent are not interested and 10 percent think the technology is too difficult (Internetstiftelsen i Sverige, 2017).

No specific data is available regarding carers and their use of Internet. What we can say is that many carers have high degree of ICT and Internet use; because they usually help others with technical matters (von Sydow et al. 2015).

2.3

Discussing the basic concepts of ehealth, mhealth and ehealth literacy and how may influence carers usage of applications

eHealth and mHealth are important concepts to understand the importance of the use of online services for carers of people with chronic disorders.

Last decade, eHealth gained the attention of researchers, policy makers and IT market, as new technologies are more and more in offer facilitating the everyday lives of people with chronic diseases. Eng (2001) defines eHealth as "the use of emerging information and communication technology, especially the Internet, to improve or enable health and health care". World Health Organisation (WHO, 2005) provides a similar definition : "eHealth is the cost-effective and secure use of information communication technologies (ICT) in support of health and health- related fields, including health-care services, health surveillance, health literature, and health education, knowledge and research"

mHealth is defined according to the WHO (2011) as a component to eHealth and provides the definition of the Global Observatory for eHealth as " medical and public health practice supported by mobile devices, such as mobile phones, patients monitoring devices, personal digital assistants and other wireless devices". In the same report (WHO, 2011) key findings of the Global ehealth survey is presented discussing the most frequently reported mHealth initiatives: health call centres/health care telephone help lines, emergency toll – free telephone services, emergencies and mobile tele-medicine".

In the systematic review by Dyer et al (2012) on the available mobile apps and Internet based approaches supporting carers of people with chronic illnesses 3 topics were discussed: how the use of these initiatives affect caregivers outcomes, what are the lessons learned and what were the major gaps in these technologies. Summarising the findings, online peer support groups and chat groups were the most used services in comparison with other type of websites and applications. Furthermore, it seems that digital skills were a core barrier in several studies discussing accessibility of the interventions. The majority of studies were small scale, testing feasibility of the technologies. Another important point of the review concerns the way that existing technologies fill the gap of existing services and how they fit in the everyday lives of carers.

Taking into consideration the gap between the use of online interventions and the offer of this type of initiatives, the concept of eHealth literacy could justify the decreased demand in use of new tech-

nologies by carers. According to Bautista (2015), eHealth literacy is seen as an extension of health literacy. Health literacy has many different definitions, but one of the most frequent is the one proposed by Ratzan& Parker(5) “The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

One of the first and most used theories of eHealth literacy has been presented by Norman and Skinner (2006b) and is called the Lily model, including 6 dimensions: Health literacy, traditional and numeracy literacy, computer literacy, media literacy, science literacy and information literacy.

- Health literacy is the ability to find, select and understand health related information
- Information literacy: the ability to find, select and use information of any kind
- Traditional literacy is the ability to read and write, understand and speak language
- Media literacy is the ability to understand the information within a social and political context
- Computer literacy is the ability to use computers
- Scientific literacy is the ability to understand the aims, methods, implementation, limitations of creating knowledge.

Based on the above model, Norman and Skinner (2006a) developed the eHealth Literacy tool – eHeals to assess the ehealth literacy level.

New models have been developed since then, trying to expand the framework including Bloom’s taxonomy of educational objectives (Chan & Kaufman, 2011). According to Norman (2011) a limitation of the Lily model was that the model could not fit the Web 2.0 technologies. Gilstad (2014) redefined eHealth literacy :” the ability to identify and define a health problem, to communicate, seek, understand, appraise and apply eHealth information and welfare technologies in the cultural, social and situational frame and to use the knowledge critically in order to solve the health problem” and more recently Bautista (2015) tried to redefine the term as “the interplay of individual and social factors in the use of digital technologies to search, acquire, comprehend, appraise, communicate and apply health information in all contexts of healthcare with the goal of maintaining or improving the quality of life throughout the lifespan”

Chiu and Eysenbach (2011), tried to identify the factors that influence the use of internet among carers of people with dementia and proposes a framework including the concepts of ICT facilitators, the caregivers needs and the style of use. ICT factors include the internet access and the perceived efforts to use the ICT intervention. Caregivers needs are categorized based on the years of care provision to new and experience carers, with new carers to be associated with changes of needs over time as in the beginning they are desperate for information. Caregivers needs are influenced by personal capacity of the user, social support, the Caregiving beliefs concerning dementia, the medical and social service usage. The second factor is the style of use, and Chiu and Eysenbach distinguishes to the reflective and interactive learner. Reflective learner are the carers who don’t use email support and are frequent users of the sites. Interactive learners seek interaction for assistance in the use of the ICT intervention (Fig 1).

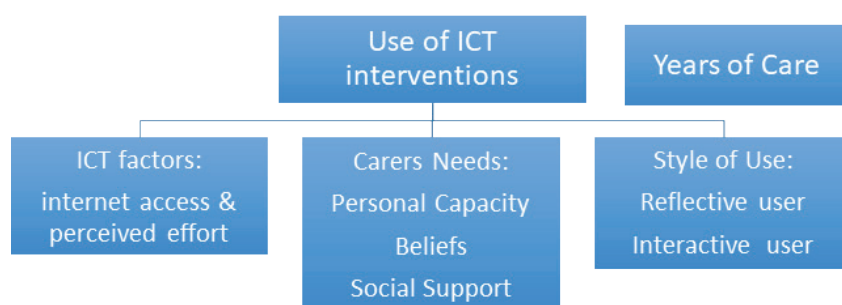


Fig 1. Factors related to Internet use according to Chiu & Eysenbach (2011)

2.4

How to assess the digital skills

Scales assessing ehealth literacy levels are not popular, hard to find and usually measure the subjective component of the participants. Scales of digital skills include both subjective and objective measurements.

As we have described in section 2.3, Norman (Norman 2006, 2006a) developed a widely used theory and a widely used tool assessing the ehealth literacy level of the user and includes 8 questions:

- 1) I know how to find helpful health resources on the Internet,
- (2) I know how to use the Internet to answer my health questions,
- (3) I know what health resources are available on the Internet,
- (4) I know where to find helpful health resources on the Internet,
- (5) I know how to use the health information I find on the Internet to help me,
- (6) I have the skills I need to evaluate the health resources I find on the Internet,
- (7) I can tell high quality from low quality health resources on the Internet,
- (8) I feel confident in using information from the Internet to make health decisions

The specific scale measures the perception that a person has concerning the eHealth literacy level and not the actual skills. In the case of Health literacy there are many tools assessing the functional literacy and not the subjective literacy, but this is not the case for eHealth literacy.

A useful way to assess the eHealth literacy level is to provide drills to the users:

Exercise 1.

- 1) select a health topic of relevant topics for older adults
- 2) Provide to the participants a number of related websites to the health-related topics
- 3) Set questions and let the participants to find the information on the related websites
- 4) Assess the most relevant information to reply your questions

Exercise 2.

- 1) Find out information about Alzheimer's Disease
- 2) Find out information about Breast Cancer
- 3) Find out information about Prostate
- 4) Find out information about Osteoporosis

The above exercises are derived by the National Institute of Ageing training course for older people "A toolkit for trainers".

Van Deursen (2014) developed a self reported questionnaire to assess internet skills including 5 domains: operational, information navigation, social, creative and mobile.

Every item of the scale uses a five point likert scale from not at all true of me, not very true of me,

neither true nor untrue of me, mostly true of me and very true of me.

The below tool might be a useful tool to level trainees in an Internet skills training course. In order for you to use proposed scale it is important to receive permission by the authors:

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Table 18. Proposed items and factors to measure Internet skills

Skill	Item
Operational	I know how to open downloaded files
	I know how to download/save a photo I found online
	I know how to use shortcut keys (e.g. CTRL-C for copy, CTRL-S for save)
	I know how to open a new tab in my browser
	I know how to bookmark a website
	I know where to click to go to a different webpage
	I know how to complete online forms
	I know how to upload files
	I know how to adjust privacy settings
Information Navigation	I know how to connect to a WIFI network
	I find it hard to decide what the best keywords are to use for online searches
	I find it hard to find a website I visited before
	I get tired when looking for information online
	Sometimes I end up on websites without knowing how I got there
	I find the way in which many websites are designed confusing
	All the different website layouts make working with the internet difficult for me
Social	I should take a course on finding information online
	Sometimes I find it hard to verify information I have retrieved
	I know which information I should and shouldn't share online
	I know when I should and shouldn't share information online
	I am careful to make my comments and behaviours appropriate to the situation I find myself in online
	I know how to change who I share content with (e.g. friends, friends of friends or public)
Creative	I know how to remove friends from my contact lists
	I feel comfortable deciding who to follow online (e.g. on services like Twitter or Tumblr)
	I know how to create something new from existing online images, music or video
	I know how to make basic changes to the content that others have produced
	I know how to design a website
	I know which different types of licences apply to online content
	I would feel confident putting video content I have created online
Mobile	I know which apps/software are safe to download
	I am confident about writing a comment on a blog, website or forum
	I would feel confident writing and commenting online
	I know how to install apps on a mobile device
	I know how to download apps to my mobile device
	I know how to keep track of the costs of mobile app use

Table 3. Proposed items and factors for Internet skills

(source: <http://www.lse.ac.uk/media-and-communications/assets/documents/research/projects/disto/Measuring-Digital-Skills.pdf>)



Aims and objectives of the A4C training

chapter 3

3.1

General aims and objectives of the A4C training course

The A4C training aims at providing a training package (containing video-tutorials, several number of informal caregivers with basic digital literacy. By conducting this training, it is expected that this group of people will be able to improve their digital skills (usage of mobile applications), but also learn from and be able to apply this training specifically to their caring roles and tasks in their day-to-day life, facilitating their lives as caregivers with the help of technological tools targeted specifically for them.

