Structural aspects of access to formal dementia care services across the European countries

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Abstract

Background
Access to formal care varies across European countries and the linkage between formal and informal dementia care is complex. The health and social care system and its organisation may have an impact on the use of services and supportive structures (Carpentier & Grenier, 2012; Luong, 2000). The social context including environmental, cultural and societal factors might also influence the access to and use of formal care structures (Pratt, R., Clare, L., Kirchner, V., 2006).

Aim
The aim was to improve the understanding of the use of formal dementia care services and to provide a better insight into (1) socio-economic and cultural characteristics of persons with dementia and their carers that influence the utilisation of dementia services and into (2) the health care structures and system-related factors.

Methods
The Andersen Behavioral Model of Health Services (Andersen, 1995) served as a framework, and the following methods were applied in order to answer the research question:

1) A systematic literature review was conducted to identify socioeconomic and cultural aspects (predisposing factors) with influence on access to or utilisation of formal dementia care services in the participating counties. Additionally, a brief overview containing some key characteristics of the health and social care systems of each country was given.

2) The formal infrastructures on access to formal dementia care were assessed in a structured and comparable way by applying a mapping system (templates).

3) Based on the information collected by the templates, each country provided a common practice example of access to formal dementia home and community care.

Results & Discussion
The report provides a brief overview on the health and social care systems of the countries participating in the ActifCare project. The findings of the literature review on (predisposing) factors influencing service were summarised in a narrative way. The literature analysis
yielded only a few and partially inconsistent data regarding factors that might influence services used in dementia long-term care. The influence of age, gender and financial aspects were investigated more often than the influence of ethnicity, education, region of residence and family relationships. None of the socioeconomic or cultural aspects were well investigated throughout the ActifCare countries. However, research findings suggest that ethnicity may influence the use of services and that people with a migrant background use long-term care services less frequently. Moreover, private out-of-pocket payments and the gender of the informal carer may contribute further to low service utilisation since female carers tend to use fewer services than male carers do.

The mapping system gives an overview of the structures and services for people with dementia and their carers in each country and seeks to compare the countries. A range of 29 different services for people with dementia and their carers were revealed and compared across the countries. In most cases reliable information on utilisation was lacking. Overall, there were slightly more dementia-specific structures reported in Norway and Sweden, where in particular a designated contact person for people with dementia and their informal carers is offered (planned in Ireland, according to the recently launched National Dementia Strategy). Team-based structures were more often available in Norway and Sweden, but also in the Netherlands, Italy, Ireland, UK and Portugal. No team-based services were found in Germany. Out-of-pocket payments are required in all ActifCare countries, with immense differences. For example, people with dementia in Ireland have to pay privately for home care, if the Home Care Packages covered by the health insurance are not sufficient. Additional payments are also common in Germany. In contrast, in Norway home care is free from additional payments, but domestic home help has to be paid privately. In Italy it is very common that migrant informal carers work irregularly at the expense of the people concerned.

The case vignettes provided a typical description of how people with dementia and their families find access to professional support in each country. Overall, in Norway and UK (and, according to case managers, probably in Sweden), service use seems to be initiated more proactively by healthcare professionals (e.g. follow-up visits in Norway include not only medical but also social care aspects). In the remaining countries the families more often have to use their own initiative to apply for or request services needed. The choice of providers is also often up to the families in Germany, Ireland and the Netherlands, which might be seen as an additional freedom (due to market principles) but could also be perceived as an extra burden.
**Introduction**

Access to and utilisation of formal care for people with dementia (PwD) and their informal carers correlates with multifaceted influences including aspects on individual, societal and institutional levels (Robinson et al., 2005). The Andersen Behavioral Model of Health Services (Andersen, 1995) provides a framework to assess the potential equality of access to and utilisation of services, by identifying associations between service use and a broad spectrum of predisposing and enabling variables, while controlling for the need. The first version of the Behavioral Model from the 60s focused on predisposing, enabling and need factors as population characteristics. In 1995 Andersen presented an update of the model which takes into account that health service use is a dynamic and circular process that requires considering - beyond population characteristics - aspects of healthcare systems, health behaviour, and outcomes (Figure 1). One aim of WP2 is to describe such aspects of the healthcare systems and population characteristics which are important for investigating access to and utilisation of formal care in dementia. The results could provide background information and contribute to investigations of health behaviour and outcomes in Work Package (WP) 2-4, and support the development of recommendations and best-practice strategies in WP5.

![Andersen Model on Health Service Utilisation (1995)](image_url)

Figure 1. Andersen Model on Health Service Utilisation (1995)
Background

The Andersen Behavioral Model (Figure 2) demonstrates that healthcare systems remain to be considered to understand the access and utilisation of healthcare services. Andersen and Newman (2005) distinguished the characteristics of resources and organization of the healthcare systems and suggested looking at resource aspects, volume and distribution on the one hand, and on organizational aspects, access and structures on the other hand.

Figure 2. The Health Service Systems (Andersen and Newman, 2005)

A complicating factor is the diversity of national health and social care systems (Robertson, 2011). In some countries, primary or local health organisations include social care while in others they deliver medical and nursing care but exclude social care. We decided on an integrated model to give a short overview of the national health and social care systems.

The main dimensions of healthcare systems are financing, health service provision and regulation. However, it might be necessary to consider how access to health services is regulated. Wendt (2009) considered this in his mapping system and distinguished three types of access regulation: the health service provision-oriented type, the universal coverage-controlled access type, and the low budget-restricted access type. The health service provision-oriented type is characterized by its high level and importance of service provision. This type of access regulation shows various indicators of comparatively smooth access for patients to service providers. The health service provision-oriented type is most often in place in 5 out of 15 European countries, which were included in Wendt’s mapping procedure.

Among these countries is the ActifCare partner Germany. The universal coverage-controlled access type is characterized by the strictly regulated patient's access to healthcare providers by the state. Equity of access is supported since the total population is covered and private out-of-pocket payments are particularly low. Wendt classifies the ActifCare partners United Kingdom, Sweden, Italy and Ireland in this type of access regulation; however, he argues that it is difficult to classify the Irish system. The low budget-restricted access type is characterized by the patient's restricted access to healthcare providers, by high out-of-pocket payments and by the regulation that patients do not have a free choice of doctors in the NHS
(‘gatekeeping system’). Wendt classifies the Portuguese health system in this type of access regulation. However, the Portuguese health system is a complex one. There is universal access to the NHS, which is mainly financed through taxation, but co-payments have been increasing and up to a quarter of the population is additionally covered by health subsystems and/or voluntary health insurance (Barros et al., 2011). Unfortunately, only Norway (as one ActifCare partner) was not included in Wendt’s analyses. The Netherlands was included, but Wendt argues that this healthcare system does not match the typologies. The Dutch healthcare system seems to be unique due to the high share of private funding, a low level of outpatient healthcare and comparatively strict access regulation. Wendt concluded that further investigations should be conducted to analyse more detailed regulations of access to health services.

Joumard et al. (2010) developed a mapping system which shows groups of countries with similar institutions (groups 1-6 in Figure 3). The Netherlands and Germany belong to the group of countries (1) which rely largely on market mechanisms for regulating the basic insurance coverage. Private providers are important and are mainly financed through fee-for-service schemes. Users can choose between providers but there are gate-keeping provisions. Sweden is part of a group (4) which is characterised by free choice of providers, which has resulted in a great increase in the number of private providers. The budget constraint in Sweden is strict. However, this gate-keeping classification for Sweden is doubtful: In the social care sector (nursing homes, home services, day care) we have the local municipal home help officers who make a decision after applications for support, whereas in the healthcare sector, primary care physicians may be regarded as partial gate-keepers for special care. Thus, Sweden would be better placed in group 6. The Portuguese healthcare system runs mainly under a heavily regulated public scheme and with a strict budget constraint. Users’ choice among providers is very limited with a large number of gate-keepers. Ireland, Italy, Norway and the United Kingdom belong to a group of healthcare systems with more stringent budget constraints than most other OECD countries. The possibility for users to choose between providers tends to be large but the basic coverage is very limited. Ireland is an exception, where duplicative coverage (public and private) is important.
Figure 3. Characterising healthcare systems: country groups (Joumard et al., 2010)

Population characteristics are an often-used subject, which Andersen and Newman (2005) distinguish as predisposing, enabling, and needs respectively illness factors (Figure 4). Predisposing factors imply that some individuals have the propensity to use services more often than others do and this might be predicted by individual characteristics. Enabling factors influence the availability of a health service for an individual. Needs factors are assessed as the most immediate reason for health service use (Andersen & Newman, 2005). Figure 4 shows a set of these factors. Babitsch et al. (2012) found numerous predisposing, enabling and need factors in a review of studies based on the Andersen behavioral model; however, some of the factors had been investigated more often than others. Further research needs to be made to determine which factors have a significant influence on the access to and the utilisation of formal dementia care.
Living with dementia is a great challenge for the person with dementia and for his/her family. Formal care services to support the caregiving situation at home are underused. Several studies have investigated the predictors of utilisation of community care services by PwD and their informal carers (Biegel et al., 1993; Toseland et al., 2002; Robinson et al., 2005), and also the reasons for utilisation and non-utilisation, respectively (Brodaty et al., 2005; Beeber et al., 2008; Bindel, 2012). The Andersen Behavioral Model of Use of Health Service has been applied frequently to explain utilisation of service use by PwD (Biegel et al., 1993; Toseland et al., 2002; Robinson et al., 2005; Beeber et al., 2008). Andersen and others have adapted the Behavioral Model to consider the complexity of service use. For example, Beeber et al. (2008) used a modified Behavioral Model, which includes predisposing, enabling and need characteristics not only for PwD, but also for the informal carers.

The identification of the influence of socioeconomic and cultural factors is part of the above studies; however, a fixed set of factors has not been investigated. Based on a review of studies where the Andersen Behavioral Model (not dementia-specific) had been applied, Babitsch et al. (2012) deduced that there were key variables which had been investigated the most. These key variables are age, gender, marital status/ family relationship, education, ethnicity, region
of residence, employment, and income. Furthermore, the Andersen model considers the
beliefs of individuals as influencing aspects, which include values concerning illness,
attitudes towards health services, and knowledge about the disease. Some studies suggest the
importance of belief factors in the utilisation of formal care by people with dementia (Brodaty
et al. 2005; Wolfs et al., 2010). The studies by Biegel et al. (1993), Pedlar and Biegel (1999),
Toseland et al. (2002), Brodaty et al. (2005), and Roeland et al. (2008) report the attitudes of
PwD towards care as being an important influencing factor.

There are few data available about the influence of socioeconomic and cultural factors on the
access to and utilisation of support services, albeit numerous studies deal with the utilisation
of support services by PwD and their informal carers. There are differences in predictors for
utilisation of healthcare services and social/psychosocial services, respectively (Kosloski et
al., 1999; Toseland et al., 2002; Bindel, 2012).

Most research regarding utilisation of support services by PwD and informal carers has been
conducted in non-European countries. However, large European studies, such as the Facing
Dementia study (Bond et al., 2005), the Eurocode study (Wimo et al., 2009) and the
EUROFAMECARE study (Trianafillou et al., 2006) show that care for older people,
especially PwD, is also an important theme in European society. The international literature
gives a small insight into the influence of socioeconomic and cultural factors on service
utilisation.

Age may have a modest influence on services used by PwD and informal carers. It seems that
older people tend to use more services (Robinson et al., 2005; Beeber et al., 2008.

Gender seems to have influence on services used and wives tend to care for their relatives
with dementia without professional help (Pedlar and Biegel, 1999; Toseland et al., 2002;
Robinson et al., 2005). This fact is also confirmed for PwD and informal carers with a
migrant background (Kosloski et al., 1999).

Few and inconsistent data were found regarding the influence of educational levels. Robinson
et al. (2002) found that the educational level of informal carers had no influence on the
services used; however, Toseland et al. (2002) identified that higher educational levels of
informal carers were associated with increased service use.

Kosloski et al. (1999) investigated differences in the perceived need of support services by
informal carers of PwD with a migrant background. Differences were found in the utilisation
of discretionary services but not in the utilisation of non-discretionary services. Non-
discretionary services are perceived as necessary by users, whereas discretionary services are judged as less urgent. Use of discretionary services depended on the estimation of the family (e.g. in-home respite, adult day care), whereas the utilisation of non-discretionary services was recommended by a professional (e.g. GP, health specialist). Toseland et al. (2002) found that the use of human services (e.g. support groups, individual counselling) was associated with a migrant background.

Trianafillou et al. (2006) found in a multinational study across Europe that apparently every country had difficulties with the distribution of support services, especially in rural areas. This study seems to be important, because half of all participants in this study (around 1,000 per each country; including DE, GR, IT, PO, SE, and the UK) had memory problems or a diagnosis of dementia. Trianafillou et al. (2006) also investigated how employment and financial aspects influence the caregiving situation. Fifteen percent of the informal carers reduced their working hours as a result of caring for elder relative, and most had experienced a decline in their income. High costs of utilisation of support services were seen as a barrier; however, this varies significantly between European countries.

Bond et al. (2005) identified attitudes towards dementia in a study across five European countries (FR, DE, IT, SP, UK). The authors found key areas that illuminated barriers to the care for PwD: first, dementia provokes a great deal of anxiety; second, the disease results in the sufferer’s isolation from his or her world; and third, there is a lack of awareness and knowledge of symptoms. Roelands et al. (2008) explored attitudes towards the care of PwD. Informal carers described both positive and negative consequences of support from professional helpers. The decrease of burden, specific knowledge or skills, and an increase of spare time were seen as positive consequences. Reduced control over the caregiving situation, lack of privacy, and financial burden were described as negative consequences. Trianafillou et al. (2006) identified a lack of information on available support services (except in SE), and the refusal of older people to accept existing services (particularly in DE, SE, and the UK) as barriers to formal dementia care.
Aim

The aim of Work Package 2/objective 1 was to describe the access to formal dementia care services in eight European countries (Germany [DE], Ireland [IE], Italy [IT], the Netherlands [NL], Norway [NO], Portugal [PT], Sweden [SE], United Kingdom [UK]). Therefore, a procedure was developed assessing conditions of formal dementia home care, community and long-term medical, nursing, and social care structures available to PwD and their informal carers in the period of the disease in which transition from informal care to formal care might take place, as well as assessing socio-economic and cultural prerequisites. In our study, formal care includes home nursing care, day care services and community or long-term medical, nursing, and social care structures and processes, and excludes domestic home help, housekeepers, volunteers, support groups, transport services, and meal programmes.

The following steps were taken to answer the research question:

4) A systematic literature review was conducted in order to identify socioeconomic and cultural aspects with influence on access to or utilisation of formal dementia care services in the participating counties.

   Additionally, a brief overview containing some key characteristics of the health and social care systems of each country was given.

5) The formal infrastructures on access to formal dementia care were assessed in a structured and comparable way by applying a mapping system (templates).

6) Based on the information collected by the templates, each country provided a common practice example of access to formal dementia home and community care.
Methods and procedures

1) Systematic literature review

The Andersen Behavioral Model of Health Service Use was used as the theoretical background for the selection procedure of socioeconomic and cultural factors, and for the description of the health and social care systems. A protocol was developed by the WP2 team and approved by the ActifCare partners.

- Characteristics of the health and social care systems

Characteristics of the healthcare systems were based on the Andersen Behavioral Model of Health Services (Figure 2). We investigated reports of official organisations, such as the OECD\(^1\), the WHO or the European Commission, conducting a web search with the search terms health care systems, Europ*, cross-European, cross-national, home care and dementia. Reference lists in the investigated documents were searched for further information.

- Socioeconomic and cultural aspects with influence on access to/utilisation of formal dementia care

Literature search and study selection

The following databases were searched (September 2014): PubMed, CINAHL, Social Science Citation Index, and PsychInfo. These search terms were combined for the search in PubMed: (dement* OR Alzheimer* OR dementia[MeSH]) AND ("professional care" OR "care" OR "care giving" OR "home care" OR "community care" OR "formal care" OR "long-term care" OR "informal care" OR "long-term support" OR "formal support" OR "Home care services"[MeSH] OR "health services for the aged"[MeSH] OR "long-term care"[MeSH] OR "community health services"[MeSH] OR "community mental health services"[MeSH]) AND (utilisation OR utilisation OR access* OR "service use" OR "service non-use" OR "Health Care Quality, Access, and Evaluation/utilisation"[Mesh] OR "Health Services Accessibility/utilisation"[Mesh] OR "health services for the aged/utilisation"[MeSH] OR "Long-Term Care/utilisation"[Mesh] OR "Community Health Services/utilisation"[MeSH] OR "Community Mental Health Services/utilisation"[MeSH]). The same search terms were used for searching in the other databases, without the MeSH terms.

\(^1\) The OECD provided data of the national healthcare systems within their reports ‘Health at a Glance’. We used the report from 2013, because the report of 2014 did not include data of long-term care. The OECD data on receivers of long-term care included people who live at home and in institutions (OECD, 2013, p.180).
The titles and the abstracts of findings retrieved by the PubMed search were screened by two researchers and checked for inclusion. For included studies, backward and forward citations were checked for additional references.

**Inclusion and exclusion criteria**

**Inclusion criteria:**
- Access to/utilisation of formal dementia care was explored taking into consideration one or several of the following factors: age, gender, family relationship, employment status, region of residence, attitudes towards dementia, attitudes towards care of people with dementia, ethnicity, education, and financial aspects.

**Population**
- People with a diagnosis of dementia at any stage
- Informal carers of people with dementia

**Setting**
- Community settings
- Countries included in the ActifCare project: DE, IE, IT, NL, NO, PT, SE, UK

**Language**
- Studies were considered if they were written in English.
- Studies in one of the languages of the Actifcare partners were considered if abstracts were available in English. Actifcare partners checked these studies.

**Type of the study**
- Quantitative, qualitative, mixed-method studies and cross-national reviews were considered. If we used reviews, country-specific data were extracted from the review. If country-specific data extraction was not possible, we retrieved the original source.

**Exclusion criteria:**
- Studies from countries which do not participate in the ActifCare project
- Studies focusing on other aspects than the above mentioned socioeconomic and cultural factors, such as medical aspects (e.g. drug treatment)
- Studies focusing on settings other than community settings
- Studies including participants with a diagnosis of alcohol-related dementia or of Huntington's disease or mental health conditions other than dementia
**Data extraction and analysis**

The data were extracted using a self-developed data extraction sheet. The sheet comprised items which addressed the following information: aim of the study, definition of formal community care used, sample, methods (data collection, data analysis, measurements, time of data collection), and the socioeconomic and cultural factors age, gender, family relationship, employment status, region of residence, attitudes towards dementia, attitudes towards care of people with dementia, ethnicity, education, and financial aspects.

The results of the studies were checked by one researcher with regard to data related to the chosen socioeconomic and cultural aspects. Unclear data were discussed several times in the research team until agreement had been reached.

We excluded studies investigating the perspectives of healthcare professionals towards caring for people with dementia. In addition, studies were excluded which investigated utilisation of community care for PwD but did consider the above-mentioned socioeconomic or cultural aspects.

**National literature searches**

The ActifCare partners complemented the search by searching in national databases and for national reports, such as

- Documents by the government or ministries of health
- Documents published by national quality institutions, like NICE in the UK or IQWiG in DE (https://iqwig.de/en/home.2724.html)
- Documents by national institutions with importance for the care of people with dementia, e.g. Alzheimer Societies

The above-mentioned search strategy was applied, supplemented by search terms in the national languages, and the same inclusion and exclusion criteria were applied.
2) **Formal infrastructures that provide access to formal dementia home and community care**

The aim was to assess the formal *infrastructures* that provide access to formal dementia home and community care in a structured and comparable way. To provide an overview, it was aimed to include information which best describes the situation of the whole country. Based on previous work within the RightTimePlaceCare (RTPC) project (Hallberg et al. 2013), a mapping system (*template*) was developed for data collection. In total, 29 services/structures were judged by the ActifCare partners to be relevant with regard to access to formal dementia home care and community support, and were therefore included in the template. The areas *diagnostic and therapeutic settings* (5 services), *home care and support for people with dementia* (15 services), *information and counselling* (4 services), *support for informal informal carers* (3 services) and *civil activities* (2 services) were covered. The following aspects were assessed per structure/service

a) availability,

b) accessibility (legal/organizational aspects),

c) utilisation by PwD and/or informal informal carers,

d) health or social care professionals predominantly involved

If possible, data collected in the RTPC project were used as a primary source of information by the ActifCare partners from DE, NL, UK, and SE (countries participating in the RTPC project). If necessary, the information was updated and/or extended. Depending on the question, the most reliable information source was used, i.e. text of a law, national dementia strategies, national policy papers, Health Technology Assessment reports, (national) clinical practice guidelines, official statistics, routine data (e.g. of sickness funds/insurances), (systematic) reviews or published research findings. Expert opinion was not considered as a valid information source and was excluded from data collection. Experts were only contacted in order to identify further relevant and reliable information sources. If no information was available, this was stated explicitly (especially regarding utilisation).

Consecutively, the WP2 working group summarised the information collected within the templates, and compared the features of the 29 structures/services across the countries.
3) **Common practice examples**

Furthermore, members of the ActifCare project delineated a realistic common practice pathway of access to formal dementia home care based on a predetermined case vignette and on the information collected within the templates. Consecutively, the common practice examples were analysed and common themes were identified by the WP2 team.

**Case vignette:**

Mrs Smith lives alone with her cat in her own house, located in a middle-sized town (*from the perspective of the respective country*). Her husband passed away a couple of years ago. She has two daughters. One daughter lives with her family in the neighbourhood. The other daughter moved to the capital due to job obligations, and can only visit her mother irregularly. Every now and then, a car drive to the next bigger city is feasible for the family. Two years ago, Mrs Smith was diagnosed with dementia. During the last months, the dementia has worsened markedly. She sometimes needs supervision, and someone has to remind her to eat and drink. Some weeks ago, she also couldn’t find the way back home. The daughter living in the neighbourhood is taking care for her mother, and a volunteer supports her with shopping and some leisure activities. However, the caring daughter is employed and has teenage children. Hence, she is not sure whether she can manage the increased need of care.
1) Results – Systematic literature review

The search in PubMed revealed 2,122 hits, 310 hits in CINAHL, n=1,062 in Social Science Citation Index, and n=161 in PsychInfo. A total of 3,531 findings were excluded, based on title and abstract. The remaining 120 publications were assessed in full text, of which 37 publications were finally included (Figure 4).

![Figure 4: Flow-chart displaying the study inclusion.](image)

Moreover, three multinational studies were included (Table 1). The EUROFAMECARE study investigated a population of older people with and without dementia and their informal carers. Approximately half of the participants were people with memory problems or dementia diagnosis. Multinational orientation, emphasis on aspects of services used, informal care for at least four hours per day, and a high proportion of PwD were reasons for the inclusion of this study. Four publications from the EUROFAMECARE study have been included. These publications are a summary of findings by Triantafillou, J. & Mesthenos, E. (2006), and the national reports for Italy (Quattrini et al., 2006), Sweden (Krevers et al., 2006), and Germany (Lüdecke et al., 2012), which explored the impact of socioeconomic factors on the utilisation of support services. Bond et al. (2005) conducted a study with 2,500 participants from six European Countries (FR, DE, IT, PT, ES and UK). Participants of this study were PwD,
informal carers, members of the general population, healthcare professionals and policy makers. The aim of the study was to explore attitudes towards inequalities in dementia care across Europe. The Eurocode project (Wimo et al., 2009) aimed to describe the economic impact of dementia in Europe in 2008. The authors distinguished between the Northern countries (including Ireland, Norway, Sweden, and the United Kingdom), the Southern countries (including Italy, and Portugal), and the Western countries (including Germany, and the Netherlands).

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Table 1: Multinational studies including ActifCare partner countries.
Germany

Characteristics of the health and social care system in Germany

1 Population
(OECD, 2013)

The absolute number of inhabitants was 83,071,404 in 2010.
In 2010 21% of the population was 65 years old and older. This will increase to 33% by 2050 (OECD Ø 2010 15%, 2050 27%).
In 2010 5% of the population were 80 years old and older, by 2050 this will increase to 15% (OECD Ø 2010 4%, 2050 10%).

11.7% of the population aged 65 years and older received long-term care in 2011 (OECD Ø 12.7%).

2 Financing
(OECD, 2013)

11.3% of GDP\(^2\) were health expenditures (OECD Ø 9.3%).
1.0% of GDP were public expenditures for long-term care with health and social components (OECD Ø 1.6%).

The health system is funded predominantly by social insurance with few out-of-pocket payments (Joumard et al, 2010).
The government finances 7% of health expenditures, 70% are financed by social security, 12% are private out-of-pocket payments and 10% are paid by private insurance.

3 Policies
(Joumard et al, 2010)

The German healthcare system is characterized by having a high publicly funded share and a lower out-of-pocket share. Wendt (2009) described the German healthcare system as having a high level of total health expenditures. This high level of expenditures is translated into a moderate level of inpatient and a high level of outpatient healthcare. However, expenditures for long-term care are on a relatively low level. The healthcare system provides comparatively smooth access for patients to service providers. Germany does not have a national dementia plan (Alzheimer Europe, 2012), but an initiative for developing a national dementia plan was started in 2012.

\(^2\) GDP: Gross Domestic Product = final consumption + gross capital formation + net exports. Final consumption of households includes goods and services used by households or the community to satisfy their individual needs. It includes final consumption expenditure of households, general government and non-profit institutions serving households (OECD,2013)
4 Home care

(Genet et al., 2013)

Among the total of 1,537,508 persons entitled to long-term care insurance benefits in 2007, 504,232 used professional home care. Germany has mandatory guidelines for the assessment of need for care. Home care is a universal benefit, mainly financed through long-term care insurance (Genet et al., 2011). Two forms of benefits for home care are available: benefits in kind (help) and money benefits. Long-term care insurance benefits are not intended to be a full coverage, but are only a subsidy. As a consequence, only the needs of a relatively small part of the population can be satisfied.

5 People with dementia

(OECD, 2013; Alzheimer Europe, 2009)

The prevalence of dementia of the population aged 60 years and over in 2009 was 5.8% (OECD Ø 5.5%). In the population aged 30 to 95+, it is estimated that 1.66% of the people have dementia (EU Ø 1.56%).

Estimated two thirds of people with dementia live at home.

6 Informal carers

(OECD, 2013)

15.7% of the population aged 50 and older were reported to be informal carers (OECD Ø 15.6%).

59% of the carers provide care daily and 41% provide care weekly (OECD Ø 66% of the informal carers provide care daily, 34% provide care weekly).

Socioeconomic and cultural aspects with influence on access to formal care in Germany

Overview

A total of 18 studies published between 1998 and 2013 were identified by literature search. Nine studies belonged to the same research project that investigated several services in the field of community care for people with dementia: day hospitals, respite care, informal carer skill training, day care, home nursing care, home care, as well as support groups for informal carers, low-threshold support services for people with dementia, counselling, and voluntary help (referred to as ‘a variety of services’ below) (Donath et al., 2009a; Donath et al., 2009b;
Donath et al., 2009c; Donath et al., 2011; Graessel et al., 2009; Graessel et al., 2011; Graessel et al., 2010a; Graessel, 1998; Graessel et al., 2010b).

One publication was found in the EUROFAMECARE study (Lüdecke et al., 2012).

Two studies focused on ambulatory medical care (Eisele et al., 2010; Koller et al., 2010). One study addressed in particular attitudes of different groups towards dementia, including informal carers, people with dementia and the general population (Bond et al., 2005), and two further studies addressed attitudes of people with dementia towards care (Ehlers, 2010; Frewer-Graumann, 2014). One study investigated the situation of people with dementia and their informal carers with migration background (Mogar & Kutzleben, 2014). Four further studies investigated the influence of different socioeconomic and cultural aspects regarding access to formal care (Georges et al., 2008; Graessel et al., 2010c; Grossfeld-Schmitz et al., 2010; Vetter et al., 1998).

Age

Findings relating to the influence of age on access to formal care for people with dementia and informal carers varied to a large extent. The age of people with dementia and informal carers had no influence on access to and utilisation of a variety of services (Donath et al., 2009b; Donath et al., 2011; Graessel et al., 2009; Graessel et al., 2010a; Graessel, 1998; Graessel et al., 2010b). The authors found that utilisation of respite care and informal carer skill training tended to increase with the age of the people with dementia (Donath et al., 2009a; Donath et al., 2009c). The increased age of the informal carers had no influence on the ability to gain an overview of available support services (Ehlers, 2010).

Gräßel et al. (2011) investigated determinants for the utilisation of home nursing care and home help for people with dementia and found that the chance of utilisation increases when people with dementia grow older, or when informal carers are younger.

However, the age of PwD had an influence on access to medical care: utilisation decreased with increased age, especially for visits by specialists (Eisele at al., 2010, Koller et al., 2010). Vetter et al. (1998) found that with increasing age the period was longer between onset of dementia symptoms and the first visit to a physician.

Gender

The gender of people with dementia and their informal carers did not seem to be a determinant of the utilisation of a variety of services (Donath et al., 2009a; Donath et al., 2009b; Donath et al., 2009c; Donath et al., 2011; Graessel et al., 2011; Graessel et al., 2010a; Graessel, 1998; Graessel et al., 2010b; Graessel et al., 2010c).
Family relationship

Employment status
Lüdecke et al. (2012) surveyed more than 1,000 German informal carers (mixed group) where about half cared for people with dementia or with memory problems. They found that nearly half of them were employed. Men were less often willing to accept occupational restrictions due to caregiving tasks, which led to increased utilisation of informal and formal support. Woman did not utilize appropriate support by informal or formal helpers. They were more restricted in their occupation when handling the caregiving situation. A special counselling program for informal carers of people with dementia was more often used by spouses who were less often employed (Grossfeld-Schmitz, 2010). Employed informal carers of people with dementia confirmed that a lack of flexibility in the support services was a barrier to utilisation of formal care, and to coordinating employment and care (Frewer-Graumann, 2014).

Region of residence
Living in a rural or in an urban area was not identified as a determinant for the utilisation of a variety of services (Donath et al., 2009a; Donath et al., 2009b; Donath et al., 2009c; Donath et al., 2011; Graessel et al., 2009; Graessel et al., 2011; Graessel et al., 2010a; Graessel, 1998; Graessel et al., 2010b; Graessel et al., 2010c). Koller et al. (2010) asked whether there was a rural-urban difference in ambulatory health service utilisation by patients with dementia, and they found that people with dementia living in an urban area had a higher chance of visiting a specialist and showed a higher rate of service utilisation in general. People with dementia in rural areas visited their GP more often, but less often a specialist (such as a neurologist). Koller et al. (2010) supposed that distance to service providers, different lifestyles and beliefs in rural areas might lead to more caregiving by families and less professional support. In particular, employed informal carers in rural areas had problems to find appropriate support services (Frewer-Graumann, 2014).

Attitudes towards dementia
The Facing Dementia Survey (Bond et al., 2005) investigated the awareness of Alzheimer’s disease and the behaviours surrounding it and found care themes which were barriers for appropriate care and support for people with dementia. First of all, dementia raises anxiety. In Germany, around half of the public, the informal carers, and the physicians agreed that anxiety hindered people from speaking with their physicians about dementia.
Secondly, dementia results in isolation. Most of all informal carers, physicians, and the general population agreed that dementia has devastating effects on informal carers and families.

Thirdly, there is a lack of awareness and knowledge about the disease and its symptoms. Informal carers were not aware that the signs they noticed were symptoms of dementia; they did not recognize the severity of the symptoms and they denied that a close relative could have dementia.

**Attitudes of people with dementia towards care**

Ehlers (2010) found that two thirds of informal carers of people with dementia assumed or experienced the reluctance of their relative with dementia to make use of professional support. Informal carers would like to be included in all decisions concerning formal support systems. Informal carers reported that they had a bad conscience about using support to reduce the distress of care (Frewer-Graumann, 2014). In addition, informal carers described internal barriers when contacting healthcare professionals. However, Frewer-Graumann (2014) found that different types of informal carers organised the caregiving situation differently, using more or less support from professional helpers.

**Ethnicity**

More than 1.5 million people with a Turkish background live in Germany, and constitute the largest part of the population with a migrant background. Only one qualitative study was identified which investigated the situation of people with with a Turkish background suffering from dementia and in need of care (Mogar & von Kutzleben, 2014). The authors asked seven Turkish female informal carers of women with dementia (taking over ADL activities) about their experiences and perspectives. The informal carers confirmed that a family member with need of care should be cared for by the family. If a family member needed care, other interests or occupation issues were judged as less important by the primary informal carer. If men were involved in a caregiving situation, they took over responsibility for organisational tasks only. The study participants did not use support services outside their own family network. It might be seen as a shameful situation, if the family could not manage the caregiving responsibilities on their own. Placing a person with dementia in a nursing home seemed not to be an option.

**Education**

The level of education does not seem to be a determinant for using a variety of services (Donath et al., 2009b; Donath et al., 2009c; Donath et al., 2011; Graessel et al., 2011;
Graessel et al., 2010a; Graessel, 1998; Graessel et al., 2010b; Graessel et al., 2010c). An exception was informal carer skill training, which was more often used by informal carers with a lower degree of education. Informal carers with a relatively low level of education more often used social support groups (help for only few hours a week) for their relative with dementia (Graessel et al., 2010). The EUROFAMECARE study found that the educational level had the greatest influence on service use. Higher educated informal carers used services more intensively than lower educated informal carers did. Well-educated informal carers presumably have better access to appropriate information about support services.

**Financial aspect**
Most of all formal care support services are covered by the German long-term care insurance, which insures 90% of German citizens. However, most informal carers have to pay additionally for support services (Georges et al., 2008), which was described as a strong reason for informal carers of PwD not to use institutional care (Frewer-Graumann, 2014). Vetter et al. (1998) found that one third of informal carers of people with dementia were not seeking financial aid, because they felt ashamed about asking for financial support.
Ireland

Characteristics of the health and social care system in Ireland

1 Population
(OECD, 2013)
The absolute number of inhabitants was 4,366,000 in 2010.
In 2010 11% of the population was 65 years old and older. This will increase to 26% in 2050 (OECD Ø 2010 15%, 2050 27%).
In 2010 3% of the population were 80 years old and older, by 2050 this will increase to 8% (OECD Ø 2010 4%, 2050 10%).
3.7% of the population aged 65 years and older received long-term care in 2011 (OECD Ø 12.7%).

2 Financing
(OECD, 2013)
8.9% of GDP are health expenditures (OECD Ø 9.3%).
No data are available about public expenditures for long-term care (health and social components) as a percentage of GDP (OECD Ø 1.6%). The cost of long-term care was 0.9% of GDP in 2010 (CARDI, 2012).
The health system is predominantly tax funded, although about half of the population also has a voluntary health insurance (Joumard et al, 2010).
The government finances 67% of health expenditures, 18% are financed by social security and 12% are private out-of-pocket payments. Financing by private insurance is of minor importance.

3 Policies
(Joumard et al, 2010)
Ireland has a two-tiered healthcare system comprising public and private sectors. Public health service is free for medical card holders. Private health insurance is often taken out to avoid large bills and to receive treatment quickly. The Irish healthcare system shows less private provision (in particular for outpatient care) and more regulation of workforce and equipment by state. Clients have more choice among providers and there are fewer gatekeeping systems for receiving healthcare. Other characteristics are low priority setting by policies, more regulation on prices paid by third-party payers and no decentralization. Wendt (2009) rated access of patients to GP's, requirement of a referral for access to a specialist and
additional co-payment as mediums of tight regulation. The National Dementia Strategy was launched in December 2014. It includes funding for three priority areas: intensive home care support, GP education and training, and dementia awareness.

4 Home care

(Genet et al., 2013)
Approximately 54,000 people needing care received formal care at home in 2012. A major characteristic of the home care system is its split provision into public providers and highly deregulated private providers (Genet et al., 2011). The HSE is in the early stages of implementing a Single Assessment Tool (SAT) but in the meantime needs assessments will continue to use the existing Common Assessment Summary Record (CSAR). Some aspects of home nursing care are fully funded, co-payments are necessary for others. Domestic and personal care is provided by the state through regional offices. This is also provided by the voluntary sector (especially domestic care) and increasingly by third sector organisations who receive HSE funding (Cahill, O’Shea & Pierce, 2012; Timonen et al., 2011).

5 People with dementia

(OECD, 2013; Alzheimer Europe, 2009)
The prevalence of dementia in the population aged 60 years and over in 2009 was 5.2% (OECD Ø 5.5%). In the population aged 30 to 95+, it was estimated that 0.96% of the people had dementia (EU Ø 1.56%).
Approximately two-thirds of the people with dementia lived at home in 2012 (Cahill et al., 2012).