The training package will impact caregivers in three different ways: in the short term the training will have an immediate benefit when it comes to social inclusion — the participants participating in the activities will exchange views, opinions and worries with other caregivers in a classroom setting. The training will equally contribute to simplify and improve the quality of care provided and to relieve the burden of the informal carer. On the other hand, a medium-long term benefit also exists when it comes to digital literacy enhancement — the caregivers are given the opportunity to develop their own ICT skills by using digital devices (tablets, cell phones, etc) throughout the whole training.

A couple of main requisites concerning the training course were considered, having in mind the focus groups previously conducted with the target group of this training:

- Most caregivers declared lack of time to participate in a long training course, therefore the training needed to be short;
- There are different kind of users: participants who are more familiar with mobile devices and those who are not or make a basic use out of it, therefore the training course needed to be modular (4 modules in total);
- A great majority of the caregivers considered video-tutorials an interesting tool, therefore a main focus of the training course has to do with use of tutorials.

As so and from the point of view of ICT literacy, the modular structure of the course and its inherent content corresponds to the needs of both basic and independent users (that is, someone who at the very least knows what a mobile device is and is able to make use of its elementary functions — turn it on/off, connect it to the internet, use the keyboard, take photos, watch videos, navigate the internet, etc).

In order to implement the training course, a series of modules (Annex 1) were created with a single main goal attached to each of them, along with expected learning outcomes, esteemed duration (in hours), and scope (general or country specific). The modules were developed in a sequential order and bearing in mind complexity of a given activity.

Therefore, Module 1 provides instructions and focuses on how to use any app on a tablet/cellphone, Module 2 on how to specifically use the A4C app, Module 3 on how to use the country-specific selected apps inside the A4C app and then Module 4 to do a catch up on all that which was taught until that point in time. Likewise, two set of equally important learning outcomes are expected to have impact on the informal carers enrolled in the course: general outcomes and ICT/digital outcomes — the first set represents a general understanding of the activity at hand and what it consists of, while the ICT/digital outcome has to do with enhancement and acquisition of digital skills throughout the course.

3.2.1 Module 1

The aim of Module 1 is to create a welcoming environment in order for participants to introduce themselves to each other, to promote a team building opportunity and to provide some basic skills to learners who may not be familiar with the use of mobile devices. Indeed, from a didactic point of view the module is focused on learning how to search, download and install an app.

Module 1 is planned to last 2 hours. The material needed to deliver the module are: multimedia tools, PPT presentations, papers, markers, pens, hand-outs. Each participant can use his/her own mobile device.

Throughout the module, a series of different and interactive activities can be put into place:

1. Ice-breaker activity: aimed to create a positive and relaxed atmosphere within the group. Each participant should write on a sheet of paper the answer to the question “If you were going to be an APP, what APP would you be?” – in turn, each participant will provide his/her answer and explain their choice and reasons.
2. Introduction to the topic: the trainer introduces the purpose of the module and asks participants about their knowledge on apps. For example, he/she can ask which apps are of the carer’s knowledge and if they have ever used any before, etc. Following that, the trainer introduces the topic of APPs with a short PPT presentation.
3. The third activity is aimed to show participants some basic procedures dealing with searching for an APP. The trainer, using a tablet connected to a monitor, show participants how to perform some basic tasks, dwelling on the different steps. Then he/she asks participants to do the same under supervision. The tasks could be related to searching an app by category and how to get information on an app, for example. After the group has familiarized itself with the procedure, the trainer puts different

cards on the table and asks each participant to take one and do what is written on it individually. Cards contain different exercises to familiarize the carers with the task (e.g “Search the app Retrica and write down its rating” or “Search for three photography Apps and write down their names”).

4. In the following step, the trainer, using a tablet connected to a monitor, shows participants how to download and install a Free App. Then he/she asks participants to do the same under supervision. After the group has familiarized itself with the procedure, the trainer invites participants to pick up a sheet of paper, which contains the name of an app, from a bag. Each participant has to search for, download and install the corresponding app individually.
5. Then the trainer shows participants a short PPT presentation which contains the most common icons (images and definitions) and prompts the carers to try and recognize these icons and if they use the apps associated to them. To help participants memorize and familiarize themselves with the icons, the trainer can put on the table different cards that represent some of the most common icons presented and involve every participant in a game. He/She reads the icon definition and participants have to select, as fast as possible, the corresponding image (e.g. “Take the airplane mode icon”). The participant who collects the largest number of cards wins the game.
6. Finally, to conclude the session, the trainer gives participants a questionnaire to collect feedbacks on the module and he/she shows and gives participants a step by step guide which contains all the instructions delivered in Module 1 and invites them to practice whenever they feel like doing it (at home, for example).

It is expected that by the end of Module 1 the participants will have strengthened the following two sets of skills:

Table 4. General learning outcomes and digital learning outcomes Module 1

GENERAL LEARNING OUTCOMES	DIGITAL LEARNING OUTCOMES
<ul style="list-style-type: none"> Identify the App store icon in the device Know the main type of APPs (free or paid) Explore available APPs by category Use the search engine by key-words Understand the additional information provided for each app Install a free app Buy a paid app Find it on the mobile device and launch it Know the most common icons 	<ul style="list-style-type: none"> Browsing, searching and filtering data, information and digital content (Identify information needs, find data, information and content through a simple search in digital environments, find how to access these data, information and content and navigate between them) Interacting through digital technologies (perform well-defined and routine interactions with digital technologies and identify appropriate and simple communication means for a given context).

The module will be evaluated by observation. During the exercises, the trainer observes if participants have acquired the necessary skills to complete the tasks autonomously. After the end of the session, the trainer will note down his/her observations.

Feedbacks and suggestions for the trainers coming from the piloting:

The actual duration of the module differed in each country. Italy, both at INRCA and ANS, presented the module in 2 hours (as originally planned), while Cyprus and Sweden used 40 minutes and 30 minutes. It is important to notice that Portugal and Cyprus did the presentation of the first 2 modules together, and their indicated time used is comprehensive of module 1 and module 2. These differences might be related to the base-line knowledge of participants in using mobile devices.

Each country used different types of materials. All groups worked with PPT presentations, and in Italy, Sweden and Portugal guidelines were also used. Portugal and Sweden worked with an iPhone and a tablet, while in Italy (INRCA) and Cyprus the participants used their own devices. In this first module Italy (INRCA) and Cyprus did not modify anything, while Sweden point out that they spent less time on step 1-5. One major change was brought by Portugal, which underlines that they focused mostly on the use of the app Apps4Carers while, simultaneously, answering and clarifying doubts/questions regarding these initially mentioned specific matters. Another significant change was brought by Italy ANS, where they didn't present Step 5 due to lack of time. They noticed that the participants already had basic knowledge regarding icons and they decided to spend more time answering participants' questions and doubts.

Two of the trainers ranked this module "Ok", while the others think it was above their expectations. Regarding eventual future changes to meliorate the module, Portugal points out that it would be important to revise the quantity of learning objectives, adjusting the module to the attention span showcased by the trainees. Portugal also emphasizes that it is essential to know the characteristics of the trainees in order to anticipate potential difficulties related to pre-existent digital skills.

Since this is the first module, trainers recommend creating a positive environment within the class, encouraging exchanges between participants and allowing adequate time to icebreaking activities. Offering refreshments was also suggested to create a positive atmosphere within the group.

3.2.2 Module 2

In Module 2, the informal carer is introduced to the Apps4Carers App, created throughout the A4C project and consists of a repository of selected apps and websites from five different countries for the informal carer to make use of in their daily routine. The main goal of this module is for the informal carer to learn how to use the A4C app to its full potential, exploring all the options allowed and available inside the app.

Module 2 has a duration of 1 hour and 30 minutes and the main material needed to deliver the activities are the PowerPoint presentation, the step-by-step guide, sheets of paper, markers, pens, handouts, tablets and computers. Each participant can also use his or her own device.

Throughout the module, a series of different and interactive activities are put into place:

1. Ice Breaker activity: the trainer prompts the participants to openly comment, speak and elaborate about their own digital skills and their interest in technology, apps and (if the case) what kind of apps they use or would like to use. A small debate can ensue on whether apps can make some sort of difference in their daily routine or emergency situations (and if any of them uses apps in direct connection with their caregiving role).
2. Introducing the purpose of the module: the trainer prompts the participants to think about the idea of having an app consisting of a repository with selected resources for informal caregivers and introduces the Apps4Carers app in this regard, with a short PPT presentation.
3. Explanation on how to use the Apps4Carers app: the trainer hands out the step-by-step guides and dis-

plays the video explaining the app. Following this, the trainer will explain how to navigate the app and prompts participants to follow him/her under supervision.

4. Exercises: participants try to use the A4C app to obtain knowledge on what it has to offer and how to use it (exploring its different actions) and are prompted to select specific apps inside the A4C app to download, test and rate them.
5. Q&A session: short period of time given to participants to share their doubts, feedback and difficulties with the whole group and answered by the trainer.

It is expected that by the end of Module 2, the participants will have strengthened the following two sets of skills:

Table 5. General learning outcomes and digital learning outcomes Module 2

GENERAL LEARNING OUTCOMES	DIGITAL LEARNING OUTCOMES
<ul style="list-style-type: none"> Understand the general structure and main functionalities of the app; Have an overview of the available resources; Understand the organization of the apps' listing: categories, filters, tags; Be able to search according to category, filter and tag; Make use of the rating systems of the A4C app; Understand how to download the referenced apps and access the websites. 	<ul style="list-style-type: none"> Browsing, searching and filtering data, information and digital content (identify and find data, information and content through a simple search, find how to access the information and content and navigate through them); Evaluating data, information and digital content; Interacting through digital technologies (perform well-defined and routine interactions with digital technologies).