6 Informal carers

No OECD data are available about the percentage of the population aged 50 and over who are reported to be informal carers (OECD Ø 15.6%). The Census 2011 (Central Statistics Office, 2012) showed 4.1% of the total population was unpaid carers.
Furthermore, no OECD data were available on the frequency of care provided by informal carers (OECD Ø 66% of the informal carers provided care daily, 34% provided care weekly). Census data 2011 (Central Statistics Office, 2012) showed that average care-giving hours per week were 33.6 hours. O’Shea (2003) found an average of 11.6 hours per day and Trepel (2011) found that the average care hours per day rise from 7.18 to 13.15 as dementia progresses.
Socioeconomic and cultural aspects with influence on access to formal care in Ireland

Overview
We applied two strategies to identify how socioeconomic and cultural factors influence access to and utilisation of formal care services for people with dementia and their informal carers. First of all, a systematic literature search in four databases was performed, but only a single study for Ireland emerged that provided anecdotic information in relation to the factor ‘Attitudes towards dementia’ (Nolan et al. 2006). Secondly, the Irish partners in the ActifCare project were asked to search for additional information that is only available locally or in their national language, but only scattered information on ‘Age’ and ‘Attitudes towards dementia’ emerged.

Age
Younger people with dementia are particularly at a disadvantage since services, where they exist, were not originally designed for this age group (Cahill, O’Shea & Pierce, 2012). This group is more reliant on community services (Alzheimer Society of Ireland ASI, 2013).

Gender
Family relationships
Employment status
Region of residence
Services available to people with dementia are frequently inadequate, inconsistent, and badly co-ordinated throughout the country (ASI, 2012), and geographical location is the strongest predictor of the level of service received (Irving & McGarrigle, 2012). Cahill and colleagues (2012) suggest that people with dementia living in rural areas may be at a particular disadvantage, as information and support services are situated predominately in urban areas.

Attitudes towards dementia
A study carried out by the Alzheimer Society of Ireland (2006) on the issues of stigma and dementia found that people with dementia and their informal carers are often subject to attitudes and experiences that present them with difficulties in navigating the available systems and services. An explorative study with mainly carers/family members of people with dementia and allied health professionals on the stigma of dementia revealed that assigning a label of dementia can
be a necessity for accessing services, and that accepting and being comfortable with the
diagnosis of dementia can be critical to accessing services (Nolan et al. 2006).

Attitudes towards care of people with dementia
The Irish National Dementia Educational Needs Analysis (Irving, Piasek, Kilcullen, Coen &
Manning, 2014) highlighted a rural/urban divide in relation to attitudes towards maintaining
the safety of people with dementia in the community. The majority of people in a city location
believed that this responsibility should be passed onto organisational security members (e.g.
retail security guards, An Garda Síochána), whereas most people in a rural community setting
said that they would try to contact a family member. This is likely to be the result of the
smaller population size, where a lot less people live in the community, many of whom know
each other.

Ethnicity
Education
Financial aspects
The limited data available suggests that only those carers with very low income are eligible
for carers’ allowances, as very strict criteria must be satisfied to avail oneself of this scheme
(Cahill, O’Shea & Pierce, 2012).
Italy

Characteristics of the health and social care system in Italy

1 Population
(OECD, 2013)

The absolute number of inhabitants was 60,508,978 in 2010. In 2010 20% of the population was 65 years old and older. This will increase to 34% in 2050 (OECD Ø 2010 15%, 2050 27%). In 2010 6% of the population were 80 years old and older, by 2050 this will increase to 14% (OECD Ø 2010 4%, 2050 10%). 4.1% of the population aged 65 years and older received long-term care in 2011 (OECD Ø 12.7%).

2 Financing
(OECD, 2013)

9.2% of GDP are health expenditures (OECD Ø 9.3%). No data are available about public expenditures for long-term care with health and social components (OECD Ø 1.6%). The healthcare system is financed by a high proportion of tax (Joumard et al, 2010). Nursing care co-payments are related to age, income and disease. Home help co-payments are only possible for those with high income. The government finances 78% of health expenditures, 18% are financed by social security and 1% are private out-of-pocket payments. Financing by private insurance is of minor importance.

3 Policies

The Ministry of Health, the Ministry of Work and Social Policy, governing organizations and local health centers are involved in home care. However, many older Italians receive care from privately hired foreign immigrants. Therefore, a large part of home care falls outside legislative jurisdiction. Wendt (2009) rated the Italian healthcare system as a universal coverage-controlled access type. That means that the patient’s access to healthcare providers is strictly regulated by the state. Italy has a recently launched a national dementia plan.

4 Home care
Around 1% of the Italian population receives home care. The GP activates the service and the social worker organizes a home visit in order to verify the actual needs. A country-wide assessment instrument is not available. Home nursing services are free of charge for people with minimum income and those over 65 years of age. Eligibility for home help (domestic aid and personal care) is means-tested and there are means-tested co-payments by clients. In the absence of national and regional guidelines, municipalities define their own criteria of eligibility.

5 People with dementia
(OECD, 2013; Alzheimer Europe, 2009)
The prevalence of dementia in the population aged 60 years and over in 2009 was 6.4% (OECD Ø 5.5%). In the population aged 30 to 95+, it is estimated that 1.74% of the people have dementia (EU Ø 1.56%).
An estimated number of 80% of people with dementia live at home.

6 Informal carers
(OECD, 2013)
19.7% of the population aged 50 and older reporting to be informal carers (OECD Ø 15.6%). 74% of the carers provide care daily and 26% provide care weekly (OECD Ø 66% of the informal carers provide care daily, 34% provide care weekly).

Socioeconomic and cultural aspects with influence on access to formal care in Italy
Overview
The report included a total of 14 publications. The search of the databases revealed four studies (Chiatti et al., 2013; Dello Buono et al., 1999; Scalmana et al., 2013; Bond et al., 2005). A further finding from the search of the databases was a literature review. One of the studies in this review fulfilled the inclusion criteria, and was added (Vellone et al., 2002). The search in national databases generated five studies with data about access to formal care for people with dementia (Metitieri & Pezzini, 2005; Micheli, 2006; Ongaro et al., 2006; Vario & Sansoni, 2000; Manigrasso et al., 2005).
Findings of the EUROFAMECARE study were added because the study is closely related to the research question (Quattrini et al., 2006; mixed group of care recipients and informal carers).

**Age**
An investigation of differences in the utilisation of community care by people with dementia and older people without dementia established no differences in age in both groups of community care users (Dello Buono et al., 1999). There were also no age differences in a comparative study of of health and social care service users and non-users with dementia (Scalmana et al., 2013).

**Gender**
Informal carer: Dello Buono et al. (1999) found that male informal carers of PwD made more use of public and private services than females did. Men are probably not traditionally and culturally designated to taking care and do not perceive the informal carer role as a duty, as women do. Men often prefer a managerial approach and contact services earlier than women (Metitieri & Pezzini, 2005).

People with dementia: Scalmana et al. (2013) found no differences between male and female health and social care service users and non-users with dementia. Possenti (2003) found no gender difference in the number of services used by men and woman informal carers of PwD; however, there is still a difference concerning information about the existence of home services. Male informal carers were more informed and they accepted formal care at home more easily. For female informal carers, it was easier to accept help on administrative and economic issues. One of the reasons for men for not accepting formal care was that they thought they needed no help. Women explained that they had to face the reluctance of their relatives with dementia to utilise a formal service.

**Family relationship**
In Italy, the general predominant thought is that taking care of a spouse is a duty to be fulfilled alone (Vellone et al., 2002). Adult children are often not involved in care tasks because of the general idea that they have to be cosseted. Spousal informal carers tend not to ask other relatives for help.

A one-year cohort study conducted in Lazio with 712 patients diagnosed with dementia showed that the probability of using any service was higher when the primary informal carer was a relative other than a spouse or child, as opposed to a paid home care worker (Scalmana et al., 2013). On the other hand, having children or a partner is a protective factor against
being institutionalized, due to the fact that Italian care culture has its roots in the Mediterranean family model, which sees the standardized and less customized care institutions offered as a fall-back choice in case they have no other option to refer to (Micheli, 2006).

**Employment status**

Every third informal carer in Italy has a paid job, and only one out of ten changes the employment status because of the caregiving situation. To combine caregiving and a paid job with help by professional support services is an important aspect for informal carers (Quattrini et al., 2006; mixed group of informal carers). A useful help for working informal carers are migrant informal carers who relieve informal carers of their care tasks, leaving to them the organization and supervision, and thus reducing institutionalization rates (Ongaro et al., 2006).

**Region of residence**

The EUROFAMECARE study investigated differences in considering the importance of several types of support by informal carers in metropolitan, urban, and rural areas. The place of living seems to be important with regard to support services, which inform and advise informal carers about the type of help and support that is available and how to access it. This was more important for people in rural than in metropolitan or urban areas.

**Attitudes towards dementia**

A frequent exclusion of dementia patients from rehabilitation services such as physiotherapy, speech therapy and psychological therapies can be noticed, mainly due to the common understanding that these interventions are oriented to complete healing only. It would therefore be ‘inconvenient’ from a cost-benefit perspective to provide such patients with these rehabilitation services (Manigrasso et al., 2005; Comitato Nazionale per la Bioetica, 2014). Bond et al. (2005) explored barriers to access to care for PwD, and found key areas. Such key areas were anxiety, which dementia provokes; isolation of the PwD; and a lack of knowledge and awareness of symptoms of dementia. The informal carers’ lack of knowledge about Alzheimer’s disease was confirmed by Vellone et al. (2002).

**Attitudes towards care of people with dementia**

The Mediterranean family care culture can explain why Italian informal carers take care of their relatives for the maximum amount of time they have available, and tend not to seek help until the situation becomes unsustainable (Vario & Sansoni, 2000). However, the informal
carers believed that the National Health System provided little support to informal carers of PwD.

A lack of information for PwD and informal carers about available formal care services seems to contribute to professional support being utilised relatively seldom (Dello Buono et al., 1999; Bond et al., 2005; Quattrini et al., 2006; mixed group of informal carers). For example, informal carers were dissatisfied that they received no information about existing services from their GP (Dello Buono et al., 1999).

A comparison of differences between informal carers of demented and non-demented older people showed that informal carers of PwD expressed an increased need for support from almost all kinds of support services. Generally, home-based services were requested as support in the care of PwD more often than out-of-home services (Dello Buono et al., 1999).

**Ethnicity**

**Education**

A one-year cohort study conducted in Lazio with 712 patients diagnosed with dementia showed that patients with more than five years of schooling were found to be more likely to use any available services (Scalmana et al., 2013). A lower education level seems to be related to higher hospitalization rates (Istat, 2007).

**Financial aspect**

Families with a PwD perceived their financial status to be significantly worse than similar families without a PwD (Dello Buono et al., 1999). Half of the participants in this study (n=30/60) had not received any state-provided financial benefits, although these had been approved. Private home care is shifting increasingly towards families with a higher socio-economic status; for example, their higher financial opportunities allow them to use help from a migrant care worker (Chiatti et al., 2013).
The Netherlands

Characteristics of the health and social care system in the Netherlands

1 Population
(OECD, 2013)

The absolute number of inhabitants was 16,615,243 in 2010.
In 2010 15% of the population was 65 years old and older. This will increase to 27% in 2050 (OECD Ø 2010 15%, 2050 27%).
In 2010 4% of the population were 80 years old and older, by 2050 this will increase to 11% (OECD Ø 2010 4%, 2050 10%).
19.1% of the population aged 65 years and older received long-term care in 2011 (OECD Ø 12.7%).

2 Financing
(ECD, 2013)

11.9% of GDP are health expenditures (OECD Ø 9.3%).
3.7% of GDP are public expenditures for long-term care with health and social components (OECD Ø 1.6%).
The health system is funded predominantly by social insurance with less out-of-pocket payments (Joumard et al, 2010).
The government finances 8% of health expenditures, 77% are financed by social security, 6% by private out-of-pocket payments and by private insurance respectively.

3 Policies
(Joumard et al, 2010)

Market mechanisms play an important role in delivering basic insurance coverage. Clients have less choice among providers and there are more gate-keeping systems for receiving healthcare. Other characteristics are: less decentralization and consistent responsibility assignment. Wendt (2009) shows that the Dutch healthcare system cannot be categorized according to the proposed three types of access to healthcare, i.e. a health service provision-oriented type, a universal coverage-controlled access type and a low budget-restricted access type. The Dutch system seems to be unique due to a low level of outpatient healthcare, entitlement on the basis of social insurance contributions and comparatively strict access regulation. Municipalities are responsible for offering support to help people stay in their
homes and participate in the society (Ministry of Health, welfare and Sport, 2015). The three-year Dutch “Dementia Care Plan” was announced in 2008 (Alzheimer Europe, 2012).

4 Home care
(Genet et al., 2013)
In 2007, 4.8% of the Dutch population above 20 years of age received home care. Well over 80% of the clients were 65 years or older. The Centre for Care Indication assesses the needs for home care. Uniform criteria for most home and personal care are applied nationwide. Eligibility is independent of income, but co-payments for nursing and personal care services depend on income, household structure and age of the client. Municipalities are responsible for access to domestic aid and supportive aids. Eligibility for domestic aid is independent of income, but co-payments are general and dependent on income and the type of services required.

5 People with dementia
(OECD, 2013; Alzheimer Europe, 2009)
The prevalence of dementia in the population aged 60 years and over in 2009 was 5.4% (OECD Ø 5.5%). In the population aged 30 to 95+, it is estimated that 1.29% of the people have dementia (EU Ø 1.56%). An estimated number of 70% of people with dementia live at home.

6 Informal carers
(OECD, 2013)
16.9% of the population aged 50 and older was reported to be informal carers (OECD Ø 15.6%). 45% of the carers provide care daily and 55% provide care weekly (OECD Ø 66% of the informal carers provide care daily, 34% provide care weekly).

Socioeconomic and cultural aspects with influence on access to formal care in the Netherlands

Overview
Only two studies fulfilled the inclusion criteria. The studies investigated among others the influence of the socioeconomic aspects age, gender and family relationships on service utilisation. No studies could be identified which investigated how employment status, region
of residence, ethnicity, education, financial aspect, attitudes towards dementia and attitudes towards care of PwD influence the access on and utilisation of formal care.

Boersma et al. (1997) investigated the service utilisation of PwD with an emphasis on determining whether sociodemographic variables are predictive of care of PwD. Participants (n=102) were investigated relating to the influence of socioeconomic and health-related variables on care utilisation.

Wolfs et al. (2010) conducted a study to identify ways in which PwD could utilise treatment options (i.e. counselling by a healthcare professional, pharmacological and non-pharmacological treatment, home care, activities, group guidance, and admission to a nursing home). According to the study, 252 PwD and informal carers were asked among others why they did not use available treatment options.

**Age**

The two studies found that age had no influence on utilisation or non-utilisation of formal care. However, Boersma et al. (1997) pointed out that older PwD were more likely to be users of institutional care, compared with younger PwD.

**Gender**

Boersma et al. (1997) explained that men with dementia who were married less often used formal services. A reason for that was seen in the fact that men with dementia were less frequently widowed that women with dementia.

**Family relationship**

Married PwD used formal services less often (Boersma et al., 1997). The study by Wolfs et al. (2010) did not confirm this finding.

**Employment status**

**Region of residence**

**Attitudes towards dementia**

**Attitudes towards care of people with dementia**

**Ethnicity**

**Education**

**Financial aspects**

**Norway**

*Characteristics of the health and social care system in Norway*
1 Population

(OECD, 2013)

The absolute number of inhabitants was 4,891,251 in 2010.
In 2010 15% of the population was 65 years old and older. This will increase to 23% in 2050
(OECD Ø 2010 15%, 2050 27%).
In 2010 5% of the population were 80 years old and older, by 2050 this will increase to 9%
(OECD Ø 2010 4%, 2050 10%).
17.4% of the population aged 65 years and older received long-term care in 2011 (OECD Ø
12.7%).

2 Financing

(OECD, 2013)

9.3% of GDP are health expenditures (OECD Ø 9.3%).
2.4% of GDP are public expenditures for long-term care with health and social components
(OECD Ø 1.6%).
The health system shows a high share of public tax financing (Joumard et al, 2010).
The government finances 73% of health expenditures, 12% are financed by social security
and 15% are private out-of-pocket payments. Financing by private insurance is of minor
importance.

3 Policies

(Joumard et al, 2010)
The Norwegian healthcare system is characterized by a lower scope of basic insurance
coverage, more choice among providers and also more gatekeeping. The system shows a
relatively high level of decentralization and high consistency across levels of regulation by
the government. The decentralization takes responsibility for the provision of healthcare
through local governments. These local authorities are expected more and more to control
costs and find cost-efficient solutions for local care needs (Vabø, 2012). Norway has a
national dementia plan, the “Dementia Plan 2015”, with emphasis on day programs, facility
improvements, and information and education (Alzheimer Europe, 2012).

4 Home care

(Genet et al., 2013)
In Norway there were about 171,226 persons who received long-term care at home in 2006.
An independent formal assessing agency in the municipalities is responsible for assessment of
individual needs, formulating contracts, ordering services and checking outcomes. The health service shall, as far as possible, be formulated, based on the individual’s wishes and needs, regardless of social status, personal finances, and place of residence or way of living. However, some local differences may occur.

5 People with dementia
(OECD, 2013; Alzheimer Europe, 2009)
The prevalence of dementia of the population aged 60 years and over in 2009 was 6.2% (OECD Ø 5.5%). In the population aged 30 to 95+, it is estimated that 1.53% of the people have dementia (EU Ø 1.56%). An estimated number of 60% of people with dementia live at home.

6 Informal carers
(OECD, 2013)
No data are available about the portion of the population aged 50 and over who are reported to be informal carers (OECD Ø 15.6%). Also no data are available on the frequency of care provided by informal carers (OECD Ø 66% of the informal carers provide care daily, 34% provide care weekly).

Socioeconomic and cultural aspects with influence on access to formal care in Norway

Overview
We applied two strategies to identify how socioeconomic and cultural factors influence access to and utilisation of formal care services for people with dementia and their informal carers. First of all, a systematic literature search in four databases was performed, but no study from Norway emerged. Secondly, the Norwegian partners in the ActifCare project were asked to search for additional information that was only available locally or in their national language, but only scattered information in relation to the factor “Gender” was identified.

Age

Gender
Male carers often accept formal care such as personal hygiene, domestic help and meals on wheels for the person they care for, while female carers more often decline this help because they perceive the tasks to be ones they ought to perform themselves (Aasgard, 2007).

Family relationships

Employment status

Region of residence

Attitudes towards dementia

Attitudes towards care of people with dementia

Ethnicity

Education

Financial aspects
Portugal

Characteristics of the health and social care system in Portugal

1 Population
(OECD, 2013)

The absolute number of inhabitants was 10,735,765 in 2010.
In 2010 18% of the population was 65 years old and older. This will increase to 32% in 2050 (OECD Ø 2010 15%, 2050 27%).
In 2010 5% of the population were 80 years old and older, by 2050 this will increase to 11% (OECD Ø 2010 4%, 2050 10%).
1.1% of the population aged 65 years and older received long-term care in 2009 (OECD Ø 12.7%).

2 Financing
(OECD, 2013)

10.2% of GDP are health expenditures (OECD Ø 9.3%).
0.2% of GDP are public expenditures for long-term care with health and social components (OECD Ø 1.6%).
Financing of the health system shows a high share of tax financing and out-of-pocket payments (Joumard et al, 2010). There are three overlapping systems. The mainly tax-funded NHS provides universal access, which may be free/almost free at the point of use. However, some people can rely on additional health insurance coverage through health subsystems for specific professions e.g. civil servants (20-25%) and/or private voluntary insurance (10-20% of the population) (Barros et al, 2011).
Private funding is essential to the Portuguese healthcare system (Genet et al, 2013). The government finances 64% of health expenditures, 1% are financed by social security, 29% are private out-of-pocket payments and 5% are paid for through private insurance (OECD, 2013). It is worth mentioning that out-of-pocket payments (including cost-sharing and direct payments for private sector services) are mainly made to pharmacies (dispensing chemists), outpatient care centres and offices of physicians, hospitals, nursing and residential care facilities, and dental care (Barros et al, 2011).
The social sector, funded by the Ministry of Social Security, plays a part in supplying formal care. There may be difficulties in the integration of the health and the social sector e.g. regarding home care (see below) (Genet et al, 2013).
The negative impacts of the 2008 economic crisis have resulted in general restrictions (Barros et al, 2011), especially in this social sector. PT is among those countries allocating less than 0.5% of their GDP to long-term care, although it had one of the highest public-spending growth rates in 2005-2011 due to the implementation of measures to expand coverage (OECD, 2013).

3 Policies
Healthcare provision includes public and private components. Public provision is predominant in primary and hospital care. Private provision includes mainly pharmaceutical products, diagnostic technologies and liberal practice by physicians (Barros et al., 2011). Overall, there is a limited choice of providers and controlled access to public specialized healthcare (gatekeeping by primary care). Other characteristics are little market orientation and less decentralization (Joumard et al., 2010). However, access to NHS primary care or emergency rooms, for instance, is unrestricted and seen as a social citizenship right: lack of a free choice of providers in the NHS does not stem from ideological reasons, but from the definition of catchment areas. Thus Wendt’s rating of the Portuguese healthcare system under a ‘low budget and restricted access type’ (Wendt, 2009) may sound misleading and must be put into context.

There have been a number of reform initiatives (Barros et al, 2011; Genet et al, 2013). Regarding primary and ambulatory care, groups of primary healthcare centres (ACES) were created in 2008, aiming for a better use of resources and management structures. In long-term care, a national network was created (2006) for elderly and dependent persons (RNCCI); since then the accessibility and quality of care have improved. Regarding the pharmaceutical market, the reforms focused on regulated prices and margins, and in ownership and entry rules. A new Mental Health Policy and Plan was also approved (2008), tracing objectives for 2007-2016 (e.g. promoting equal access to care and human rights, and decentralisation of services; integrating mental health services in general services at primary care, general hospitals and community network levels). Efforts were made towards deinstitutionalization and community-oriented services, but later difficulties had to be acknowledged (budget, financing and management issues).
In the 2008 Mental Health Plan, the frail elderly are recognized as being among vulnerable groups most in need of care, but dementia is not directly mentioned as a priority. The National Health Plan 2012-2016 (DGH, 2012) does not refer to dementia in particular, either. In the
context of the current economic crisis, calls for a National Dementia Strategy still have to be implemented, despite some government and civil society efforts (Alzheimer Portugal, 2009, Alzheimer Europe, 2013). A preliminary working draft was produced in 2013 (Directorate-General of Health, unpublished).

4 Home care
(Genet et al., 2013)

In 2007, 71,663 persons in need of care received formal care at home. This report does not give specific information about persons with dementia (PwD).

Home care is provided by public services and non-profit solidarity institutions, and, to a lesser degree, by profit organizations that only a minority of the population may be able to afford. To be eligible for home nursing care in the public network, a physician must provide written support and evidence of need. A nurse’s home care visits are free of charge. Needs assessment is mandatory and is conducted by the Local Coordinating Team (a multiprofessional team, working in hospitals, post-acute care services or the community, as part of the local health center) (UMCCI, 2008; UMCCI, 2009). The person in need of personal care and domestic aid or their relatives will usually approach a provider (Genet et al, 2013).

Health and social home care in public networks have different funding, e.g. from the Ministry of Health and the Ministry of Labour and Social Solidarity. Social care services are also funded by users’ co-payments or membership fees and donations (Genet et al, 2013).

There are overall concerns but also developments regarding home care, and the recent rise in home care services may oppose early institutionalization in cases of dementia (Genet et al., 2013). In 2011, 0.9% of the population over 65 years received long-term care in institutions (OECD Ø 4%), with only 0.2% of this population receiving care at home (OECD Ø 8.2%) (OECD Health Data 2012).

5 People with dementia
(OECD, 2013; Alzheimer Europe, 2009)

The prevalence of dementia of the population aged 60 years and over in 2009 was 5.6% (OECD Ø 5.5%). In the population aged 30 to 95+, it was estimated that 1.45% of the people had dementia (EU Ø 1.56%). It was estimated that 80% of people with dementia live at home (OECD, 2013). There is no information about numbers of PwD in residential or nursing homes. The percentage of residents in general/non-specialised residential homes who have dementia is estimated at 30% (Alzheimer Europe, 2009).
In northern Portugal a prevalence rate of 2.7% (CI 1.9–3.8%) for DSM IV dementia was found in a sample of people aged 55-79 (Nunes et al, 2010). A 10/66 Dementia Research Group community survey even found a prevalence rate of 9.6% (CI95% 8.2-11.3; 10/66 DRG dementia diagnosis), and of 3.7 (CI95% 2.8-4.8) for DSM IV diagnoses (Gonçalves-Pereira et al., 2013; Xavier & Gonçalves-Pereira, 2014).

6 Informal carers

(OECD, 2013)
15.6% of the population aged 50 and older was reported to be informal carers (OECD Ø 15.6%).
87% of the carers provide care daily and 13% provide care weekly (OECD Ø 66% of the informal carers provide care daily, 34% provide care weekly).
As in other south European countries, in PT there is a strong culture of family members providing care for their elderly parents (OECD, 2013). However, there is no reliable information on the number of informal carers supporting PwD. There are studies in non-representative samples in the community (Figueiredo & Sousa, 2008) or in clinical settings (Gonçalves-Pereira, 2010; Sequeira, 2013). A 2005 study with 544 carers from Alzheimer Portugal reported an average age of 60 years for primary carers of PwD, ages 50 to 70 being predominant (46%). Most (70%) were female. Half of these carers were spouses and 34% children of PwD; 76% were married (Instituto da Segurança Social, 2005).
There are also studies with carers of dependent elderly, not necessarily PwD (Barbosa et al. 2011; Pego, 2013). According to Portuguese data from the Survey of Health, Ageing and Retirement in Europe (SHARE – 4th wave), these carers are mainly spouses (55.5%) and children (24.2%), the remaining being neighbours, friends and other relatives. Of the spouse carers 56.3% are male, in contrast to child carers who are mainly female (71.4%)(Pego, 2013). A study on home care services found a majority of female carers (87%), with an average age of 59 (Gesaworld, 2010).

Socioeconomic and cultural aspects with influence on access to formal care in Portugal

Overview
We applied two strategies to identify how socioeconomic and cultural factors influence access to and utilisation of formal care services for PwD and their informal carers. First of all, a
Systematic literature search was performed in four databases, but no study for Portugal emerged. One reason for this could be the non-existence of abstracts in the English language. Secondly, the Portuguese partners in the ActifCare project were asked to search for additional information that is only available locally or in their national language, but only a single study emerged that provided scattered information in relation to some factors. There may be more information on demographic characteristics of people with dementia and carers for people with dementia, but none on the influence of those characteristics on access and utilisation.

Age

Gender

Family relationship

Employment status

Region of residence

Attitude towards dementia

Attitude towards care of people with dementia

Ethnicity
The collection of administrative or statistical data regarding ethnic affiliation is forbidden by law. No studies are currently available on the relationship between ethnicity and the utilisation of formal care by people with dementia.

Education

Financial aspects
The study of the Instituto da Segurança Social (2005) revealed that PwD have high levels of monthly expenses compared to low levels of monthly income (retirement or disability pensions lower than the national minimum wage - 448.92€ in 2005 - in 55% of cases). Most expenses are caused by formal services (nursing homes, home care services), domestic, rehabilitation and technical aids. Health expenditures represent a considerable part of the family budget, especially regarding medication and diapers. Higher costs for services and care relate to the severity of dementia. Users with an informal carer providing six or more hours of daily care may apply for the Dependency Subsidy (Instituto da Segurança Social, 2005).
Sweden

Characteristics of the health and social care system in Sweden

1 Population
(OECD, 2013)

The absolute number of inhabitants was 9,382,297 in 2010 and 9,648,855 in 2013. In 2010 18% (2013 19.4%) of the population were 65 years old and older. This will increase to 25% in 2050 (OECD Ø 2010 15%, 2050 27%). In 2010 5% (2013 5.2%) of the population were 80 years old and older, by 2050 this will increase to 10% (OECD Ø 2010 4%, 2050 10%). 16.3% of the population aged 65 years and older received long-term care in 2011 (2012 16.4%) (OECD Ø 12.7%).

2 Financing
(OECD, 2013)

9.5% of GDP are health expenditures (OECD Ø 9.3%). 3.6% of GDP are public expenditures for long-term care with health and social components (OECD Ø 1.6%). The healthcare system is financed by local taxes (county councils, municipalities) to a high proportion (85-90% of health and social care expenditures) (Joumard et al, 2010). County councils are mainly responsible for the financing of medical healthcare. Municipalities are mainly responsible for social care. Private out-of-pocket payments and financing by private insurance are of minor importance.

3 Policies

Care for older people is the responsibility of the municipalities. Publicly financed home help service is a universal right; no means-testing takes place and it is independent of available informal care. Clients are given an extensive choice among providers but the regulation of provider prices is strict (Joumard et al, 2010). Wendt (2009) rated the Swedish healthcare system as a universal coverage-controlled access type. This type is characterized by equity of access because the total population is covered and co-payments are particularly low. Sweden was the first country in Europe where a National Dementia Strategy was developed and implemented (Alzheimer Europe, 2012) and where the National Board of Health and Welfare has presented guidelines for dementia care as well as indicators of quality of care (Socialstyrelsen, 2010).
4 Home care
(Genet et al., 2013)
In 2012 about 4.9% of the population received home care. To access home care one can apply to one of the home help officers in the municipality. The home care officer has the responsibility for providing healthcare and social home care services and for following up of the decisions made by home care services. The home care officer makes the needs assessments in cooperation with healthcare professionals. There is a standard formula of options, but the municipality has to consider the person’s functional status and the situation in which the person lives.

5 People with dementia
(OECD, 2013; Alzheimer Europe, 2009)
The prevalence of dementia of the population aged 60 years and over in 2009 was 6.3% (OECD Ø 5.5%). In the population aged 30 to 95+, it was estimated that 1.78% of the people had dementia (EU Ø 1.56%). In 2012 it was estimated that 158,000 persons had a dementia disorder (Wimo et al., 2014).
An estimated number of 55% of people with dementia live at home.

6 Informal carers
(OECD, 2013)
Some 20% of the population aged 65 and older were reported to be informal carers (OECD Ø 15.6%).
One third of the carers provide care daily and 45% provide care weekly (OECD Ø 66% of the informal carers provide care daily, 34% provide care weekly).

Socioeconomic and cultural aspects with influence on access to formal care in Sweden
Only one Swedish study fulfills the inclusion criteria. Nordberg et al. (2005) conducted a Swedish population-based study investigating the amount of informal and formal care among non-demented and demented elder people.
The National Survey Report of Sweden from the EUROFAMECARE study has been added, which included experiences in accessing services (Krevers et al., 2006; mixed group of care recipients and informal carers).

Age
Gender
Nordberg et al. (2005) found that with advanced dementia, men receive more informal and formal care than women do.

Family relationship

Employment status
Three quarters of informal carers who combined their paid work and the caregiving situation explained that support services were very important to them; two thirds of the employed informal carers used support services (Krevers et al., 2006; mixed group of informal carers).

Region of residence

Attitudes towards dementia

Attitudes towards care of people with dementia
About half of informal carers involved in the EUROFAMECARE study (mixed group of care recipients and informal carers) had experienced difficulties in accessing services in Sweden. Perceived barriers were lack of information, bureaucratic difficulties, few available services, and poor quality. Informal carers who did not use professional support reported that their own attitudes or attitudes of the care dependent person were the dominant reason for objecting professional help.

Ethnicity

Education

Financial aspect
Informal carers explained that especially social services were too expensive; however, it is less common in Sweden that the users have to pay for healthcare services (Krevers et al., 2006; mixed group of informal carers). Moreover, there is a great variation in the out-of-pocket levels (long-term care, home help, day care) between municipalities but all care recipients have a guaranteed level of own money if the fees are too high.
United Kingdom

Characteristics of the health and social care system in the UK

1 Population

(OECD, 2013)

The absolute number of inhabitants was 62,066,350 in 2010.
In 2010 16% of the population was 65 years old and older. This will increase to 24% in 2050 (OECD Ø 2010 15%, 2050 27%).
In 2010 4% of the population were 80 years old and older, by 2050 this will increase to 10% (OECD Ø 2010 4%, 2050 10%).
No data are available about the proportion of the population receiving long-term care in 2011 (OECD Ø 12.7%).

2 Financing

(OECD, 2013)

9.4% of GDP are health expenditures (OECD Ø 9.3%).
No data are available about public expenditures for long-term care with health and social components (OECD Ø 1.6%).
The health system shows a high proportion of tax-financed public spending and low out-of-pocket payments (Joumard et al, 2010).
The government finances 83% of health expenditures, 10% are financed by social security and 3% are private out-of-pocket payments. Financing by private insurance is of minor importance.

3 Policies

The (devolved) Departments of Health are responsible for regulation and implementation of policy on home care. Service provision and development is split between the Local Authority Departments of Social Services with Adult Responsibilities and local health services (Genet et al., 2013). Users of the UK healthcare system have a more restricted choice among providers. There is a high degree of priority setting but low consistency in responsibility assignment across government bodies (Joumard et al, 2010). In 2009 the “National Dementia Strategy for England: Living well with dementia” was launched (Alzheimer Europe, 2012); Scotland also has a National Dementia Strategy (initially published in 2010; up-dated in 2013) and Wales has a National Dementia Vision (2012).

4 Home care
A total of 1,521,000 services were provided to people over 18 years by local authorities during 2006/7. No referrals are needed for assessment for state funded home care services in England. Under statute, the local authorities make the needs assessment and assess funding requirements using a Single Assessment Process. This is done increasingly in partnership with the National Health Services. Local authorities no longer provide domestic help, but may provide grants to the voluntary sector to provide services to the client for a fee. National minimum standard regulations govern eligibility for home care services, and national assessment criteria have been in place since 2004.

5 People with dementia

(OECD, 2013; Alzheimer Europe, 2009)

The prevalence of dementia of the population aged 60 years and over in 2009 is 6.1% (OECD Ø 5.5%). In the population aged 30 to 95+, it is estimated that 1.54% of the people have dementia (EU Ø 1.56%). An estimated two thirds of people with dementia live at home.

6 Informal carers

(OECD, 2013)

18.2% of the population aged 50 and older was reported to be informal carers (OECD Ø 15.6%).

No data are available on the frequency of care provided by informal carers (OECD Ø 66% of the informal carers provide care daily, 34% provide care weekly).

Socioeconomic and cultural aspects with influence on access to formal care in the UK

Overview

In a systematic literature search in four databases, we identified 11 studies providing information on the influence of socioeconomic and cultural aspects on access to formal care in the UK. Findings concerned the factors ‘Age’, ‘Family relationships’, ‘Region of residence’, ‘Attitude towards dementia’, ‘Ethnicity’, and ‘Education’, and are detailed below.

Age

Regarding age, two studies were identified that expressed concerns that existing dementia care services may not be appropriate for younger people with dementia.
Specifically, Beattie et al. (2004) described that dementia care and services offered are generally within an older person’s setting. Younger people with dementia expressed an overwhelming need for age-appropriate services. While mixing with other younger people with memory problems was seen as a positive experience, care and services in an older person’s settings were viewed negatively by many younger people. Along the same lines, Regan (2014) reported that the dementia advocacy service admitted to being ill-informed about how to provide support for persons with early onset dementia. Another finding regarding age was that age did not differ between people with memory problems (rather than diagnosed dementia) who did or did not seek formal help (Begum et al. 2013).

**Gender**

**Family relationship**

Miranda-Castillo et al. (2010) found that people with dementia living alone were receiving significantly more formal services than those living with others. Significantly more people with dementia living alone had received help from a home care worker, and had used the meals-on-wheel service, compared to those living with others. Schneider et al. (2002) also compared people with dementia in co-resident vs. non-co-resident living arrangements. They found that non-co-resident people with dementia were less likely to see a psychiatrist, a GP or to be taking medication. They were also less likely to receive respite services (e.g. monitoring the PwD while the informal carer is absent). They were, however, more likely to receive two forms of social care: home help and meals on wheels, a finding in line with the Miranda-Castillo study presented above.

**Employment status**

**Region of residence**

Region of residence appears to be an important factor influencing access to and utilisation of dementia care services.

Burholt et al. (1997) reported differences in use of healthcare services among dementia sufferers between an urban (Liverpool) and a rural (Gwynedd) area of the UK. A higher level of contact in Gwynedd than in Liverpool was seen for geriatricians (19% vs. 7%) and chiropodists (58% vs. 38%). A higher level of contact in Liverpool than in Gwynedd was seen for community or district nurses (40% vs. 28%), home visits of GP (69% vs. 50%) and home visits of community or district nurses (40% vs. 22%). Level of contact with GP was not
significantly different between Gwynedd (64%) and Liverpool (80%), despite greater age and physical impairment in Liverpool. Overall low levels of contact in both Liverpool and Gwynedd were found for psychiatrists (6% vs. 6%), health visitors (4% vs. 11%), community psychiatric nurses (2% vs. 6%), and dentists (0% vs. 3%).

Innes et al. (2005) examined attitudes and opinions about dementia care provision in rural Scotland. Thirty-five of the 45 participants highlighted the gaps in services available to the service user, suggesting that services did not necessarily meet their needs. In addition, 26 participants refused services offered because they were unsuitable for their needs. The authors identified five primary gaps in services, which relate at least partly to the service users’ rural location.

**Attitude towards dementia**

An interview study with people with dementia and their unpaid carers stated that early diagnosis was perceived as crucial, as it afforded service users’ access to appropriate services and medication (Gorska et al. 2013).

A study on people with early memory problems found that concern, worry and fear regarding dementia was the key distinguishing feature between people who did or did not seek formal help (Begum et al. 2013).