This module will be evaluated by means of observation. During the exercises mentioned above, the trainer will observe if the participants are (with more ease or more difficulty) acquiring the necessary skills to complete the task autonomously. The trainer can also take notes on his or her observations. Homework can be delivered to the informal carers if they show interest in it and it acts as a form of self-evaluation. This is important because it allows informal carers to further interact with the A4C app at home throughout the week (for example) and the trainer can and should encourage this assignment.

Feedbacks and suggestions for the trainers coming from the piloting:

In this module the duration presents some slightly differences. The longest one was in Italy (ANS) with two hours, while the other Italian group (INRCA) used 1.5 hours, (as originally planned), followed by Cyprus (1 hour and 20 minutes). The shortest session was in Sweden (1 hour). The material used by the groups replicate the ones of module 1 (PPT presentations, learning guides, projectors). Cyprus and Italy (ANS) also used video tutorials.

Sweden points out that step 1 of this module was shortened, while Portugal made more significant changes. In specific, they “decided to adapt the initial technical information on basic use of devices and focused mostly on the use of the app Apps4Carers and apps in general while simultaneously answering and clarifying doubts/questions regarding these initially mentioned specific matters” as they did in Module 1. It is important to remember that Portugal did the presentation of the first 2 mod-

ules together, and their indicated time used is comprehensive of module 1 and module 2, presenting the same changes and suggestions in both modules.

Four partners think this module was above their expectation while only Portugal rated it as “ok”. Regarding the changes, they made, Italy (INRCA) provided additional explanations about the app features (i.e. tags, filters, categories, search engine), while Sweden shorten the information about the project and start working with the app.

3.2.3 Module 3

Module 3 is divided into two submodules — Module 3A and Module 3B. They can both be delivered together or separately, according to the needs of the target group at hand.

In this Module 3 the participants learn about using a selection of available apps related to their daily tasks as caregivers (per scope and per disease accordingly). This module is the only one which is country specific, which means that each country participating in the A4C project developed its own training contents while following a common template focusing on at least four useful apps related to caregiving tasks. The apps selection process by each country took considered the following aspects:

- Complexity vs available time: due to time constraint of the training session, both a simple and easy app with limited functions/features and a more complex app were chosen for this Module in order for there to exist variety in the training session;
- Interest of the target group: apps were selected according to the main interests of the target group at hand (ideally it is better to choose apps representing different areas/scopes).

Moreover, for each app there is a corresponding step-by-step guide and video-tutorial in the native language of each participating country. For each app chosen, it was highlighted the learning outcomes that could be achieved in terms of ICT literacy following the framework given by the European Union’s “Digital competence framework for citizens”.

It is expected that by the end of Module 3, the participants will have strengthened the following two sets of skills:

Table 6. General learning outcomes and digital learning outcomes Module 3A and 3B

	GENERAL LEARNING OUTCOMES	DIGITAL LEARNING OUTCOMES
Module 3A	<ul style="list-style-type: none"> • Understand what it is meant for “scope” • Understand why the APP(s) has been considered useful for the “scope” • Set up the APP according to his/her caring needs (if relevant) • Use autonomously all the key-features of the APP according to his/her caring needs 	<ul style="list-style-type: none"> • Browsing, searching and filtering data, information and digital content; • Evaluating data, information and digital content; • Managing data, information and digital content;
Module 3B	<ul style="list-style-type: none"> • Understand what it is meant for “disease” • Understand why the APP(s) has been considered useful for the “disease” • Set up the APP according to his/her caring needs (if relevant) • Use autonomously all the key-features of the APP according to his/her caring needs 	

Module 3 has a combined duration of 3 hours (each of them with a duration of 1 hour and 30 minutes) and the main material needed to deliver the activities inherent to this module are the PowerPoint presentation, tablets, computers, the step-by-step guides, sheets of paper, markers and pens.

Throughout the module, a series of different and interactive activities are put into place similar to the ones already mentioned for Module 1 and 2. The trainer introduces the topic of the module with a PowerPoint presentation and prompts participants to reflect and debate about the importance of apps usage in a specific task related to caregiving or about a specific disease according to the apps available and chosen in each country.

Afterwards, the trainer offers a small explanation on how to use the apps selected with the help of user guides delivered to the participants and explanatory videos about those apps. Through exercises the participants can familiarize themselves with the tablets and manoeuvre in the designated apps as to gain knowledge on its functions and what it has to offer. In this phase and when necessary, the trainer should intervene in order to help the participants and guide them through their task.

In the end, the trainer can close the training session with a Q&A and evaluate the participants' knowledge and understanding of the apps and its functions with a quick set of questions (quiz) regarding the apps' functionalities. The trainer might also prompt the participants to autonomously use the tablet and manoeuvre around the selected apps (performance test) to see if they are able to do it without any major obstacle or second party help. This will allow the trainer to observe if the digital literacy of the participants improved (or not) in comparison with when they first started the course.

Feedbacks and suggestions for the trainers coming from the piloting:

It is important to notice that Sweden did not include this module in the training because in their opinion there was no need for any of the participants to work more on downloading, opening and using an app.

Module 3 presents more differences regarding the time usage. The longest session was taken in Italy, both INRCA and ANS used 2 hours, while the shortest session was in Cyprus (40 minutes) as it was combined with module 4. The material used was similar to the same of the previous modules. Italy (ANS) used also the step by step guides for 4 apps, such as "Pharmaround", "Training Autogeno", "My family" and "My therapy".

There were only two changes in the way this module was presented: Portugal divided the module in 2 parts, and Italy (ANS) decided to work with four apps instead of two. All the partners rated this module "above their expectations". Regarding the changes brought in the presentations, Cyprus says that they "would integrate both modules 3A and 3B, keeping the most related apps for the target group and skipping steps 1 and 6". When it comes to suggestions, Italy (INRCA) suggests allowing enough time for practice and for the autonomous exploration of resources by participants, while Cyprus points out that the module 3A and 3B could be combined with 4 in one session, of maximum 2 hours.

3.2.4 Module 4

The general aim of Module 4 is to answer any emerging questions/doubts, collect feedbacks about the apps, encourage participants to review them and provide useful information and referrals on

activities that meet carer's needs. More specifically, the goal is that by the end of the module, participants will have been answered any doubts they might have about the usage of the Apps4Carers App and the apps inherent to it; they will have gained more confidence in the use of apps and corresponding devices and they will have acquired information and referrals on activities, events or groups, organized locally, that can be useful in their caring activity.

Module 4 has an expected duration of 1 hour and the main material needed to deliver the activities are multimedia, papers, post-it, white board, markers and pens.

Throughout the module, a series of different and interactive activities are put into place:

1. Ice-breaker activity: the trainer presents to the participants a word chain game that deals with the terms used during the training (e.g Apps, devices, icons...). He/she asks them to sit around in a circle and, in turn, list words in a category. They must remember the words previously mentioned and think of unique words to add to the category chosen. Example: First word in the chain: App. The second person will have to repeat the chain and add a unique word that fits the category. Example: App, Icon. Each person will have a certain amount of time (10 seconds) after correctly reciting the chain to add another new word. When someone makes a mistake, said person will sit out and the game shall continue until a champion of Word Chains is found.
2. Session dedicated to answering emerging questions/doubts
3. Feedback gathering: collection of feedback about the Apps4Carers App and inherent Apps.
 - a. First, the trainer will ask participants their overall opinion about the Apps4Carers App: if they have encountered any difficulties in its use and which are its positive aspects. Then the trainer gives out to each participant a sheet of paper with 5 stars (resembling the way to rate Apps on Apple Store and Google Play Store) and asks them to rate the Apps4Carers App by colouring a different number of stars on the basis of their overall satisfaction (from 1- "I don't like" to 5- "I like very much"). The trainer should encourage the exchange of views between the participants.
 - b. Second, the trainer gives each participant some post-it and asks them to write down the names of some Apps they have used and are collected in the Apps4Carers App (5 apps at most, one per each post-it). Then he/she draws a traffic light on a board: the red light means "This app isn't useful for me", the orange one means "This app could be useful for me but..." and the green one means "This app is very useful for me". Each participant has to attach their post-it in the correct place and explain their choices to the rest of the group. If a participant has used one of the apps rated by another participant, he/she has to share his/her opinion about it with the rest of the group.

The trainer should encourage participants to rate and review the Apps used in the Apps4Carers App.

Finally, he asks each participant to fill in a questionnaire whose aim is to collect information on the apps downloaded: how many apps does the participant download, what kind of apps (the scope they respond to), if he/she found the apps downloaded relevant to the scope and useful for his/her caring activities, etc.

4. Giving out useful information: the trainer provides useful information and referrals on activities, events or groups, organized locally, that meet carer's needs (e.g. self-help groups, workshops...). The aim is to encourage networking and referrals to useful services.

5. Finally, the trainer asks participants to give feedback on the module and on the entire training. The trainer prompts them to think about, and then share with the rest of the group the results achieved (competences developed, improvement of digital skills, the impact of using Apps4Carers App in caring activities). Finally, to finish the training with laughter, the trainer shows participants a short video that shows the funny side of tablet use. <https://www.youtube.com/watch?v=nnYvaRatVJg>

Feedbacks and suggestions for the trainers coming from the piloting:

Module 4 was developed by Italy (INRCA) in 2.5 hours, by Portugal in 2 hours, by Italy ANS in 1.5 hours and in 30 minutes by both Cyprus and Sweden. Portugal used learning guides, PPT and tablets, while Cyprus and Italy ANS used Annex 1, Annex 2 and the final assessment.

Italy (INRCA) decided to conduct this session as a group discussion. The most significant changes were brought by Italy and Sweden. In Italy (INRCA), the trainers managed the networking activity differently (step 5), asking directly participants about their knowledge and experiences with local networks and support groups. The ANS Italian group also adjusted this module by not using Step 1. They also point out that before using Step 2, 3 and 4 they allowed participants to spend some time using the Apps4Carers App. In Sweden, the trainers talked about the different apps and what they thought about them instead of writing post-its notes in step 3. Italy (INRCA) rated this module “very much above their expectation”. On the contrary, Cyprus rated it as “below their expectations”. Sweden, Portugal and Italy (ANS) think it was “above their expectations”. Regarding future changes, Sweden suggests gathering feedback from the participants digitally by using a tool like Google Forms. Italy (ANS) points out that it could be better to plan this module after at least 2 or 3 weeks from the previous one to give participants the time to use the Apps4Carers App. Cyprus proposes to combine step 2 and 3 and omit step 1 and 4. Italy (INRCA) points out that the discussion among the participants should be encouraged, in particular for what concerns networking activities.

The A4C training provides a training package full of useful resources aimed at informal caregivers with low digital literacy. Once this training, composed of four Modules is fully completed, it is expected that they will not only have improved their own digital skills, but also will have felt more encouraged at making use of technological resources as a facilitator in their daily lives as caregivers.

The trainer plays an important role in this regard, because he or she is the one who will guide the informal carer through this modular course and therefore should have a clear route of his/her teaching path. Along with transmitting information, he/she is responsible for the practical knowledge a certain caregiver obtains. Therefore, the trainer should prompt the informal carer, participating in the training and experimenting with the technological devices at his/her disposal through exercises, quizzes, homework, etc. Only then can this course be successfully implemented.

The feedbacks and suggestions for the trainers arriving from the piloting tests conducted in the A4C project also allows the trainer to have access to a number of critical guidelines and previous experiences that will assure that future trainers are more prepared for what to expect, and how to behave and interact with this target group, before they decide to give out the course. This, in turn, will maximize the learning potential and process of informal carers in the course.



Exploitation Strategy

chapter 4

This section is aimed at describing the recruitment strategies used by partners during the pilot testing phase and the dissemination tools that, according to their experiences, proved to be more effective in terms of positive response by the target group.

It will also provide indications on how to organise at best the training course, and on how to teach effectively to adult learners. Finally, recommendations issued from the partners' experiences with carers, and examples about other possible contexts of application of the training programme will be provided.

Recruitment channels

In order to suggest possible strategies to reach carers easily, we listed below the dissemination channels considered most effective by partners, as highlighted by their experience in using them during the pilot testing phase.

According to LNU (SE), the best option is to disseminate information about the training course through social media, websites, newsletters and via carers organisations. Through these means, indeed, it is possible to reach a wider audience including carers, care recipients, volunteers, health professionals etc., which in turn can pass the information to other relevant stakeholders.

According to ANS(IT), it is important to network with local associations and NGOs, either targeting older persons organisations or condition-specific associations (which normally engage a lot with informal carers). Social networks help, too, but rather as a mean to reach other NGOs or umbrella organizations, rather than carers themselves.

For INRCA (IT), too, it is important to mobilise local networks and cooperate with health professionals, as they usually have frequent contacts with informal carers. It can also be useful to organize project presentations to local associations, and participate in community events to circulate the information about the project.

For CUT (CY, GR), non-for profit associations working with families/patients are a valuable link to pass the message, as these associations regularly organise education campaigns, which can easily reach carers. Other possible channels are health and social services devoted to dependent people (e.g. home care services, nursing homes, etc.), and places usually attended by carers, e.g. community centres, pharmacies and parishes.

For Virtual Campus (PT), contacts with local stakeholders (specifically caregiver's organization/association and municipalities) and use of social media/internet are the most effective channels to reach the target group.

4.2

Recommendations to engage with informal carers

LNU (SE) suggests cooperating with carers organisations and working with them in “Blended learning network” groups (BLNs). BLNs are groups where different stakeholders (older people, carers, care providers, policy makers, social services providers) cooperate together, with the aim of improving the care for older people at local and regional level (Hanson, Magnusson, & Sennemark, 2011).

ANS (IT) thinks it might be useful to advertise the training course, pointing out that it is an opportunity to improve knowledge on the use of mobile devices, and not only as a training course for informal carers to use dedicated APPs. This is important for two reasons: 1) because informal carers might still have difficulties in recognizing that their training needs in relation to their caring role (this is for many of them considered as something “natural”, for which they do not need to be trained, or that “they already know everything about”); 2) because often informal carers feel the need to do something just for themselves, and not only because they are carers.

INRCA (IT) suggests that emphasizing to carers the advantages linked to the use of new technologies, in particular with regard to the improved access to information and communication opportunities. It can be also useful to present the training as an opportunity to meet, discuss and get help from other carers facing similar problems.

According to CUT (CY, GR), it is important to approach directly carers through face-to-face communication. Providing training at home would be the best option, as carers can have difficulty to access the services, since these are usually based in large cities only. In Greece, people are more positive about new technological solutions and interventions provided through the internet, this being true especially for the adult children who provide care to older parents. In both Cyprus and Greece, inter-generational programmes could become of use to engage people who are over 65 years , in order to participate in new social innovations.

According to Virtual Campus (PT), the most important aspect to engage carers is to provide them with a comfortable environment in which they can freely talk about their life, worries and emotions, making sure they are being listened to. It is up to the trainer to create a welcoming environment, in which each participant feel can freely share its thoughts and views.

4.3

Organization and implementation of the training course

This paragraph has to be considered as a guidance for the course implementation. We collected here tips and recommendations issued on the background of partners' experiences with the target group, as well as of inputs taken from existing literature.

In particular, you will find here suggestions on classes' composition, teaching adult learners and precautions to be taken while working with adult or senior carers.

4.3.1. Class size and composition

According to our experience, classes of *small dimensions* (up to 10 participants) are preferable to larger groups, as they allow a more intimate experience within the class and a personalised attention to each participant. Whenever possible, it is recommended to group participants by *proficiency level*, in order to ensure that the class proceeds at the same speed and no one is left behind.

In this respect, it is worth to remember that the A4C training course is designed for basic and intermediate ICT users (2), thus it may not be suitable for novice users.

Novice users should be instructed on some basic ICT course before accessing the A4C training course. For instance, you can refer to the training programme developed by some of the A4C partners within a previous project, i.e. the UISEL project <http://uisel.eu/>, which was specifically designed to tackle technological illiteracy in adult citizens aged 50 and above.

4.3.2. Teaching adult learners

Adult learning theory, also defined as “andragogy”, refers to the practice of teaching and educating adults. The term “andragogy” was made popular in the late 60s by Malcolm Knowles, an American educator who first attempted to build a comprehensive theory (or model) of adult learning, based on the characteristics of adult learners. Over the years, there have been a number of adult learning theory models, but Knowles' work is still the most relevant and well-known in adult education.

His andragogy model is based on six assumptions about adult learning, that can be translated into concrete recommendations for classroom practice. In the following, we summarize these principles, including some practical suggestions for teachers.

Table 7. Andragogic model - Assumptions about Adult Learners

1. Need to know	Adults need to know why something is important prior to learning.
2. The learner's self-concept	Adults feel responsible for their own learning.
3. The role of the learner's experience	The learner's experience has great importance in favouring new learning steps.
4. Readiness to learn	Adults are most interested in learning subjects having immediate relevance to their lives.
5. Orientation	Adults learn best through problem-based learning.
6. Motivation	Adults respond to internal motivators rather than to external ones.

Source: Knowles et al. 1998

Here are some additional comments concerning the principles indicated in the table above:

1. **Need to know:** Adult learners want to know why they need to learn something. They need to be told or, even better, to be led to discover why certain *knowledge is worth learning*.
2. **The learner's self concept:** Differently from children, adult learners tend to feel responsible for their own learning. This means that they are less teacher-centred than young learners; thus, an *interactive approach* to get them personally involved in the learning process is recommended.
3. **The role of the learner's experience:** Adult learners have their own distinct and unique characteristics. They possess wealth of knowledge and experiences that represent a valuable contribution to learning. In addition, they have a wide range of individual differences and learning styles, which make every learner unique. Consequently, it is preferable to use different modes of teaching, using a *variety of materials and methods* that take account for differences in style, type and pace of learning of each participant.

Readiness to learn: Adult learners are ready to learn when they have some need to fulfil. It follows that any training activity devoted to them should clearly be *connected with their needs and expectations*, to be of value to them.
4. **Orientation:** Adult learners tend to be problem-centered and wants to apply new learning immediately. This implies that experiential learning (*learning by doing*), instead of memorization of content, is preferable for this group.
5. **Motivation:** Adults are best motivated to learn by internal factors, such as self-esteem, self-actualization and, above all, the need for recognition. It is important to consider their need to be appreciated and respected, in order to foster an environment conducive to learning. It is also important to create a *nurturing and non-judgmental climate* within the class, allowing participants to feel at ease, and not to fear to feel embarrassed in front of peers because of their mistakes or failings.

A last aspect that characterizes the Andragogic model regards the role of teachers that in the context of adult education are called to act as facilitators, rather than as instructors.