**Attitude towards care of people with dementia**

**Ethnicity**

The role of ethnicity in accessing and using services has gained some attention in UK-based dementia research. In summary, studies repeatedly highlighted the inadequacy of existing services for people from minority ethnic groups or from differing religious affiliations. Bowes & Wilkinson (2003) studied South Asian people with dementia and their carers and reported that South Asians expressed a desperate need for support while having no access to appropriate services. None of the existing services was responsive enough to the needs of South Asian people. Services needed are services at home, since families want to care for their relatives and often expressed strong views against residential care.

Lawrence et al. (2008) compared carers with traditional vs. non-traditional beliefs (however, both groups contained Black Caribbean, South Asian, and White British). They found that carers with non-traditional ideologies were more demanding of services and more likely to feel that their needs were not being met, described lacking the necessary resources to pursue the help they needed, and reflected that they had been bewildered about the availability of
services and how they could be accessed. Carers across the sample occasionally likened accessing services to a battle in which they were constantly fighting to receive information, advice and practical assistance.

Regan (2014) presented a case study about a Pakistani-Muslim service user accessing UK dementia health and social care services, whose care seeking behaviour could be viewed as atypical. Regan reported that the ‘Dementia advocacy service’ viewed the case as atypical to their usual service-user base since he was the only non-white service user, and that ‘Dementia café’ facilitators and representatives admitted being ill-informed about how to provide support for Muslim persons.

**Education**
A study comparing people with early memory problems who did or did not seek formal help revealed little difference in education between the two groups (Begum et al. 2013).

**Financial aspects**
2) Results – Formal infrastructures (templates)

### Availability of national dementia strategies

<table>
<thead>
<tr>
<th>Country</th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Dementia strategy available</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

1) Diagnostic and therapeutic settings (A1-A5)

The primary care sector and acute medical services are able to provide access to formal dementia care within the community. Five services that are important with regard to accessing formal dementia care are described as follows: General Practitioners (GP), specialised physicians, outpatient clinics for memory problems, outpatient clinics specifically for dementia, and discharge planning from acute care/rehabilitation to home care. Overall, primary care and acute care services are available in all the countries. However, the most dementia-specific medical services are found in Italy and Norway, and overall the lowest level of access restrictions is reported for Norway and Germany.

GP visits are usually not restricted; they are regarded as the first point of contact and have an important gatekeeping function in all the countries. In most of them, the GPs have a defined function regarding access to formal dementia care (detecting, diagnosing or referring patients). The access to specialised physicians is limited in every country (e.g. mandatory referral, waiting time, out-of-pocket payments). Outpatient clinics for memory impairment, where a multi-professional team is engaged, play a subordinate role in DE, while outpatient clinics specifically for dementia are available nationwide in IT. In the UK, out-patient Memory Services are available nationwide, established primarily for the diagnosis and support of early-stage dementia. In NO, multi-professional dementia teams have been implemented all over the country. Generally, specialised physicians do not have a defined function regarding access to formal dementia care, except in Sweden where they may be involved in establishing care plans. Discharge planning/transition management from acute hospital care to home care is available nationwide in all countries; PwD, however, are not considered explicitly.
A1) General Practitioner

**Definition:** General Practitioners’ practice/surgery. Facility where a General Practitioner practices medicine and can be consulted.

**Availability**

General Practitioners (GPs) are available nationwide in all the countries but regional differences exist in DE, IE and PT. GPs do not have a defined function (e.g. within a national dementia strategy) regarding access to formal dementia care in DE and PT, but they are generally considered as the first point of contact for PwD and their families, and they usually take over an important gatekeeping function. In the other countries, GPs have a defined function that includes detecting and diagnosing dementia (and excluding other diagnosis), and referrals to other services or specialised physicians. The GP is considered to be a continuous reference person in IE, IT, UK and SE. To some extent, this also applies to PT (notwithstanding referrals to secondary care, GPs maintain their role as pivotal health professionals, contributing to detection and follow-up of dementia in the universal coverage NHS).

**Accessibility and utilisation**

In most countries, no access restrictions exist for GPs (DE, IT, NL, NO, UK). However, in some countries out-of-pocket-payment is required, ranging from 5 € per visit in PT (note: pensioners on low income and persons with chronic diseases and a verified level of disability ≥ than 60% are exempted) to 45-60 € in IE (note: in IE, ca. 43% of the general population is entitled to free GP visits; in PT ca. 56% in 2014, 1/5 of which due to high levels of disability or chronic disease), and a certain capped amount of co-payment per year in SE (for all types of health and social services).

Data about utilisation of GPs by people with dementia is scarce in all countries. However, different estimates are available per country (see table A). In NO, each citizen is assigned to a designated GP, and study findings suggest that the vast majority of people with dementia (PwD) in DE regularly visit the same GP, albeit the GPs in Germany are not designated.

A2) Specialised physician
Definition: Specialised Physicians' practice/surgery. Facility where a Specialised Physicians (e.g., old age psychiatrist, neurologist, geriatrician) practises medicine and can be consulted.

Availability
Specialised physicians are available nationwide in most countries (IE, IT, NL, PT, SE, NO, UK), regional differences being reported in DE and PT. In most countries, neurologists and psychiatrists are involved (in IT only a few psychiatrists, in UK only a few neurologists). In IE, UK and IT geriatricians are also involved. In NO neurologists, geriatricians and old age psychiatrists are involved in the diagnostic assessment of persons with dementia. The distribution between these specialists varies considerably between counties. In DE, only a few geriatricians are available, and in PT a differentiation of geriatric medicine has recently started. Specialised physicians generally do not have a defined function regarding access to formal dementia care, but if so, it focuses on diagnostics (e.g. subtyping of dementia) and therapeutic plans (IE, IT, NO, PT). In IE, old age psychiatry plays a key role in all stages of dementia care, from detection, assessment and diagnosis, right through to care of PwD of all types, at all stages of the illness trajectory and in all clinical contexts. In SE, specialised physicians may be involved in establishing care plans.

Accessibility and utilisation
Everywhere waiting time is described as a possible access restriction, and in every country, except DE, a referral from a GP is required before visiting a specialised physician (in PT in the public sector). Moreover, out-of-pocket payment may be required in IE (depending on the eligibility status and the type of medical cover held), and in NO, PT (exceptions see A1) and SE, a certain level of co-payment is required. Information about utilisation is rare, and no national data are available in IT, NL, NO, UK and PT. In DE, it is estimated that approximately 30% of PwD are examined by specialised physicians. In IE PwD living in the community pay on average less than one visit per year to specialised physicians (see table A).

A3) Outpatient clinic for memory impairments (A3)

Definition: Outpatient clinic specifically for memory impairments: Outpatient clinic for examination and treatment of memory impairments, not only suspected dementia diseases.

Availability
Outpatient clinics for memory impairments are only available regionally in most of the countries (NO, PT, SE, IE, DE, UK). Outpatient clinics for memory impairments are not part of standard care in DE and hence play a subordinate role. In PT, similar outpatient clinics in public hospitals (mainly connected to neurology services) may be called either ‘for cognitive problems’ or ‘for dementia’ (despite different designations, influenced by stigma and reimbursement-related factors, both address memory impairments in general with a focus on dementia). The term ‘memory clinic’ is uncommon and only used in private practice. In IT outpatient clinics are dementia-specific; however, people with all types of memory impairment are treated. In all of the countries, multi-professional teams are involved, consisting of medical specialists, (neuro-) psychologists, nurses, therapists and social workers (may vary, even within one country).

**Accessibility and utilisation**

Outpatient clinics for memory impairments have some access restrictions in most countries. Considerable waiting time is described (DE, IE, PT, SE, NL, NO, UK) e.g. from up 2-4 weeks in the NL to 24 weeks in DE. In the NL and partly in SE and PT, a formal referral is required; in IE all clinics (except two) accept only referrals from GPs or specialised physicians. A certain level of out-of-pocket payment may be necessary in the NL, NO and SE and PT. In IE, most outpatient clinics are publicly funded and therefore free of charge; costs may be incurred only for certain investigations (such as scans). Four clinics are privately funded and thus out-of-pocket payment is required. Long waiting times (public sector), out-of-pocket payments (mainly in private care) and sometimes travel distances might be access restrictions in PT. The lowest access restriction exists in NO (only a certain amount of private payment) and the UK (no payment needed and some clinics accept self-referrals).

Data on utilisation is scarce; no national data is available for DE and PT. It is estimated that approximately 25% of PwD in the NL are diagnosed at an outpatient clinic for memory impairments. In NO, 74% of GPs in municipalities with dementia teams refer their patients to specialist services suggesting a high utilisation. In addition, the utilisation in SE seems to be high, indicated by approximately 14,000 diagnostic procedures performed in outpatient clinics in 2012. In IE the average number of patients seen during 2011 was 126 (range was 18–404/data supplied by 8 outpatient clinics; four of these eight MCs saw fewer than 100 patients [<2patients/week], whilst the remaining four saw more than 100 patients). In the UK, a national audit of Memory Clinics and Memory Assessment Services in Wales (2014) identified 7480 new patients being seen in these services over the previous 12 months – this
would indicate that as many as 150,000 new patients would have been seen across the UK, assuming similar activity levels (see table A).

**A4) Outpatient clinic specifically for dementia**

*Definition:* Outpatient clinic specifically for dementia diseases: Outpatient clinic in primary health care or in hospital, including care by physicians and nurses specialised in dementia.

*Availability*

Outpatient clinics specifically for dementia are available nationwide in IT (so-called *Alzheimer Evaluation Units*), offering diagnostics, care and a wide range of treatment for any type of dementia (pharmacological and non-pharmacological), as well as informal carer support. In NO, so called *dementia teams* operate nationwide (but not in all municipalities), assisting with the assessment procedure and supervising the PwD and their families. In SE, outpatient clinics specifically for dementia are only regionally available. In DE, IE, UK and the NL, no dementia-specific structures are available (albeit the staff might be specialised in dementia); services are covered by outpatient clinics for memory impairment. In PT so-called ‘outpatient clinics for dementia’ (at main hospitals) also address cognitive impairments in general (a diagnosis of dementia is not mandatory to be seen as an outpatient there); we took the option of describing these services under A3.

*Accessibility and utilisation*

In NO, dementia teams are accessible without restrictions and utilisation is believed to be high (in municipalities with dementia teams, 81% of GPs refer their patients to dementia teams). In IT, Alzheimer Evaluation Units are free of charge, only the waiting time might be a problem (first visit within 30 days guaranteed). A long waiting time and out-of-pocket payment might be an access restriction in SE. No data on utilisation is available.

**A5) Discharge planning /transition management from acute institutional care to home**

*Definition:* Discharge planning /transition management focusing from institution to home: Discharge planning describes identifying and preparing for the patients’ anticipated healthcare needs on discharge from an inpatient facility (hospitals/ rehabilitation units) including interventions or the initiation of formal home care (Bauer et. al, 2009). Transitional care is defined as a set of actions designed to ensure the coordination and continuity of healthcare as patients transfer between different locations or different levels of care within the same location (Coleman, 2003).
**Availability**

Discharge planning or transition management from acute institutional care to home care is available nationwide in all of the countries, and is regulated by national regulations/guidelines, except in the NL, UK and IT. Dementia-specific discharge management is available in none of the countries (recommendations have been made in IE). Different disciplines are involved in discharge planning, including nurses, social workers or physicians in most of the countries. In PT, teams including a nurse, social worker and physician are involved in discharge planning in all public hospitals.

**Accessibility and utilisation**

None of the countries reported any formal access restrictions regarding discharge planning (however, out-of-pocket payment may be necessary for hospital admissions or for the subsequent care requirements; implementation problems of discharge planning are reported for IE and PT). Data on utilisation of discharge planning for people with dementia are not available. However, some data on the number of PwD in hospitals/ or among the discharged patients have been found in DE, IE, PT and SE (see table A). These data suggest that a considerable number of people with dementia are hospitalized and might potentially benefit from transition management.
2) Home care and support for people with dementia (B1-B15)

The section home care and support for people with dementia covers entirely 15 services and structures.

A reference person for people with dementia (B1) is available in the NL, NO (dementia teams) and SE (dementia specific reference professionals in NO and SE) and, in varying form, in the UK. According to the recently launched dementia strategy in IE, a key contact person for PwD and their informal carers is considered. In IT, the GP is considered as a fixed reference person. Team-based community services (B2-B4) are reported in most of the countries (to a different extent), except in DE, where team-based approaches seem to be less often available. Specialised psychiatric home nursing care (B5) does not seem to be a suitable service for PwD due to a number of access restrictions or barriers (availability in IT and PT, age restriction < 65 years in NO and SE, limited duration and focus on other psychiatric diseases), except in the UK, where it forms a core part of community mental health teams for older people, with support for people with dementia as a major role. Day care structures are available in all the countries and lowest access restrictions are reported for the NL, NO and SE.

Home help with IADL/ADL (B8-B9) is available in every country, common access requirements are needs assessment (see B7) and possible co-payment (or full-payment in case of private services). Therapeutic care (B10) and rehabilitation at home (B1, rarely in DE) are available nationwide in all of the countries but require needs assessment or prescriptions; co-payment is usually required in DE. Respite care is available in all the countries (B12, only regionally available in IT); however, needs assessment, co-payment, limited duration in terms of nights/year (varies per country), and limited bed-capacity connected with waiting times may be access restrictions. Residential home/sheltered housing/assisted living arrangements (B13) are available in every country. However, such intermediate living arrangements between home and institutional care structures are mainly not dementia-specific, and dementia itself is a known access restriction in some countries (DE, IE and PT). Social support (B14) is available in all of the countries and predominately provided by third sector organisations (e.g. volunteer organisations). Thus few access restrictions are described.

Personal safety alarms for PwD (B15) are available in all the countries and require co-payment or needs assessment/prescription for cost takeover (DE, IT, NO, sometimes in PT). In general, data on utilisation of these services by PwD are scarce in all countries.
B1) Healthcare professional serving as a reference person

Definition: Healthcare professional serving as a reference person (e.g., dementia nurses, case manager, 'admiral nurses'): a healthcare professional specialised in dementia care serving as the main contact person for the person with dementia and the informal carer during the course of the disease. Tasks are mostly needs assessment, service allocation, coordination, monitoring and evaluation and may continue until admission to institutional care or death of the person with dementia (Koch et al., 2012; Ward-Griffin et al., 2012).

Availability
An approved healthcare professional serving as a reference person for PwD and their families is available in NO (dementia teams), the NL, SE and the UK. In IT, the GP is considered to be the main reference person and in PT the same applies in practice, not specifically on account of a dementia diagnosis (case management is under implementation but only in severe mental illness). In DE, a kind of case management is provided by the health insurances. In IE, a reference person is not available. However, the recently launched dementia strategy promises to appoint a named key worker who will play a key role coordinating each person's care, promote continuity, and ensure that the person knows where and how to access information and services. While general case managers are implemented in the NL, dementia-specific structures are in operation in NO (dementia teams) and SE (dementia nurse).

Accessibility and utilisation
In DE, case management from the health insurances is only available on demand for people with a degree of disability (Social Code XI). The level of information, awareness and hence utilisation is low (approx. 10% of the cases in 2011), albeit increasing and higher among PwD (50%). In the NL, case management is also available on demand but requires a referral. The dementia nurses in SE and the dementia teams in NO seem to be involved regularly and no access restrictions are mentioned (despite regional differences in availability). There is great variability in the UK regarding this role, but is often undertaken by Community Mental Health Teams for older people. No data about utilisation are available in the NL, NO, SE and UK (see table B).

B2) Mobile comprehensive expert team

Definition: Mobile multi-professional team with specialist competences in dementia care.

Availability
Mobile comprehensive expert teams are only available regionally in the NL, NO and SE. They are described as outreaching services in the NL and SE, whereas they are located at hospitals in NO (and are outreaching). Mainly physicians are involved (GPs, specialised physicians and nursing home physicians) in the NL.

**Accessibility and utilisation**
A mobile comprehensive expert team is part of standard care in the NL, NO (but only regionally available) and SE. Co-payment may be required in the NL. No data about utilisation are available (see table B).

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**B3) Team-based home healthcare**

*Definition:* Healthcare provided in the patient’s own home by a multidisciplinary team (not specialised in dementia). The team is in charge of the treatment and monitoring of the patient with dementia and his/her informal carer.

**Availability**
Team-based home healthcare is available nationwide in NO, and regionally in IT, PT (actually available nationwide with regional asymmetry of access and quality) and SE. In DE, IE and the NL home healthcare is not provided by professional teams (in DE only available for palliative care). Mainly nurses, occupational therapists, physiotherapists and social workers are involved but also physicians (GPs and specialised physicians).

**Accessibility and utilisation**
Few access restrictions are reported. In IT, the complex application procedure (initiated by a GP and with multi-disciplinary evaluation) and waiting times may be a barrier. In PT, the application procedure may also be complex. In NO and PT, a needs assessment is a mandatory precondition as well, and in PT and SE co-payment may be necessary (see table B).

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**B4) Team-based community mental healthcare for older people**

*Definition:* Specialised, multidisciplinary team including for instance psychiatrists, psychiatric nurses, social workers, occupational therapists, psychologists and sometimes 'support workers'.

**Availability**
Except in DE, team-based community mental healthcare for older people is available in all countries. However, such structures are only rarely available in PT (and not formally designated as such) and NO. In SE, community mental healthcare services are geared to the adult population between 18 and 65; in IT, mental healthcare services focus mainly on mood and anxiety disorders. In the UK, these teams are the cornerstone of specific NHS support for people with moderate to severe dementia living at home. In all of the countries, multi-professional teams are involved, including specialised physicians (such as psychiatrists, old age psychiatrists), psychologists, social workers, nurses, occupational therapists and so on. While physicians are regularly involved in IE (teams in IE are led by an old age psychiatrist), IT, the NL and PT (a general psychiatrist leads), professional teams in NO and SE are more nurse-led and physicians serve mainly as consultants.

**Accessibility and utilisation**

Since these structures are part of standard care, there are only a few access restrictions described. In IT and the NL, referral is required, and co-payment may be necessary in the NL. Community mental healthcare services in NO and SE are restricted to adults <65. In IE, distances, waiting-times or insufficient staffing/equipment of community mental healthcare services can be a problem with regard to access. No data about utilisation are available (see table B).

**B5) Specialised psychiatric home nursing care**

*Definition: Supervision, support, treatment and monitoring by community psychiatric nurses.*

**Availability**

In the NL, psychiatric home nursing care is only available regionally, in PT rarely (within the kind of multi-professional team described in B4). This service is available nationwide in NO but not in all municipalities. In SE, IE, UK and PT, psychiatric home nursing care is part of the team-based community mental healthcare services (see also B4). In SE, services are geared to adults between 18 and 65. In Germany, two structures are available. While comparable services provided by the municipalities are available nationwide, *specific psychiatric home nursing care* is only available regionally. In all of the countries, mainly nurses with psychiatric qualifications are involved but also social workers, therapists, psychologists and specialised physicians. In IE, Community Mental Health Nurses attached to
old age psychiatry teams have a generic rather than disease-specific remit and often lack specialist dementia knowledge. Comparable services are not available in IT (see table 2).

**Accessibility and utilisation**

Some access restrictions are mentioned. While social psychiatric services provided by the municipalities are available without access restrictions in DE, some access restrictions are described for specialised psychiatric home nursing care: co-payment, prescription required (only a certain number of prescriptions are allowed by health insurances), a positive evaluation is required after 14 days of utilisation and the overall duration is limited to four months. In IE, a referral is also required; waiting time and insufficient information may further hinder utilisation. In the NL, co-payment may be required and as in DE, the duration is limited as the intervention should only be a stabilising one. In NO and SE, psychiatric home nursing care is mainly restricted to the adult population <65 years. In IE, it is estimated that approximately 50% of the caseload of Community Mental Health Nurses in rural areas are PwD. In none of the other countries is information on utilisation available (see table B).

**B6) Day care/Day activity/Day Care Centre/Day hospital**

*Definition: Clinic or agency providing social activities and, activities to stimulate physical, mental and intellectual functional ability, daytime; might be specialised for people with dementia.*

**Availability**

Day care structures are available in all of the countries, often differentiated in social care and medical care services. Considerable regional differences are reported for DE, IE, IT, UK and PT, while nationwide availability is reported for NL, NO and SE. In PT there are very few day centres specifically for dementia and only regionally available. A huge range of healthcare professionals may be involved in DE, IE, IT and PT, including (auxiliary) nurses, social workers, occupational, speech and physiotherapists, psychologists, and physicians but also nutritionists and socio-cultural animators (latter in PT). In the NL, NO and SE, day care services seem to be predominantly nurse-led and fewer professions are involved, mostly (auxiliary) nurses, social workers and different types of therapists. In IE day care services are generally nurse-led with support from other nurses, care staff and volunteers. In the UK, many day hospitals, provided by the NHS, have closed in recent years, replaced by teams providing additional support at home.

**Accessibility and utilisation**
Overall, the fewest access restrictions are described in the NL, NO and SE. In all of the countries, different levels of co-payment may be required. In IT, IE, UK and NO, a dementia diagnosis is necessary to assess dementia-specific day care; in DE, NL and PT needs assessment is required (in DE and NL to get the costs covered by the health insurances). In DE, IE IT and PT day care services are not available in all areas (and high transportation costs can be a problem in IE and PT). In IE and UK, a formal referral is required for visiting day hospitals. In IT, a stable living situation is a precondition for visiting a dementia-specific day care to ensure continuity in care. In PT, day centres for older people are restricted to people ≥ 65 years. While in IE a lack of awareness and knowledge about day care services is mentioned (Cahill, O’Shea & Pierce, 2012), awareness was described as high among informal carers of PwD in DE, who generally found only a few restrictions when assessing day care services (Donath, 2011).

In DE, approx. 43,000 people in need of care used day care services in 2011 (Pfaff, 2013). A survey among informal carers of PwD (n=400) in DE revealed that one third was using day care (Donath, 2011). In NO, approximately 9% of the PwD living at home made use of day care in 2011 (Eek & Kirkevold 2011), and in SE about 6% of all people with dementia used day care services in 2012 (Wimo 2014). In PT, generic day centres for older people are used by approximately 4% of the older population, mainly by the lower income classes (CEDRU, 2008); no data is available for use of day centres specifically for PwD. No data on utilisation are available for IE, IT, UK and NL (see table B). Since the establishment of the day hospitals and day centres in IE, little descriptive or evaluative research has been undertaken (Hickey, Moran & Walsh 2003)

B7) Needs assessment

Definition: Assessment of needs for care and social services in any kind of organisation prior to decision and receiving care, including deciding on eligibility.

Availability

Needs assessment is available nationwide in all countries. The organisation differs between the countries with regard to the institutions and instruments used. In all of the countries needs assessment is a mandatory precondition for receiving publicly funded health and social services. Different healthcare professionals are involved. While in IE, IT, PT, NO, UK and SE the needs assessment is performed by different professionals if required, such as nurses, social workers, physicians and therapists (or even by multi-professional teams as in IE, IT and PT),
in DE the needs assessment is performed by specially trained nurses or physicians, in the NL by nurses.

**Accessibility and utilisation**

Needs assessment is part of standard care in all countries and no access restrictions are mentioned. In most countries, an application is required to initiate the assessment procedure (DE, IE, IT, NL, PT, SE, UK). In DE, needs assessment has to be performed within five weeks (one week in urgent cases) after application. Overall, there is no data available on the utilisation of needs assessment by people with dementia. However, it may be assumed that utilisation is high. In DE, there were more than 1,580,000 assessments in 2012 (every assessment, including first and re-assessments and objections). In the NL, around 20,000 assessments were performed in 2013 (see table B).

**B8) Home help/care with IADL and B9) Home care with basic ADL/fundamentals**

*Definition B8):* Help provided with Instrumental Activities of Daily Living (IADL) at home by paid professionals, such as housework, shopping, cooking (Asberg & Sonn 1989).

*Definition B9):* Help provided with Basic Activities of Daily Living (ADL) at home by paid professionals (such as bathing, dressing, eating, mobility) (Katz et al. 1963).

**Availability**

Home help with IADL and ADL is available nationwide in all of the countries. In most of the countries, no clear distinction is made between home help with IADL and ADL. Only in DE, certain domestic tasks and personal care tasks are explicitly defined and covered by long-term care insurance. Although home help is not part of standard care in IE, it is regularly provided by public HSE.

In all of the countries, home help with IADL and ADL is performed mainly by (auxiliary) nurses and people who received a short training/training on the job, such as help workers (DE), healthcare assistants (IE, SE), home or social assistants (IT), family auxiliaries (PT), home care workers (UK). In the NL mainly unskilled personnel and in NO mainly (auxiliary) nurses and people who received a short training/training on the job are involved.

**Accessibility and utilisation**

In most of the countries, needs assessment is required before home help services can be used (DE, IT, NL, NO, PT, SE, UK). Moreover, in all of the countries co-payment may be
necessary; in IE and PT even full payment may be required when private services are used or a migrant informal carer is involved like in IT. Private services, possibly involving migrant formal informal carers as in IT, are involved to some extent in PT. In PT, users of day care services are excluded from home help services. Low quality or organisational problems in service provision might further impede utilisation in IT and PT. Moreover, a stable living situation and a GP as a reference professional is a necessary precondition for using home help in IT. The absence of entitlement to home care services may be a barrier to living at home in IE (Cahill et al, 2012). In DE, the narrow definition of eligibility (focusing on time targets) by the Social Code XI may impede utilisation and be a disadvantage especially for people with cognitive impairments. Data on a national level describing the utilisation of home help with IADL and ADL by PwD is not available for the countries. However, different statistics and estimations are reported in table B.

**B10) Therapeutic care**

*Definition:* Therapeutic care provided at home, for instance wound dressing or injections, by nurses and/or licensed practical nurses/auxiliary nurses.

**Availability**

Therapeutic care is available nationwide and part of standard care in all countries. In PT, although with regional variations, therapeutic care is provided as part of team-based home healthcare (see also B3). In all of the countries, nurses (specialised and auxiliary) provide therapeutic care, in IT and SE also in collaboration with GPs. In IE, public health nurses are responsible for performing therapeutic care along with other tasks.

**Accessibility and utilisation**

In DE, IT, UK and PT, a prescription by a GP or needs assessment is required in order to get therapeutic care. In DE, incorrect prescriptions or a missing diagnosis may impede getting appropriate therapeutic care. In IE, public health nurses do not have a dementia-specific training which may hamper getting therapeutic care.

A regular co-payment of a fixed amount of the total costs (plus 10 € per prescription) is required only in DE. In the remaining countries, very low or no co-payment is required (IE, IT, NL, NO, PT, UK and SE). Data on utilisation on a national level are not available (see table B)
B 11) Rehabilitation at home

Definition: Training at home by occupational therapists, physiotherapists and/or nurses and/or auxiliary nurses or others to improve or maintain functional ability.

Availability
In IE, IT, NL, PT, UK and SE, rehabilitation at home is available nationwide; in PT, although with huge regional variations, it is provided as part of team-based home health care (see also B3). In DE and NO, rehabilitation at home is only partially available. In all of the countries, except IE, it is part of standard care. Physiotherapists and occupational therapists are involved in every country, while in NO, the NL and IE nurses are involved as well. In DE, geriatric rehabilitation at home is provided by a team consisting of different professions, which is supervised by a physician.

Accessibility and utilisation
In DE, co-payment is required regularly (10 €/day for 28 days at the most) and in the NL only a limited number of visits is covered by the insurance. Of the remaining countries, no co-payment is required in IT or UK. In IE no co-payment is required if the service is fully covered by a Home Care Package. If the Home Care Package cannot be made available in time or if it does not cover all needs, an additional, privately funded top-up may be required. Little co-payment may be required rarely in some other countries (NO, PT, SE). In DE, IE, NL, UK and PT, a referral or needs assessment is required, and in IE and PT the public access to home-based rehabilitation is extremely limited, leading to long delays.

Data on utilisation on a national level is not available. However, utilisation is assumed to be low in DE and NO. In IE, holding a Medical Card and living in certain regions may increase the chance of receiving rehabilitation at home. In SE, it is estimated that PwD use rehabilitation at home on average four times per year, which suggests a high utilisation (see table B).

B12) Respite care for people with dementia or mixed with other older people

Definition: Residential care around the clock for relief to informal carer who provides care for a family member/close friend. In a nursing home, residential living or comparable, but not at home.

Availability
Respite care is available in all of the countries: available nationwide in the NL, NO, PT, SE, UK and regionally in IT. Regional variations are to be found for IE and DE. In IE and IT, respite care is not part of standard care, and in PT it is only so in the RNCCI (long-term care network) not e.g. in public hospitals. Facilities offering respite care are nursing homes, care homes or sections of sheltered living; care and support is mainly provided by (aux.) nurses or trained healthcare workers.

**Accessibility and utilisation**

A considerable number of access restrictions are described. In IE, NO, UK and PT, needs assessment is required. In SE, the home help officer decides about using respite care, and in DE, a defined degree of disability according to Social Code XI is required to get the costs covered by health and long-term care insurances. Co-payment is necessary in all of the countries. However, the amount varies. In DE, only care costs are covered by long-term care insurance and costs for accommodation and catering have to be paid for privately. In IE, private payment is necessary unless respite care is provided as part of a Home Care Package but so called ‘Respite Care Grants’ are available as a support. In IT, the level of co-payment varies considerably per region. While in NO a fixed amount of co-payment (120NKR/day) is mentioned, in PT co-payment is adjusted to income in the public sector, but full out-of-pocket payment is required in the private sector. In the NL, there are no costs if respite care is allocated according to a needs assessment, and in the UK there are no costs if the respite is provided in an NHS hospital, an increasingly rare occurrence. All of the countries have a limited bed capacity and/or waiting times. In IE, two weeks/year are considered to be the mainstream, while in DE 28 days/year and in PT 30/days per year are covered by the public sector (longer periods in health subsystems/voluntary insurance schemes, or entirely depending on out-of-pocket payments in the private sector). Moreover, a dementia diagnosis is a precondition in IE and there is a shortage of good quality respite care in that country.

Data on utilisation are scarce. In SE, approximately 4% of the PwD used residential respite care in 2012 (Wimo et al., 2014). Utilisation seems to be higher in DE, where a study revealed that 20% of PwD used respite care during the last year (Schneekloth & Wahl, 2005). However, no recent data on a national level are available. Utilisation also seems to be high in IE with 15 days of respite care per year on average (data not dementia-specific) (Cahill et al., 2012). Though no data are available in PT, under-utilisation is assumed, probably due to a lack of awareness on the part of the informal carer (Ribeiro et al, 2011, Santa Casa de
Misericórdia de Lisboa, 2007). No information is available for IT, the NL, UK and NO (see table B).

**B 13) Residential home/Sheltered housing/Assisted living**

*Definition:* Housing/facilities (not "licensed" nursing homes) with different levels of services for people who are not in need of 24 hours nursing care. Those facilities offer access to formal care if required, e.g. interventions in case of emergency (Jann 2012, Sloane et al. 2003, Zimmerman and Sloane 2007).

**Availability**

Comparable living facilities are available nationwide in DE, IE, the NL, NO and UK but only available regionally in IT, PT and SE. In most of the countries, such facilities are not dementia-specific; in IE very few facilities exist especially for PwD. In the UK, a number of residential homes are specifically for people with dementia. In IE, facilities are registered and have to be inspected; this applies to UK residential homes also. No statutory standards exist in DE, but minimum standards are recommended. In all of the countries, age-adapted accommodation is combined with different levels of support according to the needs of the inhabitant. Providers are public entities and non-profit organisations but also a considerable number of private organisations. Different healthcare professionals may be involved: mainly nurses but also therapists. In PT, sociocultural animators may be involved.

**Accessibility and utilisation**

Considerable access restrictions are indicated. In the NL, costs are covered but such facilities can only be accessed based on a needs assessment applying strict criteria since public resources are limited. In all the other countries, rents have to be paid for accommodation and co-payment may incur partially for the care or social services or housekeeping used (DE, IE, IT, NO, SE, UK). Thus low income and high care needs are described as barriers in DE and PT. Moreover, in DE, IE and PT, having dementia turned out to be a barrier for living in such facilities; this applies also in the UK to extra-care housing and sheltered housing, but not residentia homes. Insufficient availability and long waiting times may be a further problem in IE, IT and SE.

Data on utilisation are limited. In SE, approx. 14,000 PwD lived in comparable facilities in 2005, while it is estimated that around 17% of PwD in the NL live in such facilities. No information on the utilisation by PwD is available in the other countries (see table B).
B 14) Social support

Definition: Service for people with dementia, e.g. accompanying a person to appointments or individually supporting leisure, or in terms of support groups for people with dementia.

Availability
Social support is available in all of the countries, but is only available regionally in IE, IT and PT. In IT, NO and SE, services are not dementia-specific, while in DE, UK and IE a dementia-specific direction is evident. In IE, IT and PT, social support is not part of standard care. In most of the countries, social support is provided predominantly by third sector organisations such as volunteer or non-profit organisations. But municipalities (in NO and SE) or professional home care organisations (DE) also provide social support. In all of the countries, volunteers, trained or untrained healthcare workers but also (aux.) nurses are involved.

Accessibility and utilisation
Few access restrictions are described. In DE and NO, where social support is covered, needs assessment is a precondition for utilisation. In IE, IT, PT and SE, co-payment may be necessary. In the NL, social support may be covered by personal budgets. Depending on the type of service, a dementia diagnosis is required in IE, and waiting time may be a problem in NO. Moreover, social support services in SE are geared to adult people below 65 years and hence the majority of PwD is excluded.

No data on utilisation is available in most of the countries (IE, IT, NL, NO, PT, SE, UK). It is reported that in DE about one third of PwD living at home use social support services, and overall 190,300 people in need of care used such services in 2012 (see table B).

B 15) Personal safety alarm or surveillance/monitoring systems

Definition: Alarm systems or special sensor technology to monitor a person's movement, either positioned within the living area on the body (Kenner 2008).

Availability
In all of the countries, personal safety alarm systems are available nationwide (monitoring systems are less frequently found), although in PT these are mainly pilot projects with still limited availability. In the NL, NO, UK and SE, such services are provided by the
municipalities, while in the remaining countries mainly private companies or non-profit organisations offer these alarm systems.

Accessibility and utilisation
Except in IT, co-payment or full payment (in IE, unless covered by a Senior’s Alert Grant) is required in all of the countries. In IT, a prescription is required and in DE, UK and NO needs assessment is required (in DE in order to receive reimbursement from the long-term care insurance; in the UK to receive assistance from the local authority). No data about utilisation by PwD are available.
3) Information and counselling (C1-C4)

The section on information and counselling includes information regarding advanced directives/advanced care planning for PwD, information delivery structures, counselling for PwD and legal guardianship for PwD. Advanced directives are available in all of the countries but regulated diversely. Only in the NL are advanced directives part of the National Dementia Strategy and a GP is necessarily involved. Legal guardianship for PwD is implemented in all countries. However, in PT the process is described as long-lasting and still unknown to many so that the family often takes over the responsibility in good faith, but without a legal basis. Public authority guardians are not available in practice. For institutionalized PwD, directors in charge may be appointed as guardians. In the UK, the person may appoint another person (often a relative) to act on their behalf if he/she loses capacity in the future, to make decisions regarding finance and/or welfare; in the absence of this ‘lasting power of attorney’, such a person may be appointed by the relevant court – a process some families find complex and expensive.

In the countries DE, IE, IT, UK and PT nationwide information delivery structures are mainly provided by large third sector organisations (Alzheimer Societies, volunteer and patient/informal carer organisations). Mainly web-based information is provided or help-lines are offered. In the NL, a national care portal is under development, and in SE and NO nationwide initiatives exist. However, only in NO is information (on a national level) provided actively and personally via the dementia teams, although this also occurs in parts of the UK (see also A4 and B1). Special counselling for PwD in a structured way is only available in the NL (provided in memory clinics) and NO (provided by dementia teams), though it may be provided by private societies or third sector organisations in the remaining countries. Sometimes no clear distinction is made between counselling of PwD and the informal carer (see also D2).

C 1) Advance directive/ advance care planning

Definition: Process of discussing and recording preferences concerning (goals of) care for people who may lose capacity or communication ability in the future (Brinkman-Stoppenburg 2014).

Availability

In DE, NL, PT, UK and SE, advanced directives are regulated by law. In the NL, advanced directives are part of the National Dementia Strategy. In IE, a comparable law is under development, while a private society in NO and National Ethics Committees in IT provide
information and offer national registers. Only in the NL do formal procedures exist to involve a GP or other healthcare professionals in writing advanced directives. The involvement of healthcare professionals is recommended in every country (see table C).

Utilisation
No data on utilisation by PwD are available.

C 2) Information delivery structures

Definition: Information structure/programmes aiming to provide information for people with dementia and their informal carers regarding dementia and supporting services (e.g., structured awareness/education programmes).

Availability and Providers
In most of the countries, the National Alzheimer Societies constitute the most significant information delivery structure on a national level, complemented by volunteer and patient/informal carer organisations (IE, IT, NL, PT, DE, UK). In DE, the government provides additional public web-based information databases, and in IE the government and several national organisations are involved in supplying information as well. In the NL, a web-based National Care Portal is under development and will be part of the National Dementia Strategy.

In SE and NO, nationwide public health initiatives exist regarding structured information supply. In SE, national institutions provide web-based training courses and information as part of the Dementia Strategy. Structured information supply is part of the National Dementia Strategy in NO and the UK as well.

Information is in general web-based and provided in an impersonal way, only in NO is structured information (as part of a national public health initiative) provided actively and in a personal way by the dementia teams (see table C).

C 3) Counselling for people with dementia

Definition: Agencies or professionals providing counselling to people with dementia (alone, in groups, or together with their families).

Availability
Specific counselling structures for people with dementia are available nationwide in the NL and NO. In the NL, counselling is offered in memory clinics and by community mental health teams, in NO by the local authorities and by the dementia teams. In the UK, pre-diagnostic counselling is widely recommended, but post-diagnostic support is more variable. In SE, the distinction between counselling for people with dementia and informal carers is less clear, but covered in a structured way. In the NL, NO and SE, counselling is part of the National Dementia Strategy. The recently published strategy in IE mentions the importance of emotional support but no provision is made to provide this support. It is mentioned that in DE, IE, IT and PT no formal counselling services for people with dementia are available (refer therefore to D2). Nevertheless, counselling in these countries may be provided by private societies, volunteer organisations or non-profit organisations such as Alzheimer Societies. In PT, it may also be part of standard care in a few specialized clinical settings.

**Accessibility and utilisation**

Overall, there are few access restrictions. Services by third sector organisations are mainly free of charge. Services of psychotherapists generally require fees in IE, and in the NL and SE a small co-payment may be necessary. A lack of information (NO), insufficient standardisation and availability (IT) or insufficient staffing (SE, UK) may be barriers. The utilisation is unknown except in the NL, where counselling is proposed to 93% of the people with dementia and used by 88% (see table C).

**C 4) Legal guardianship**

*Definition: Authority to care for the personal interests of a person, and to manage legal affairs (e.g., property).*

**Availability**

Processes and regulations regarding legal guardianship are in place in all of the countries, and certain tasks of daily living are covered. In PT and SE, the concept of a trustee is in place and is applied when less support is required; in the UK, the person can specify who he/she wishes to act on their behalf if at some future point capacity is lost. Formal procedures on how an application can be made and regarding necessary evaluations of the ward’s capacity are established in all of the countries. In PT, the process of obtaining legal guardianship is extensive and slow. Therefore, a huge number of PwD still does not have a legal guardian and the family often acts on their behalf without a legal basis. Paid professionals act as public
authority guardians except in PT. In DE and in PT, mainly family members are supposed to take over the legal custodian- or guardianship (for more detailed information see table C).

**Number of PwD with legal guardianship**

There are no data available, except in IE, where it is estimated that approximately 30% of the wardship cases are due to dementia.
4) Support for informal carers (D1-D3)

The section support for informal carers includes information regarding informal carer education, informal carer counselling and financial support. Third sector organisations seem to be an important provider of informal carer education and counselling programmes in all countries, but particularly in countries in the initial stages (IE, IT) or without National Dementia Strategies (DE, PT). In the NL and UK, memory clinics regularly provide education and counselling. In NO, the municipalities are in charge (through dementia teams) while in SE the municipalities have the main responsibility (according to law since 2009) to provide support. In DE, health and long-term care insurances also provide a considerable number of counselling and education services. In general, formal access restrictions regarding education and counselling seem to be low.

Financial support is regularly available in all of the countries, except in SE (cash benefits are rarely granted). Access restrictions exist in all countries, such as needs assessment (all countries), monitoring mechanisms (DE, IT), or means testing (IE, IT, PT). Data on the overall utilisation suggest that financial support is widely used in DE, IE and NL. In PT, a few health services may provide educational programmes/counselling for carers, but mainly on an irregular and/or small scale basis.

D 1) Informal carer education

Definition: Training for informal carers in care and service for people with dementia, education about needs and symptoms.

Availability

Informal carer education is available nationwide in DE, IE, IT, NL, NO, SE, UK and regionally in PT. In the NL, informal carer education is part of the Dementia Strategy and is provided as an outreaching service. In IE, the current strategy proposes a delivery mechanism but this is still in development. In DE, NL, NO, UK and SE, informal carer education is part of standard care. In the NL, providers are memory clinics, in NO local authorities are in charge together with third sector organisations, and in SE the ‘National Competence Centre for Informal carer Support’ and the ‘Swedish Dementia Centre’ (SDC) provide courses for informal carers. In the remaining countries, mainly non-profit organisations such as Alzheimer Societies or other volunteer organisations provide informal carer education. In DE, health and long-term care insurances run educational programmes as well.
**Accessibility and utilisation**

For the most part, no payment or just a small co-payment may be required. In DE, a lack of awareness and unspecific offers not focusing on dementia may constitute a barrier for utilisation. Staff restrictions in IT or regional differences in availability in NO may hinder utilising educational programmes. Overall, data on utilisation are scarce. In DE, study findings suggest that around 13% of informal carers of PwD utilised informal carer education. In IE, national programmes were used by more than 1,000 informal carers (see table D).

**D 2) Informal carer counselling**

*Definition: Agencies or professionals providing counselling for informal carers of people with dementia.*

**Availability**

Counselling for informal carers is available nationwide in most countries, and regionally in PT. In IE and SE, no counselling structures exist that distinguish clearly between counselling for informal carers or for PwD. In DE, counselling is usually focused on informal carers (see also section C3). In NO and SE, counselling of informal carers is covered by the National Dementia Strategy and it is part of standard care in DE, NO, UK and SE. In none of the countries is counselling for informal carers initiated regularly, e.g. as post-diagnostic process. In DE, regular counselling is mandatory for informal carers receiving cash-benefits from the long-term care insurance (see also D3). In most of the countries, counselling is predominantly provided by non-profit organisations (such as Alzheimer Societies or volunteer and patient organisations). In DE, welfare organisations and health insurances provide a considerable level of counselling services. Municipalities are in charge in NO and in SE the National Competence Centre for Informal Carer Support and the Swedish Dementia Centre (SDC) are in charge of providing nationwide counselling services (partially overlapping with informal carer education, see D1).

**Accessibility and utilisation**

Few access restrictions are reported. In most of the countries, no out-of-pocket payment is required (DE, IT, NO, PT), while in IE private psychotherapists generally charge a fee and small co-payments may arise in SE. In DE, comprehensive counselling (or even case management that is offered by long-term care insurances) requires a defined degree of disability according to Social Code XI. Staff restrictions and a shortage of resources may
impede the use of counselling services in IT and SE. Data on utilisation by informal carers of PwD is rare. A study suggests that any kind of counselling was used by approximately 50% of the informal carers of PwD in DE (see table D).

D3) Financial support for informal carers

Definition: Financial support paid by government/insurance to the informal carers.

Availability
Financial support is available nationwide in most of the countries and regionally in SE. The policy in SE has changed over the last decades and direct financial benefits are nowadays not usual. The amount of payment varies considerably per country and can comprise financial compensation (IT, NL, IE), or monthly payments in IT, PT and DE (in DE according to the level of disability). In DE, UK and PT, financial support is granted to the person in need of care. In IE, several support-programmes exist, offering financial support and household benefits for the informal carers.

Accessibility and utilisation
Access restrictions vary per country. In all of the countries, needs assessment of any kind is required. In DE, receiving cash-benefits requires continuous monitoring in terms of counselling the informal carer (see also D2). Monitoring is also implemented in IT. In SE, the capacity of the carer is evaluated before financial support is granted. In IE, IT and PT, means testing is a precondition and in IE, financial support is granted only for full-time caregiving with high care requirements.

Data on utilisation by PwD and their informal carers are not available. However, data on the overall utilisation suggest that financial support is used in NO and widely used in DE, IE and the NL, (see table D).
5) Civil activities (E1-E2)

The section civil activities includes information regarding voluntary organisations and self-help organisations that are available in all countries, initiated and supported mainly by national umbrella organisations such as the Alzheimer Societies.

E 1) Voluntary organisation

Definition: Unpaid or paid civil organisation providing care and service to persons with dementia disease on a voluntary basis.

Availability
Voluntary organisations are available nationwide in most of the countries and are regionally available in PT. However, no national programme/initiative exists in any of the countries, although key organisations such as Alzheimer Societies operate on a national level.

Utilisation
Data on utilisation is scarce. It is estimated that about 1% of PwD in DE use support by voluntary organisations.

E 2) Self-help organisation

Definition: An organisation may offer individual support by peers.

Availability
Self-help organisations are available nationwide in DE, IE, IT, NO, UK and SE, but only regionally in the NL and PT. In all of the countries, self-help structures are initiated or facilitated by national umbrella organisations. There are additional local initiatives (see table E).

Utilisation
No data on utilisation are available.
6) Addendum

A few services/structures have been added by the ActifCare partners. In IE, *Home Care Packages* were described. In the NL, PT and SE, institutional long-term care structures have been added because they were considered to be an important part of dementia care structures, also influencing the utilisation of home and community care structures.

6.1) Addendum Ireland - Home Care Packages

*Availability*

A Home Care Package (HCP) is a set of community services and supports to assist an older person, depending on their individual, assessed care needs. A HCP refers to the enhanced level of services needed beyond mainstream levels. HCPs do not replace existing services. Services provided through a HCP might include additional home help hours, nursing care, physiotherapy, respite care, and other services to support the individual's needs. The Care Plan will set out the agreed care outcomes and actions to be undertaken by all services, supports and care staff, taking account of the assessed care needs of the applicant. HCPs are available nationwide and are managed by Local Area Health Offices (LHOs).

The Regional Directors of Operations (RDO) are fully responsible for all service delivery and reconfiguration/integration of hospital/community services within their geographic regions and within the agreed Annual Service Plan and Regional Performance Contracts. Local Health Office managers have responsibility within their own areas for overall service delivery including providing HCPs. The HCP manager in each LHO area is responsible for the day-to-day allocation of the HCP resources. Public Health Nurses (PHN) and other relevant healthcare professionals carry out regular HCP reviews.

The Health Service Executive (HSE) supports the concept of multi-disciplinary (MDT) working. The majority of HCPs will involve service delivery directly by the HSE or on behalf of the HSE by voluntary or private providers who already have a service level agreement in place (indirect HCP)

*Accessibility and utilisation*

As HCPs are based on assessed needs, there are no upper or lower time limits for a HCP. Review arrangements are put in place at the time of approval of the package to ensure that the individual’s care needs continue to be supported in the most appropriate way in the most
appropriate setting. These are generally carried out by the PHN and/or other relevant healthcare professionals. No other formal access restrictions are described.

When limited resources for HCPs are fully allocated at LHO level and waiting lists are in operation, a prioritisation mechanism for allocating resources (services & supports) to approved applicants is implemented (HSE, 2010). A lack of adequate services and the uneven distribution of services pose a problem for home-based care. In many cases the HCP alone, without additional family inputs or private 'top-ups', would not be sufficient to maintain a person with dementia at home (CIB, 2009). The HSE does not capture data regarding the primary reason for HCP approval, so dementia-specific utilisation is not available. The actual overall utilisation for 2013 was 11,873, an increase of 850 on 2012 (HSE, 2014e).

6.2) Addendum - Institutional long-term care structures

F1) Group dwelling/Small-scale living/Dementia patients´ house unit

*Definition:* Care provided in small-scale units, with a specially planned and adapted milieu to meet the needs of persons with dementia. Staff trained in dementia care. Only people with dementia are signed in.

**Availability**

Group dwelling or small-scale living is available in DE, IE, NL, UK, NO (partially) and in SE. In SE, specialised dementia care units are designed as group dwellings and located as separate housing units or within the nursing home (thus see also F2, F3). In NO, group dwelling is a type of accommodation and people are considered as living at home. Small initiatives from different institutions exist in the NL. It is not part of standard care in the NL and NO. In IT and PT, group dwelling is not available.

**Accessibility and utilisation**

Most often, co-payment is required (DE, NL, SE, UK); in NO a normal rent has to be paid. In DE, a degree of disability is a precondition for getting a place at a group dwelling unit/facility and in NO certain admission criteria may have been established (indicating a low level of physical or cognitive impairment). In the NL and UK, the level of co-payment depends on income and family situation. Moreover, certain admission criteria exist in NO. In SE, a decision of a home help officer is required and in the NL and DE a certain degree of disability is a necessary prerequisite.
Data on utilisation by PwD is scarce. It is estimated that 1.3% of places in institutional long-term care facilities in DE are group dwellings, thus it plays a subordinate role. In NO and SE, group dwelling seems to be more common. In NO, 26% of the municipalities offer at least one unit, while in SE about one third of the beds in sheltered living facilities were group dwelling places.

**F 2) Nursing home for older people not specifically for those with dementia disease or mixed with other older people**

*Definition:* Facilities with available 24-hour nursing care provided by employed staff. May also include short-term rehabilitation as well as long-term care for people with chronic impairments or disabilities who require daily attention of RN’s in addition to help with personal care or/and mobility.

**Availability**

Regular nursing homes are available in all the countries (regional differences in IT). They are provided by a mix of public, voluntary (or charity organisations) and private providers in DE, IE, IT, UK, NL (and municipalities in the NL) and PT (contracts with the government). In IE, the number of private beds has even increased due to a common funding scheme and the majority of people with dementia actually live in private facilities.

In NO and SE, nursing homes are mainly provided by the municipalities (or by private providers with contracts with the municipalities). Mainly nurses (registered and auxiliary) are involved but also care assistants, physiotherapists, and occupational therapists as well as pharmacists, nutritionists and psychologists in PT. In IT, the NL and PT physicians are also employed. In IT one nurse is in charge of no more than seven patients.

**Accessibility and utilisation**

In most countries, co-payment is required (DE, IE, IT, NO, PT, SE, UK); in the NL co-payment is only required if this service was not allocated by CIZ. However, the amount can vary considerably. While co-payment is capped at a certain amount per month in SE, a financial assessment is carried out in other countries to determine the amount of financial contribution one has to make (IE, IT, NO, UK), which can be up to 75% of one’s pension in NO. In PT, co-payment may be requested according to the PwD’s family income.

A kind of needs assessment is required in IE, NO (and referral required), PT and in SE. In DE, a degree of disability (Social Code XI) is a precondition for entering a nursing home, and in the NL, the eligibility criteria are becoming stricter. Waiting time is described as a problem in IT, NO and PT. In IE, the assessment for financial approval is quite complex and can take
up to 12 weeks. Moreover, the financial situation of younger families (e.g. with mortgages) is not adequately considered, so that nursing home admission may cause a high financial burden. Additionally, no legal entitlement for financial support exists in IE, it is depends on the available resources.

In the NL, 17.8% of PwD live in a nursing home. In DE, it is estimated that approximately 25% of PwD live in nursing homes, while in SE approximately 40-45% of people with dementia live in long-term care institutions (group dwelling or service houses, see addendum).

No comparable information about utilisation by PwD is available from the remaining countries. In IT, 1.8% of people over 65 years are admitted to residential care facilities, in the UK 3.2%. In NO, 176 beds are available per 1,000 inhabitants aged 80 years and older. In PT, 4,094 long-term care beds were available nationwide, occupancy was 96% (data relating to December 2014) (ACSS, 2014).

F 3) Nursing home with dementia care units

Definition: Facilities with available 24-hour nursing care provided by employed staff. May include short-term rehabilitation as well as long-term care for people with chronic impairments or disabilities who require daily attention of RN’s in addition to help with personal care or mobility. Including units with staff specialised in dementia care.

Availability

In DE, NO, UK and SE, specialised dementia care units are available nationwide and are part of nursing home structures (see F2, respectively F1 in SE and the NL). In IE and IT, specialised dementia care units are only available regionally, and in PT they are available either very restrictedly or only regionally.

Significant inequalities among regions are described in IE, where dedicated dementia-specific beds are the exception rather than the rule. The vast majority of people with dementia living in residential care are cared for within generic care facilities for older people, most of which are not purpose-built for dementia and many of which are not designed to cater for the complex, challenging, and unique needs of people with dementia. Moreover, over 50% of all special care units were located in only four of the 26 counties in IE.

In PT, these units are not standard care, but if these structures exist, a full multidisciplinary team is involved: physicians, nurses, healthcare assistants, social care workers, rehabilitation technicians (physiotherapy, occupational therapy), pharmacists, nutritionists and psychologists.
Accessibility and utilisation

Co-payment is required in all countries (which may even exceed the costs of a regular nursing home in DE). In PT, very few non-profit institutions provide this kind of care with state funding (co-payment may be required according to the PwD’s income). Some private institutions provide this kind of care in return for full out-of-pocket payment, which may constitute strong financial restrictions.

Moreover, certain admission criteria are applied in IE and IT (such as a pre-admission assessment, dementia diagnosis and challenging behaviour). In PT, diagnosis of dementia, strict eligibility criteria and needs assessment are considered as standard good practice procedures and not as access restrictions.

In IE and PT, considerable waiting time is described (mean time 22 weeks in IE). Data on utilisation by PwD is rarely available with the exception of IE, where about 2% of the people with dementia (4.5% of the people in long-term care facilities) reside in special care units.

F4) Nursing home specialised in dementia care.

Definition: Facilities with available 24-hour nursing care provided by employed staff. May include short-term rehabilitation as well as long-term care for people with dementia disease who require daily attention of RN’s in addition to help with personal care or mobility. Including staff specialised in dementia care.

Availability

Nursing homes specialised in dementia are frequently found in the UK, but are not available in DE, IT and NL, and are only rarely available in IE, NO, PT and SE. However, in SE and IE it is not possible or only difficult to differentiate between special dementia units and nursing homes specialised in dementia care (see F2, respectively F1). In PT it is not part of standard care and non-profit (União Misericórdias Portuguesas, Sisters Hospitallers, Brothers of St John of God and others) and private institutions provide this service or similar ones. Health insurances and health subsystems are reluctant to cover expenses, unless acute health problems coexist with dementia (see also F3).

Addendum Germany: Special care units for people with advanced dementia

Definition: Special care units for PwD with advanced dementia (so called care oases) are single rooms for three to eight people with advanced dementia and 24/7 nursing care (Brandenburg, 2011).

Availability
Only rarely available, not part of standard care.

**Accessibility and utilisation**

Co-payment is required which may exceed the level of co-payment for a regular nursing home. Only people with advanced dementia and severe care needs are admitted. In 2011, 23 special care units with 213 places existed nationwide (Schuhmacher and Klie, 2011).

**Addendum Portugal: Residential structures for the elderly ERPI (Estruturas residenciais para pessoas idosas)**

**Availability**

Available nationwide (Gil, 2007) but more often in urban areas (CEDRU, 2008). Inspected and registered. No statutory standards but recommendations for minimum standards: social support, catering, temporary or permanent assistance with ADL/IADL. In PT, most of the institutional long-term care for the elderly is provided by ERPI (Estruturas residenciais para pessoas idosas - Residential structures for the elderly) (Joel, 2010). These structures do not have 24h nursing care (although relying on different degrees of support from RN's), but provide permanent care by trained healthcare assistants (Instituto de Segurança Social, 2011). ERPI may fit under the umbrella term 'care home', just as the nursing homes described above, providing a higher level of care than so-called 'residential houses' described earlier (B13). In PT this is the usual residential solution for elderly dependent persons, including PwD. They are provided by non-profit organizations or private providers, sometimes with state funding. There is increasing awareness of the specific needs of PwD, and some institutions are evolving to adapt and respond to these needs (Barbosa, 2011). Social care workers, nurses (part-time), doctors (part-time, typically a GP but including other specialists), healthcare assistants and sometimes socio-cultural animators or other professionals are involved (Instituto de Segurança Social, 2011).

**Accessibility and utilisation**

If the institution has state funding, co-payment might be required according to the resident’s income. Otherwise, payment is fully out-of-pocket. A diagnosis of dementia may be a barrier, depending on the institution and its stated mission. Needs assessment is required by the government (for licensing purposes). Waiting time may be a barrier (Instituto de Segurança Social, 2011).
In 2007, there was a total provision of 1,583 institutions with 61,757 users (Gil, 2009) located mainly in the greater urban areas (Lisbon and Porto). Coverage rate (number places/population) 3.4% (age >= 65) and 7.7% (ageb >= 75) (Joel, 2010). The percentage of residents in general/non-specialised residential homes who have dementia is estimated at 30% (Alzheimer Europe, 2009). A 2010 study found that 29% of the users of the residential homes have dementia (Paquete & Silva, 2011).

**Addendum Sweden: Service houses**

**Availability**

Service houses are nationwide available (in all regions) and part of standard care. They are provided by municipalities (or by private providers with contracts with municipalities). Mainly LPNs, nurse aids, and fewer registered nurses are employed. The services houses are regulated according to the Social Services Act. However, another form of low staffed living facilities is emerging in Sweden, which not is regulated according to the Social Services Act. These living facilities are often labelled as "Safety living" ("Trygghetsboende" in Swedish) or "senior living" and they are not designed, staffed or planned for people with dementia.

**Accessibility and utilisation**

Co-payment is required (not exceeding a certain amount per month, see F2), and the resources may differ per municipality. Moreover, a decision of a municipal help officer is required. In the Swedish cost of illness study it was estimated that about 40-45% of the dementia population live in long term care institutions (95,000 beds). The low staff living facilities constituted about 35,000 out of the 95,000 "beds" (or rooms) of sheltered living in Sweden and that about 14,000 PwD out of these 35,000 lived in that kind of living facility. The trend is that Service houses are decreasing while the non-regulated living forms ("safety living" or "senior living") are increasing.
3) Results – *Common practice examples (case vignettes)*

The appendix presents all the case vignettes representing common practice examples of access to formal care. Several common themes can be extracted, comparing similarities and differences across countries.

**Access to formal care**

In most common practice examples, the general practitioner (GP) was the first point of access for family informal carers to seek help. When problems in the home situation arose and progressed, GPs played a role in diagnosis and further referral to specialist diagnostic services. In Ireland, people also have an established connection to a secondary clinician after having received a dementia diagnosis (mostly a consultant psychiatrist or consultant geriatrician). After the diagnosis, this consultant prescribes medication and arranges follow-up appointments (usually twice a year), notifying the GP. This is also the case in PT, most often with neurologists but also with psychiatrists, working either in the NHS or in private practice. In many examples, the GP may refer to a specialist unit for further diagnosis and assessment (e.g. memory clinic in the NL or Alzheimer Evaluation Unit in IT). In the UK, the diagnosis is most likely to be made at the NHS Memory Clinic, where nurses monitor the patients every three months. Thus the Memory Clinic was most likely the first point of contact in the UK.

In almost half of the common practice examples, the first access point towards formal care is performed by an external organization (NL, DE, IE, UK). In these examples a standardized needs assessment procedure is conducted in which a care package for people with dementia is decided on, depending on the level of needs. In Ireland, a public health nurse conducts such an assessment, whereas in the NL and DE this is conducted in close cooperation with the long-term care insurance agencies. In DE, health and social care are covered by the same insurance and one comprehensive assessment is conducted. In the NL, health and social care are split and paid for by different financing structures, each having their own assessment. In PT, there also issues regarding differences between health and social care structures. In the NL, you also have the option to apply for a personal budget. You can choose to either carry out care activities yourself while using the personal budget for financing, or you can outsource care to external organizations or finance this with the personal budget. In the UK, Local Authority Social Services Departments carry out a so-called Carers Assessment both of the patients and the carers (separately). In other countries, access to formal care is guided.
through municipalities in NO and SE (through dementia teams in NO) or via a specialist unit (IT).

**Formal care services available**

Most mentioned formal care services are home care support with ADL (IT), medication (prescription and monitoring) and day care services. Not all people are willing to accept these services, mainly because they feel it does not fulfil their needs. The choice of formal care organisations varies across countries. In the NL, DE and IR, sometimes in PT, informal carers have to decide for themselves, which organisations they would like to choose. In other countries, this is arranged in close contact with a dementia team (e.g. NO) or local municipalities (e.g. NO, SE).

Payment of these structures varies widely across countries. In NO, many services are for free (i.e. technical aids, home support). In other countries, part of the care is covered via insurance but people can ‘top-up’ their care if they feel they need more support (e.g. IE). In PT large differences exist between regions (major urban centres versus middle sized towns, or rural regions) and use of services depends largely on income. Subsidized home care may be provided by public services and several non-profit organizations (e.g. Misericórdias). The user contribution is determined by the type of services requested and by the family income, applying a percentage of 50% on the ‘per capita’ household income (up to 60% depending on extra services). People from middle to higher incomes probably hire caregivers (not necessarily professionally well-trained ones) or private home care services, or even apply directly for a private nursing home. Major private players or mutual associations that provide nursing/residential homes/assisted living facilities tend to operate in major urban centres.

In the UK, care packages with different types of support are granted, including meal services and attendance at a day centre, and the informal carer can apply for allowance (e.g. for visiting a day centre).

**Informal carer support**

In IT, it is very common for people to have a migrant informal carer, who are reached via volunteer associations, religious associations or by word of mouth. They are employed under a private contract, at the informal carer’s own expense. This could be done legally (with fiscal subsidies) or illegaly (still a very common approach). Similar structures exits in PT.

In the UK, a Carers Assessment is performed as part of the needs assessment and a social worker may assist the informal carer in applying for the allowances in question, or in finding
out how further support (such as assistive technology) or respite options (such as respite care in care homes) can be applied for.

Furthermore, all of the countries have informal carer support groups; counselling and other types of social support are also mentioned. In many countries these are provided by volunteer organizations or by the Alzheimer's society.
Discussion/Conclusion

Summary and discussion – systematic literature review

The results of the literature search showed that despite extensive searches also in national databases only few and partially inconsistent data were available, which might explain the influence of socioeconomic or cultural aspects on access to and utilisation of formal care services for PwD and their informal carers. None of the chosen socioeconomic or cultural aspects were well investigated within the ActifCare countries. The influence of age, gender and financial aspects were investigated more often than the influence of ethnicity, education, region of residence and family relationships.

The international literature showed that age had only modest influence on service utilisation (Robinson et al., 2005; Beeber et al., 2008). However, there are differences between medical and social care services (Eisele at al., 2010, Koller et al., 2010). Therefore, medical care, especially visits by specialists, decreased with the increased age of the PwD. An important aspect seems to be the fact that younger PwD have no appropriate service offers (Beattie et al., 2004; Cahill, O’Shea & Pierce, 2012; Regan, 2014). Gender related international findings agreed with the findings of the ActifCare partners in that especially the wives of PwD tended to use fewer services than male informal carers do (Pedlar & Beigel, 1999; Toseland et al., 2002; Robinson et al., 2005; Boersma et al., 1997). Neither international literature nor studies by the ActifCare countries explored the influence of family relationships on access to formal care for PwD. It is therefore unknown whether spouse or child informal carers differ in terms of accessing services. Few international data were available to give an insight how paid work influences informal carers of PwD with regard to accessing formal care. Some studies suggested that employment of informal carers may have influence on service use (Ongaro et al., 2006; Gillespie et al., 2013; Frewer-Graumann, 2014). The few studies investigating the influence of the region of residence on services suggested that PwD and informal carers in rural areas have more difficulties to access appropriate services, with exception of the Nordic countries SE and NO, where fewer differences in service provision were described (Burholt et al., 1997; Koller et al., 2010). The influence of attitudes towards dementia on access and service use was seldom investigated. An exception was the Facing Dementia Study with participation of the ActifCare partners UK, IT, and DE (Bond et al., 2005). The authors summarized attitudes towards dementia which may be barriers to appropriate care of PwD in Europe and identified these key themes: anxiety, isolation, and lack of awareness and knowledge. Anxiety prevents PwD from seeking help (Begum et al. 2013), but a timely
diagnosis was explored as a prerequisite of access to support services (Gorska et al. 2013; Nolan et al. 2006). **Attitudes towards care of PwD**, for example perceiving positive and negative consequences of support by professional helpers (Roeland et al., 2008) may also contribute to use or non-use of services. The lack of knowledge about available services was identified repeatedly (Dello Buono et al., 1999; Bond et al., 2005; national surveys in Italy and Sweden of the EUROFAMECARE study). The impact of **ethnicity** of access to formal care was described in only a few studies. The findings were consistent in the conclusion that PwD and informal carers with a migrant background have even less access to support services than other people and thus experienced additional barriers (Kosloski et al., 1999; Bowes & Wilkinson, 2003; Mogar & Kutzleben, 2014). The findings related to the influence of **education** were inconsistent. **Financial aspects** as influencing factors of access to formal care were investigated with regard to private payments for utilisation of support services. Private or co-payment seems to be an important fact in understanding access to and utilisation of formal care (Instituto da Segurança Social; 2005; McNamara et al., 2013; Krevers et al., 2006; Dello Buono et al., 1999; Frewer-Graumann, 2014).

Overall, the influence of socioeconomic and cultural factors on the access to and utilisation of formal care services is unclear. This is in line with the results of a literature review, investigating use and non-use of community-based long-term care services by informal carers of PwD (Markle-Reid & Browne, 2001). The authors suggested looking at service utilisation as a complex and subjective decision-making process, which is unrelated to objective circumstances. The recent adaptations of the Andersen Behavioral Models considered the argument that predisposing, enabling and need factors (socioeconomic and cultural aspects are predisposing and enabling factors) of the person with need for care did not explain appropriately why people use support services or not, and that it is necessary to consider further aspects, such as social relationships and contextual characteristics (Andersen, 1995; Andersen and Newman, 2005).

**Summary and discussion – formal infrastructures (template) and common practice examples**

Overall, 29 services and structures were identified as relevant regarding utilisation of and access to formal dementia care at home, and are thus described within the templates. Each ActifCare partner provided country-specific information regarding its availability, accessibility and utilisation. Moreover, following discussions among the ActifCare partners,
information regarding institutional long-term care structures was incorporated. Subsequently, common practice examples (based on the collected information and using the same case vignette) illustrated the access to formal dementia care in all of the countries.

The collected information illustrated the complexity of services for supporting PwD and their families as well as services that may provide or enhance the access to formal care at home (such as GPs, specialised physicians, volunteer organisations etc.). Based on a discussion among the ActifCare partners, the discussion highlights the following aspects: (1) Availability of dementia specific structures/of a determined reference person or institution, (2) Availability of team-based or integrated services, (3) Pro-active initiation of services, (4) Influence on access from the budget/financing point of view.

**Availability of dementia specific structures**

We assessed the availability of dementia specific structures, i.e. *outpatient clinic specifically for dementia, a reference person for PwD and their informal carers, mobile comprehensive expert team with specialised competences in dementia care, team-based community mental health for older people and specialised psychiatric home nursing care*. Moreover, *information delivery structures about dementia and specialised counselling structures for PwD were requested*.

*Outpatient clinics specialised in dementia* were available in IT (so called Alzheimer Evaluation Units) and in NO, where so-called dementia teams are in charge to assist the GP with diagnostic procedures. In PT and SE, dementia specific outpatient clinics are only available regionally. In the UK, Memory Clinics and Memory Services in effect serve this function. A *special reference person for people with dementia and their carers* is only available in NO (through dementia teams) and in SE, where nurses with dementia-specific training are in charge. In IT (where GPs are designated as a continuous reference person) and in the NL (case management), a reference person is available but this healthcare professional is not necessarily specialised in dementia. In PT, case management structures are currently implemented. In IE, the recently launched national dementia strategy plans to appoint a key worker to coordinate care of people with dementia and their families. In DE, a kind of case management is provided on request by the health insurances; however, this is not dementia-specific.
A mobile comprehensive expert team with specialised competences in dementia care was only available regionally in the NL, NO and SE. Team-based community mental health structures for older people are available in IE, IT, UK and the NL; however, these services may not necessarily be dementia-specific. In SE, community mental health is designed mainly for younger people with psychiatric diseases. In NO and PT, comparable services are only rarely available while team-based community mental health services are not available in DE. Specialised psychiatric home nursing care is available nationwide in DE, UK and IE (see above) but is not necessarily dementia-specific (see above), and is available regionally in PT and the NL. In NO, specialised psychiatric home care is not available in all of the municipalities, while this service is not designed for older people in SE. Only in NO, UK and SE is a national public health initiative implemented to provide dementia-specific information (based on the national dementia strategies). Special counselling for PwD is available nationwide in the NL and NO (provided by dementia teams in NO). In the remaining countries, such a specialised counselling is not available or the differentiation between informal carer counselling and counselling for PwD is not possible.

According to our assessment, dementia-specific services, such as an especially designated reference person, seem to be available more frequently in NO and SE and partially in the NL, while services designed for older people in general or people with psychiatric diseases (not necessarily dementia-specific) are involved in most of the other countries. Nevertheless, it has to be noted that our overview may not cover all the available services or local initiatives and the healthcare professionals involved may have a dementia-specific training, which was not covered in all detail within our data collection sheet.

Study findings reveal that informal carers found it hard to navigate a diverse and complex healthcare system (Peel & Harding, 2014; Singh, Hussain, Khan, Irwin, & Foskey, 2014), and a systematic review on the perceptions and experiences of people with dementia highlighted a lack of specialist dementia support, especially after getting the diagnosis (Bunn et al., 2012). Moreover, the large number of different healthcare professionals working with people with dementia and their families may further increase the complexity and hampers clear responsibilities (Hallberg et al., 2014). Healthcare systems with clear responsibilities and dementia-specific structures and services, such a designated contact person, may enhance the access to and utilisation of services for people with dementia and their families.

**Availability of team-based or integrated services**
The overview (templates) comprises certain team-based home care structures (i.e. mobile comprehensive expert teams, team-based home healthcare or team-based community mental health for older people) and provides information on healthcare professionals and whether a multi-disciplinary team is involved.

The described team-based structures were more often available in NO, UK and SE, partially in the NL, IT, IE and PT. Home care in Portugal is provided by so-called home care teams (multidisciplinary teams offering healthcare and psychosocial support in the patient’s own home. ‘Integrated Continuous Care Teams’ provide care and service including help with ADL, medical treatments, etc. ‘Palliative Care Community Teams’ provide technical support/training to health/social professionals). No team-based services were found in DE.

GPs in IE, the NL, UK, PT and SE often work with nurses within their practices, while this is not the case in DE, IT and NO. However, in NO so-called dementia teams consisting of registered nurses, occupational therapists, auxiliary nurses and physical therapists, assist with the diagnostic procedures. Outpatient clinics for people with memory problems/for people with dementia employ multi-professional teams in all of the countries (dementia teams in NO).

The needs assessment – a precondition for accessing formal dementia care services in all of the countries – is performed by multi-professional teams in IR (sometimes), IT and PT; in NO, UK and SE several disciplines are involved (unclear whether they work as teams), while the needs assessment is performed by one healthcare professional in DE (a nurse or a physician) and in the NL (nurse).

Day care centres/day hospitals employ different healthcare professionals (therapeutic, social and nursing professions) in all of the countries in order to meet the diverse needs of the people with dementia. Multi-professional teams are in charge of information and counselling in NO (dementia teams) and IE. Moreover, in NO dementia teams also serve as a continuous reference person for people with dementia and their families, ensuring that a multi-professional team is involved during the course of the dementia.

Studies suggest that there might be a poor intersection between medical and non-medical services (Singh et al., 2014). For example, informal carers in Australia reported particular difficulties in receiving information about non-medical (social) support services from their general practitioners/medical institutions, albeit informal carers perceived information on support services to be of equal importance as receiving a proper diagnosis (Singh et al., 2014).
Thus, improved intersections between medical and non-medical services may enhance needs-oriented and timely service use.

Furthermore, the professional background of the healthcare professional seems to be of importance when recommendations about appropriate long-term care services are made (Kane, Bershadsky, & Bershadsky, 2006). Kane et al. compared the recommendations on appropriate long-term care service made by different healthcare professionals based on the same case vignettes. Considerable differences were found, indicating that each discipline has its own experiences and values that may impact their recommendations and decisions (Kane et al., 2006). Further research has shown that variations between the judgments of single experts were high but working in small groups of experts harmonized the judgments across the groups (Saks et al., 2014). A multidisciplinary approach may therefore lead to more reliable recommendations that reflect the diverse needs of the person in need of care and their families better, and thus may be favorable in dementia care.

Overall, more team based structures seem to be available in NO and SE, but also in IE, the NL, IT, UK and PT certain services are provided by multi-professional teams. The least number of team-based approaches and services was found in DE. The German health and social care system offers a wide range of treatment and care, but there is no systematic coordination in the complex and fragmented system. Against this background, during the last years, so-called dementia networks have been established in many regions, seeking to overcome interface problems and to promote an interdisciplinary approach (Köhler et al., 2014). However, these networks are predominantly pilot projects and may differ in organisation, thus they were not systematically assessed or considered within this report.

Moreover, there is no single definition of multi-professional teams or integrative services (Boon, Verhoef, O'Hara, & Findlay, 2004). Thus, it is not clear how the multi-professional services in the countries are designed or under which paradigm they are working and whether they are comparable. Nevertheless, it may be assumed that more team-based multi-professional approaches enhance the access to services for people with dementia and their families and contribute to a timely service use.

**Pro-active initiation of services**

The country-specific case vignettes describing common practice pathways to formal dementia care have been reviewed. An overall impression is given of how services work in each
country and whether support may be initiated more proactively or whether the informal carers or people concerned are responsible for taking the initiative.