The facilitator's role is that of initiating, monitoring and supporting the learning process, allowing each learner to obtain the highest level of performance possible for him/her. In practical terms, this means that with adults the goals of learning are in the *process* instead of in the content being taught, and the participants' active involvement is crucial to make the course effective.

In summary:

- 1) Explain how the new knowledge and skills provided by the training can be applied to care-giving (*for instance, you can refer to daily activities of carers which can be better performed using digital tools*).
- 2) Make lessons as interactive as possible.
- 3) Use a variety of teaching materials and methods (*for instance, you can use oral presentations, written materials, group discussion, small work group, games, multimedia etc.*).
- 4) Prefer a learning by doing approach, instead of a passive teaching style.
- 5) Create a supportive environment within the class.
- 6) Encourage interactions and cooperation among participants.
- 7) Act as a facilitator rather than as an instructor.

4.4

Precautions to be taken into account while working with carers

According to our experience, the following suggestions are useful to ensure a positive carers' engagement in the training:

- **Improving training course attendance:** Carers are often very busy and overwhelmed by their multiple roles (i.e. carers, workers, spouses, parents), therefore it might be difficult for some of them to find the time to attend the course. According to our experience, the following tips can help improve attendance. In particular, it can be useful to:
 - o Communicate well in advance the timetable of the sessions, thus allowing participants enough time to find alternative arrangements for their loved ones;
 - o Agree with them on the time of the day that better suits their needs (for instance, employed carers might prefer evening classes instead of morning classes).
- **Social dimension of the training course:** For most carers the course attendance represents a social event, rather than a mere learning opportunity. They usually do not have much time to spend in leisure time activities, and even less to meet, talk and connect with other carers.

As a consequence, allowing them enough time to discuss, socialise, share information and offer each other support can be highly rewarding for carers, bringing at the same time benefit to the whole course.

To this purpose, it can be helpful to arrange the classroom so that interacting among participants is facilitated. For instance, you can use a circular seating arrangement to allow participants engaging and interacting with each other.

- **Class comprehension:** It may happen that some carers, in particular those who perceive themselves as less competent, remain silent when they do not understand something. It is important to pay attention to them, checking frequently the class comprehension and being attentive to possible nonverbal signs of anxiety or discomfort.

In most cases, it might be sufficient to sit next to them and review together the lesson to solve these difficulties. Moreover, it might be helpful to address participants with regard to the training materials developed within the A4c course, i.e. using the step by step guides and video tutorials that can help them review the lesson again once at home.

- **Allow enough time for repetition and practice:** As most carers, in particular those who are less digital competent, tend to require much more practice and exercise before new skills are acquired, it is recommended to allow enough time for repetition and practice throughout the lesson.
- **Evaluate the satisfaction of participants:** a satisfaction questionnaire can help you to get a comprehensive idea of strengths and weaknesses of the course you offered, and to revise it accordingly.

4.5

A4C Training course transferability

The A4C training programme was tested successfully in organisations with different backgrounds and aims, such as two universities (LNU and CUT), a geriatric hospital (INRCA), a non-profit organisation (ANS), and an ICT company (Virtual Campus).

It can be easily adapted to other informal educational settings, such as Voluntary Associations, Third Age Universities, and ICT training centres interested in providing lifelong learning opportunities.

For instance, ITC training providers might be interested in increasing the digital skills of this target group, or Voluntary Associations might be interested in providing detailed information about online resources devoted to specific diseases.

The A4C training programme is currently available in five languages: Swedish, Greek, Italian, Portuguese and English. This will allow future adaptations in other languages.

All the materials developed within the project are available through the project dissemination channels, i.e. the website <http://www.appsforcarers.eu/> and the A4C Youtube channel: https://www.youtube.com/channel/UCiFUn-Z_lvwGMS8SDWrfkoA, where both carers and interested stakeholders can find information about the project and its products.

References

1. Alzheimer Europe. (2013). *Prevalence of dementia in Europe*. [Accessed 19 May 2018: <http://www.alzheimer-europe.org/Research/European-Collaboration-on-Dementia/Prevalence-of-dementia/Prevalence-of-dementia-in-Europe>]
2. Anandarajan, M., Simmers, C., & Igbaria, M. (2000). An exploratory investigation of the antecedents and impact of internet usage: An individual perspective. *Behaviour & Information Technology* 19(1):69–85. doi: 0.1080/014492900118803
3. Andrianakos, A., Trontzas, P., Christogiannis, F. et al. (2003). Prevalence of rheumatoid diseases in Greece: Descriptive epidemiological study. *The study ESORDIG. IATRIKI* 84: 18-206
4. Barbabella, F., Chiatti, C., & Di Rosa, M. (2015). *La bussola di NNA: lo stato dell'arte basato sui fatti*. In: *Network Non Autosufficienza (a cura di) L'assistenza agli anziani non autosufficienti in Italia*. 5° Rapporto. Santarcangelo di Romagna, Maggioli Editore, pp. 15-33 [Accessed 03 May 2018: http://www.maggioli.it/rna/2015/pdf/V-rapporto-assistenza_anziani.pdf]
5. Bautista, J.R (2015). From solving a health problem to achieving quality of life: Redefining eHealth literacy. *Journal of Literacy and Technology* 16(92):33-54
6. Carretero, S., Stewart, J., & Centeno, C. (2015). Information and communication technologies for informal carers and paid assistants: benefits from micro-, meso-, and macro-levels. *European Journal of Ageing*, 12:163–173. doi 10.1007/s10433-015-0333-4
7. Carretero, S., Stewart, J., Centeno, C., Barbabella, F., Schmidt, A., Lamontagne-Godwin, F., & Lamura, G. (2012). *Can Technology-based Services support Long-term Care Challenges in Home Care? Analysis of Evidence from Social Innovation Good Practices across the EU: CARICT Project Summary Report*
8. Carretero, S., Vuorikari, R., & Punie, Y. (2017). *DigComp 2.1: The digital competence framework for citizens with eight proficiency levels and examples of use*, Publications Office of the European Union, EUR 28558 EN. doi:10.2760/38842
9. Censis. (2017). *14th Report on Communication*. Franco Angeli, Bologna. [Accessed 08 July 2018: http://www.censis.it/17?shadow_publicazione=120577]
10. Chan, C. V., & Kaufman, D. R. (2011). A framework for characterizing ehealth literacy demands and barriers. *Journal of Medical Internet Research*, 13(4), 1–24. doi: 10.2196/jmir.1750
11. Chiu, T., & Eysenbach, G. (2011). Theorizing the health service usage behaviour of family
12. caregivers: a qualitative study of an internet based intervention. *International Journal of Med-*

13. Constantinou, E., Koupi, S., Ioannidou-Efstathiou, C., Kliridis, M., & Kouloumas, M. (2011). *National strategy of rheumatoid diseases*. Ministry of Health, Nicosia. [Accessed 19 May 2018: [https://www.moh.gov.cy/Moh/MOH.nsf/All/7ACB889DB4F9ABF8422579D7003A25DA/\\$file/Εθνική%20Στρατηγική%20για%20την%20Αντιμετώπιση%20Ρευματικών%20Παθήσεων.pdf](https://www.moh.gov.cy/Moh/MOH.nsf/All/7ACB889DB4F9ABF8422579D7003A25DA/$file/Εθνική%20Στρατηγική%20για%20την%20Αντιμετώπιση%20Ρευματικών%20Παθήσεων.pdf)]
14. Dyer, E.A., Kansagara, D., McInnes, D.K., Freeman, M., & Woods, S. (2012). *Mobile Applications and Internet-based Approaches for Supporting Non-professional Caregivers: A Systematic Review*. VA-ESP Project #05-225. [Accessed 26 July: https://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0050675/pdf/PubMedHealth_PMH0050675.pdf]
15. Eng, T.R. (2001). *The eHealth landscape A terrain map of emerging information and communication technologies in health and health care*. Princeton, NJ: The Robert Wood Johnson foundation. [Accessed: http://www.rwjf.org/app/rw_publications_and_links/publications/Pdfs/eHealth.pdf]
16. Eurocarers. (2016a). *Informal carers' skills and training – a tool for recognition and empowerment*. [Accessed 20 May 2018: http://www.eurocarers.org/userfiles/files/factsheets/Eurocarers%20-%20Skills%20and%20training_final.pdf]
17. Eurocarers. (2016b). *Information and Communication Technology (ICT) for carers*. [Accessed 20 May 2018: http://www.eurocarers.org/userfiles/files/factsheets/Eurocarers%20-%20ICT_final.pdf]
18. Eurocarers. (2016c). *Reconciling work and care: the need to support informal carers*. [Accessed 20 May 2018: http://www.eurocarers.org/userfiles/files/factsheets/Eurocarers%20-%20Work%20Life%20balance_final.pdf]
19. Eurocarers. (2016d). *What do informal carers need? Towards a fair and rights-based deal*. [Accessed 20 May 2018: http://www.eurocarers.org/userfiles/files/factsheets/Eurocarers%20-%20Needs_final.pdf]
20. Eurocarers (2016e). *Why addressing the needs of informal carers is a crucial issue for Europe*. [Accessed 20 May 2018: http://www.eurocarers.org/userfiles/files/factsheets/Eurocarers%20-%20Intro_final.pdf]
21. Eurocarers. (2017a). *Overview of carers' needs and existing support measure across Europe*. [Accessed 19 May 2018: <http://www.eurocarers.org/userfiles/files/factsheets/Eurocarers%20Situation%20of%20carers%20in%20EU.pdf>]
22. Eurocarers. (2017b). *The relevance of EU policy development to carers and vice versa - An overview*. [Accessed 03 May 2018: <http://www.eurocarers.org/userfiles/files/policy/The%20relevance%20of%20EU%20policy%20development%20to%20carers%20and%20vice%20versa%20-%202017.pdf>]
23. Eurofamcare. (2004). *Services for supporting family carers of elderly people in Europe: Characteristics, coverage and usage. National background report for Portugal*. Hamburg. [Accessed 06 May 2018: https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0a-hUKEwjKzo605fHaAhWjQJoKHfYcB34QFggoMAA&url=https%3A%2F%2Fwww.uke.de%2Fextern%2Feurofamcare%2Fdocuments%2Fnaabares%2Fnaabare_portugal_rc1_a5.pdf&usg=AOvVaw1on6628Aboj9OrHgn8W-04]
24. Eurofound. (2015). *Working and caring: Reconciliation measures in times of demograph-*

ic change. [Accessed 20 May 2018: <http://maennerundvereinbarkeit.at/wp-content/uploads/2017/01/Working-Caring-Eurofound-2015.pdf>]