The General Practitioner is the first point of contact in all of the countries and most often specialised physicians or specialised outpatient clinics for memory impairment are in charge of performing the diagnostic procedures. In IE, NO and the UK it is described that regular follow-up visits will take place (twice per year or every three months in the UK) as part of the routine medical care. In Italy these follow-up visits are part of a national project and in NO they are performed by multi-disciplinary dementia teams and cover a carer’s assessment as well as monitoring the medical situation of the person with dementia. Moreover, a member of the dementia team serves as a designated contact person for the people with dementia and their families. In SE, a case manager is involved. In the UK, follow-up visits are performed by a Memory Clinic Nurse. Contacts with other healthcare professionals will be initiated by the Memory Clinic Nurse, who may involve, for example, the Community Mental Health team, if required. The performed assessment includes a carer’s assessment and the assessment of the person with dementia.

In DE, IE, IT, the NL and PT the proactive initiation of services is less distinct in the case descriptions. It seems to be more common that families receive information about whom they should contact, but have to take the initiative on their own and apply for or request suitable services. Moreover, in DE and IE it seems to be up to the informal carer which services provider they choose (in both case vignettes informal carers are described as searching the internet for an appropriate provider). The situation in the NL may be comparable since, for example, the personal budgets offer considerable freedom of choice. In PT, the situation is diverse since support services are available more frequently in urban areas. Moreover, a public and a private sector exist and also financial aspects may influence the decision which service to choose. In IT, most often migrant carers are engaged in order to maintain care at home. The migrant informal carer has to be hired by the family, the contract is private and at the expense of the contracting party; it can be legal (with fiscal subsidies) or illegal (still a very common approach).

Overall, in NO and the UK (and due to case managers probably also in SE), services are initiated more proactively. For instance, follow-up visits in NO include not only medical but also social care aspects. In the remaining countries, the families more often have to actively apply for or request the services needed. The choice of providers is also often up to the
families, which may be perceived as an additional freedom (due to market principles) but could also be perceived as an additional burden (Singh et al., 2014).

The provision of services by public, private and local systems may result in multiple providers that in some cases may offer similar or the same type of services. This may lead to confusion and requires additional time for managing these diverse services (Singh et al., 2014). Research further implies that carers of people with dementia find accessing support services challenging and stressful, which may contribute to a low uptake of services (Peel & Harding, 2014). Even systems which appear more guided and proactive according to the descriptive information in this report, like the common practice example from the UK, are still perceived as confusing and inaccessible for informal carers of people with dementia (Peel & Harding, 2014).

**Influence on access as seen from the budget and financing aspects**

We looked at the financing aspects of expenditures for long-term care, national financing systems, private payments, and financial support for informal carers.

Public expenditures for long-term care in percent of the GDP (average between 2006 and 2010) differ strongly within the ActifCare countries. These range from a lower level in PT (0.1%) and IE (0.4%), to a middle level in SE, IT (both 0.7%), in the UK and DE (both 0.9%), and to a higher level in NO (2.1%) and the NL (2.3%) (OECD, 2013). OECD countries’ average public healthcare expenditure is predicted to increase from 5.5% of GDP in 2010 to 8% in 2060; whereas public long-term care expenditure is predicted to increase from 0.8% to 1.6% of GDP in 2060 (OECD, 2013). Dementia is seen by the OECD (2013) as a reason for the high increase of expenditures for long-term care.

NO and the NL have the highest proportion of formal home care for people aged 65 years and older (19.3% in NO and 21% in the NL) (Bettio & Verashchagina, 2012). This is around three or four times higher than expenditures for formal home care in the other ActifCare countries (DE 6.6%, IE 6.5%, IT 4.9%, PT 4.3%, and UK 6.9%). The Swedish coverage rate of formal home care lies in the middle of this field (9.4%). The differences in expenditures for long-term care and the coverage rates for formal home care show that the countries have different emphases on the funding of long-term care.

National financing systems are either mainly tax financed (IE, IT, NO, PT, SE, and the UK), or are financed by social security. The German and the Dutch healthcare systems are financed
mainly by social security; however, financing by social security plays also a small role within the Italian, Norwegian, Swedish, and the British healthcare systems (Joumard et al., 2010). Private insurance is of minor importance. The market for private long-term care insurance is small in most OECD countries (OECD, 2011). Ireland has a mix of funding sources.

Costs are divided in direct costs (e.g. medical costs), indirect costs (refer to production losses in the working population), informal costs (refer to the amount of unpaid informal carer’s time provided for care), and total costs (a societal perspective considered all relevant types of cost - Wimo et al. 1997, Schaller et al., 2015). Direct costs are highest within the Nordic European countries (including IR, NO, SE and the UK); however, the Southern European countries (including IT and PT) have the highest informal costs (Wimo et al., 2011). Total costs of dementia are highest within the Nordic countries (35,987 € per capita and per year). In Western Europe (including DE and the NL) the total costs lie at 18,149 €; and in the Southern countries at 22,343 €. In general, costs increase with disease severity (Schaller et al., 2015). Moreover, in a review these authors found that the main cost drivers in dementia are informal costs, which range from 60% to 84% of the total costs of dementia.

Out-of-pocket payments are required in all ActifCare countries, with immense differences between the countries. For example, PwD in IE have to pay privately for home care, if covered Home Care Packages are not sufficient. Additional payments for home care are also common in DE and UK. In contrast, PwD in NO are free from additional payments for home care, but they have to pay for domestic home help. SE has various but limited out-of-pocket payments. In IT, it is very common that migrant informal carers work illegally at the expense of the PwD or the family. The OECD found (2011) that average long-term care expenditures can represent as much as 60% of the discretionary income for those in the upper quintile of the income distribution. Therefore, the oldest people and those with severest care needs are especially at risk of formal care becoming unaffordable.

Carers’ allowance or financial support for informal carers is available in DE, IE, IT, the NL, NO, PT, and the UK. Limited Irish data suggests that only those informal carers with very low income are eligible for carers’ allowance (Cahill, O’Shea & Pierce, 2012). A considerable amount of help is a prerequisite for financial support for informal carers in NO (Genet, 2013). Informal carers in PT receive financial support if they care for more than six hours a day (Genet, 2013). In the UK, the carer’s allowance is criticized as being too restricted (Genet, 2013). Half of all people with need for care in DE are dependent on the care allowance.
The OECD (2011) points to the possible effect of financial support for informal carers that this can leave informal carers dependent on the care recipient. Risks are further seen in trapping informal carers in low-paid roles with few incentives for participating in the labour market. We found no data for the ActifCare countries as to whether reimbursements or financial support for PwD and informal carers influence the use of professional help. A US-American investigation found that reimbursements enabled PwD to purchase some services; however, the average use of services did not increase to a higher amount in comparison to a control group, which received no financial support (Newcomer et al., 1999).

**Limitations**

The report provides an overview of different aspects in relation to the access to formal dementia care services in eight European countries. In the first part, existing literature was reviewed in order to describe the health and social care systems of each country by focusing on only a few selected key aspects. Moreover, studies investigating the impact of socio-demographic and cultural characteristic of people with dementia and their carers were systematically searched and summarised in a narrative way. Only a few studies were available and the information about these influencing factors is scarce, and partially contradictory.

In the second part (templates and common practice examples), it was sought to cover all relevant structures and services. However, the descriptions needed to be broad and information had to be reduced to key aspects. Thus, the complex system of health and social care services of the countries had to be simplified in a way and it was not possible to cover the services’ aspects in every detail. Moreover, only a few data on utilisation were available and the available information was often not comparable across the countries.
### Table A: Description of diagnostic and therapeutic settings as access to formal dementia home and community care (A1-A5).

<table>
<thead>
<tr>
<th>A1) General Practitioners’ practice/ surgery</th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Availability</strong></td>
<td>Nationwide, regional differences</td>
<td>Nationwide, regional differences</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide, regional differences</td>
<td>Nationwide</td>
<td>Nationwide</td>
</tr>
<tr>
<td><strong>Defined function regarding access</strong></td>
<td>No defined function; GPs are considered first point of contact/gatekeepers, supporting the application for long-term care. (German Society of General Practice/Family Medicine, 2008)</td>
<td>GPs are considered first point of contact/gatekeepers and permanent reference person (Cahill, O’Shea &amp; Pierce, 2012, Department of Health, 2014, p20)</td>
<td>Regional plans defining GP as a reference professional (detecting PwD, referring to specialised centres, follow-ups)</td>
<td>Detecting, diagnosis and referrals (Moll van Charante et al., 2011)</td>
<td>Detecting, diagnosis and referrals (together with dementia team and dementia coordinator)</td>
<td>No defined function; GPs are considered first point of contact/gatekeepers and pivotal health professional contacts for every citizen, involved in medical and long-term care (Firmino, 2005; Barros et al, 2011).</td>
<td>Diagnosis, follow-ups, involved in medical and long-term care.</td>
<td>GPs are considered first point of contact/gatekeepers and permanent reference person.</td>
</tr>
<tr>
<td><strong>Prescription of anti-dementia medication</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>No (only with permission of specialised physicians)</td>
<td>No</td>
<td>Yes</td>
<td>Possibly (but infrequently and not reimbursed)</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Medication usually initiated by specialist services;
<table>
<thead>
<tr>
<th>Healthcare professionals</th>
<th>GPs, medical technical assistants</th>
<th>GP, small or independent practices are most common; may work with another GP or a nurse.</th>
<th>GP</th>
<th>GP, 75% employed practice nurses</th>
<th>GP, specialised physicians</th>
<th>GP, nurses</th>
<th>GPs, district nurses, occupational therapists</th>
<th>GPs, district nurses, practice nurses</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Standard care</strong></td>
<td>Yes</td>
<td>Partially (public and private sectors)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Accessibility</strong></td>
<td>No access restrictions described.</td>
<td>Out-of-pocket-payment (45-60€ per visit; 43% of population are entitled to free GP visits) (Cahill, O’Shea &amp; Pierce, 2012), practices overstretched in deprived urban areas (Teljeur et al., 2013)</td>
<td>No access restrictions described.</td>
<td>No access restrictions described.</td>
<td>Co-payment is NKR 141 per consultation of a GP up to an annual limit of NKR 2670. For GPs specialized in General Medicine the fees are higher.</td>
<td>Out-of-pocket-payment (5€ per visit) (European Observatory on the Social Situation (2005), Health Status and Living Conditions in an Enlarged Europe, London School of Economics) Sometimes distances to health centres N.B. PwD may be entitled to free visits (exemptions from</td>
<td>Out-of-pocket-contribution for primary care. Waiting time one week.</td>
<td>No access restrictions.</td>
</tr>
</tbody>
</table>
**Utilisation**

| Most PwD visit the same GP regularly (van den Bussche, 2011; Schubert, 2007). First contact person (Hausner, 2010), often makes the initial diagnosis (van den Bussche, 2013). | PwD living in the community pay 4.4 visits/year to the GP (Cahill, O’Shea & Pierce, 2012). | No national data available. It is estimated that each GP has approximately 30 PwD among their patients. (The Italian Longitudinal Study on Aging Working Group, 1997). | Prevalence in GP practice is about 1.7% (Alzheimer Nederland, 2008) | People are assigned to a designated GP (Norwegian ministry of health and care services, 2012) | Prevalence in GP practice is about 0.48% of all users (DGH, 2013) across regions of the country (DGH, 2014). | 10,000 diagnostic procedures in 2012 | People with an established diagnosis of dementia are placed on a primary care (GP) register. The number registered in each practice is compared with the expected number from epidemiological prevalence studies, to give a 'diagnosis rate'. This varies regionally and across the UK | OOP include low-income, chronic diseases or high levels of disability; owing to the first two, 10% of the population are entitled to free visits in the NHS (Ministry of Health, 2014). |
nations, and increasing it has been a governmental priority.
<table>
<thead>
<tr>
<th>A2) Specialised Physicians’ practice/ Surgery</th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Defined function regarding access</strong></td>
<td>No defined function</td>
<td>Old age psychiatry plays a key role in all stages of dementia care, from detection, assessment and diagnosis, right through to care of PwD of all types, at all stages of the illness trajectory and in all clinical contexts (Department of Health, 2014, p21).</td>
<td>Regional plans available: Set up a therapeutic plan, including referral to day care facilities or nursing homes (ASL Brescia, 2013).</td>
<td>No defined function</td>
<td>Diagnostics of dementia</td>
<td>No defined function (formally).</td>
<td>Urban areas: involved in care planning</td>
<td>No defined function in relation to access to services (formally) but diagnosis may assist access to certain services.</td>
</tr>
<tr>
<td><strong>Prescription of anti-dementia medication</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>Yes (if they work in Alzheimer Evaluation Units)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes (co-payment from the NHS only if prescribed by neurologists/ psychiatrists)</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Healthcare professionals</strong></td>
<td>Neurologist, psychiatrist, neuropsychiatric specialist, geriatricians (few), medical technical assistant</td>
<td>Old age psychiatrists, general psychiatrists, neurologists and geriatricians</td>
<td>Neurologists, geriatricians, psychiatrists (few)</td>
<td>Medical specialists and specialised nurses</td>
<td>Old age psychiatrists, neurologist, geriatrician, registered nurses</td>
<td>Neurologists, psychiatrists (sometimes collaborating with GPs with a special interest in dementia), psychiatric nurses, clinical psychologists, social workers</td>
<td>Specialised physicians, registered nurses, occupational therapists, psychologists, speech therapists, physiotherapists</td>
<td>Old age psychiatrists, general psychiatrists, neurologists and geriatricians</td>
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</tr>
<tr>
<td><strong>Standard care</strong></td>
<td>Yes</td>
<td>Partially (public and private)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Accessibility</strong></td>
<td>Minimal out-of-pocket-payment or free of charge for public patients. You must pay the full costs of treatment if you opt for private health care. However, this cost may be fully or partially covered by PHI (Burke, 2009; HSE, 2014d; McNamara, Normand &amp; Whelan, 2013).</td>
<td>PwD are entitled to free visits (otherwise out-of-pocket-payment)</td>
<td>Out-of-pocket payment (280 NKR/visit)</td>
<td>Out-of-pocket-payment (people with chronic diseases, with low-income or high level of disability are entitled to free visits within the NHS)</td>
<td>Out-of-pocket-contribution.</td>
<td>No access restrictions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Waiting time</td>
<td>Referral by GP</td>
<td>Waiting time</td>
<td>Referral by GP</td>
<td>Waiting time</td>
<td>Referral by GP</td>
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<tr>
<td>up to 3 months, particularly in rural areas; faster access for patients with private insurances (Hausner &amp; Froelich, 2010)</td>
<td>Referral by GP is required (Burke, 2009)</td>
<td>up to several months; faster access for patients with private insurances (Cahill 2008, ASI, 2011)</td>
<td>Referral by GP required (Decreto Legislativo 19 giugno 1999, n. 229, 1999)</td>
<td>waiting time may occur</td>
<td>Referral by GP required (Brækhus et al. 2011)</td>
<td>waiting time. Faster access within the health subsystem/private care sector.</td>
<td>Referral by GP required</td>
<td>Waiting time (maximum 3 months)</td>
</tr>
</tbody>
</table>

| Waiting time may occur (varies regionally) | Waiting time should be 6 to 8 weeks |

| Utilisation | Approximately 30% of PwD are examined by a specialised physician (Hausner & Froelich, 2010) | PwD living in the community pay 0.50 visits/year to a geriatrician, 0.12 visits/year to a Neurologist, and 0.52 | No data available on a national level. | No data available on a national level. | No data available on a national level. | No recent data available on a national level. PwD represented about 3% of psychiatric outpatient consultations and 4% of emergency | 14,000 diagnostic procedures undertaken at specialist centres in 2012. | No data available on a national level. |
visits/year to a psychiatrist. (Cahill, O’Shea & Pierce, 2012).

visits in 2001 (DGH, 2004).

Many PwD are moderate/severe cases when referred to specialists. The overall number of people >65 treated by psychiatrists seems to be low (Firmino, 2005), but is increasing (Ribeiro et al., 2010).
### A3) Outpatient clinic for memory impairments

<table>
<thead>
<tr>
<th><strong>Availability</strong></th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nationwide, regional differences.</td>
<td>Nationwide, regional differences.</td>
<td>Nationwide</td>
<td>Nationwide See section A4</td>
<td>Nationwide</td>
<td>Regionally</td>
<td>Regionally (overlapping with ‘dementia outpatient clinics’ in public hospitals; some private services)</td>
<td>Regionally</td>
<td>Nationwide</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Healthcare Professionals</strong></th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatrists, neurologists, geriatricians, psychologists, nurses, occupational therapists, physiotherapists, social workers (Lautenschläger und Kurz, 2009), headed by physicians.</td>
<td>Led by consultant medical doctors (old age psychiatrists, geriatricians, psychologists, physicians), nurses or both. Some clinics employ neuropsychologists, occupational therapists and social workers whilst others are more stand-alone (Cahill, O’Shea &amp; Pierce, 2012; Cahill, Pierce &amp; Moore, 2013).</td>
<td>Neurologists, geriatricians, psychiatrists, (neuro) psychologists, dementia nurses.</td>
<td>Old age psychiatrists, neurologists, geriatricians.</td>
<td>Neurologists, a few psychiatrists, and (neuro) psychologists (seldom collaborating with nurses, occupational therapists and social workers). Multiprofessional team composition, resources and services vary considerably.</td>
<td>Specialised physicians, registered nurses, occupational therapists, psychologists, speech therapists, physiotherapists.</td>
<td>Multi-disciplinary Memory Services. Nurses, clinical psychologists, occupational therapists, speech and language therapists, social workers. Medical input usually from old age psychiatrists, but occasionally geriatricians, GPs and (less often), neurologists.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Standard care</td>
<td>No (subordinate role)</td>
<td>Partially (public versus private)</td>
<td>Yes</td>
<td>Yes</td>
<td>Partially</td>
<td>Yes</td>
<td>Yes</td>
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</tr>
<tr>
<td><strong>Accessibility</strong></td>
<td>Distances can be problematic because not all clinics operate nationwide (most clinics based in Dublin)</td>
<td></td>
<td></td>
<td></td>
<td>Sometimes distances can be problematic</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>4 of the 17 memory clinics in Ireland require out-of-pocket payment</td>
<td>Out-of-pocket payment required</td>
<td>Out-of-pocket payment required</td>
<td>From 0 (free visits e.g. on account of a neurodegenerative disease diagnosis) to full out-of-pocket payment (private sector, although may be partially covered by some insurances).</td>
<td>Out-of-pocket payment</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Waiting time up to 24 weeks (Aguirreche et al., 2003)</td>
<td>Waiting time up to 20 weeks (Cahill et al. 2012; Cahill, at al. 2013)</td>
<td>Waiting time 2-4 weeks</td>
<td>Waiting lists in the NHS.</td>
<td>Waiting time up to 12 weeks</td>
<td>Waiting times vary locally Waiting time should be 6 to 8 weeks</td>
<td></td>
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<tr>
<td>Formal referral required for most</td>
<td>Formal referral required</td>
<td></td>
<td>Formal referral required mostly; sometimes free access depending on some hospitals’ internal</td>
<td>Partially referral required</td>
<td>Referral from GP required. But some allow self referral</td>
<td></td>
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<tr>
<td>Frequency of service provision (weekly to every two months)</td>
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</tr>
<tr>
<td><strong>Utilisation</strong></td>
<td>No data available on a national level.</td>
<td>Average number of patients seen during 2011 was 126 (range was 18–404/data supplied by 8 outpatient clinics. Four of these eight MCs saw fewer than 100 patients [&lt;2patients/wee k], whilst the remaining four saw more than 100 patients)</td>
<td>25% of PwD in the general population is diagnosed at the memory clinic (Verhey et al.,2009)</td>
<td>74% of the GPs in municipalities with dementia teams had referred patients to specialist health service (Gausdal &amp; Michelet 2011)</td>
<td>No data available on a national level.</td>
<td>14,000 diagnostic procedures undertaken at specialist centres in 2012</td>
<td>7480 new patients assessed in Wales (2014 Wales National Audit Memory Clinics and Memory Assessment Services) – would equate to 150,000 across the UK as a whole.</td>
<td></td>
</tr>
<tr>
<td><strong>A4) Outpatient clinic specifically for dementia</strong></td>
<td><strong>DE</strong></td>
<td><strong>IE</strong></td>
<td><strong>IT</strong></td>
<td><strong>NL</strong></td>
<td><strong>NO</strong></td>
<td><strong>PT</strong></td>
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</tr>
<tr>
<td><strong>Availability</strong></td>
<td>Not available</td>
<td>Not available. There are some outpatient clinics where physicians and nurses are specialised in dementia, but the clinic itself may not be specifically for dementia.</td>
<td>Nationwide</td>
<td>Not available</td>
<td>Nationwide (dementia teams)</td>
<td>In this report, these outpatient clinics (related to neurology services) are described conjointly with A3 (cf. above). In exceptions, a few psychiatric services provide outpatient services targeting PwD in un-named dementia clinics (focusing on behavioural and psychopathological problems and less diagnosis-oriented): these overlap with B4 below.</td>
<td>Regionally (dementia clinics)</td>
<td>See A3 – Memory Services provide this function.</td>
</tr>
<tr>
<td><strong>Healthcare Professionals</strong></td>
<td></td>
<td></td>
<td>Neurologists, geriatricians, psychologists, nurses, occupational therapists, physiotherapists,</td>
<td></td>
<td>Registered nurses, occupational therapists, auxiliary nurses, physical therapists, GPs</td>
<td></td>
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<td></td>
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</tbody>
</table>
Social workers (less often psychiatrists) work in so-called Alzheimer’s Evaluation Units (Sorrentino et al. 2005), headed by physicians.

<table>
<thead>
<tr>
<th>Standard care</th>
<th>Yes</th>
<th>Yes</th>
<th>Partially</th>
<th>physiotherapists</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accessibility</td>
<td>No access restrictions described</td>
<td></td>
<td></td>
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<tr>
<td>Waiting time (first visit guaranteed within 30 days)</td>
<td></td>
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<tr>
<td>Formal referral required</td>
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<tr>
<td>Out-of-pocket payment, full payment for private clinics (up to 12,000 SEK)</td>
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<tr>
<td>Utilisation</td>
<td>No data on a national level available.</td>
<td>81% of GPs in municipalities with dementia teams referred patients to dementia team in 2010 (Gausdal &amp; Michelet 2011)</td>
<td></td>
<td>No data on a national level available.</td>
</tr>
<tr>
<td>A5) Discharge planning /transition management</td>
<td>DE</td>
<td>IE</td>
<td>IT</td>
<td>NL</td>
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<tr>
<td><strong>National guideline/ regulation</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td><strong>Healthcare Professionals</strong></td>
<td>Specialised nurses, social workers, case managers collaborate with GPs, nurses/ nursing home staff</td>
<td>Discharge is a multidisciplinar y process involving physicians, nurses, social workers, and other health and social care professionals.</td>
<td>Physicians, physiotherapist s, occupational therapists, registered, nurses, social/ social health workers.</td>
<td>Specialised nurses</td>
</tr>
<tr>
<td><strong>Standard care</strong></td>
<td>Yes</td>
<td>Partially</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Accessibility</strong></td>
<td>No access restrictions described.</td>
<td>No formal access restrictions. Implementation problems described.</td>
<td>No access restrictions described.</td>
<td>No access restrictions described.</td>
</tr>
</tbody>
</table>
Utilisation: No data available on a national level.

A national survey revealed proportion of PwD on various hospital wards: 40% on geriatric wards, 20% on accident surgery, internal medicine and neurology (Isfort et al., 2014).

In 2010, 1.1% (n= 6702) of all discharges from acute hospitals had diagnosis of dementia. However, as a large proportion of those with dementia remain undiagnosed, it is likely that this figure is underestimated (Connolly & O'Shea, 2013).

In 2013, 838 PwD were discharged from the NHS hospitals, where dementia as a secondary diagnosis is increasing (DGH, 2014).

In 2011, there were about 4,500 hospital care episodes with a dementia diagnosis (Swedish hospital register). Due to the complexity of dementia care, it can be assumed that discharge planning was undertaken in most of these discharges.
Table B: Description of home care and community support structures as access to formal dementia community care (B1-B15).

<table>
<thead>
<tr>
<th>B1) Healthcare professional serving as a reference person</th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Availability</td>
<td></td>
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<tr>
<td>Similar services available.</td>
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<tr>
<td>Health insurances provide a kind of case management on demand. Provided information refers to case management.</td>
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<tr>
<td>Not available.</td>
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<td><em>The Irish Dementia strategy promises to appoint a named key worker to co-ordinate care (DoH, 2014)</em></td>
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<tr>
<td>Not available.</td>
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<tr>
<td>Case management structures differ per region (<a href="http://www.nivel.nl">www.nivel.nl</a>)</td>
<td>Nationwide.</td>
<td></td>
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</tr>
<tr>
<td>Nationwide, regional differences.</td>
<td>Not available.</td>
<td></td>
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<tr>
<td>Dementia teams serve as a reference professionals (Gausdal &amp; Michelet 2011)</td>
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<tr>
<td>Nationwide, regional differences.</td>
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<tr>
<td>With regional differences, case management structures are under implementation, but only for severe mental illness.</td>
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<tr>
<td>Nationwide, regional differences.</td>
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<tr>
<td>Nationwide, but regional differences in availability and implementation.</td>
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<tr>
<td>Outreaching</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
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<td>Yes</td>
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<tr>
<td>Regularly initiated</td>
<td>No – on demand</td>
<td>No – on demand</td>
<td>Yes</td>
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<td></td>
<td>Yes (usually)</td>
<td>No – varies greatly</td>
</tr>
<tr>
<td>Healthcare professionals</td>
<td>Nurses, case managers, social workers, staff members of the healthcare insurance with certain additional qualifications</td>
<td>Case managers, nurses</td>
<td>Registered Nurses, occupational therapists, aux. nurses, physical therapists, GPs</td>
<td>Registered nurses with special training in dementia care (e.g. profiled education programme at “Silviahemmet”)</td>
<td>Community Mental Health Nurses, care managers, social workers, ‘Admiral nurses’ (specialist dementia care)</td>
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</tr>
<tr>
<td>Standard care</td>
<td>Accessibility</td>
<td>Utilisation</td>
<td></td>
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</tr>
<tr>
<td>Yes</td>
<td>Referral required</td>
<td>Intensive counselling/case management was used in 10% of the cases; amount increasing (BMG, 2011). Approx. 50% of the people with dementia used comprehensive counselling/case management (GKV-Spitzenverband, 2011)</td>
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<tr>
<td>Little information and low awareness (BMG, 2011)</td>
<td>Distances are a barrier (not all local authorities provide dementia teams)</td>
<td>No data available on a national level.</td>
<td></td>
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<tr>
<td></td>
<td>Distances are a barrier (not available in all regions)</td>
<td>No data available on a national level.</td>
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<tr>
<td></td>
<td>Availability varies greatly</td>
<td>No data available on a national level.</td>
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</tr>
<tr>
<td>B2) Mobile comprehensive expert team</td>
<td>DE</td>
<td>IE</td>
<td>IT</td>
<td>NL</td>
<td>NO</td>
<td>PT</td>
<td>SE</td>
<td>UK</td>
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</tr>
<tr>
<td><strong>Availability</strong></td>
<td>Not available</td>
<td>Not available</td>
<td>Not available</td>
<td>Regionally (located at hospitals)</td>
<td>Not available</td>
<td>Regionally</td>
<td></td>
<td>Nationwide (described under B4)</td>
</tr>
<tr>
<td><strong>Outreaching</strong></td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td><strong>Mandatory</strong></td>
<td>No (Helms et al. 2008)</td>
<td>No</td>
<td></td>
<td></td>
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<td>No</td>
<td></td>
</tr>
<tr>
<td><strong>Healthcare professionals</strong></td>
<td>Nursing home physician, geriatrician</td>
<td>Multi-professional teams</td>
<td>Physicians from primary care or specialists</td>
<td></td>
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</tr>
<tr>
<td><strong>Standard care</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
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</tr>
<tr>
<td><strong>Accessibility</strong></td>
<td>Co-payment required (350 Euro)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Dementia diagnosis</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Distances are a barrier (not available in all regions)</td>
<td>Distances are a barrier (not available in all regions)</td>
<td>Distances are a barrier (not available in all municipalities)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Utilisation</strong></td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Availability</td>
<td>DE</td>
<td>IE</td>
<td>IT</td>
<td>NL</td>
<td>NO</td>
<td>PT</td>
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</tr>
<tr>
<td><strong>Team-based home healthcare</strong></td>
<td>Not available</td>
<td>Not available</td>
<td>Nationwide, huge regional differences (Integrated Home Care)</td>
<td>Not available</td>
<td>Nationwide, regional differences</td>
<td>Nationwide, regional differences</td>
<td>‘Community Care Units’ - multidisciplinary teams provide healthcare, psycho-social support in the patients’ own home.</td>
<td>Not available (see B4) This function partially served by the primary care team, including GPs and District Nurses</td>
</tr>
<tr>
<td><strong>Healthcare</strong></td>
<td>Nurses, aux.</td>
<td>Nurses</td>
<td>Nurses</td>
<td>Basic team:</td>
<td>Nurses</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**professionals**

| nurses, physiotherapists, occupational therapists, social health workers, and specialised professionals according to individual treatment plans. | specialised in dementia/geriatrics | nurses, physicians, social workers. Further: occupational therapists, physiotherapists, psychologists | occupational therapists, physiotherapists, social workers, aux. nurses (physicians primary care or specialists) |

| **Standard care** | Yes | Yes | Yes | Yes |

**Accessibility**

| Complex application process: Initiated by a GP, multi-disciplinary evaluation | Needs assessment | Needs assessment | Co-payment (measured acc. to individual income) | Small co-payment |

| Waiting time |  |

**Utilisation**

<p>| Overall, 4.8% of older people used team-based home help (regional differences). | No data available on a national level. | No data about PwD available. The ‘Integrated Continuous Care Teams’ assisted 7,668 users in 2012 (UMCCI, 2012). | No data available on a national level. |</p>
<table>
<thead>
<tr>
<th>B4) Team-based community mental health care for older people</th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Availability</td>
<td>Not available</td>
<td>Nationwide, regional differences</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Rarely (not in all municipalities)</td>
<td>Rarely (not necessarily dementia-specific) (No formal community mental health centres available but some local mental health services develop community-sensitive practices; legislation available (not specifically for elderly services) but problems with implementatio n (WHO, 2009; ACSS, 2014))</td>
<td>Nationwide (but not for older people)</td>
<td>Nationwide</td>
</tr>
<tr>
<td>Healthcare professionals</td>
<td>Multi-disciplinary team including</td>
<td>Psychiatrists, psychologists, social workers,</td>
<td>Geriatricians, social workers,</td>
<td>Nurses, aux. nurses specialised in</td>
<td>Psychiatrists; nurses; psychologists;</td>
<td>Nurses, social workers, home aids,</td>
<td>Community Mental Health Nurses, old age psychiatrists, clinical</td>
<td></td>
</tr>
</tbody>
</table>

community mental health nurses, led by a consultant old age psychiatrist. Further: psychologists, social workers, physiotherapists, occupational therapists, public health nurses, speech therapists (Cahill, O'Shea & Pierce, 2012).

<table>
<thead>
<tr>
<th>Standard care</th>
<th>Yes</th>
<th>Yes</th>
<th>Yes</th>
<th>Yes</th>
<th>Partially</th>
<th>Yes</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accessibility</td>
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<tr>
<td>Initial referrals to old age psychiatry services are made by GPs or other medical doctors (Farrell, Cahill &amp; Burke, 2007).</td>
<td>Referral required</td>
<td>Referral required (only more complex cases)</td>
<td>Referral may be required (generally complex cases)</td>
<td>Referral required from GP / Memory Clinic etc. – focus generally on complex needs</td>
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<tr>
<td>PwD are entitled to free Co-payment required (up</td>
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<tr>
<td><strong>Visits</strong> (otherwise out-of-pocket-payment)</td>
<td>to 350 Euro</td>
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<tr>
<td><strong>Waiting times</strong></td>
<td>Waiting time (up to 60 days)</td>
<td>Usually minimal waiting time</td>
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<tr>
<td><strong>Distances</strong> (not available in all regions)</td>
<td></td>
<td>Not available in most regions</td>
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<tr>
<td><strong>Insufficient staffing/low resources</strong></td>
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<td>Insufficient staffing/low resources</td>
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<tr>
<td><strong>Utilisation</strong></td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
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</tr>
<tr>
<td>B5) Specialised psychiatric home nursing care</td>
<td>DE</td>
<td>IE</td>
<td>IT</td>
<td>NL</td>
<td>NO</td>
<td>PT</td>
<td>SE</td>
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</tr>
<tr>
<td><strong>Availability</strong></td>
<td>Nationwide available: Social-psychiatric services. Regionally available: Psychiatric home nursing care</td>
<td>Nationwide (see also B4)</td>
<td>Not available.</td>
<td>Regionally</td>
<td>Nationwide (but not in all municipalities for older people).</td>
<td>Rarely available. (Few exceptions, see B4)</td>
<td>Nationwide (but not for older people, see also B4)</td>
</tr>
<tr>
<td><strong>Healthcare professionals</strong></td>
<td>(Psychiatric) nurses, social workers, specialised physicians, occupational therapists.</td>
<td>Community mental health nurses under the auspices of psychiatrists of old age community mental health teams (Cahill, O'Shea &amp; Pierce, 2012)</td>
<td>Psychiatric nurses</td>
<td>Nurses specialised in psychiatric healthcare</td>
<td>Psychiatrists, psychologists, psychiatric nurses, occupational therapists, physiotherapists</td>
<td>Community mental health nurses and Admiral nurses</td>
<td></td>
</tr>
<tr>
<td><strong>Standard care</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Accessibility</strong></td>
<td>No access restrictions for social-psychiatric services</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Co-payment required for psychiatric home nursing care.</td>
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<tr>
<td>Co-payment required (up to 350 Euro)</td>
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</tr>
<tr>
<td>Needs assessment</td>
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<tr>
<td><strong>Prescription required.</strong></td>
<td>Formal referral required</td>
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<tr>
<td>Overall duration limited to four months (positive evaluation required after the first 14 days)</td>
<td>Temporary intervention to stabilise a situation</td>
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<tr>
<td>Certain number of prescriptions are rejected by health insurances.</td>
<td>Age restrictions (18-65 years)</td>
<td>Age restrictions (18-65 years)</td>
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<tr>
<td>Waiting time</td>
<td></td>
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<tr>
<td>Lack of information (Cahill, O'Shea &amp; Pierce, 2012; Farrell, Cahill &amp; Burke, 2007)</td>
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</tr>
<tr>
<td><strong>Utilisation</strong></td>
<td>No data available on a national level.</td>
<td>Approx. 50% of the caseload in rural areas are PwD (Farrell, Cahill &amp; Burke, 2007)</td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Availability

<table>
<thead>
<tr>
<th>Country</th>
<th>Day Care/Day activity/Day Care Centre/Day hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>DE</td>
<td>Nationwide, regional differences (Day care services = social care; day hospitals = medical care)</td>
</tr>
<tr>
<td>IE</td>
<td>Nationwide, regional differences (Day care services = social care; day hospitals = medical care)</td>
</tr>
<tr>
<td>IT</td>
<td>Nationwide (de Bruin 2009)</td>
</tr>
<tr>
<td>NL</td>
<td>Nationwide</td>
</tr>
<tr>
<td>NO</td>
<td>Nationwide, regional differences (Distinction between three types: day centres = social care for elderly people in general; day-care services = focus on medical care; and very few day hospitals (or so-called ‘dementia day-centres’) accepting or targeting PwD)</td>
</tr>
<tr>
<td>PT</td>
<td>Nationwide</td>
</tr>
<tr>
<td>SE</td>
<td>Nationwide, regional differences (Day hospitals provided by NHS; day care services = social care; some specialist for people with dementia, some generic for older people)</td>
</tr>
<tr>
<td>UK</td>
<td>Nationwide</td>
</tr>
</tbody>
</table>

### Healthcare professionals

<table>
<thead>
<tr>
<th>Country</th>
<th>Day hospital: Multi-disciplinary team including physicians, nurses, occupational therapists, psychologists, social workers, dieticians, speech therapists and other HSCPs. Day care:</th>
</tr>
</thead>
<tbody>
<tr>
<td>DE</td>
<td>Nurses, geriatric care nurses, social workers, help workers, volunteers, occupational therapists, physiotherapists, physicians</td>
</tr>
<tr>
<td>IE</td>
<td>GP, nurses, aux. nurses, physiotherapists, occupational therapists, social workers, volunteers</td>
</tr>
<tr>
<td>IT</td>
<td>Social workers, nurses</td>
</tr>
<tr>
<td>NL</td>
<td>Aux. nurses, occupational therapists</td>
</tr>
<tr>
<td>NO</td>
<td>Day centres: sociocultural animators; auxiliary and cooking staff; drivers (Instituto da Segurança Social, 2010). Day hospitals: physicians, nurses, psychologists, physiotherapists, occupational therapist nutritionists; healthcare assistants;</td>
</tr>
<tr>
<td>PT</td>
<td>Nurses, aux. nurses, occupational therapists, physiotherapists.</td>
</tr>
<tr>
<td>SE</td>
<td>Day hospitals: multi-disciplinary team including nurses, occupational therapists, old age psychiatrists, clinical psychologists, physiotherapists</td>
</tr>
<tr>
<td>UK</td>
<td>Day hospitals: multi-disciplinary team including nurses, occupational therapists, old age psychiatrists, clinical psychologists, physiotherapists and input from social workers.</td>
</tr>
</tbody>
</table>
Generally nurse-led with support from other nurses, care staff and volunteers. Most centres also have a branch chairperson (Cahill et al., 2003). May have input from other disciplines for example chiropody, physiotherapy, and occupational therapy (Cahill, O'Shea & Pierce, 2012). Most centres also have a branch chairperson (Cahill et al., 2003). May have input from other disciplines for example chiropody, physiotherapy, and occupational therapy (Cahill, O'Shea & Pierce, 2012).

<table>
<thead>
<tr>
<th>Standard care</th>
<th>Yes</th>
<th>Yes</th>
<th>Yes</th>
<th>Yes</th>
<th>Yes</th>
<th>Yes, partially</th>
<th>Yes</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accessibility</td>
<td>Co-payment might be necessary (cost about 70€ per day)</td>
<td>Minimal co-payment might be necessary</td>
<td>Co-payment depending on income; Dementia-specific day</td>
<td>Payment without needs assessment (CIZ)</td>
<td>Co-payment often required (Eek &amp; Kirkevold)</td>
<td>Day centres: co-payment depending on income (average fees 71.02€ per user (Gil, 2009);</td>
<td>Minimal co-payment may be required (ceiling of</td>
<td>Co-payment often required for day care (social care)</td>
</tr>
</tbody>
</table>

Social services and the voluntary sector provide Day care centres: community care workers, care staff, activity organisers and volunteers;

Very few have input from community mental health nurses, social workers, occupational therapists and physiotherapists.

Many day hospitals closing in recent years as part of move to crisis teams to help people remain at home.
<table>
<thead>
<tr>
<th>Needs assessment and an established degree of disability required to receive financial support</th>
<th>Dementia diagnosis required</th>
<th>Needs assessment typically required for dementia-specific day care services.</th>
<th>Needs assessment required</th>
<th>Dementia diagnosis usually required</th>
<th>Formal referral is required for day hospitals.</th>
<th>Dementia diagnosis required for dementia-specific day care services.</th>
<th>Overall care costs to the amount of 1,776-1,850 SEK/month</th>
<th>Dementia diagnosis usually required</th>
<th>Formal referral is required for day hospitals.</th>
<th>Dementia diagnosis required for dementia-specific day care services.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of awareness</td>
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<tr>
<td><strong>High awareness of informal carers of PwD (Donath, 2011)</strong></td>
<td><strong>Low perceived access restrictions by informal carers of PwD (Donath, 2011)</strong></td>
<td><strong>Distances are a barrier (service is not available in all areas) → high transportation costs (Cahill, O’Shea &amp; Pierce, 2012).</strong></td>
<td><strong>Distances are a barrier (service is not available in all areas)</strong></td>
<td><strong>Distances are a barrier (service is not available in all areas)</strong></td>
<td><strong>Availability of transport may be a problem in rural areas.</strong></td>
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<tr>
<td><strong>Dementia-specific day care: Stable living situation to ensure continuity of care (reliable nuclear family/secure housing condition)</strong></td>
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<tr>
<td><strong>Some variability has been found across the day</strong></td>
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<td>Day centres (social care) restricted to people ≥ 65 years</td>
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<tr>
<td><strong>Utilisation</strong></td>
<td><strong>43,000 people in need of care used day care services in 2011, number increasing (Pfaff, 2013). According to a survey with n=400 carers, one third of PwD used day care (Donath, 2011).</strong></td>
<td><strong>No data available on a national level</strong></td>
<td><strong>No data available on a national level</strong></td>
<td><strong>No data available on a national level</strong></td>
<td><strong>In 2010, 9% of PwD living at home received day care (n=3257) (Eek &amp; Kirkevold 2011).</strong></td>
<td><strong>Day centres (social care) reach 4% of the elderly population, mainly people with lower level of income (CEDRU, 2008).</strong></td>
<td><strong>Approx. 6% of PwD entered day care 2-3 times a week in 2012 (n=10,000/158,000) (Wimo et al 2014).</strong></td>
<td><strong>No data available on a national level.</strong></td>
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<tr>
<td>B7) Needs assessment</td>
<td>DE</td>
<td>IE</td>
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<td>NL</td>
<td>NO</td>
<td>PT</td>
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<td>UK</td>
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<tr>
<td><strong>Availability</strong></td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
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<tr>
<td>Description: Standardised assessment according to the Social Code XI: certain aspects of basic care (personal hygiene, nutrition, mobility and domestic help) are covered. Further benefits are granted for people with reduced competences in daily living (mainly people with dementia).</td>
<td>Description: Common Assessment Summary Record (CSAR) provides the information relevant to a decision on an individual’s care needs at a given point in time (HSE, 2010). The recommendation must indicate the capability of living at home with identified supports in order for the application for a Home Care Package to be progressed (HSE, 2010). CSAR will be replaced by a single tool based on the interRAI, and will be implemented nationwide in 2014/2015.</td>
<td>Description: No single assessment/institution responsible nationwide, structures vary per region. Individual need's complexity is evaluated taking social and health issues into account, and the district Multidimensional Evaluation Unit is activated for the final acceptance of responsibility. This evaluation outlines a tailored care path (Individual Assistance Plan) for the care dependent patient, which states services, goals and expected results. The</td>
<td>Description: Needs assessment by the local authorities represented by the RN in charge; or the municipalities have a special organisation carrying out needs assessment that is separated from the executing organisation (which may be organised public or private). (NIBR, 2012)</td>
<td>Description: CIZ allocate care (CIZ Basisrapportage AWB, 2013)</td>
<td>Description: Under the scope of the National Network of Long-Term Integrated Care (RNCCI), needs assessment identifies functional, physical, mental and social limitations, and defines an individual plan in order to maintain/recov er total or partial, or lost capacities (Decree-law No 101/2006). The system used is Integrated Bio-psychosocial</td>
<td>Description: The municipalities have a special organisation carrying out needs assessment (home help officers) that is separated from the executing organisation (which may be organised publicly or privately). Carers are also entitled to a separate assessment of their needs.</td>
<td>Description: Local authorities are responsible for undertaking needs assessment. The form this assessment takes varies across the UK nations, as do eligibility criteria to receive such an assessment (typically complex needs).</td>
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<tr>
<td>Content of the CSAR: personal details; personal circumstances; current services, diagnosis, medical and mental health summary, and medications; Barthel Index; communication, cognitive, pressure sores, falls, nutrition, and other relevant assessments (type of assessment may differ in different areas); mental health status; employment, recreational and social needs; medical and social risk factors; health professional reports (e.g. geriatric services, old age psychiatry, rehabilitation consultants, neurologists, and others as appropriate).</td>
<td>patient acknowledges the plan and signs a &quot;contract of care&quot; which can also eventually state an economic contribution.</td>
<td>Assessment Instrument (IAI) (Nogueira et al., 2010a; Nogueira et al., 2010b; UMCCI, 2008).</td>
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<tr>
<td><strong>Outreaching</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td><strong>Mandatory</strong></td>
<td>Performed on demand/ mandatory for receiving benefits of the long-term care insurance (Social Code XI)</td>
<td>Performed on demand/ mandatory for receiving benefits in terms of Home Care Packages (HCP)</td>
<td>Performed on demand/ mandatory for receiving a tailored care path (Individual Assistance Plan) to benefit from social and health care or residential care</td>
<td>Mandatory procedure, needs and eligibility are evaluated</td>
<td>Performed on demand/ mandatory for support from public services</td>
<td>Performed on demand, mandatory for care and social service in any kind of organisation, prior to decision and receiving care</td>
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<tr>
<td><strong>Healthcare professionals</strong></td>
<td>Carried out by the Medical Service of the Statutory Health Insurance/MEDIC PROOF of the private health insurances. Performed by specially trained nurses or physicians.</td>
<td>Carried out by the HSE. Typically performed by physicians and nurses (or other professions, e.g. therapists), or by multi-disciplinary teams. Local Health Offices are responsible for linking community and acute services as well as previous history and recent and future care</td>
<td>Carried out by districts, in collaboration with the Local Health Agencies. Performed by a team (GPs, nurses, social assistants, health district directors, other professionals if required)</td>
<td>Carried out by CIZ, for the more severe cases. Carried out by municipalities for less severe cases such as applying for a ‘walker’ (rollator); performed by nurses.</td>
<td>Carried out by the local authorities, performed by (aux.) nurses, occupational therapists, physiotherapists</td>
<td>Carried out by doctors, nurses, social workers and any other relevant healthcare or professional staff. Where a multi-disciplinary team exists, one person coordinates the assessment</td>
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<td>Carried out by the municipalities, performed by home help officers, social workers, home aids, (aux.) nurses</td>
<td>Carried out by social workers, care managers</td>
<td></td>
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<tr>
<td><strong>Standard care</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td><strong>Accessibility</strong></td>
<td>Application required</td>
<td>Application required</td>
<td>Application required</td>
<td>Application required</td>
<td>(Usually) application required</td>
<td>Application required</td>
<td>Application /referral required</td>
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<tr>
<td>Performed within 5 weeks after application (within 1 week in urgent cases)</td>
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<tr>
<td><strong>Utilisation</strong></td>
<td>1,580,984 assessments (first applications, applications for a higher degree of disability, and objections) performed in 2012. Majority (1,457,054) within the community (Gesundheitsberichtigterstattung des Bundes, 2014). Overall, dementia and stroke are the most frequent diagnosis when people are in need</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>19,480 assessments in 2013 (CIZ Basisrapportage AWBZ, 2013)</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
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</tbody>
</table>
of care (Rothgang et al., 2013).
**Availability**

<table>
<thead>
<tr>
<th>Country</th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
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</thead>
<tbody>
<tr>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
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</table>

Description: Certain housekeeping activities are covered by long-term care insurance (Social Code XI): Shopping, cooking, cleaning, washing the dishes, changing and washing of bedding and clothing, and heating (of the apartment etc.)

Description: No distinction is made between IADL and ADL.

Description: Part of Home Care Packages by HSE including a set number of hours’ assistance each day or each week. Financing of services organised by community and/or voluntary organisations, or through private providers is also possible (Timonen, Doyle, & O'Dwyer, 2011).

Description: No distinction is made between IADL and ADL.

Description: Public home care service or privately organised by migrant paid informal carers.

Description: No distinction is made between IADL and ADL.

Description: Home care service, help with practical household chores (Norwegian Ministry of Health and Care Services, 2011, §3.2).

Description: No distinction is made between IADL and ADL.

Description: "Provision of care to individuals who are at home, dependent, and unable, temporarily or permanently, to meet their basic needs or perform basic activities of daily living, and without family support for that purpose" (Administrative Rule No. 38/2013). May be organised by non-profit solidarity institutions, or through private providers.

Description: May be provided by social services, voluntary sector or private organisation.

Description: Typically emphasis is on providing care, rather than household tasks, but will depend on the agreed package of care based on the needs assessment. More flexible where the person is able to commission their own service under the Direct Payments arrangements. Some specialist
<table>
<thead>
<tr>
<th><strong>Healthcare professionals</strong></th>
<th>Help workers, people trained in household activities.</th>
<th>Provided by HSE, performed by healthcare assistants, practical assistance for housework duties and home care (feeding, dressing and other personal care).</th>
<th>Home assistants, social assistants, volunteers, with GPs as reference professional (Camera dei deputati, Senato della Repubblica, 1992). Migrant paid informal carers.</th>
<th>No specific education required</th>
<th>Auxiliary nurses and people who received a short training/training on the job, such as healthcare assistants. Domestic help with household chores is mainly performed by unskilled personnel.</th>
<th>Social worker (service manager) and technicians (in areas of social services or gerontology, e.g., social worker, gerontologist, psychologist); family auxiliaries (with little formal training)</th>
<th>Aux. nurses, nurse aids, healthcare assistants</th>
<th>No but Home care workers.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Standard care</strong></td>
<td>Yes (only certain tasks)</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Co-payment may be necessary (depending on the level of disability according to Social Code XI, see B7)</td>
<td>Co-payment or full-payment may be necessary.</td>
<td>Co-payment may be necessary (or full payment in case of migrant informal carers).</td>
<td>Co-payment may be necessary (if not allocated by CIZ)</td>
<td>Co-payment necessary</td>
<td>Co-payment may be necessary or full-payment when private services are used.</td>
<td>Co-payment may be necessary</td>
<td>Co-payment often required.</td>
<td></td>
</tr>
<tr>
<td>Utilisation</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
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<td></td>
<td>A study with 300 cognitively impaired people revealed that 8% used help with housework, 12% meal services, 17% received support from privately paid helpers (Schneekloth und Wahl, 2005).</td>
<td></td>
<td>No data available on a national level. 596,315 patients received help with IADL in 2010 (Hakkart-van Roijen et al., 2010)</td>
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</tbody>
</table>
about 1 hour/day. There is no split in IADL and basic ADLs but IADL support is in general greater than support in Basic ADL
<table>
<thead>
<tr>
<th>B9) Home care with Basic ADL/ Fundamentals</th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Availability</strong></td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide, regional differences</td>
<td>See above</td>
</tr>
<tr>
<td></td>
<td>No clear distinction is made between IADL and ADL (see also B8)</td>
<td>No clear distinction is made between IADL and ADL (see also B8)</td>
<td>No clear distinction is made between IADL and ADL (see also B8)</td>
<td>No clear distinction is made between IADL and ADL (see also B8)</td>
<td>No clear distinction is made between IADL and ADL (see also B8)</td>
<td>No clear distinction is made between IADL and ADL (see also B8)</td>
<td>No clear distinction is made between IADL and ADL (see also B8)</td>
<td>No clear distinction is made between IADL and ADL (see also B8)</td>
</tr>
<tr>
<td><strong>Healthcare professionals</strong></td>
<td>(Aux.) nurses, geriatric care nurses, helpers</td>
<td>Provided by HSE, performed by healthcare assistants, practical assistance for housework duties and home care (feeding, dressing and other personal care).</td>
<td>Home assistants, social assistants, volunteers, where GPs are the reference professional (Camera dei deputati, Senato della Repubblica, 1992). Migrant paid informal carers.</td>
<td>Aux. nurses, volunteers.</td>
<td>(Aux.) Nurses</td>
<td>Social worker (service manager) and technicians (in areas of social services or gerontology, e.g., social worker, gerontologist, psychologist); family auxiliaries (with little formal training)</td>
<td>Aux. nurses, nurse aids, healthcare assistants</td>
<td>Home care workers</td>
</tr>
<tr>
<td><strong>Standard care</strong></td>
<td>Yes Only four domains of daily living are covered by Social Code XI:</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Accessibility</td>
<td>Co-payment may be necessary</td>
<td>Co-payment or full-payment may be necessary.</td>
<td>Co-payment may be necessary (or full payment in the case of migrant informal carers).</td>
<td>Out-of-pocket payment may be necessary (without needs assessment)</td>
<td>Usually no co-payment</td>
<td>Co-payment may be necessary or full-payment when private services are used.</td>
<td>Co-payment may be necessary</td>
<td>Co-payment often necessary</td>
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<tr>
<td>Narrow definition of eligibility by the Social Code XI based on time targets for certain tasks.</td>
<td>No entitlement</td>
<td>Users of day care excluded</td>
<td>Quality/organisation of services (Pesaresi, 2008)</td>
<td>Quality/organisation of service provision (Gil, 2009).</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Stable situation required (GPs and family support) (Ministero della Salute, 2006)</td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
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</tbody>
</table>

Utilisation
Approx. one third of all people with a degree of disability according to Social Code XI who live at home receive support by home care services, mainly with basic ADL (Pfaff, 2013). Cognitively impaired people might use slightly more services (Weyerer & Schäufele, 2009).

In 2005, home care services reached 246,469 people (188,959 older people), 78,708 people (70,271 older people) received Integrated Home Care (including home care services) (Pesaresi, 2008). In 2011, migrant paid informal carers were estimated to be more than 770,000, part of them without a legal contract. (Ministero del lavoro e delle politiche sociali, 2011).

Estimated to be widely used (Hakkart-van Royen et al., 2010) Statistics of utilisation including IADL, ADL and therapeutic care. 50-66 years: 13,541, 67-79 years: 14,616, 80-89 years: 18,950, <90 years: 5,525. (Satatstics Norway 2013) 41.5% of people >70 receiving in-home care have dementia (Wergeland et al., 2014).

Dementia population at home (92,000 of 158,000 in 2012) received on average about 0.5 hours of support/day. For users of services (not necessarily PwD) the average was about 1 hour/day. There is no split in IADL and basic ADLs but IADL support is in general greater than support in Basic ADL.
<table>
<thead>
<tr>
<th>B10) Therapeutic care</th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
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<tbody>
<tr>
<td><strong>Availability</strong></td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
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<tr>
<td><strong>Healthcare professionals</strong></td>
<td>Nurses, geriatric care nurses (home care services)</td>
<td>Provided by HSE at local health centres or part of Home Care Packages, performed by public health nurses.</td>
<td>GPs, nurses</td>
<td>(Specialised) Nurses</td>
<td>(Aux. or registered) Nurses</td>
<td>(Specialised) Nurses as part of home care teams, see also B3</td>
<td>(Aux.) Nurses, GPs as consultants</td>
<td>District nurses</td>
</tr>
<tr>
<td><strong>Standard care</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Accessibility</strong></td>
<td>Prescription required</td>
<td>People may be referred to the public health nurse by their GP or on discharge from hospital, or they may contact the service themselves through their local health centre or local area health office</td>
<td>Needs assessment by a GP required</td>
<td>Needs assessment</td>
<td>Needs assessment</td>
<td>Low co-payment may be necessary</td>
<td>Healthcare provided free of charge</td>
<td></td>
</tr>
<tr>
<td>Co-payment required (10 € per prescription plus 10% of the costs within the first 28 days/year)</td>
<td>Co-payment may be necessary (certain groups are exempted from co-payment, such as Medical Card holders, older people and chronically ill or dying people)</td>
<td>Out-of pocket payment only for private services</td>
<td>Co-payment may be necessary</td>
<td>Co-payment may be seldom necessary</td>
<td>Co-payment may be seldom necessary (if service is not allocated by CIZ)</td>
<td>Co-payment may be seldom necessary (measured at individual income)</td>
<td>Low co-payment may be necessary</td>
<td>Referral by GP etc.</td>
</tr>
<tr>
<td>Missing diagnosis (Grass-Kapanke, 2008) and incorrect prescriptions (Zimmermann,</td>
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141
<table>
<thead>
<tr>
<th>2013)</th>
<th>Public health nursing services not dementia-specific (Farrell et al., 2007; De Siún and Manning, 2014, Department of Health, 2011).</th>
<th></th>
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<th></th>
<th>District nursing services not dementia specific</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Utilisation</strong></td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
</tr>
<tr>
<td>A study with approx. 350 nurses suggests that the majority of care recipients also receive therapeutic care, but the amount seems to be decreasing with cognitive decline (van den Bussche 2012)</td>
<td>Recent study suggests that only a fraction of people with dementia in Ireland are known to public health nurses (Cahill, O'Shea &amp; Pierce, 2012). Overall, 13% of people over 65 years of age avail themselves of public health nursing services (McGee et al. 2005), utilisation increases with age and holding a Medical Card (McNamara et al. 2013)</td>
<td>Statistics of utilisation including IADL, ADL and therapeutic care. 50-66 years: 13,541, 67-79 years: 14,616, 80-89 years: 18,950, &lt;90 years: 5,525. (Statistics Norway 2013) 41.5% of people &gt;70 receiving in-home care have dementia (Wergeland et al., 2014).</td>
<td>Lower amount than support in basic ADLs and IADL, roughly about one-tenth.</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
</tr>
<tr>
<td>B 11) Rehabilitation at home</td>
<td>DE</td>
<td>IE</td>
<td>IT</td>
<td>NL</td>
<td>NO</td>
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<tr>
<td><strong>Availability</strong></td>
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<tr>
<td>Regionally</td>
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<tr>
<td>Nationwide</td>
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<td>Nationwide</td>
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<td>Regionally</td>
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<tr>
<td><strong>Healthcare professionals</strong></td>
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<tr>
<td>Multi-professional team</td>
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<tr>
<td>(occupational therapists,</td>
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<tr>
<td>physiotherapists, speech</td>
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<tr>
<td>therapists, nurses, nutritionists, social workers), supervision by a physician (Schmidt-Ohlemann &amp; Schweizer, 2008).</td>
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<tr>
<td>Public health nurses,</td>
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<tr>
<td>physiotherapist, occupational therapists, voluntary organisations, private home care providers</td>
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<tr>
<td>Physiotherapists, occupational therapists</td>
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<tr>
<td>Occupational therapists,</td>
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<tr>
<td>(aux.) nurses</td>
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<td>Occupational therapists,</td>
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<tr>
<td>physiotherapists, (aux.) nurses</td>
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<td>Occupational therapists,</td>
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<tr>
<td>physiotherapists, nurses as part of team-based home care (see also B3)</td>
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<tr>
<td>Physiotherapists, occupational therapists</td>
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<tr>
<td>Physiotherapists, speech &amp; language therapists</td>
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<td>Clinical psychology</td>
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<td><strong>Standard care</strong></td>
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<td>Yes</td>
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<tr>
<td>No Part of Home Care Packages</td>
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<td>Yes</td>
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<td>Yes</td>
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<td>Yes (primary care, municipal organisation or private)</td>
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<tr>
<td><strong>Accessibility</strong></td>
<td></td>
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<tr>
<td>Co-payment required (10 € per day for no more than 28 days/year)</td>
<td></td>
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<tr>
<td>Usually no co-payment (covered by Medical Card or included in Home Care Packages)</td>
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<tr>
<td>Co-payment</td>
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<tr>
<td>Only a limited number of visits covered by insurances</td>
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<tr>
<td>Co-payment may be seldom necessary</td>
<td></td>
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<tr>
<td>Co-payment may be seldom necessary (measured on individual income), full payment in the case of private services.</td>
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<tr>
<td>Low co-payment may be necessary</td>
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<tr>
<td>Healthcare free of charge</td>
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<tr>
<td>Prescription by a specialised</td>
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<tr>
<td>Needs assessment</td>
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<tr>
<td>Referral required by</td>
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<td>Needs assessment</td>
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<tr>
<td>Referral required by</td>
<td></td>
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<tr>
<td>Physician (Füsgen 2007)</td>
<td>GP or specialised physician</td>
<td>Distances (only available in some areas)</td>
<td>Distances (only available in some areas)</td>
<td>Distances (only available in some areas)</td>
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<tr>
<td>------------------------</td>
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<tr>
<td>Public access is extremely limited, leading to long delays (Cahill et al. 2012; O'Shea &amp; O'Reilly, 1999).</td>
<td>Overall, holding a Medical Card doubles the chance of using physiotherapy services, as does having a restriction in ADL and/or IADL. Those living in Dublin were more likely to use occupational therapy (McNamara et al. 2013)</td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
<td></td>
</tr>
<tr>
<td>Low utilisation is suggested (Korczak et al 2012).</td>
<td></td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
<td></td>
</tr>
<tr>
<td>Utilisation</td>
<td>The utilisation is low (Birkeland et al 2012)</td>
<td></td>
<td></td>
<td>It was estimated that PwD used these services on average 4 times/year (Wimo et al. 2014)</td>
<td></td>
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<td>When utilised likely to be in relation to other health problems rather than dementia-specific issues</td>
<td></td>
</tr>
<tr>
<td>B 12) Respite care</td>
<td>DE</td>
<td>IE</td>
<td>IT</td>
<td>NL</td>
<td>NO</td>
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</tr>
<tr>
<td><strong>Availability</strong></td>
<td>Nationwide (few exceptions)</td>
<td>Nationwide, regional differences</td>
<td>Regionally</td>
<td>Nationwide</td>
<td>Nationwide</td>
</tr>
<tr>
<td><strong>Healthcare professionals</strong></td>
<td>(Geriatric care and aux.) nurses (in care homes/nursing homes 50% of the staff has to be nurses)</td>
<td>Provided in public, private, and voluntary nursing homes, by public health nurses, GPs and trained care workers</td>
<td>Different types of healthcare professionals, social workers or GPs as coordinators.</td>
<td>Nurses, paid healthcare workers</td>
<td>(Aux. or registered) Nurses</td>
</tr>
<tr>
<td><strong>Standard care</strong></td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Accessibility</strong></td>
<td>Needs assessment required for cost takeover (degree of disability according to Social Code XI)</td>
<td>Needs assessment required</td>
<td>Needs assessment</td>
<td>Needs assessment with strict eligibility criteria (Ribeiro et al., 2011)</td>
<td>Decision by a municipal home help officer is needed in most cases.</td>
</tr>
<tr>
<td><strong>Payment</strong></td>
<td><strong>Private payment required/ Respite Care Grants are provided by the government, or covered as part of a Home Care Package</strong></td>
<td><strong>Services fees may vary greatly between structures and regions/local funds may be allocated by CIZ</strong></td>
<td><strong>Co-payment may be necessary (if service not allocated by CIZ)</strong></td>
<td><strong>User fee. 120 NKR/24hrs (Norwegian Ministry of Health and Care Services, 2011b)</strong></td>
<td><strong>Co-payment by the patient according to the individual income or the household income</strong></td>
</tr>
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</tr>
<tr>
<td><strong>accommodation/catering. Costs of care are covered by long-term care insurance up to 28 days/year.</strong></td>
<td><strong>Bed capacity and budgetary resources differ per area (HSE, 2010).</strong></td>
<td><strong>Public sector (RNCCI): Limit of 30 days/year Private sector: limited bed capacity</strong></td>
<td><strong>Limited capacity of municipalities</strong></td>
<td><strong>Variability in availability</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Waiting time/distances (Schneekloth &amp; Wahl, 2005)</strong></td>
<td><strong>Shortage of good quality respite services in Ireland (CIB, 2009)</strong></td>
<td><strong>Waiting time may occur</strong></td>
<td><strong>Waiting time</strong></td>
<td><strong>Waiting time, distances are a barrier</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Utilisation</strong></td>
<td><strong>No data available on a national level. In 2011, a total of 20,000 people</strong></td>
<td><strong>No data available on a national level. Based on the 2006 census, it is estimated that a total of 26,104 people with dementia live in</strong></td>
<td><strong>No data available on a national level. No data available on a national level.</strong></td>
<td><strong>No data available on a national level. No data available on a national level.</strong></td>
<td><strong>No data available on a national level. Approx. 4% of PwD (3,900 out of 92,000 living at home) used respite care in</strong></td>
</tr>
</tbody>
</table>
in need of care according to Social Code XI used respite care (Pfaff, 2013). Research suggests that approximately 20% of PwD used respite care (Schneekloth & Wahl, 2005) the community (Cahill et al. 2012). On average, these individuals have 15.20 Respite Care days/year (total annual usage is 396,781 days).

Whilst it is likely that a large proportion of the respite care beds are used by people with a dementia, the latter are not differentiated in national monitoring systems (Cahill et al., 2012).

awareness of respite care by informal carers although it is considered important (Ribeiro et al, 2011, Santa Casa de Misericórdia de Lisboa, 2007) 2012 (Wimo et al 2014)
<table>
<thead>
<tr>
<th>B13) Residential home/ Sheltered housing/ Assisted living</th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Availability</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Locally</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Residential home facilities are regionally available; sheltered housing and assisted living accommodation are not available to PwD.</td>
<td>Regionally</td>
<td>Residential homes are available nationwide. Availability of sheltered housing and extra-care housing varies regionally.</td>
</tr>
<tr>
<td>Description</td>
<td>Not specifically for PwD.</td>
<td>Mainly not specifically for PwD. Inspected and registered. Considerable variability in the levels of support provided (Approx. 25% provide basic benefits of clustered housing arrangements, approx. 40% provided social)</td>
<td>Lodging facilities and nursing services</td>
<td>Not specifically for PwD</td>
<td>Not specifically for PwD. Housing adapted for wheelchair users. 24hrs home care services must be available in the community. The adapted housing facility is often located closely to the home care service</td>
<td>Not specifically for PwD. In PT residential home institutions are designed for autonomous older people looking for fewer burdens with some IADLs (e.g. cooking, house cleaning). As an exception, help with ADLs may be available at an extra cost. Higher levels of formal care (e.g. supervised)</td>
<td>Not specifically for PwD</td>
<td>Dementia-specific residential homes for people requiring 24 hour care, but not 24 hour care from registered nurses. Residential homes are registered and subject to inspection. Sheltered-housing and extra-care housing based</td>
</tr>
<tr>
<td>Organisation/Institutions</td>
<td>Provided by private and non-profit organisations, often part of larger care organisations.</td>
<td>Housing associations, local authorities. Often exist in tandem with other services such as long-term residential care, day-care, home-care services (Cahill, O'Shea &amp; Pierce, 2012).</td>
<td>Private structures and facilities provided by local health agencies/districts</td>
<td>Private structures and non-profit structures, often part of a healthcare organisation</td>
<td>Provided by municipalities</td>
<td>Provided by some non-profit organisations, co-funded by the State, and mostly by private organisations.</td>
<td>Provided by municipalities or private providers</td>
<td>Residential homes provided by local authorities (now rarely) and independent sector providers (including charities). Sheltered housing and extra-care housing provided by local authorities and (not-for-profit) housing associations and independent...</td>
</tr>
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</tr>
<tr>
<td>Healthcare professionals</td>
<td>Social workers, (aux.) nurses are involved</td>
<td>Home Care Packages, Home Help Schemes, and through the PHN</td>
<td>Nurses</td>
<td>Nurses, social workers, physiotherapists, occupational therapists, gerontologists, nursing home assistants</td>
<td>(Aux.) Nurses, home care personnel</td>
<td>Health professionals are not mandatory. Social workers, sociocultural animators, nursing home assistants and others may be involved.</td>
<td>(Aux.) Nurses, healthcare assistant</td>
<td>No but Care workers.</td>
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</tr>
<tr>
<td>Standard care</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes (partially)</td>
<td>Yes</td>
</tr>
<tr>
<td>Accessibility</td>
<td>Costs incur for accommodation and basic services. Housekeeping/ personal care may be covered by long-term care insurance depending on</td>
<td>Rents required, amount depends on the level of service used (a fixed amount of care costs are covered by HSE).</td>
<td>Private payment</td>
<td>No private payment if service allocated based on needs assessment</td>
<td>Rents required</td>
<td>Co-payment required and non-profit organisations. Full-payment in private organisations</td>
<td>Rents required</td>
<td>Co-payment for care services. Rents required for sheltered housing and extra-care housing. Local authorities contribute to costs of</td>
</tr>
</tbody>
</table>

- **Healthcare professionals**
  - Social workers, (aux.) nurses are involved
  - Home Care Packages, Home Help Schemes, and through the PHN
  - Nurses
  - Nurses, social workers, physiotherapists, occupational therapists, gerontologists, nursing home assistants
  - (Aux.) Nurses, home care personnel
  - Health professionals are not mandatory. Social workers, sociocultural animators, nursing home assistants and others may be involved.
  - (Aux.) Nurses, healthcare assistant
  - No but Care workers.

- **Standard care**
  - No
  - No
  - Yes
  - Yes
  - Yes
  - No
  - Yes (partially)
  - Yes

- **Accessibility**
  - Costs incur for accommodation and basic services. Housekeeping/ personal care may be covered by long-term care insurance depending on
  - Private payment
  - No private payment if service allocated based on needs assessment
  - Rents required
  - Co-payment required and non-profit organisations. Full-payment in private organisations
  - Rents required
  - Co-payment for care services. Rents required for sheltered housing and extra-care housing. Local authorities contribute to costs of
<table>
<thead>
<tr>
<th>Low income and high care needs (Engels, 2001, Theobald, 2004)</th>
<th>Low income and high care needs</th>
<th>Dementia is described as a barrier (Cullen et al., 2007)</th>
<th>Dementia is described as a barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia is described as a barrier (Engels, 2011)</td>
<td>Dementia is described as a barrier (Engels, 2011)</td>
<td>Insufficient availability and waiting lists, especially for dementia-specific arrangements (Cullen et al., 2007)</td>
<td>Insufficient availability</td>
</tr>
<tr>
<td>Insufficient availability and waiting lists, especially for dementia-specific arrangements (Cullen et al., 2007)</td>
<td>Insufficient availability and waiting lists, especially for dementia-specific arrangements (Cullen et al., 2007)</td>
<td>Waiting lists</td>
<td>Waiting lists</td>
</tr>
<tr>
<td>Low awareness (Schreiner et al., 2011)</td>
<td>Low awareness (Schreiner et al., 2011)</td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
</tr>
<tr>
<td>No data available on a national level. Overall, 1.6% of people over 65 years live in an assisted</td>
<td>No data available on a national level. Overall, 1.6% of people over 65 years live in an assisted</td>
<td>17% of PwD live in residential homes (from Right Time Place Care project) (CIZ Basisrapportage AWBZ, 2013) 32,000 people</td>
<td>17% of PwD live in residential homes (from Right Time Place Care project) (CIZ Basisrapportage AWBZ, 2013) 32,000 people</td>
</tr>
<tr>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
</tr>
<tr>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
<td>About 14,000 PwD lived in low staff living facilities in 2012 (Wimo et al., 2014).</td>
<td>About 14,000 PwD lived in low staff living facilities in 2012 (Wimo et al., 2014).</td>
</tr>
<tr>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
</tr>
<tr>
<td>living facility (Saup, 2007)</td>
<td>were living in residential homes in 2001 (Gezondheidsraad, 2002)</td>
<td>adapted housing in 2005 (Norwegian Ministry of Health and Care Services, 2006)</td>
<td></td>
</tr>
<tr>
<td>B 14) Social support</td>
<td>DE</td>
<td>IE</td>
<td>IT</td>
</tr>
<tr>
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</tr>
<tr>
<td><strong>Availability</strong></td>
<td>Nationwide</td>
<td>Regionally</td>
<td>Locally</td>
</tr>
<tr>
<td><strong>Organisation/Institutions</strong></td>
<td>Home care services or volunteer organisations</td>
<td>Mainly third sector</td>
<td>Voluntary organisations (Cahill et al., 2012), dementia-specific home care services (by Alzheimer Society Ireland), Social Clubs or Alzheimer Café’s, voluntary “befriending” services</td>
</tr>
<tr>
<td><strong>Healthcare professionals</strong></td>
<td>No special training required, volunteers</td>
<td>Trained dementia care workers or other professionals or trained or untrained volunteers</td>
<td>Volunteers, social workers</td>
</tr>
<tr>
<td><strong>Standard care</strong></td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td><strong>Accessibility</strong></td>
<td>Needs assessment</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
required (reduced competences in daily living have to be assessed) | Co-payment may be necessary for home care services | Co-payment may be necessary | No co-payment, included in personal budgets (CIZ Basisrapportage AWBZ, 2013) | Co-payment may be necessary | Co-payment may be necessary
---|---|---|---|---|---
Dementia diagnosis is required for home care services | | | Waiting time | | Availability limited in some areas

**Utilisation**

<p>| In 2012, 190,300 people received social support. Approx. one third of PwD living at home used social support services. (Rothgang et al., 2013). | In 2008, the ASI reported that it provided people with dementia with 748,902 care hours including social support (ASI, 2008). | No data available on a national level. | No data available on a national level. | No data available on a national level. | No data available on a national level. |</p>
<table>
<thead>
<tr>
<th>B15) Personal safety alarm or surveillance/monitoring systems</th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Availability</strong></td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Regionally available</td>
<td>Nationwide</td>
<td>Nationwide</td>
</tr>
<tr>
<td><strong>Organisation/Institutions</strong></td>
<td>Private providers, non-profit organisations</td>
<td>Private companies, non-profit organisations (community groups, volunteer groups), research projects</td>
<td>Private companies</td>
<td>Municipalities</td>
<td>Municipalities</td>
<td>Private companies, public entities and non-profit institutions.</td>
<td>Municipalities</td>
<td>Local authorities and private companies</td>
</tr>
<tr>
<td><strong>Standard care</strong></td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Accessibility</strong></td>
<td>Co-payment</td>
<td>Private payment unless eligible for the Seniors Alert grant scheme (except pilot projects)</td>
<td>No co-payment required</td>
<td>Covered by insurance, co-payment up to 350 €</td>
<td>Out-of-pocket payment</td>
<td>Private payment or co-payment may be required</td>
<td>Small co-payment may be required</td>
<td>Co-payment may be required</td>
</tr>
<tr>
<td><strong>Utilisation</strong></td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
</tr>
</tbody>
</table>
2% of the German people aged 65 years and older use a personal alarm system (European Union, 2010).

13-15% of the total population over the age of 65 using the Seniors Alert Grant Scheme (CARDI, 2011).

73,431 people used safety alarms in 2013 (Statistics Norway 2013).
Table C: Description of information and counselling as access to formal dementia community care (C1-C4).