25. European Commission. (2017). *Commission staff working document. Europe's digital progress report 2017*. Brussel. [Accessed 30 April 2018: <https://ec.europa.eu/digital-single-market/en/news/europes-digital-progress-report-2017>]
26. European Commission. *The European pillar of social rights in 20 principles*. [Accessed 19 May 2018: https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights/european-pillar-social-rights-20-principles_en]
27. Ferlay, J., Steliarova-Foucher, E., Lortet-Tieulent, J., Rosso, S., Coebergh, JWW., Comber, H., Forman, D., & Bray, F. (2013). Cancer incidence and mortality patterns in Europe: estimates for 40 countries in 2012. *European Journal of Cancer*, 49(6): 1374-403. doi: 10.1016/j.ejca.2012.12.027
28. Ferrari, A. (2012). *Digital competence in practice: An analysis of frameworks* (p.92). Luxembourg: Publication Office of the European Union
29. Ferrari, A. (2013). *DIGCOMP: A Framework for Developing & Understanding Digital Competence in Europe*. JRC Scientific and Policy Report (European Commission)
30. Gilstad, H. (2014). Toward a comprehensive model of eHealth literacy. *CEUR Workshop Proceedings*, 1251(Pahi): 63–72.
31. Handel, M. J. (2011). mHealth (Mobile Health) – Using apps for health and wellness. *Explore*, 7(4): 256–262. doi: 10.1016/j.explore.2011.04.011
32. Hanson, E.; Magnusson, L.; Sennemark, E. (2011). Blended learning networks supported by information and communication technology: An intervention for knowledge transformation within family Care of older people, *The Gerontologist*, 51(4), 561-570. doi: 10.1093/geront/gnr015
33. Hargittai, E., & Hinnant, A. (2008). Digital inequality, differences in young adult's use of the internet. *Communication Research*, 35(5): 602-621.
34. Hellenic Statistical Authority. (2014). *Announcement of the results of the 2011 Population Census for the Resident Population*. [Accessed 19 May 2018: <http://www.statistics.gr/el/statistics/-/publication/SAM03/->]
35. Helsper, E., & Eynon, R. (2013) Distinct skill pathways to digital engagement. *European Journal of Communication* 28(6):696-671. doi: 10.1177/0267323113499113
36. Internetstiftelsen in Sweden (2017). *Svenskarna och Internet 2017*. Stockholm [Accessed 20 February 2018: <http://www.soi2017.se/vuxnas-digitala-kompetens/>]
37. ISTAT. (2017). *Cittadini, imprese e ICT*. [Accessed 27 July 2018: <https://www.istat.it/it/archivio/207825>]
38. ISTAT. (2017). *Rapporto sulle condizioni di salute e ricorso ai servizi sanitari in Italia e nell'Unione Europea*
39. Knowles, M. (1978). *The adult learner: A neglected species*. Houston: Gulf Publishing Company
40. Knowles, Malcolm S., Elwood F. Holton III, & Richard A. Swanson. (1998). *The Adult Learner*. Hous-

ton: Gulf Publishing.

41. Knowles, M., Swanson, R., & Holton, E. (2012). *The adult learner: The definitive classic in adult education and human resource development* (7th Ed.). Abingdon/New York: Routledge
42. Kondilis, B.K., Magoulas, C., Ioannidis, E., & Agrafiotis, D. (2012). The European Health Literacy Survey - case of Greece. Executive Agency for health and Consumers. [Accessed: 27 July 2018: http://www.nsph.gr/files/006_Koinoniologias/HLS-EU%20country%20report_Greece_2012_ENG.pdf]
43. Lamura, G. (2017). *Interventions and policy measures to support unpaid carers effectively in country report on emerging policy developments in the long-term sector in Italy*, CEQUA Network, August 2017
44. Mossberger, K., Tolbert, C.J., & Stansbury, M. (2003). *Virtual Inequality: Beyond the Digital Divide*. Georgetown University Press
45. NBHWS (National Board of Health & Welfare Sweden). (2012). *Anhöriga som ger omsorg till närstående – omfattning och konsekvenser [Family members who provide care to relatives. Prevalence and consequences]*. NBHWS, Stockholm. [Accessed 04 May 2018: <http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/18811/2012-8-15.pdf>]
46. NBHWS (National Board of Health & Welfare Sweden). (2014). *Anhöriga som ger omsorg till närstående – fördjupad studie av omfattning och konsekvenser [Family members who provide care to relatives. A detailed study of prevalence and consequences of informal caring]*. NBHWS, Stockholm. [Accessed 09 May 2018: <https://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/19540/2014-10-10.pdf>]
47. NBHWS (National Board of Health and Welfare Sweden). (2016). *Stöd till anhöriga. Vägledning till kommunerna för tillämpning av 5 kap. 10 § socialtjänstlagen*. [Accessed 04 May 2018: <http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/20286/2016-7-3.pdf>]
48. Nielsen-Bohlman, L., Panzer, A.M., Kindig, D. (2004). Health literacy: A prescription to end confusion. National Academy of Sciences. Washington, DC: The National Academies Press. doi: 10.17226/10883.
49. Norman, C.D., & Skinner, H.A. (2006b). eHealth literacy: Essential skills for consumer health in a networked world. *Journal of Medical Internet Research*.
50. Norman, C. D., & Skinner, H. A. (2006a). eHEALS: The eHealth literacy scale. *Journal of Medical Internet Research*, 8(4):1-7. doi: 10.2196/jmir.8.4.e27
51. Norman, C. (2011). eHealth literacy 2.0: Problems and opportunities with an evolving concept. *Journal of Medical Internet Research* 13(4):2-5. doi:.org/10.2196/jmir.2035
52. OECD/European Observatory on health systems and policies (2017), *Cyprus: Country Health Profile 2017, State of Health in the EU*, OECD Publishing, Paris/European Observatory on Health Systems and Policies, Brussels. [Accessed 19 May 2018: <http://dx.doi.org/10.1787/9789264283329-en>]
53. Panagiotakos, DB., Georgousopoulou, EN., Pitsavos, C., Chrysoshoou, C., Metaxa, V., Georgiopoulos, GA., Kalogeropoulou, K., Tousoulis, D., Stefanadis, C., & ATTICA Studygroup. (2015). Ten-year (2002-2012) cardiovascular disease incidence and all-cause mortality, in urban Greek population: the ATTICA Study. *International Journal of Cardiology*, 1(180): 178-84. doi: 10.1016/j.ijcard.2014.11.206

54. Papastavrou, E., Andreou, P., Middleton, N., Tsangari, H., & Papacostas, S. (2015). Dementia caregiver burden association with community participation aspect of social capital. *Journal of Advanced Nursing* 71(12): 2898-910. doi: 10.1111/jan.12762
55. Papastavrou, E., Charalambous, A., Tsangari, H., & Karayiannis, G. (2012). The burdensome and depressive experience of caring: what cancer, schizophrenia, and Alzheimer's disease caregivers have in common. *Cancer Nursing* 35(3):187-94. doi: 10.1097/NCC.0b013e31822cb4a0
56. Papastavrou, E., Kalokerinou, A., Papacostas, SS, Tsangari, H., & Sourtzi, P. (2007). Caring for a relative with dementia: family caregiver burden. *Journal of Advanced Nursing*, 58(5): 446-57. doi: 10.1111/j.1365-2648.2007.04250.x
57. Papastavrou, E., Tsangari, H., Karayiannis, G., Papacostas, S., Efstathiou, G., & Sourtzi, P. (2011). Caring and coping: the dementia caregivers. *Aging & Mental Health* 15(6):702-11. doi: 10.1080/13607863.2011.562178
58. Pavlou, P., & Demetriou, A. (2016). *Cyprus Cancer Registry: Progress Report (Data 2011-2013)*. Publications: Ministry of Health, Nicosia. [Accessed 19-05-2018: [https://www.moh.gov.cy/moh/moh.nsf/All/A0B4FEC0AC7BB073C22579C7002A9683/\\$file/Εκθεση%20Προόδου%20Αρχείου%20Καρκίνου.Αύγουστος%202016,%20\(Στοιχεία%202011-2013\).pdf](https://www.moh.gov.cy/moh/moh.nsf/All/A0B4FEC0AC7BB073C22579C7002A9683/$file/Εκθεση%20Προόδου%20Αρχείου%20Καρκίνου.Αύγουστος%202016,%20(Στοιχεία%202011-2013).pdf)]
59. Piirto, J., Johansson, A., & Strandell, H. (2015). *Key figures on Europe 2015 – 2015 Ed.* 1-180 p. Hellenic Statistical Authority. Press Release Households and Individuals. Luxembourg: Publications Office of the European Union. Doi: 10.2785/850110
60. Rathnayake, R., Moyle, W., Jones, C., & Calleja, P. (2018). mHealth applications as an educational and supportive resource for family carers of people with dementia: An integrative review, *Dementia*, (0)0:1–22 doi: 10.1177/1471301218768903
61. Resolution WHA58.33. *Sustainable health nancing, universal coverage and social health insurance*. In: Fifty-eighth World Health Assembly, Geneva, 16–25 May 2005. Resolutions and decisions annex. Geneva: World Health Organization; 2005 (WHA58/2005/REC/1. [Accessed 26 October 2016: http://apps.who.int/gb/ebwha/pdf_files/WHA58-REC1/english/A58_2005_REC1-en.pdf].
62. Riedel, M., & Kraus, M. (2011). *Informal care provision in Europe: Regulation and profile of providers*. Centre for European Policy Studies. [Accessed 19 May 2018: http://www.ancien-longtermcare.eu/sites/default/files/RR%20No%2096%20_ANCEIN_%20Regulation%20and%20Profile%20of%20Providers%20of%20Informal%20Care.pdf]
63. SCB (2017). IT bland individer 2017. Enheten för IKT, näringslivets konjunktur och FoU. [Accessed 30 April 2018: <http://www.scb.se/hitta-statistik/statistik-efter-amne/levnadsforhallanden/levnadsforhallanden/it-bland-individer/pong/statistiknyhet/it-bland-individer-2017/>
64. SFS (2001:453). *Social Services Act (Socialtjänstlag)*. Svensk författningssamling. Socialdepartementet: Regeringskansliet. [Accessed 06 May 2018: https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/socialtjanstlag-2001453_sfs-2001-453]
65. SFS (2017:30). *Health Care Act (Hälso- och sjukvårdslag)*. Svensk författningssamling. Socialdepartementet: Regeringskansliet. [Accessed 06 May2018: https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/halso--och-sjukvardslag_sfs-2017-30]