<table>
<thead>
<tr>
<th>C1) Advance directive/advance care planning</th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Availability of a nationwide public health initiative</td>
<td>No nationwide initiative</td>
<td>#</td>
<td>#</td>
<td>Nationwide (dementia strategy)</td>
<td>#</td>
<td>No nationwide initiative</td>
<td>No nationwide initiative</td>
<td>No nationwide initiative</td>
</tr>
<tr>
<td>Part of dementia strategy</td>
<td>Not available</td>
<td>No</td>
<td>#</td>
<td>Yes</td>
<td>No</td>
<td>Not available</td>
<td>An update of the national dementia strategy has just started and this issue may come up</td>
<td>No</td>
</tr>
<tr>
<td>Description of content and scope</td>
<td>Advanced directives are regulated by the government (§1901 Civil Code) and have to respected when making medical decisions (Wiesing et al., 2010). Therefore, the evident wish of a living person must have more weight than an</td>
<td>Content and scope cannot be determined because dementia is not covered explicitly. The Assisted Decision-Making (Capacity) Bill 2013 is currently making its way through the Irish Parliament and is expected to be enacted into law</td>
<td>No national law available regulating advanced directives. National Bioethical Committee legitimates advance care directives (National Bioethics Commettees, 2003).</td>
<td>Advanced directives are regulated by the government. Allow people with dementia to register choices of treatment and of euthanasia. These matters should be discussed with your GP, and the GP should also be updated</td>
<td>Offered by a private society (“My life testament”) (livtestament.org)</td>
<td>A binding advance directive (AD) is possible, in terms of a living will/or healthcare proxy (since 2012). It may include: artificial support for vital functions, futile (not-useful) treatments, adequate palliative care</td>
<td>Under discussion: Ability for PwD to make decisions. How and by whom such decisions are made, for example regarding advanced care issues, questions about safety and protection, and safety and care planning.</td>
<td>Advance decisions are a legally binding aspect of advance care planning, alongside Lasting power of attorney. They are effective after the person loses mental capacity.</td>
</tr>
<tr>
<td><strong>Healthcare professional</strong></td>
<td>A professional should be involved. No further information available</td>
<td>No formal procedures available. Involving a GP or consultant is recommended</td>
<td>No formal procedures</td>
<td>GP or professionals working at the memory clinics</td>
<td>Volunteers</td>
<td>Not mandatory to engage a physician but the Ministry of Health recommends discussing the matter with a health professional or the healthcare team.</td>
<td>Physicians</td>
<td>Informing the GP is recommended so that the GP is aware of the existence of the advanced decision. If the person already has a dementia diagnosis, then assessment of capacity by competent professional is recommended</td>
</tr>
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<tr>
<td><strong>advanced directive</strong> (German Ethics Council, 2012)</td>
<td>in 2014, which has not yet happened so far (Fitzgerald, 2014). It will include a law to govern Advance Healthcare Directives. The Irish Strategy also states that the HSE will promote awareness of this bill, thereby demonstrating support for this legislation.</td>
<td>An unofficial Biologic Testament Register has been adopted locally throughout the country.</td>
<td>regularly that you are still standing behind your choices (<a href="http://www.rijksoverheid.nl/">http://www.rijksoverheid.nl/</a>).</td>
<td>and consent to participate in research or clinical trials. The AD must be renewed every 5 years. If loss of capacity occurs, the AD remains in force. (Portuguese Act on Living wills and Healthcare Proxy, Law No 25/2012, 16/6).</td>
<td></td>
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</tr>
<tr>
<td>Utilisation</td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
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<tr>
<td>A survey revealed that about 10% of the German population hold an advanced directive (Lang &amp; Wagner, 2007).</td>
<td>Between 10% (Irish Council for Bioethics, 2007) and 14% of the Irish public stated that they had written an advanced directive (Weafer, 2004).</td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
<td>Regulations regarding the Rentev database – national registry of AD – were only published in 2014.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>C2) Information provision structures</td>
<td>DE</td>
<td>IE</td>
<td>IT</td>
<td>NL</td>
<td>NO</td>
<td>PT</td>
<td>SE</td>
<td>UK</td>
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</tr>
<tr>
<td>Availability of a nationwide/ public health initiative</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Public web-based databases exist</td>
<td>Alzheimer Society of Ireland (ASI) operates a national helpline</td>
<td>National awareness campaigns conducted</td>
<td>Web-based information on activities and information by Alzheimer Nederland, telephone helpline</td>
<td>Information provision structures are regionally or locally available, mainly by Alzheimer Portugal.</td>
<td>No Information provision structures are regionally or locally available, mainly by Alzheimer Portugal.</td>
<td>Yes National competence centres</td>
<td>Yes – in England, Wales and Scotland</td>
<td></td>
</tr>
<tr>
<td>Part of dementia strategy</td>
<td>Not available</td>
<td>One of the guiding principles of the Irish Strategy (DoH, 2014) is that relevant information should routinely be given to PwD and their families although no specific actions have been identified to ensure that this occurs.</td>
<td># National care portal will be part of dementia strategy</td>
<td>Yes</td>
<td>Not available</td>
<td>Yes</td>
<td>Yes – in England, Wales and Scotland</td>
<td></td>
</tr>
<tr>
<td>Description</td>
<td>Public online database providing information about dementia (daily living, online or in printed booklet form.</td>
<td>Information about symptoms, services and structures for PwD and their families</td>
<td>Information provided by Alzheimer Nederland and local branches</td>
<td>Active and personal information delivery</td>
<td>Information provided by Alzheimer Portugal, websites, help-lines, Web based training courses and information</td>
<td>In England and Wales, Alzheimer’s Society information packs given at</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Institution/Organisation</td>
<td>Alzheimer Society of Ireland (ASI), the government, different organisations (Dementia Services Information and Development Centre, The Living with Dementia Programm, the DSIDC and the National volunteers’ and relatives’ associations, districts and regions)</td>
<td>Alzheimer Society Netherlands</td>
<td>Municipalities</td>
<td>Alzheimer Portugal, local cooperating partners</td>
<td>Swedish Dementia Centre, National competence centre for informal carer support, volunteer and patient</td>
<td>Alzheimer’s Memory Services National Accreditation Network</td>
<td></td>
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</tbody>
</table>

Alzheimer Society of Germany is web-based, telephone or personal.

Information provided by Alzheimer Society through meetings in their local branches and their websites.

Leaflets, Alzheimer Café.

Time of diagnosis and books providing information on dementia available ‘on prescription’ in all public libraries; dedicated help-line available.

Awareness and education programmes widely available.
<p>| Healthcare professional | Germany, Healthcare insurances. | Dementia Elevator programme, The Irish Hospice Foundation (IHF), The Clare Mental Health Services) | No information available | Any member of an old age psychiatry team, social workers, public health nurses, GPs, home care workers, physiotherapists, occupational therapists, psychologists and counsellors | Volunteers, psychologists, social workers, depending on the focus and the aims of the initiative | Social workers, psychologists | Provided by dementia teams (Gausdal, M., &amp; Michelet, M., 2011), (aux.) nurses, occupational therapists, physiotherapists | No information available | (Aux.) Nurses, social workers, occupational therapists, physiotherapists, physicians | Information provided by trained information officers and volunteers. Education sessions may be provided by members of multi-disciplinary teams e.g. Memory Clinics | organisations |</p>
<table>
<thead>
<tr>
<th>C3) Counselling for PwD</th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Availability</strong></td>
<td>No specific counselling for people with dementia. See D2 informal carer counselling</td>
<td>No formal counselling services for people with dementia and informal carers available (see also D2, informal carer counselling)</td>
<td>Self-help support is offered by the Alzheimer Society Ireland, counselling services are offered by therapists. Local programme on dyadic support in Dublin</td>
<td>No formal counselling services for people with dementia available. Self-help support is offered by the Alzheimer Society, volunteer and patient-relative organisations</td>
<td>Nationwide (Wolfs et al., 2010, Verhey et al., 2009)</td>
<td>Nationwide</td>
<td>No specific counselling for people with dementia. See D2 informal carer counselling (See also D2 informal carer counselling)</td>
<td>Available in some areas Requirement of Memory Services National Accreditation Network</td>
</tr>
<tr>
<td><strong>Part of dementia strategy</strong></td>
<td>Not available</td>
<td>The Irish Strategy acknowledges that considerable emotional support will be required post-diagnosis but it does not make any provision to provide specific counselling support as part of the strategy (DoH, 2014)</td>
<td>#</td>
<td>Yes</td>
<td>Yes</td>
<td>Not available</td>
<td>Yes</td>
<td>Not a specific aspect of the strategies</td>
</tr>
<tr>
<td><strong>Outreaching</strong></td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes (usually initiated without application)</td>
<td>Yes</td>
<td>No</td>
<td></td>
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<tr>
<td>Mandatory/ post diagnostic counselling</td>
<td>No, post-diagnostic counselling is not usually offered to people immediately after diagnosis (Cahill, O'Shea &amp; Pierce, 2011).</td>
<td>No</td>
<td>No</td>
<td>Not mandatory, but recommended in the Norwegian dementia plan 2015</td>
<td>Provision is obligatory by municipalities</td>
<td>Pre-diagnostic counselling is recommende d particularly for genetic disorders, but post-diagnostic support is more variable in nature</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Standard Care</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Covered by insurance</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Institution/ Organisation</td>
<td>Private services, Alzheimer Society Ireland (self-help structures)</td>
<td>Volunteers’ and patients’/ relatives’ organisations</td>
<td>Memory clinics, community mental health teams, a variety of organizations</td>
<td>Local authorities. Provided by dementia teams or dementia coordinators. (Gausdal, M., &amp; Michelet, M., 2011). 20% of the municipalities offer group counselling (Eek &amp; Kirkevold 2011)</td>
<td>National level: National competence centre for informal carer support, the Swedish Dementia Centre (SDC), Local level: municipalities, patient/informal carer advocacy groups (Demensförbundet, Alzheimerföreningen)</td>
<td>Most often provided by Memory services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Healthcare professional</td>
<td>Counsellors, Psychotherapists</td>
<td>Volunteers, psychologists, educators</td>
<td>Psychologist, social workers</td>
<td>Geriatricians, nurses, occupational therapists</td>
<td>en)</td>
<td>Nurses, clinical psychologists</td>
<td></td>
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</tr>
<tr>
<td><strong>Accessibility</strong></td>
<td>Services of therapists are not free of charge</td>
<td>Small co-payment may be necessary</td>
<td>Lack of standardisation and availability</td>
<td>Lack of information in some communities</td>
<td>Small co-payment may be necessary</td>
<td>Lack of resources/staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Lack of resources and staff</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td><strong>Utilisation</strong></td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>Proposed to 93%, utilized by 88% of patients (Wolfs et al., 2010)</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
C4 Legal guardianship

<table>
<thead>
<tr>
<th>Availability</th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

**Content and reach**

- Legal act defined within the German Civil Law Code. 1992 renamed into custodianship, refers to a group of tasks in which custodianship is actually necessary, e.g., determination of the place of residence, health issues, or property administration that are determined by a custodian court. The ward has full capacity with all human rights (such as marrying, voting or making a will) and basically has the capacity to make a contract.


  - **a) Ward of Court**
    Wards are not permitted to make their own financial or medical decisions, travel, make a will, or marry with the approval of the court. Wardship does not invalidate an existing marriage.

  - **b) Power of Attorney** is a legal device that can be set up by a person (the donor) when he or she is in good mental health. It allows another specially appointed person (the support administrator) to take care of themselves due to physical or cognitive impairment (Verzoni M., 2004).

- There are different guardianship s possible: financial, care and housing issues are taken over by a legal guardian. This guardian can be either a partner, family member or a (paid) professional (Source: Alzheimer Nederland).

- The person maintains the right to handle economical and legal affairs that lie within the reach of their mental capacity. Issues relating to voting, marriage, paternity, donation of organs, changing of legal will or coercion are excepted and must be authorized by virtue of other specific laws (Ministry of Justice, 2013).

- A person who lacks mental capacity may be either subject to incapacitation or even interdiction, depending on the degree of lack of competence (according to the Portuguese Civil Code and as regulated by the Code of Civil Procedure).

- A trustee is appointed for people who have been declared incapacitated. His approval is needed to sell or donate properties.

- A guardian is appointed for people who are subject to interdiction. The guardian is the person who acts in the person's name, excepting at the level of mental capacity (Ministry of Justice, 2013).

- There are two legal support instruments ("Trustee", (a rather weak support instrument) and "Förvaltare" (rather similar to guardian)).

- In emergency situations, the Compulsory Psychiatric Care Act (§4) or The Penal Code can be used for protection of the patient.

1) Lasting power of attorney allows a person to appoint other people to look after financial and welfare affairs if they subsequently lose capacity.

2) If no lasting power of attorney is made, then the Court of Protection can be asked to appoint a Deputy for the person with dementia if they lack capacity to make decisions regarding finance or health and welfare.
attorney) to take actions on the donor’s behalf if he or she is absent, abroad, or incapacitated through illness. An Enduring Power of Attorney (EPA) also allows the attorney to make ‘Personal Care Decisions’ on the donor’s behalf once he or she is no longer fully mentally capable. It should be noted that healthcare decisions are not covered by this legislation although the borderline between personal and healthcare decisions is not always clear.

<table>
<thead>
<tr>
<th>Process</th>
<th>Appointed by a custodianship court based on a formal application (formal procedures protecting the rights of the ward are implemented). At the lasted after a period of 7 years, the court will</th>
</tr>
</thead>
</table>
|         | **a) Ward of Court**  
Formal application must be made including two medical affidavits (supporting statements from two doctors). It is possible but not usual for someone to be released from |
<p>|         | The support administrator is nominated by the local judge based on an application/a petition by the persons themselves, their relatives or by the public |
|         | The partner or a family member of the person with dementia has to arrange this with a trustee. A judge has to approve the |
|         | The County Governor is the local and initial authority for constituting legal guardianship. Legal complaints are to be |
|         | Before a formal application is made, a medical, psychological and social evaluation should be carried out by health or social professionals. The legal process of obtaining |
|         | Someone (it may be the persons him/herself, a family member, a professional etc.) makes a formal application. For a trustee or |
|         | 1) Person completes a lasting power of attorney form, registered with the Office of the Public Guardian – becomes active if / |</p>
<table>
<thead>
<tr>
<th>reconsider the legal custodianship and check whether the preconditions are still fulfilled.</th>
<th>reconsider the legal custodianship and check whether the preconditions are still fulfilled.</th>
<th>reconsider the legal custodianship and check whether the preconditions are still fulfilled.</th>
</tr>
</thead>
<tbody>
<tr>
<td>In case a power of attorney is in force, the custodianship court will not be involved. (Bundesministerium der Justiz und für Verbraucherschutz, 2014)</td>
<td>In case a power of attorney is in force, the custodianship court will not be involved. (Bundesministerium der Justiz und für Verbraucherschutz, 2014)</td>
<td>In case a power of attorney is in force, the custodianship court will not be involved. (Bundesministerium der Justiz und für Verbraucherschutz, 2014)</td>
</tr>
<tr>
<td>(B) Enduring Power of Attorney (EPA) Setting up an EPA requires the involvement of a solicitor and a doctor. The document follows a prescribed format: a statement by a doctor verifying that the donor has the mental capacity; a statement from the attorney indicating comprehension, a statement from a solicitor indicating that both parties understand the effects, a statement from the solicitor that indicates that the donor was not acting under undue influence.</td>
<td>(B) Enduring Power of Attorney (EPA) Setting up an EPA requires the involvement of a solicitor and a doctor. The document follows a prescribed format: a statement by a doctor verifying that the donor has the mental capacity; a statement from the attorney indicating comprehension, a statement from a solicitor indicating that both parties understand the effects, a statement from the solicitor that indicates that the donor was not acting under undue influence.</td>
<td>(B) Enduring Power of Attorney (EPA) Setting up an EPA requires the involvement of a solicitor and a doctor. The document follows a prescribed format: a statement by a doctor verifying that the donor has the mental capacity; a statement from the attorney indicating comprehension, a statement from a solicitor indicating that both parties understand the effects, a statement from the solicitor that indicates that the donor was not acting under undue influence.</td>
</tr>
<tr>
<td>guardianship is extensive and slow. Thus a large number of PwD are cared for by their families/carers whose decisions on behalf of the PwD may not always be legally valid, albeit generally in good faith. Information on the legal procedures has been scarce and interdiction may be regarded as a social punishment to Alzheimer patients (Firmino, 2008). However, recent civil society efforts (e.g. Alzheimer Portugal) to educate PwD, carers and public are acknowledged.</td>
<td>guardianship is extensive and slow. Thus a large number of PwD are cared for by their families/carers whose decisions on behalf of the PwD may not always be legally valid, albeit generally in good faith. Information on the legal procedures has been scarce and interdiction may be regarded as a social punishment to Alzheimer patients (Firmino, 2008). However, recent civil society efforts (e.g. Alzheimer Portugal) to educate PwD, carers and public are acknowledged.</td>
<td>guardianship is extensive and slow. Thus a large number of PwD are cared for by their families/carers whose decisions on behalf of the PwD may not always be legally valid, albeit generally in good faith. Information on the legal procedures has been scarce and interdiction may be regarded as a social punishment to Alzheimer patients (Firmino, 2008). However, recent civil society efforts (e.g. Alzheimer Portugal) to educate PwD, carers and public are acknowledged.</td>
</tr>
<tr>
<td>2) When the person lacks capacity, an application is made to the Court of Protection – Deputy appointed can be a family member, or a friend or a professional. Many decisions are in practice made under the ‘best interests’ provisions of the Mental Capacity Act.</td>
<td>2) When the person lacks capacity, an application is made to the Court of Protection – Deputy appointed can be a family member, or a friend or a professional. Many decisions are in practice made under the ‘best interests’ provisions of the Mental Capacity Act.</td>
<td>2) When the person lacks capacity, an application is made to the Court of Protection – Deputy appointed can be a family member, or a friend or a professional. Many decisions are in practice made under the ‘best interests’ provisions of the Mental Capacity Act.</td>
</tr>
</tbody>
</table>
At least two additional closely related people must be notified. Registered with the Registrar of Wards of Court required. Once the EPA has been registered, it cannot be revoked even if the donor is mentally capable. To revoke a registered EPA, an application would need to be made to the courts and they would need to approve the revocation. Finally, an EPA ceases on the death of the donor. Where a spouse or civil partner is the attorney, it also ceases in the event of annulment, divorce or dissolution of the partnership.

| Healthcare professionals | Public authority custodians (different professions), court-appointed special advocates and judges are involved. Most custodians are | Public authority custodians, court-appointed special advocates and judges are involved. | A partner, family member or (paid) professional | No healthcare professional involved, except for the evaluation. | Initiative may be taken by care professionals (municipal, county councils, etc.) | Healthcare professionals usually only involved in relation to evaluation of capacity. |

verdict (Verzoni, 2004.; Bergamaschi et al., 2005).
next of kin (approximately 60%); only around 40% are public authority custodians (Deinert, 2013)

judges are involed.

care and Social Services managing directors have the duty to submit the petition to the local judge supervising cases concerning guardianship whenever they know about facts that make it necessary (Verzoni M., 2004).

<table>
<thead>
<tr>
<th>Amount of PwD with legal guardianship</th>
<th>No data available on a national level</th>
<th>The Health Services Executive (HSE, 2014h) suggest that approximately 30% of all wardship cases made in Ireland involve dementia.</th>
<th>No data available on a national level</th>
<th>No data available on a national level</th>
<th>No data available on a national level</th>
<th>No data available on a national level</th>
</tr>
</thead>
</table>

| private). For the certificate: physicians. The chief guardian is a member of the municipal staff. |
Table D: Description of support for informal carers as access to formal dementia community care (D1 –D3).

<table>
<thead>
<tr>
<th>D1) Informal carer education</th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Availability</strong></td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide, regional differences</td>
<td>Regionally (e.g. psycho-educational groups/overlap with informal carer counselling - D2)</td>
<td>Nationwide</td>
<td>Nationwide with regional variations</td>
</tr>
<tr>
<td><strong>Part of dementia strategy</strong></td>
<td>Not available</td>
<td>Yes</td>
<td>#</td>
<td>Yes</td>
<td>Yes</td>
<td>Not available</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Outreaching</strong></td>
<td>Partially</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes (usually initiated without application)</td>
<td>No (although recommended by proposed guidelines for cognitive disorders – DGH, 2011)</td>
<td>Yes</td>
<td>Partially</td>
</tr>
<tr>
<td><strong>Mandatory</strong></td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td><strong>Standard Care</strong></td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Institution/ Organisation</strong></td>
<td>Healthcare insurance, welfare</td>
<td>Alzheimer Society Ireland, Home Instead</td>
<td>National volunteer organisations/</td>
<td>Memory clinics, Steunpunt Mantelzorg,</td>
<td>Local authorities often in collaboration</td>
<td>Non-profit organisations (e.g. Portuguese)</td>
<td>See C3/D2 (overlap with informal carer counselling)</td>
<td>Alzheimer Societies, local</td>
</tr>
<tr>
<td>Healthcare professionals</td>
<td>Nurses, care managers, social workers or health insurance employees</td>
<td>Members of the organising institution</td>
<td>Psychologist, educators</td>
<td>Social workers, nurses, others</td>
<td>Geriatricians, nurses, occupational therapists</td>
<td>Mainly nurses, psychologists, social workers and others</td>
<td>See C3/D2 (overlap with informal carer counselling)</td>
<td>Alzheimer’s Society staff, nurses, social workers, psychologists, occupational therapists, physiotherapists, pharmacists and others.</td>
</tr>
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<td>------------------------------------------------------------------</td>
</tr>
<tr>
<td>Accessibility</td>
<td>No out-of-pocket</td>
<td>Courses may be</td>
<td>No out-of-</td>
<td>Co-payment may</td>
<td>No out-of-pocket</td>
<td>No out-of-pocket</td>
<td>See C3/D2</td>
<td>Free of charge</td>
</tr>
<tr>
<td>Payment</td>
<td>Free of charge or out-of-pocket payment may be required</td>
<td>Pocket payment be required</td>
<td>Payment</td>
<td>Payment (except in private services)</td>
<td>(overlap with informal carer counselling)</td>
<td></td>
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<tr>
<td>Lack of awareness (Donath et al., 2009)</td>
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<td></td>
<td></td>
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<td></td>
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<td></td>
<td></td>
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<tr>
<td>Services too unspecific (Dörpinghaus, 2006)</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Utilisation</td>
<td>No data available on a national level.</td>
<td>Courses by Alzheimer Society Ireland have been used by around 1,000 informal carers; courses by DSIDC have been joined by</td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
<td>No data available on a national level.</td>
<td>Variability in extent of service offered; may be difficult to access in rural areas or timing (day-time or evening) may not be convenient for some carers</td>
<td></td>
</tr>
<tr>
<td>education (Donath et al., 2009)</td>
<td>around 30 informal carers.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D2) Informal carer counselling</td>
<td>DE</td>
<td>IE</td>
<td>IT</td>
<td>NL</td>
<td>NO</td>
<td>PT</td>
<td>SE</td>
<td>UK</td>
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<td>--------------------------------</td>
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</tr>
<tr>
<td><strong>Availability</strong></td>
<td>Nationwide (See also C3, no clear distinction)</td>
<td>Nationwide</td>
<td>Nationwide (see C3)</td>
<td>Nationwide</td>
<td>Regionally (See also D1)</td>
<td>No clear distinction between counselling for PwD and informal carer (See also C3/D1 informal carer counselling)</td>
<td>Nationwide but regional variation</td>
<td></td>
</tr>
<tr>
<td><strong>Part of dementia strategy</strong></td>
<td>Not available</td>
<td>The Irish Strategy (DoH, 2014) acknowledges that considerable emotional support will be required post-diagnosis but it does not make any provision to provide specific counselling support as part of the strategy, nor does it distinguish between supports for the PwD and informal carers.</td>
<td>#</td>
<td>Yes (priority)</td>
<td>Not available</td>
<td>Yes</td>
<td>Not specifically, but recommended in practice guidelines And in Memory Services National Accreditation Network</td>
<td></td>
</tr>
<tr>
<td><strong>Outreaching</strong></td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes (usually initiated without application)</td>
<td>No (although recommended by proposed guidelines for cognitive disorders – DGH,</td>
<td>Yes</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td><strong>Mandatory</strong></td>
<td>Only for people receiving cash benefits from long-term care insurance (see also D3)</td>
<td>No, post-diagnostic counselling is not usually offered to people immediately after diagnosis (Cahill, O'Shea &amp; Pierce, 2011).</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Provision is obligatory by municipalities</td>
<td>No</td>
</tr>
<tr>
<td><strong>Standard Care</strong></td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Institution/ Organisation</strong></td>
<td>Welfare organisations, non-profit organisations, long-term care insurances (Klie et al., 2011).</td>
<td>Self-help support is offered by Alzheimer Society, volunteer and patient/relative organisations, private services</td>
<td>National volunteer organisations/ informal carer patient organisations, Local Health Agencies (Agenzie Sanitarie Locali, ASLs), local residential homes, Alzheimer Evaluation Units</td>
<td>Municipalities</td>
<td>Provided by few non-profit organizations (e.g. Alzheimer Association).</td>
<td>National level: National competence centre for informal carer support, the Swedish Dementia Centre (SDC), Local level: municipalities, patient/informal carer advocacy groups (Demensförbundet, Alzheimerföreningen)</td>
<td>Formal counselling mainly provided by NHS. Some third-sector organisations and local authorities may also offer counselling; private counselling services also available.</td>
<td></td>
</tr>
<tr>
<td><strong>Healthcare professionals</strong></td>
<td>Nurses, health insurance employees, or social workers (Klie, et. al, 2011).</td>
<td>Counsellors psycho-therapists</td>
<td>Psychologists, educators</td>
<td>Nurses, psychologists, social workers and other</td>
<td>Counsellors, nurses, Admiral Nurses, clinical psychologists, psychological...</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Accessibility</strong></td>
<td>No out-of-pocket payment</td>
<td>Services of therapists require fees</td>
<td>No out-of-pocket payment</td>
<td>No out-of-pocket payment</td>
<td>No out-of-pocket payment</td>
<td>Small co-payment may be necessary</td>
<td>Payment only required for private services.</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Comprehensive, individual counselling requires a confirmed degree of disability</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Staff restrictions</td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Utilisation</strong></td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td></td>
</tr>
</tbody>
</table>
### D3) Financial support for informal carer

**Availability**
- Care recipients receive a lump sum depending on the degree of disability as assessed by expert raters of the Medical Service of the Statutory Health Insurance in Germany.
- Citizens with a physical or mental disablement can benefit from a monthly payment to the amount of 504.07 € (INPS, n.d., “Indennità di accompagnamento (invalidi civili)”).
- Informal carers can benefit from a regionally available care check delivered by Local Health Agencies or districts.
- People with disability and an informal carer providing six or more hours of daily care may apply for the Dependency Subsidy. Payment is made by the Social Security for individuals who are in need of help from another person to satisfy their basic needs because of age, physical or learning disability, or illness, including mental illness. Not granted to pensioners whose pension amount exceeds 600 €.
- Employed informal carers (few), personal assistants (age restrictions) or financial support for terminal care (up to 100 days).

<table>
<thead>
<tr>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Regionally</td>
<td>Nationwide</td>
</tr>
</tbody>
</table>

1) Carers Allowance – paid directly to the carer
2) ‘Attendance Allowance’ and ‘Personal Independence Payments’ are technically, payments for the person with dementia, but contributes to care-giving costs.
<table>
<thead>
<tr>
<th>Healthcare professionals</th>
<th>Expert raters (see needs assessment)</th>
<th>Social Welfare Inspector, GP</th>
<th>Social workers, Multidisciplinary Evaluation Units</th>
<th>Municipalities and social workers</th>
<th>Nurses and administrative personnel in the local authorities health department</th>
<th>Physicians</th>
<th>Different professionals</th>
<th>Different professionals may assist in the completion of the (lengthy) application forms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accessibility</td>
<td>Needs assessment required</td>
<td>Depending on the programme</td>
<td>Needs assessment (100% disabled and dependent on ADLs and IADL)</td>
<td>The care receiver must be receiving care allocated by CIZ for at least 51 weeks.</td>
<td>Needs assessment: For persons with comprehensive care responsibilities. The local authorities must confirm that this kind of care is the best solution.</td>
<td>Needs assessment by a commission composed of three physicians (ISS, 2013).</td>
<td>Needs assessment/ or physician’s certificate and a decision by the Swedish Social Insurance Agency</td>
<td>1) Person with dementia must be receiving Attendance Allowance or Personal Indepence Payment following a needs assessment and must be providing care for at least 35 hours a week</td>
</tr>
<tr>
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<td></td>
<td></td>
<td></td>
<td>2) Needs</td>
<td></td>
</tr>
<tr>
<td>Means testing</td>
<td>Means testing (informal carer checks)</td>
<td>Means testing</td>
<td>1) Restriction on carer’s other income</td>
<td>2) Not means tested</td>
<td></td>
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</tr>
<tr>
<td>Full-time caregiving and high care requirements</td>
<td></td>
<td>Dependency subsidy to be received in addition to Home Care Services or other formal services provided by institutions co-financed by the Government or private entities with public utility (Nogueira, J. M., 2009).</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Living together</td>
<td></td>
<td></td>
<td></td>
<td>Attendance Allowance for people with dementia 65 and over; Personal Independence Payment for under 65s (includes mobility as well as daily living)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Monitoring</td>
<td>Yes (see D2, counselling is mandatory)</td>
<td>No</td>
<td>Constant monitoring through timely follow-ups (Gori, 2004).</td>
<td></td>
<td>Capacity of the informal carer is checked</td>
<td></td>
<td>Regular monitoring</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Utilisation</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
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</tr>
<tr>
<td></td>
<td>Widely used: in 2011, 70% of the 2.5 million people in need of care lived at home and received payment in kind or cash benefit (Statistisches Bundesamt, 2011).</td>
<td>In 2013, there were 57,136 recipients (12,742 male and 44,394 female) of a Carer’s Allowance in Ireland.</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>Overall utilisation in 2013: 0-66 years: 7,849. &gt;67 years: 1,668 (Statistics Norway 2013)</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
</tr>
</tbody>
</table>
Table E: Description of civil activities as access to formal dementia community care (E1-E2).

<table>
<thead>
<tr>
<th>E1) Voluntary organisation</th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Availability - National programme/initiative</strong></td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Nationwide</td>
<td>Regionally</td>
<td>Nationwide</td>
<td>Nationwide</td>
</tr>
<tr>
<td>No national programme/nationwide initiative</td>
<td>But no national programmes/initiatives exist. Several key organisations operate on a nationwide or local level</td>
<td>There is no nationwide initiative.</td>
<td>(Alzheimer Nederland, Alzheimer Centra, Alzheimer Café)</td>
<td>Common training for volunteers available.</td>
<td>Local programmes exist. (SCML, Cruz Vermelha, Coração Amarelo, Alzheimer Café)</td>
<td></td>
<td>National organisations and local/initiatives programmes exist.</td>
<td>(Alzheimer’s Society / Alzheimer’s Scotland)</td>
</tr>
</tbody>
</table>

<p>| <strong>Utilisation</strong> | Approx. 1% of people with dementia use support by voluntary organisations (Ulbrecht, 2010) | No data available on a national level. | No data available on a national level. | No data available on a national level. | No data available on a national level. | No data available on a national level. | No data available on a national level. | No data available on a national level. |</p>
<table>
<thead>
<tr>
<th>E 2) Self-help organisation</th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Availability</strong></td>
<td>Nationwide</td>
<td>Nationwide, regional differences</td>
<td>Nationwide</td>
<td>Regionally</td>
<td>Nationwide</td>
<td>Regionally (overall 8 support groups available as at September 2014; most address carers, only a few PwD)</td>
<td>Nationwide</td>
<td>Nationwide with regional differences</td>
</tr>
<tr>
<td><strong>Organisational level</strong></td>
<td>Initiated and facilitated by national umbrella organisation (Alzheimer Society), and local initiatives</td>
<td>Initiated and facilitated by national umbrella organisations</td>
<td>Initiated and facilitated by national umbrella organisations (national self-help coordination board) and local initiatives</td>
<td>Initiated and facilitated by national umbrella organisations</td>
<td>Initiated and facilitated by national umbrella organisations</td>
<td>Initiated and facilitated by national umbrella organisations</td>
<td>Initiated and facilitated by national umbrella organisations</td>
<td>Initiated and facilitated by national umbrella organisations (Alzheimer Society /Alzheimer Scotland), and from local initiatives Age Concern</td>
</tr>
<tr>
<td><strong>Utilisation</strong></td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
<td>No data available on a national level</td>
</tr>
</tbody>
</table>
### Addendum Table F: Description of institutional long-term care structures (F1-F4).

<table>
<thead>
<tr>
<th>F1) Group dwelling/Small-scale living/Dementia patients’ house unit</th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Availability</strong></td>
<td>Nationwide.</td>
<td>Nationwide.</td>
<td>Not available</td>
<td>Nationwide</td>
<td>Partially</td>
<td>Not available</td>
<td>Nationwide (with regional differences)</td>
<td>Very few stand-alone small-scale group dwellings, but nationwide examples of larger care homes including ‘small’ group living units (8-12 residents)</td>
</tr>
<tr>
<td>Group dwelling is covered partially by insurance, and some of the German federal states support the development of new group</td>
<td></td>
<td></td>
<td>Small initiatives from different institutions, it is not offered as standard care</td>
<td>Is not defined as an institution but as living accommodation. No treatment or care is provided. Home care services are provided the same way as for other people living in their</td>
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</tr>
</tbody>
</table>
dwellings offers. (Wolf-Ostermann et al., 2013)

own home (Kirkevold et al 2012).
26% of the municipalities had at least one such unit in 2010/2011 (Kirkevold et al 2012)

the care units specifically for dementia care were set up more and more as separate wards in nursing homes/institutions. However, from a national viewpoint, it is not possible to know how many of the estimated 30,000 places that is located as separate housing units or within nursing homes or similar.