66. Socci, M., Santini, S., Lamura, G., & Principi, A. (2016). *Supporting measures and individual strategies to reconcile work and care in Italy. Paper presented at the Eurocarers Workshop on 'Working Carers'*, London 3-4 March 2016 [Accessed 8 June 2018: http://eurocarers.org/userfiles/files/Socci_Santini_Lamura_Principi_INRCA.pdf]
67. Spitzberg, BH. (2006). Preliminary development of a model and measure of computer-mediated
68. communication (CMC) competence. *Journal of the Computer-Mediated Communication*, 11(2), 629-666. doi: 10.1111/j.1083-6101.2006.00030.x
69. Stylianou, S., & Millionis, D. (2016). The Internet in Cyprus 2014-Final Research Report. Doi: 10.13140/RG.2.2.12809.54881
70. Szebehely, M., Ulmanen, P., & Sand, A-B. (2014). *Att ge omsorg mitt i livet: hur påverkar det arbete och försörjning?* Arbetsrapport/Institutionen för socialt arbete – Socialhögskolan. Stockholms universitet. [Accessed 06 May 2018: <https://www.socarb.su.se/polopolyfs/1.161219.1388762411!/menu/standard/file/Att%20ge%20omsorg%20mitt%20i%20livet.pdf>]
71. Triantafyllou, J., Mestheneos, E., Prouskas, C., Goltsi, V., Kontouka, S., & Loukissis, A. (2006). *"The national survey report for Greece. EUROFAMCARE – Services for supporting family carers of dependent older people in Europe: Characteristics, coverage and usage"*. [Accessed 19 May 2018: http://www.uke.uni-hamburg.de/extern/eurofamcare/documents/deliverables/nasure_el.pdf]
72. Vaccaro, M. (n.d). *Sintesi della condizione del caregiver nella realtà italiana da indagine Censis*. [Accessed 28 July 2017: http://www.agenas.it/images/agenas/oss/assistenza/care%20giver/contributi/3_Sintesi_della_condizione_del_caregiver_nella_realt_italiana_da_indagine_Censis.pdf]
73. Van Deursen, A., Helsper, E., & Eynon, R. (2014). *Measuring digital skills. From digital skills to tangible outcomes project report*. [Accessed 08 July 2018: <https://www.oii.ox.ac.uk/research/projects/measures-and-models-of-internet-use>]
74. Van Deursen, A., & Van Dijk, J. (2009a). Using the internet: skills for related problems in users'
75. online behavior. *Interacting with Computer*, 21:393-402. doi: 10.1016/j.intcom.2009.06.005
76. Van Deursen, A., & Van Dijk, J. (2009b). Improving digital skills for the use of online public information and services. *Government Information Quarterly* 26:333-340. doi: 10.1016/j.giq.2008.11.002
77. Van Deursen A., & van Dijk, J. (2010). Internet skills and the digital divide. *New Media & Society*, 13(6):893–911. doi: 10.1177/1461444810386774
78. Van Deursen, A., & Van Dijk, J. (2010). Measured Internet skills. *International Journal of Human – Computer Interaction* 26(10):891-916. doi: 10.1080/10447318.2010.496338
79. Van Deursen A., & Van Dijk, J. (2014). Internet skills, sources of support and benefiting from internet use. *International Journal of Human-Computer Interaction*, 30(4): 278-290. doi: 10.1080/10447318.2013.858458

80. Van Dijk, J. (2005). *The deepening divide. Inequality in the information society*. London: Sage Publication
81. WHO mHealth report (2011).mHealth: New horizons for health through mobile technologies. [Accessed 08 July 2018: http://www.who.int/goe/publications/goe_mhealth_web.pdf]
82. Winqvist, M. (2014). *Anhörigkonsulentens arbete och yrkesroll – Resultat från en enkätundersökning*. Kalmar: Nationellt kompetenscentrum anhöriga
- Winqvist, M. (2016). *Individualisering, utvärdering och utveckling av anhörigstöd*. Kalmar: Nationellt kompetenscentrum anhöriga
83. Von Sydow, I., & Bergqvist, M., Fristedt, J., Fröberg, M., Hägglund, S., Lind, L., & Åberg, A. (2015).
84. BoNUS VO - Brukar- och närståendeportal för uppföljning och stöd i vård och omsorg (2015). [Accessed 30 April 2018: <http://docplayer.se/5368233-Bonus-vo-brukar-och-narstaendeportal-for-uppfoljning-och-stod-i-var-d-och-omsorg-slutrapport-preliminar-version-mars-2015.html>]

Common Training Modules in English

annex **1**

Module 1 SEARCH, DOWNLOAD AND INSTALL AN APP

GENERAL GOAL(S):	<i>The general aim of the activity is to learn how to search, download and install an App.</i>
LEARNING OUTCOMES (general):	<p>By the end of the module, participants will be able to:</p> <ul style="list-style-type: none"> • <i>Identify the App store icon in the device</i> • <i>Know the main type of APPs (free or paid)</i> • <i>Explore available APPs by category</i> • <i>Use the search engine by key-words</i> • <i>Understand the additional information provided for each app</i> • <i>Install a free app</i> • <i>Buy a paid app</i> • <i>Find it on mobile device and launch it</i> • <i>Know the most common icons</i>
LEARNING OUTCOMES (ICT):	<p>By the end of the module, participants will have strengthen the following digital skills:</p> <ul style="list-style-type: none"> • <i>1.1 Browsing, searching and filtering data, information and digital content (Identify information needs, find data, information and content through a simple search in digital environments, find how to access these data, information and content and navigate between them)</i> • <i>2.1 Interacting through digital technologies (perform well-defined and routine interactions with digital technologies and identify appropriate simple communication means for a given context).</i>
DURATION:	2 hours
MATERIAL NEEDED:	<i>Multimedia, PPT presentations, papers, markers, pens, hand-outs. Each participants can use his/her own device.</i>
ORDER OF ACTIVITIES:	<p>Step 1 – Ice breaker: 10 Min</p> <p><i>“If I were an APP...” – Each participant should write on a sheet of paper the answer to the question “ If you were going to be an APP, what APP would you be?” – in turn, each participant will provide his/her answer and explain it.</i></p> <p>Step 2 – Introduction to the topic : 20 Min</p> <ul style="list-style-type: none"> • <i>Trainer introduces the purpose of the module and asks participants about their knowledge on Apps (Which Apps do you know? Have you ever used an App? If yes, what kind of App? Have you ever tried to download and install an App? Have you found it difficult? If yes, which difficulties have you found?)</i> • <i>Trainer introduces the topic with a short PPT presentation (What is an App, Google Play/ Apple Store, Apps’ categories – with a special mention to Apps that can be useful in their caring activities – Differences between free and paid Apps). (<u>Annex 1</u>)</i>

Step 3 – Search for an App: 25 Min

- *Trainer, using a tablet connected to a monitor, shows participants how to search for an App by Category, dwelling on the different steps. He/she asks participants to do the same under supervision.*
- *Trainer, using a tablet connected to a monitor, shows participants how to search for a specific App, dwelling on the different steps. He/she asks participants to do the same under supervision.*
- *Trainer shows participants how to get information on a App.*
- *Trainer put different cards on the table and asks each participant to take one and do what is written on it individually. Cards contain different exercises to familiarize with the task (e.g “Search the App Retricta and write down its rating” or “Search for at list three photography Apps and write down their names”) ([Annex 2](#))*
- *Trainer asks participants to share doubts and difficulties with the group.*

Step 4 – Download and install Apps: 30 Min

- *Trainer, using a tablet connected to a monitor, shows participants how to download and install a Free App, dwelling on the different steps. He/she asks participants to do the same under supervision.*
- *Trainer invites participants to pick up a sheet of paper, which contains the name of an App, from a bag. Each participant has to search for, download and install the corresponding App individually.. ([Annex 3](#))*
- *Trainer asks participants to share doubts and difficulties with the group.*

Step 5 – List of common icons: 25 Min

- *Trainer shows participants a short PPT presentation which contains the most common icons (images and definitions). ([Annex 4](#)) Then he/she asks them what icons do they know and usually use.*
- *To memorize and familiarize with the icons trainer puts on the table different cards that represent some of the common icons presented and involves participants in a game. He/She reads the icon definition and participants have to take, as fast as possible, the corresponding image (e.g.”Take the airplane mode icon”). The participant that collects the largest number of cards wins the game.([Annex 5](#))*


Step 6 – Q&A session: 5 Min

- *Trainer invites participants to ask further questions and share doubts with the group.*

Step 7 –Closing activity: 5 Min

- *Trainer gives participants a questionnaire to collect feedbacks on the module*
- *Trainer shows and gives participants a step by step guide which contains all the instructions presented and invites them to practice. ([Annex 6](#)). He/she also explains them how to enter the respective video tutorial that will be available on the website...*

EVALUATION OF THE MODULE:	The module will be evaluated by observation. During the exercises trainer observes if participants have acquired the necessary skills to complete the tasks autonomously. After the end of the session trainer will note down his/her observations.
BACKGROUND CONTENTS AND HANDOUTS	<u>Annex 1:PPT Presentation -App</u> <u>Annex 2:Cards –Search for an App</u> <u>Annex 3:Apps Names</u> <u>Annex 4: PPT Presentation - Icons</u> <u>Annex 5:Cards – Icons</u> <u>Annex 6:Step by Step Guide</u>

 Module 2 THE APPS4CARES APP	
GENERAL GOAL(S):	<i>The Apps4Carers app consists in a repository of selected apps and websites from 5 countries. The general aim of the activity is to learn how to use the app to its full potential.</i>
LEARNING OUTCOMES (general):	<p>By the end of the module, participants will:</p> <ul style="list-style-type: none"> • <i>Understand the general structure and main functionalities of the app</i> • <i>Have an overview of the available resources</i> • <i>Understand the organization of the apps' listing: categories, filters, tags</i> • <i>Be able to search according to category, filter and tag</i> • <i>Make use of the rating systems</i> • <i>Understand how to download the referenced apps and access the websites</i>
LEARNING OUTCOMES (ICT):	<p>By the end of the module, participants will have strengthened the following digital skills:</p> <ul style="list-style-type: none"> • <i>1.1 Browsing, searching and filtering data, information and digital content (Identify information needs, find data, information and content through a simple search in digital environments, find how to access these data, information and content and navigate between them);</i> • <i>1.2 Evaluating data, information and digital content;</i> • <i>2.1 Interacting through digital technologies (perform well-defined and routine interactions with digital technologies).</i>
DURATION:	1h30 min
MATERIAL NEEDED:	<i>The material needed to deliver the activities are PPT presentation, step by step guide, paper, markers, pens, hand-outs, tablets, computers. Each participant can use his/her own device.</i>

ORDER OF ACTIVITIES:

Step 1 – Ice breaker: 10 Min

The participants are asked to openly comment on their digital skills, what they can and/or can't do, if they're interested in technology and the use of apps and what kind of apps they use or would like to use. They are also prompted to debate whether the use of apps could (or not) make a difference in their daily routine or in emergency cases. They are asked if any of them has ever used Apps for the specific purpose of manage medication or to contact doctors, etc.

Step 2 – Introduction to the topic: 15 Min

- *Trainer introduces the purpose of the module and asks participants about what they think about the idea of having an app repository for informal carers.*

Trainer introduces the Apps4Carers app and its purpose with a short PPT presentation (context, why was it relevant to create this app, what is the main goal, show the app,...). Note: part of the annexed presentation describes the Apps4Carers project. This might have been addressed in Module 1 therefore it is up to the trainer to decide which content will be shown here.


Step 3 – Explanation of how to use the Apps4Carers app: 25 min

- *Trainer hands out the step by step guide on how to use the app and shows the explanatory video.*
- *Trainer, using a tablet connected to a monitor, explains how to navigate the app:*
 - *How to select "Region/Language";*
 - *How to search for a specific App or website, dwelling on the different steps (chose category, filters and tags; use the rating system; search function...);*
 - *How to watch the video tutorial;*
 - *How to gain access to A4C information;*
 - *How to access the referenced websites or how to download the referenced apps*
- *The trainer then asks participants to do the same under supervision.*
- *The trainer asks participants to share doubts and difficulties with the group and answers the questions raised by them.*

Step 4 – Exercises to familiarize with the task: 30 min

- *Participants are asked to use the tablets (with help from the trainer) and manouver in the designated app in order to gain knowledge about it and what it offers.*
- *Participants are asked to use the Apps4Carers app to select a specific app, to download it and test it. Then participants are invited to rate it on the Apps4Carers app.*

	Step 5 – Q&A session as closing activity: 10 min <ul style="list-style-type: none"> Participants share doubts and difficulties with the group. The trainer specifically answers those questions.
EVALUATION OF THE MODULE:	The module will be evaluated by observation. During the exercises trainer observes if participants have acquired the necessary skills to complete the tasks autonomously. After the end of the session trainer will note down his/her observations.
BACKGROUND CONTENTS AND HANDOUTS	Annex 1: PPT presentation Annex 2: Step by Step Guide Annex 3: Video tutorial on the Apps4Carers use

 Module 4 FOLLOW UP SESSION	
GENERAL GOAL(S):	The general aim of the activity is to answer to emerging questions/doubts, collect feedbacks about the Apps, encourage participants to review them and provide useful information and referrals on activities that meet carer's needs.
LEARNING OUTCOMES (general):	By the end of the module, participants will have satisfied any doubt about the use of APPs4Carers App and the apps collected in it; they have gain confidence in the use of apps and the devices and they have acquired information and referrals on activities, events or groups, organized locally, that can be useful in their caring activity.
LEARNING OUTCOMES (ICT):	----
DURATION:	1 hour
MATERIAL NEEDED:	Multimedia, papers, post-it, white board, markers, pens.
ORDER OF ACTIVITIES:	Step 1 – Ice breaker: 5 min <p>Trainer presents to participants a word chain game that deals with the terms used during the training (e.g Apps, devices, icon...). He/she asks them to sit in a circle and, in turn, list words in a category. They must remember the words said previously and think of unique word to add that belongs to the category chosen. Example: First word in the chain: App. The second person will have to repeat the chain, and add a unique word that fits the category. Example: App, Icon.. Each person will have 10 seconds after correctly reciting the chain to add another new word. When someone makes a mistake sit out and the game continues until you find the champion of Word Chains.</p>

Step 2 – Answering to emerging questions / doubts: 10 min

- *Trainer asks participants if they have any questions about the use of APPs4Carers App, the use of the different apps, the procedures to download/install apps, to find data and information..*
- *Trainer invites participants to share doubts and difficulties with the rest of the group.*

Step 3 – Collect Feedbacks about APPs4Carers App: 10 min

- *Trainer asks participants some questions about APPs4Carers App:*
 - *Their overall opinion about the App*
 - *Any difficulties encountered in its use (e.g searching for an App, using filters, understanding labels, rating Apps, downloading and installing...)*
 - *Positive aspects (e.g the App has been useful for..)*
- *Trainer gives each participant a sheet of paper with 5 stars (resuming the way to rate Apps on Apple Store and Google Play Store) and asks them to rate APPs4Carers App colouring a different number of stars on the basis of their overall satisfaction (from 1- “I don’t like” to 5- “I like very much”). (Annex 1)*
- *Trainer has to encourage the exchange of views between the participants.*

Step 4 – Collect Feedbacks about the Apps: 20 min

- *Trainer gives each participant some post-it and asks them to write down the names of some Apps they have used and that are collected in APPs4Carers App (5 Apps at most, one on each post-it) . Then he/she draws a traffic light on a board: the Red light means “This App isn’t useful for me”, the Orange one means “This App could be useful for me but..” and the Green one means “This App is very useful for me”. Each participant has to attach their post-it in the right place and explain their choices to the rest of the group. If a participant has used one of the App rated by another participant has to share his/her opinion about it with the rest of the group.*
- *Trainer encourages participants to rate and review the Apps used on APPs4Carers App.*
- *Trainer asks each participant to fill in a questionnaire whose aim is to collect information on the Apps downloaded: how many Apps does the participant download, what kind of Apps (the scope they respond to), if he/she found the Apps downloaded relevant to the scope and useful for his/her caring activities; how do he/she rate them... (Annex2)*

Step 5 - Networking : 10 min

Trainer provides useful information and referrals on activities, events or groups, organized locally, that meet carer’s needs (e.g self help groups, workshops...).

N.B Each partner has to develop their own material on the basis of the events/ activities organized in their territories.

	<p>Step 6 - Closing activity and Achievements Celebration: 5 min</p> <ul style="list-style-type: none"> • <i>Trainer asks participants to give feedbacks on the module and the entire training.</i> • <i>Trainer asks them to think about, and then share with the rest of the group, the results achieved (competences developed, improvement of digital skills, the impact of using APPs4Carers App in caring activities)</i> • <i>To finish the training with laughter trainer shows participants a short video that shows the funny side of tablet use. https://www.youtube.com/watch?v=nnYvaRatVJg</i>
<p>BACKGROUND CONTENTS AND HANDOUTS</p>	<p><u>Annex 1: Rating APPs4Carers App</u></p> <p><u>Annex 2: Apps Questionnaire</u></p>

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