<table>
<thead>
<tr>
<th>Standard Care</th>
<th>Yes</th>
<th>No</th>
<th>No</th>
<th>Yes</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Provider</strong></td>
<td>Unknown (Wolf-Ostermann et al., 2013)</td>
<td>Care organizations funded by the government</td>
<td>Municipalities</td>
<td>Municipalities or private providers</td>
<td>Independent care providers</td>
</tr>
<tr>
<td><strong>Healthcare professionals</strong></td>
<td>Nurses, geriatric care nurses, social workers, help workers, occupational therapists, physiotherapist</td>
<td>Nurses, care assistants, social workers</td>
<td>(Registered and aux) nurses, care assistants, unskilled carers.</td>
<td>(Registered and aux) nurses, nurse aids – all trained in dementia care.</td>
<td>If registered as a residential home, care workers; if registered as a nursing home, registered nurses and care</td>
</tr>
</tbody>
</table>

<p>| 187 |</p>
<table>
<thead>
<tr>
<th>Accessibility</th>
<th>Co-payment required</th>
<th>Co-payment required (dependent on income and family situation)</th>
<th>Rent to live in this facility (financial support from the governmental Housing Bank is possible)</th>
<th>Co-payment required (The maximum fee for all municipal services in the social care/geriatric care sector (including services at home, living in nursing homes/long term care facilities, day care, respite care etc. is 1,776–1,850 SEK/month)</th>
<th>Co-payment required</th>
</tr>
</thead>
</table>
| A degree of disability (Social Code XI) is a necessary prerequisite for gaining a place in a group dwelling. | A moderate to severe degree of disability is a necessary prerequisite. | Admission criteria
In relation to patient's physical functions and mobility. If a person does not benefit from living in this facility due to progression of the dementia or to severe somatic illness, it is | A decision by a municipal home help officer is needed in most cases. | Needs assessment required for financial contribution from local authority or NHS |
<table>
<thead>
<tr>
<th><strong>Utilisation</strong></th>
<th></th>
<th></th>
<th></th>
<th>recommended that the person should move to a special care unit or a nursing home (Kirkevold et al 2012).</th>
<th></th>
<th>Different levels of resources within the municipalities.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>It is estimated that only 1.3% of places in institutional LTC are places in group dwelling services (Wolf-Ostermann 2013)</strong></td>
<td></td>
<td></td>
<td></td>
<td>There are 465 initiatives in the Netherlands (<a href="http://www.databankwonenzorg.nl/">http://www.databankwonenzorg.nl/</a>)</td>
<td></td>
<td>In the Swedish cost of illness study it was estimated that these living facilities constituted about 30,000 out of about 95,000 &quot;beds&quot; (or rooms) of sheltered living in Sweden (Wimo et al. 2014).</td>
</tr>
<tr>
<td></td>
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<td></td>
<td>26% of the municipalities had at least one such unit in 2010/2011 (Kirkevold et al 2012). Number of beds designated for persons with dementia in 2004/2005: Beds in sheltered housing (bokollektiv /andre): 1,268 Beds in housing collective (bokollektiv ):86 (Eek &amp; Nygård 2006)</td>
<td></td>
<td>No national data available</td>
</tr>
</tbody>
</table>
F2 Nursing home. For older people not specifically for those with dementia disease or mixed with other older people

<table>
<thead>
<tr>
<th>Availability</th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
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</thead>
<tbody>
<tr>
<td>Dedicated dementia-specific beds are the exception rather than the rule: In 2010, 21 of the 151 (c.a. 14%) public/voluntary care units in Ireland had dementia-specific beds (Cahill, O’Shea &amp; Pierce, 2012).</td>
<td></td>
<td>According to the Ministry of Health's 2009 yearly report, Italy has 201,180 beds, unevenly allocated throughout the country. The greatest part of them (80%, coverage of 590 beds every 100,000 inhabitants) in the northern health care structures. 162,576 (the 84.3% of the total) elderly dedicated beds, in</td>
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<tr>
<td>Standard Care</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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</tr>
<tr>
<td>Providers</td>
<td>Private organisations (40%), independent charity organisations (55%), and public organisations (5%) (Gesundheitsberichterstattung des Bundes, 2015).</td>
<td>Public, voluntary, and private providers. Since the start of the NHSS (Fair Deal scheme), the proportion of public beds has decreased and the majority of people with dementia currently reside in private facilities (Cahill et al., 2012).</td>
<td>Public or private</td>
<td>Municipalities, public or private care organizations</td>
<td>Municipalities</td>
<td>Private and non-profit organisations provide care within a contract with the government</td>
<td>Municipalities or private providers with contracts with municipalities.</td>
<td>Largely private organisatio ns, some with charitable status</td>
</tr>
<tr>
<td>Healthcare Professionals</td>
<td>Nurses, geriatric care nurses, social workers, help workers, occupational therapists, physiotherapists</td>
<td>Doctors; nurses (1 head nurse, 1 nurse for every 7 users, and 1 for administrative tasks); physiotherapists, occupational therapists, professional educator. Part-time professionals as psychologists, social workers. (Ministro della</td>
<td>Nurses, doctors, social workers, occupational therapists, physiotherapists, psychologists</td>
<td>(Registered and aux.) nurses, care assistants, unskilled carers.</td>
<td>Physicians, nurses, healthcare assistants, social care workers, rehabilitation technicians (physiotherapy, occupational therapy), pharmacists, nutritionists, psychologists. (UMCCI, 2008, Directiva</td>
<td>(Reg. or aux.) nurses, LPNs, sometimes physiotherapists and occupational therapists</td>
<td>Registered nurses and healthcare support workers; other professionals including GPs called in as required</td>
<td></td>
</tr>
<tr>
<td>Sanità &amp; Federazioni nazionali dei pensionati CGIL, CISL, UIL, 1991</td>
<td>técnica</td>
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<td></td>
</tr>
<tr>
<td>Accessibility</td>
<td>Co-payment required</td>
<td>Co-payment required.</td>
<td>Co-payment required</td>
<td>Co-payment required</td>
<td>Co-payment may be requested according to PwD family income (UMCCI, 2008, Directiva técnica).</td>
<td>Co-payment required</td>
<td>Co-payment required</td>
<td></td>
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</tr>
<tr>
<td>Considerable private payment is necessary, because the LTC insurance does not cover all of the costs.</td>
<td>A financial assessment (all income and assets; their material wealth) is carried out to determine the contribution the resident should make. The Nursing Home Support Scheme aims to create equity in state support for all people receiving long-term care by applying the scheme to all HSE-approved public, private, and voluntary nursing homes. The National Treatment Purchase Fund (NTPF) negotiates and agrees payments on the cost of long-term residential care service with approved private and voluntary</td>
<td>20-50% of the hospitality costs. Fees can vary between 1,100 and 1,400 €/month depending on income and region of residence (Auser, 2012).</td>
<td>Must not exceed 75% of a sum called “the social security basic sum/amount (G)” i.e the patients are to keep 25% of the pension for personal use. An amount of the pension (mean about Nkr 7,250 per year) is subtracted to secure a minimum personal income. Other types of pensions can be reduced by 85% after tax. (Norwegian Ministry of Health and Care Services 2012).</td>
<td>Financial support from local authority and / or NHS is subject to needs assessment and means testing.</td>
<td>20-50% of the hospitality costs. Fees can vary between 1,100 and 1,400 €/month depending on income and region of residence (Auser, 2012).</td>
<td>20-50% of the hospitality costs. Fees can vary between 1,100 and 1,400 €/month depending on income and region of residence (Auser, 2012).</td>
<td>Financial support from local authority and / or NHS is subject to needs assessment and means testing.</td>
<td></td>
</tr>
</tbody>
</table>
nursing home owners. The NTPF has no role in establishing costs paid to the public sector; these are established internally by the HSE (Cahill, O’Nolan, O’Caheny, & Bobersky, 2015). Currently the agreed average weekly price paid to private and voluntary facilities is €888, whilst the agreed average weekly price paid to public (HSE) facilities under the NHSS is €1,404 (Cahill et al., 2015).
| A degree of disability (Social Code XI) is a necessary prerequisite for gaining a place in a nursing home. | Long waiting lists (90-180 days, up to 11 months in certain regions (i.e., Lazio) (Auser, 2012). | Waiting time | Waiting time may be long. | Lack of professionals working in these structures (Guerrini, 2011). | Different levels of resources within the municipalities. | Assessment for financial approval under the NHSS takes up to 12 weeks (Cahill et al., 2015). | Needs assessment | After application, needs assessment is carried out. Eligibility criteria are defined (e.g. acute or stabilized chronic conditions that lead to functional losses, need for nursing care and medical surveillance, absence of rehabilitation potential in the short/medium term). Respite care is included as an admission criteria (UMCCI, 2008, Manual de |
| Planeamento e Gestão de Altas | Referral required | A decision by a municipal home help officer is needed in most cases.

The NHSS financial assessment does not consider the financial circumstances of families of younger people with chronic illness (Office of the Ombudsman, 2010).

There is no legal entitlement to financial support - it is dependent on available resources (Office of the Ombudsman, 2010).

(3) The NTPF does not base their negotiations on any 'cost of care' model (Cahill et al., 2012). The cost of public long-term care facilities is
higher than the agreed prices paid for private nursing homes. However, private facilities tend not to provide allied health services, whereas public facilities by and large provide a wider range of services (Cahill et al., 2012).

### Utilisation

- **Approximately 25% of PwD live in nursing homes** (Sütterlin et al., 2011).

- The National Register of Public and Voluntary Units and Beds does not provide information on the number of public beds occupied by people with dementia, diagnosed or otherwise.

The vast majority of people with dementia in Ireland living in residential care are cared for within generic care facilities for older people, most of whom are women (Auser, 2012).

- 2% of people over 65 years are admitted to residential structures, 1.8% of them to health care residential structures. The 50% of these users are older than 85 years, 2/3 are women (Auser, 2012).

- 17.8% in a nursing home, 30,318 beds available in 2000. 2,210 institutions that provide residential and/or nursing care in 2015 (www.zorgkabinet.nl).

- Number of beds per 1,000 inhabitants of 80 years of age or above: 175.63 (Statistics Norway).

- Data relating December 2014: 4,094 long term care beds were available nationwide, occupancy was 96% (ACSS, 2014).

- In the Swedish cost of illness study it was estimated that about 40-45% of the dementia population live in long-term care institutions (95,000 beds). The high staff living facilities constituted about 25,500 out of the 95,000 "beds" (or rooms) of sheltered living in Sweden and about 19,000 PwD out of these 25,500 lived in that kind of accommodation (Wimo et al. 2014).

- In 2011, 291,000 people aged 65 and over lived in care homes (which is the general term including residential and nursing homes) in England and Wales (3.2% of population in this age group) (ONS Census data). No
which are not purpose-built for dementia and many of which are not designed to cater for the complex, challenging, and unique needs of people with dementia (Cahill et al., 2012).

| Breakdown available in relation to nursing v residential care or in relation to people with dementia / others, although estimates suggest up to two-thirds of care home residents have dementia |
### F 3) Nursing home with dementia care units

<table>
<thead>
<tr>
<th>Availability</th>
<th>DE</th>
<th>IE</th>
<th>IT</th>
<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nationwide</td>
<td></td>
<td></td>
<td>Regionally available</td>
<td>National availability (See F2)</td>
<td>Very restricted availability, only regionally available (Bettio, 2012).</td>
<td>See F1</td>
<td>Nationwide</td>
<td></td>
</tr>
</tbody>
</table>

There are significant inequalities across Ireland regarding specialist care units (SCU) (Cahill et al., 2015). Over 50% of all SCUs were located in only four of the 26 counties in the Republic of Ireland. Six counties appear to have no provision at all, while clusters of SCUs are found in other counties (such as Cork, Dublin, Galway, Donegal, Cavan, Louth, Meath, and Monaghan).

### Standard Care

<table>
<thead>
<tr>
<th>Standard Care</th>
<th>DE</th>
<th>IE</th>
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<th>NL</th>
<th>NO</th>
<th>PT</th>
<th>SE</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No (see F2)</td>
<td>Yes</td>
<td>Yes</td>
<td>It is not standard care. Very few</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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</tbody>
</table>
non-profit institutions provide this kind of care with state funding (co-payment may be required according to PwD income). Some private institutions deliver this kind of care with full out-of-pocket payment (Instituto da Segurança Social, 2005).

<table>
<thead>
<tr>
<th>Provider</th>
<th>See F2</th>
<th>The private sector provides the majority of specialist dementia care (63%), followed by public facilities (HSE, 30%) and voluntary not-for-profit (7%) (Cahill et al., 2015).</th>
<th>Public, private committed, or fully private.</th>
<th>Non-profit organisations, private organisations</th>
<th>Largely private organisations, some with charitable status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare professionals</td>
<td>See F2</td>
<td>Every 20 beds dementia unit needs 8 full time professionals (doctors, nurses, educator,</td>
<td>See F2</td>
<td>Full multidisciplinary team: physicians, nurses, healthcare assistants, social care workers,</td>
<td>Registered nurses and healthcare support workers; other</td>
</tr>
<tr>
<td>Accessibility</td>
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<tr>
<td><strong>See F2</strong></td>
<td><strong>Co-payment</strong> required (see F2)</td>
<td><strong>Co-payment</strong> required</td>
<td><strong>See F2</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Places in dementia care units are more expensive than common nursing home places. Pwd or their relatives have to pay for the additional costs (Weyerer, 2005).</td>
<td>(Social care is not covered, can be covered by the district in case of low income (ASL Milano, 2014, &quot;Demenza: aiutare chi assiste&quot;).</td>
<td><strong>See F2</strong> Co-payment may be requested according to PwD family income (UMCCI, 2008, Directiva técnica) Strong financial restrictions in access exist in private providers (Bettio, 2012).</td>
<td>Co-payment required. Financial support from local authority and / or NHS is subject to needs assessment and means testing.</td>
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<tr>
<td><strong>Access</strong></td>
<td><strong>Admission criteria.</strong></td>
<td><strong>Admission criteria/ multiprofessional assessment required. Admission is temporary (Ferrario, 1995)</strong></td>
<td><strong>Diagnosis of dementia, strict eligibility criteria and needs assessment are considered as standard good practice procedures, and not as access restrictions (Bettio, 2012).</strong></td>
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<tr>
<td><strong>criteria.</strong></td>
<td>Most often used criteria: Pre-admission assessment Moderate or severe dementia and some behavioural</td>
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<td>(almost 90%), clinical diagnosis (66%), and challenging behaviours (41%).</td>
<td>disturbances which are not manageable at home. Psychiatric symptoms represent an exclusion criteria (ASL Milano, 2014, &quot;Demenza: aiutare chi assiste&quot;).</td>
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<tr>
<td>F4) Nursing home, specialised in dementia care</td>
<td>DE</td>
<td>IE</td>
<td>IT</td>
<td>NL</td>
<td>NO</td>
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</tr>
<tr>
<td><strong>Availability</strong></td>
<td>Not available.</td>
<td>See F3.</td>
<td>Not available.</td>
<td>Not available</td>
<td>Partially.</td>
</tr>
</tbody>
</table>

It is difficult to separate this category from the previous one in Ireland. There are no nursing home or healthcare organisations that provide ONLY dementia care although many of the specialist dementia care units are stand-alone facilities within an existing nursing home - these are captured in the details in the previous table. In one instance, there is no general long-term care provided, but there is an Alzheimer unit.
and a unit specifically for people with other mental health difficulties. These numbers are embedded in those reported in the line above and they cannot be separated.

<table>
<thead>
<tr>
<th>Standard Care</th>
<th>Yes</th>
<th>No</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Provider</strong></td>
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<tr>
<td><strong>Healthcare professionals</strong></td>
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</table>

Municipalities
Non-profit (União Misericórdias Portuguesas, Sisters Hospitallers, Brothers of St. John of God and others) and private institutions provide this service or similar ones (Instituto da Segurança Social, 2005)

Largely private organisations, some with charitable status

A full multidisciplinary team is always involved as above, in this case involving

Registered nurses and healthcare support workers; other
<table>
<thead>
<tr>
<th>Accessibility</th>
<th></th>
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<th>psychiatrists and/or neurologists.</th>
<th>professionals, including GPs called in as required</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Accessibility</strong></td>
<td></td>
<td></td>
<td>See F2</td>
<td>Co-payment required. Financial support from local authority and / or NHS is subject to needs assessment and means testing.</td>
</tr>
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<td></td>
<td></td>
<td></td>
<td>A unit run by União das Misericórdias Portuguesas is the only portuguese dementia unit included in the long-term care network (co-payment applies as explained above); other non-profit organisations receive public</td>
<td></td>
</tr>
</tbody>
</table>
funding and may request co-payment. Private institutions are paid out-of-pocket. Health insurances and health subsystems are reluctant to cover expenses, unless acute health problems coexist with dementia (Bettio, 2012).

Health and non-profit organisations are scarce, and waiting time may be a serious restriction access. Financial restrictions in access may exist with private providers.

| Utilisation | 2004/2005: Beds in special care units: 7,724 (Eek & Nygård 2006) | No data available on utilisation | No national data available specifically on this form of care home |
Common practice examples (case vignettes)

Germany

The daughter contacts her mother’s general practitioner (GP) and asks for help. The physician advises her to ask for individual counselling at the long-term care insurance. Following this advice, the daughter contacts her mother’s long-term care insurance. As a first step, Ms Smith and her daughter receive individual counselling in their own home. The employee from the long-term care insurance gives information about the legal preconditions for receiving benefits from the long-term care insurance. She helps Ms Smith and her daughter to fill in the application for a degree of disability (according to Social Code XI). The employee explains that another person employed by the Medical Service of the Statutory Health Insurance will perform a needs assessment Ms Smith’s home of.

The assessment takes place some weeks later, and Ms Smith answers a lot of questions about her abilities in daily living. Based on the needs assessment, she receives the degree of disability I (according to Social Code XI). The benefits from the long-term care insurance cover also social support because the assessment has confirmed that Ms Smith has reduced competences in daily living. Ms Smith and her daughter decide that a home care service should be involved. Ms Smith’s daughter searches the internet for an appropriate home care service. She uses the database of the largest long-term care insurance, which offers an overview of most of the support services. The daughter has to decide between several offers for home care service. She involves her sister and her mother in the decision-making process, and asks her friends about their experiences with home care services. Finally, she chooses a small private home care service which also offers day care for people with dementia. Both types of support, care at home every morning and day care, relieve the caring daughter of stress and burden.

At first, Ms Smith needs only minor assistance in daily activities, such as clothing and toileting. A couple of months later, Ms Smith is visiting the day care centre five days per week. She likes visiting the day care centre, where she meets an old girlfriend.

However, her mental difficulties increase over time, and Ms Smith needs more and more help in daily activities. The manager of the day care centre proposes to apply for a higher degree of disability. Consequently, Ms Smith receives a degree of disability II (Social Code XI) so that professional helpers have more time to support her in daily activities.
Ms Smith’s caregiving daughter now observes that her mother is increasingly restless and is wandering more. She consults her mother’s GP once more. The GP prescribes drugs, which should help to reduce distress and agitation. As a consequence of the drug treatment, Ms Smith is calm, but she walks less and lies on her sofa many hours of the day. She sometimes has walking problems and suffers from severe vertigo. One day, the daughter finds the mother lying on the floor and calls an ambulance. The mother is admitted to a hospital where a femoral neck fracture is diagnosed. Surgery becomes necessary. After the surgery, Ms Smith does not understand the advice given by nurses and the physiotherapist. Therefore, the physician and the social worker at the hospital propose a special geriatric rehabilitation for Ms Smith. However, the geriatric rehabilitation unit is full and the staff has no capacity to take care for Ms Smith. The clinic social worker recommends looking for a place in a nursing home because it becomes clear that Ms Smith cannot stay at home on her own anymore. She supports the daughter in searching for an appropriate place. Unfortunately, they can only find a place far away from home. Hence, Ms Smith seldom receives visits from her relatives. She does not recover and becomes bed-ridden. Her few abilities in speaking and orientation get lost completely. Ms Smith contracts pneumonia and passes away some weeks later.

**Ireland**

Ms Smith was diagnosed with dementia two years ago. In Ireland, it is usual that she would already have a good relationship with her GP and that the GP would be aware of her diagnosis. Ms Smith would also have established a connection with a secondary care clinician, most likely a consultant psychiatrist or a consultant geriatrician. At the time of her diagnosis, the consultant will have put a medication regime in place and notified the GP of the prescribed drugs. It is also usual that Ms Smith would have follow-up appointments with the consultant twice a year (this number may vary per clinician and patient). The consultant may then organize repeat prescriptions, or this may be done by the GP. Finally, it is likely that Ms Smith (and possibly also her daughter) was told about the Alzheimer’s Society of Ireland (ASI) when she was diagnosed.

Now that the daughter is concerned about her ability to manage perceived increased levels of care, it is likely that she will discuss these concerns either with her mother’s GP, or with the consultant at the next scheduled appointment; a consultant would most likely direct her back to the GP. On hearing about these concerns, the GP will explain that Home Care Packages (HCP) are available from the Health Service Executive (HSE) in Ireland to help provide
support at home, and that a needs assessment will be required in order to determine the levels and type of care needed. The GP will most likely direct the daughter to the Public Health Nurse (PHN) at that point, or suggest that the daughter contacts the HSE and/or the ASI for more information. The GP will also talk to Ms Smith and her daughter about future planning (i.e. creating an Enduring Power of Attorney, if they have not already done so).

Regardless of the person who initiates the HCP application, the PHN will carry out the needs assessment and this assessment will most likely involve input from an occupational therapist. Once the needs assessment is complete, a level of home care will be authorized. In this case, this care is likely to include assistance with shopping, cleaning and cooking/eating (or access to a meals-on-wheels service), and assistance with washing and dressing in the mornings. Although the HSE can provide these services directly themselves, their ability to be able to cater for the times where the daughter most needs help (i.e. in the mornings so that the daughter can get to work on time) is very limited. Instead, the daughter chooses to use the services of a home care provider authorized by the HSE. Choosing this option also gives the daughter the ability to ‘top-up’ these services at her own expense if she finds that the authorized levels of care are insufficient to allow her to manage her work and family as well as to provide care for her mother. Given that Ms Smith will have some help with shopping as part of the HCP, she no longer needs volunteer support for this, but she will continue to use the volunteer service so that she can maintain some of her leisure activities. This will help her to maintain social contact but also to have someone with her when she leaves the house.

In the course of finding out more about the supports that are available at home, Ms Smyth’s daughter spends some time researching these supports on the internet and/or in conversation with the ASI. She is now more aware of informal carer supports that are available, both financial and social, and she decides to investigate local informal carer support groups and the local Alzheimer Café.

**Italy**

Ms Smith lives in a middle-sized city in Italy.

She accessed formal care services before being diagnosed with dementia; in fact, her GP sent her to the nearer Alzheimer Evaluation Unit (UVA, Unità Valutazione Alzheimer) with a referral for a specialist visit. There the UVA specialist (mostly neurologists or geriatricians) subjected her to instrumental examinations to confirm a different diagnosis of dementia. Due
to her Alzheimer’s dementia, the specialist included her in the CRONOS national project, which guarantees her biannual follow-up visits together with the free supply of anti-dementia drugs.

The UVA specialist also recommended her to follow a couple of cognitive rehabilitation courses (to be performed within the UVA structures) and a supportive and informational service for her daughter and her migrant informal carer (still within the UVA). In Italy it is very common practice to hire a migrant informal carer, who can be accessed through volunteer associations, religious associations (which engage migrants) or by word of mouth. The contract with the migrant informal carer is private and at the expense of the contracting party; it can be legal (with fiscal subsidies) or irregular (a still very common approach).

When the migrant informal carer goes back to her native country, Ms Smith benefits from a temporary respite care service at a public or private (for profit or non-profit) nursing home (Residenza Sanitaria Assistenziiale, RSA) connected to the Local Health Agency (Azienza Sanitaria Locale, ASL).

To access to this service her daughter had to give the RSA medical papers (drafted by both GP and UVA specialist) to certify her condition, together with income-related papers; this way she has been included in the long waiting list. The fee for the respite care is usually totally at the user’s expense.

Ms Smith also benefits from an assistance check (Assegno di accompagnamento); her daughter made a telematic request to INPS, attaching medical papers. A specialized commission evaluated and assessed Ms Smith and certified that she had an adequate level of disability to access the service. Her daughter then contacted the prefecture and since then INPS pays a monthly check to her mother. Ms Smith’s daughter could request to become her mother’s support administrator (“amministratore di sostegno”) but this is still a very infrequent procedure and only a few Italian people with dementia have a support administrator.

If behavioural issues (such as aggressiveness, insomnia, etc.) occur, Ms Smith could access an RSA; this access could be arranged either by contacting the local Multidimensional Evaluation Unit (UVM, Unità Valutazione Multidimensionale) or by direct contact with the facility (more frequently). In both cases medical and income-related papers would be requested. She would then be put on one of the long waiting lists, which are a known barrier to access this service.
The Netherlands

Ms Smith lives alone together with her cat, in her own house, which is located in a middle-sized town (from the perspective of your country). Her husband passed away a couple of years ago. She has two daughters. One daughter lives with her family in the neighborhood. The other daughter moved to the capital city due to job obligations, and can only visit her mother irregularly. Every now and then, a car drive to the next larger city is feasible for the family.

Two years ago, Ms Smith was diagnosed with dementia in a memory clinic. First of all, she visited her GP with memory complaints, and he referred her to the memory clinic. Here, a screening by a psychiatrist took place. Next, neuropsychological testing and questionnaires assessed Ms Smith's functioning, she gave a blood sample and an MRI-scan was done. Based on this information, she was diagnosed with mild dementia. The neuropsychologist offered her support in the hospital, but Ms Smith was not eager to do this and declined help at that time.

During the last months, the dementia has markedly worsened. She sometimes needs supervision, and someone has to remind her to eat and drink. Some weeks ago, she also couldn't find the way back home. The daughter living in the neighbourhood is taking care for her mother, and a volunteer supports her with shopping and some leisure activities. However, the caring daughter is employed and has teenage children. Hence she is not sure whether she can manage the increased need of care.

In the Netherlands the overall aim is to eventually close all residential care homes (not the nursing homes!), by asking children/family to take care of their loved ones and additionally have professional help at home. In this way, people with dementia can live at their own home as long as possible. The first step for Ms Smith would be to apply for homecare, where she will be supported with activities of daily life. This homecare has to be requested at the CIZ (Centrum Indicatiestelling Zorg), which decides if care should be allocated based on the severity of impact in one's life. In less severe cases, the municipality decides whether homecare will be allocated. At a later stage, if day-care is required, CIZ also decides whether this should be allocated. In less severe cases, the municipality decides whether day-care should be allocated. To relieve the daughter she can apply for PGB (personal budget). With this PGB, you can choose either to carry out care activities yourself while using the personal budget for financing, or to outsource care to external organizations and finance this with the PGB.
**Norway**

Her regular GP (RGP) has assessed Ms Hansen two years ago in close cooperation with the local dementia team and diagnosed her with dementia. The dementia team has been in contact with Ms Hansen twice a year. They have had a conversation with her and her daughter about how she is coping at home (including IADL and PADL) and have done a reassessment of her cognitive functioning. The dementia team has put her in contact with the local home service office, and Ms Hansen has accepted help with cleaning every three weeks. She also receives pre-packed medication doses from the local pharmacy (a service arranged by the home service office). The daughter has attended the local dementia education programme provided by the local branch of the Voluntary National public health association and the dementia team. The daughter has been given a telephone number for a person in the dementia team in case she needs to discuss her informal carer situation. She has contacted them twice during the last year for advice about how to handle frustrating situations with her mother.

Recently the daughter contacted the dementia team again, this time she demanded more practical help with the situation. The dementia team has recommended the home service office to provide a day activity centre for Ms Hansen three days a week. Here she will join a walking group. She will also have two meals a day at the centre. The home care service visits her on the remaining four days of the week. They serve breakfast and prepare lunch for her to eat by herself and give her her medication (she also gets her medication at the day care centre when she is there three days a week.). She receives dinner from Meals on Wheels four days a week.

She would very much like a Red Cross volunteer to support her with shopping and some leisure activities, but the volunteer service is limited and very few get this service. The dementia team has helped Ms Hansen to apply for a support contact provided by the local authorities, but the waiting list for this service is long. Because she has lost her way when she ventured out alone, the dementia team has discussed the use of GPS with her and her daughter. Ms Hansen is positive, the daughter is positive regarding administrating the GPS, but finds the cost of the service and equipment expensive (GPS is not free of charge, unlike many other technical aids, like electronic calendars, safety equipment etc).
Portugal  

Case study 1  

(rural area, middle-sized town, patient from low/medium-income family)  

Ms S., 73 years-old, lives alone in her own house, together with her cat, in a middle-sized old town centre in Portugal. She worked as a housekeeper until she was 65. Her husband, formerly a blue-collar worker in a factory, passed away a couple of years ago. She has two daughters. The oldest daughter lives with her family on the outskirts of the town. The other daughter moved to the capital city due to job obligations, and can only visit her mother irregularly. Every now and then, a car drive to the next larger city is feasible for the family.

Four years ago, the daughters started to notice that their mother had some memory problems and difficulties in performing certain tasks (e.g. preparing meals). The oldest daughter accompanied her mother to the GP, albeit with some difficulty, as she usually was ‘not fond of doctors’. After a clinical assessment of Ms S., the problems detected were attributed to the aging process. Her condition has worsened afterwards, but she has always resisted going back to the GP’s office.

Two years ago, Ms S.’s daughter was wakened up in the middle of the night by a phone call from her mother’s neighbour. Her mother somehow managed to go out into the street and seemed quite disorientated, shouting in loud voice. Her daughter took her to the emergency room of the local general hospital, where a specialist in Internal Medicine examined her and diagnosed a urinary tract infection. Ms S. was also seen by a psychiatrist who prescribed low-dose risperidone and, given the overall situation, referred her to an outpatient consultation where she was eventually diagnosed with dementia. The family was advised to provide extra help.

During the last months, the dementia has markedly worsened. Ms S. often needs supervision, and someone has to remind her to eat, drink and take a bath. Some weeks ago, she also could not find the way back home. The oldest daughter living nearby visits her mother on a daily basis and has asked a neighbour to support her mother at lunchtime, as well as with shopping and some leisure activities. However, the caring daughter is employed, has teenage children and feels the need to have additional support.

The Town Hall co-ordinates a network of local social institutions and she was put in contact with one of these (a Private Institution of Social Solidarity - IPSS - that provides home care,
subsidised by the Ministry of Social Security\(^3\). Both daughters agreed to share the costs of the home care (around 75 € a month corresponding to 50\% of the individual retirement pension of Ms S.\(^4\)). A team from the IPSS helps with the Basic Activities of Daily Living (ADL) once a day during weekdays. Until recently, subsidised home care was not available during weekends and the oldest daughter took her mother to her house to spend those days. Meanwhile, the IPSS has started to provide this kind of weekend care.

Over the last weeks, the caring daughter is becoming unsure whether she can manage the increased need of care. So she is trying to find a subsidised institutional placement (which they may be able to afford but has a waiting list)\(^5\).

The following examples (case studies 2 and 3) illustrate different and also typical pathways in Portugal. Case study 2 is typical of a major part of the population, concentrated in major cities closer to the coast (namely Lisbon, Oporto and Braga).

**Case study 2**

*(urban area, patient from low-income family)*

Ms S., 73 years old, a retired gardener from the municipal services, lives alone in a rented apartment on the 4th floor (without a lift). Her husband passed away a couple of years ago. She has two daughters. One daughter lives with her family in the neighbourhood. The other daughter moved to the capital city due to job obligations, and can only visit her mother irregularly.

Two years ago, Ms S. went to her GP on account of chest pain. Clinical assessments led to a diagnosis of coronary heart disease, which was managed in primary care. But the GP also suspected dementia and eventually referred the patient to a neurologist, at the public hospital for a more comprehensive cognitive assessment. In this particular catchment area there was

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\(^3\) There may be public services (such as Local Parishes) and several non-profit organisations (IPSS or equivalent as catholic non-profit organisations) providing subsidised home care in this kind of town. An increasing number of for-profit entities are entering the market of home care, providing healthcare, personal care, domestic help or a mix of these, but these companies are mainly located in major urban centres.

\(^4\) The user contribution is determined by the type of services requested and the family income, applying the percentage of 50\% on the "per capita" household income (up to 60\% depending on extra services).

\(^5\) A patient from a medium or high income family in a major urban centre would probably hire caretakers (not necessarily professional well-trained ones) or private home care services, or would even apply directly for a private nursing home. Private players or mutual associations that offer nursing/residential homes/assisted living facilities are controlled either by major financial institutions or by healthcare services and are focused on high-income older people. They tend to operate in major urban centres.
no consultation specialised in dementia, thus Ms S. was seen some months later by a general neurologist; the diagnosis was confirmed and memantine prescribed. Ms S. returned to the neurologist only once, last year, since she needed new prescriptions from a specialist (either a neurologist or a psychiatrist) to buy the medication subject to co-payment.

The children of Ms S. decided to request the support of the local Parish Council, as they could not afford to hire someone to provide care for their mother or even to help with the housework.

The social worker at the Parish Council suggested the support of the day centre provided by the Parish Social Centre (Private Institution of Social Solidarity - IPSS, connected to the Catholic Church) that assists 65 users during daytime, including meals. This service has its own transportation and takes the users from their homes to the day centre. The children agreed to share the costs of the day centre (around 71.02 € a month per person, fee calculated on the basis of the individual retirement pension of Ms S). The day centre services are limited with reduced hours during weekdays.

The daughter living in the neighbourhood is currently taking care of her mother. Over the last weeks, the clinical condition of Ms S. got worse and the daughter is becoming unsure whether she can manage the increased need of care. The caring daughter is employed and has teenage children. She can’t miss work because she faces financial difficulties and is at the moment afraid of losing her job. She would like to request additional support but individuals using day care services are not eligible for subsidised home care support. So the daughter is trying to find volunteer support to help her mother with some shopping and leisure activities. However, these volunteering initiatives are mainly concentrated in major urban centres.

**Case study 3**

*(urban area, patient from medium/high-income family)*

Ms S., 73 years-old, a retired teacher, lives alone in her own home, together with her cat, in a middle-sized coastal town near Lisbon, the capital of Portugal. Her husband, who had been a lawyer, passed away a couple of years ago at the age of 71.

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6 The fee was based on the average cost for a day centre: Ana Gil (2009). *Serviços de Apoio Domiciliário. Oferta e custos no mercado privado*. Instituto da Segurança Social.
Two years ago, after some time of evolving memory problems, the family finally took Ms S. to a neurologist, in private practice. A diagnosis of dementia was made. After further exams, a cholinesterase inhibitor was prescribed. Ms S. had follow-up consultations with the neurologist at 3 and 6 months.

One year ago, she sometimes needed supervision, and someone had to remind her to eat and drink. During the last months, the dementia has markedly worsened and eventually she also couldn't find the way back home on one occasion. Thus the children of Ms S. (two daughters, one of them living with her family in the neighbourhood and more in touch with her mother) had to increase the amount of help and decided to hire the services of a private operator that provides home care. Since then, Ms S. has the support of two immigrant non-professional paid carers that help, during weekdays and weekends, with the basic Activities of Daily Living (ADL), like bathing, dressing, eating and mobility, and also perform other household tasks like cleaning. During the holidays of the paid carers, the children assumed, on a rotation basis, their mother’s care. Eventually, there was family concern about Ms S. being depressed and now she also goes twice a year to a private psychiatrist accompanied by one of her daughters.

The idea of trying a day centre for Ms S. to socialize was abandoned, as her children felt she would be among other users from different social and cultural backgrounds, and (they thought) with more severe neuropsychiatric problems that might frighten their mother.

The siblings agreed to keep their mother at home as long as she could recognize her house and perform some daily activities without major help. As the condition of Ms S. has worsened, there was some family disagreement regarding the care. One daughter was in favour of putting her mother in a nursing home but the other daughter disagreed with this solution. She argued that it would be a shock for their mother to leave home, but she never managed to provide actual support on a daily basis due to her own family commitments.

Recently, as the clinical condition got worse, they have decided to put their mother in a private nursing home. Ms S. seems to agree with the decision. In the nursing home, where Ms S. has her own bedroom, she will receive support with the ADL and the Instrumental Activities of Daily Living (IADL), and has access to activities to stimulate physical and mental functional ability. The nursing home also offers access to healthcare if required (extra costs). Monthly fees start at 2,500 € plus an initial fee of between 60,000 € and 80,000 €.
These private players or mutual associations\(^7\) that offer nursing/residential homes/assisted living facilities are controlled either by major financial institutions or by healthcare services and are focused on high-income elders.

**Sweden**

Ms Sjölund, 85 years of age, is a widow and a retired registered nurse, living in a house located in a middle-sized town. She has two daughters. One daughter lives with her family in the neighbourhood. The other daughter moved to the capital city due to job obligations, and can only visit her mother irregularly. The daughter living in the neighbourhood noticed that her mother started to telephone her more and more frequently, repeating the same issues. When the daughter got calls during the nights, she contacted their family physician (GP). The GP, who knew the family well, did a basic diagnostic assessment, ending in a diagnosis of Alzheimer’s disease in a mild stage. As part of this process, care planning in collaboration with the local municipal authorities was initiated. It was noticed that Ms Sjölund was on the border to malnutrition and that there was a great need for cleaning in the big house. Home support from assistant nurses started which Ms Sjölund accepted reluctantly. She was offered a day care service, which she visited irregularly since, from her point of view, there was no use in spending her days with “senile persons”. She continued to drive her care even after her driving license was withdrawn until her son-in-law removed a specific cable, making it impossible to drive the car. Her children had frequent contacts with the GP and the municipal case manager since the dementia progressed and she also started to walk around in the neighbourhood and had problems finding her way home. The neighbours often supported her. The children initiated that a trustee was appointed to manage the financial affairs. In the beginning, Ms Sjölund did not like that but later she had no insight in these matters. The children also visited her often even if it was problematic due to their own living situations. As the wintertime got closer, it was obvious that it would be problematic and risky for her to go on living at home.

Mrs Smith lives alone together with her cat in her own house, located in a middle-sized town (from the perspective of your country). Her husband passed away a couple of years ago. She has two daughters. One daughter lives with her family in the neighbourhood. The other daughter moved to the capital city due to job obligations, and can only irregularly visit her mother. Every now and then, a car drive to the next larger city is feasible for the family. Two years ago, Mrs Smith was diagnosed with dementia.

Mrs Smith was diagnosed with dementia at a multi-disciplinary NHS Memory Clinic and was prescribed donepezil (provided free of charge). She is monitored by a Memory Clinic nurse every three months. Soon after diagnosis, Mrs Smith and her (local) daughter were directed to an Alzheimer’s Café, operated by the Alzheimer’s Society, which meets monthly – however, because of the daughter’s job, they only attended a couple of times.

During the last months, the dementia has worsened markedly. She sometimes needs supervision, and someone has to remind her to eat and drink. Some weeks ago, she also couldn’t find the way back home. The daughter living in the neighbourhood is taking care for her mother, and a volunteer supports her with shopping and some leisure activities. However, the caring daughter is employed and has teenage children. Hence she is not sure whether she can manage the increased need of care.

The worsening of the dementia was reported to the Memory Clinic nurse, who asked a Community Mental Health Nurse from the NHS Community Mental Health Team for Older People to meet with Mrs Smith and her daughter. She immediately made a referral to the Local Authority Social Services Department, who carried out an assessment both of Mrs Smith and (separately) a Carers Assessment in relation to the daughter. The outcome has been the provision of a care package for Mrs Smith, with half-hour visits from home carers four times a week, to ensure Mrs Smith has a midday meal and something to drink. One day a week, Mrs Smith attends a day centre, run by a voluntary agency, funded by the Local Authority, where she has a meal and is encouraged to engage in social activities with other people with dementia. A minibus takes her to and from the Centre. Mrs Smith’s daughter was assisted by the Social Worker in applying for Attendance Allowance, a non-means tested benefit, which she uses to pay Mrs Smith’s contribution for the costs of home carers and day care. The Social Worker has also discussed respite care – a week in a local privately run care
home – but Mrs Smith is reluctant, as she is worried about her cat. The Social Worker also discussed the possibility of Direct Payments, where Mrs Smith and her daughter would receive a regular sum of money which they could spend directly to support care at home, without Social Services involvement in establishing the care package. They decided not to pursue this. The Social Worker has also made a referral to the assistive technology team, to explore whether there might be devices or equipment that would assist if she became lost whilst out.
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countries; their training and involvement in early dementia stage and in home care.


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