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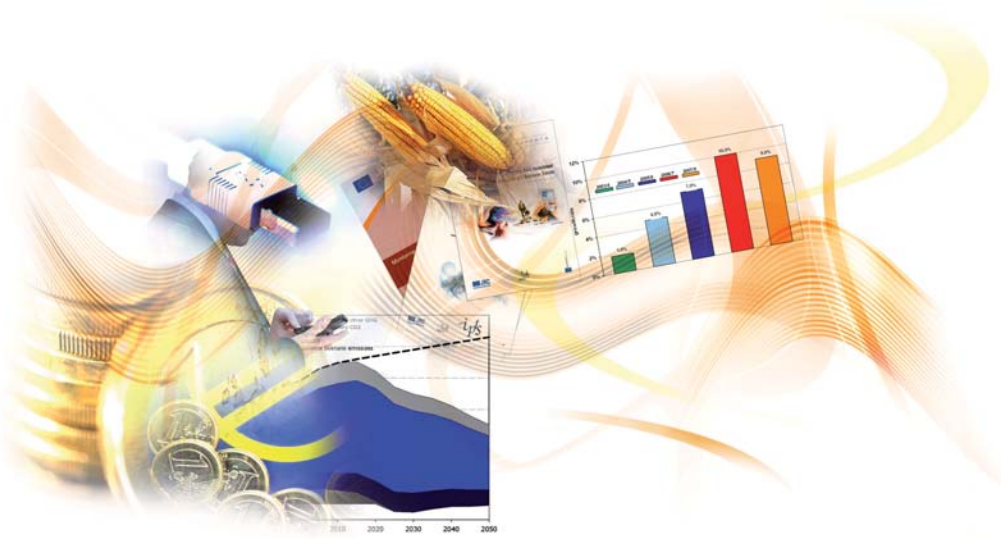
Long-term Care Challenges in an Ageing Society: The Role of ICT and Migrants

Results from a study on England, Germany, Italy and Spain

Authors: Stefano Kluzer, Christine Redecker and Clara Centeno



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Preface

Launched in 2005 following the revised Lisbon Agenda, the policy framework 'i2010: A European Information Society for Growth and Employment' has clearly established digital inclusion as an EU strategic policy goal. Everybody living in Europe, especially disadvantaged people, should have the opportunity to use information and communication technologies (ICT) if they so wish and/or to benefit from ICT use by service providers, intermediaries and other agents addressing their needs. Building on this, the 2006 Riga Declaration on eInclusion defined eInclusion as meaning "both inclusive ICT and the use of ICT to achieve wider inclusion objectives" and identified, as one of its six priorities, the promotion of cultural diversity in Europe by "improving the possibilities for economic and social participation and integration, creativity and entrepreneurship of immigrants and minorities by stimulating their participation in the information society."

In the light of these goals, and given the dearth of empirical evidence on this topic, DG Information Society and Media, Unit H3 (eInclusion) asked the Institute for Prospective Technological Studies (IPTS) to investigate from different angles the adoption and use of ICT by immigrants and ethnic minorities (henceforth IEM) in Europe and the related policy implications. In response to this request, IPTS carried out the study 'The potential of ICT for the promotion of cultural diversity in the EU: the case of economic and social participation and integration of immigrants and ethnic minorities', the results of which are available at: http://is.jrc.ec.europa.eu/pages/EAP/eInclusion.html.

As part of the investigation of ICT's contribution to the labour market and economic participation of IEM in Europe, IPTS decided to look at long-term care, specifically of elderly and dependent people at home, given the large presence of people from migration backgrounds known to work in this domain, along with the ongoing diffusion of different types of ICT-based devices and services. IPTS thus launched a pilot study on 'Immigrants, Personal Care Jobs and ICT' carried out in early 2008 in Italy, followed about a year later by three parallel, linked studies conducted in Germany, Spain and the UK, entitled 'The potential of ICT in supporting the provision of domiciliary care, with particular attention to the case of migrant care workers and informal carers'. The study on Italy explored almost exclusively how migrants working as care assistants can act as mediators for the use of ICT in a domiciliary context. Based on its results, the following studies looked more broadly at the long-term care sector and policies in each country, at the current diffusion of ICT in that context and, specifically, at the current and potential support they provide to informal caregivers, including those from a migration background.

This report provides a cross-analysis of the four country studies done on behalf of IPTS by different contractors in each country and it is primarily based on these studies' final reports. However, given the partially different focus of the study on Italy, and given the wide diversity of background research and statistics available in each of the other countries, in order to develop a more systematic presentation of themes across the four countries, other sources have been used to integrate the missing information; in particular, a report on long-term care in Europe and North America (Huber, Rodrigues, Hoffmann, Gasior, & Marin, 2009) and a report on ICT and the ageing market in Europe (Cullen & Kubitschke, 2010).

This and the other reports are available at:

http://is.jrc.ec.europa.eu/pages/EAP/eInclusion.html

Executive Summary

Research Background

One of the key challenges in Long-term Care (LTC) is the increasing tension between a growing demand for care, and a decreasing number of available carers, together with a preference for domiciliary over residential care. Currently, two trends can be observed which support long-term care at home: (a) the use of technology, in particular information and communication technologies (ICT) to facilitate care provision and assist caregivers in their tasks and (b) the presence of migrant labour – either employed formally by care providers or informally by families – to address shortages in the availability of long-term care provision. Evidence on how ICT are, and can be, used in domiciliary care by caregivers – and especially caregivers of migrant origin – is scarce. A recent set of exploratory studies in four countries (Germany, Italy, Spain and the UK), launched by IPTS in 2008-2009, sheds some light on this research field. This report illustrates and compares their main findings.

Patterns in Long-term Care Provision at Home

Although public support to Long-Term Care provision at home has grown over the past years, informal care, predominantly given by family members, but also by friends, volunteers or other caregivers employed by the family, currently represent the bulk of care provided to the elderly.

In Germany, in 2007, 2.25 million people received care benefits from the social LTC Insurance system, 1.54 million or 68% of which were cared for in their homes. Of these people, one million (or 65%) were cared for exclusively by family members and other informal caregivers, and the remaining half a million received additional assistance from formal care workers.

In the UK, almost 6 million people (11% of the population) were recorded as providing unpaid care in the 2001 Population Census. Of these, 70% of the men and 60% of the women also worked. In England, in 2007-2008, only 1 in 8 people of the 75+ age cohort in England benefited from formal care.

In Italy and Spain, where formal care is less available, informal care provision at home is overwhelmingly the dominant approach to care of dependent elderly people. In Italy, there were 2.1 million dependent older people living at home in 2005, of which only 580,000 received publicly-funded formal care services. Hence, at least 1.5 million old dependent people were more or less exclusively cared for by informal caregivers.

In Spain in 2004, 85% of dependent people aged 65+ received almost exclusively informal care at home. The rest received either long-term care in residential settings (10%) or relied exclusively on private (4%) or public (1%) home help. About 1.6 million people provided home care in 2004: about 600,000 of them on a continuous basis and 1 million irregularly. The profile of the carer in Spain is a woman between the age of 45 and 65; 43% are daughters, 22% are wives and 7.5% are daughters-in-law of the care recipient. The majority of carers are married (75.2%) and are not in paid employment (73.1%).

In addition to informal caregivers, a significant number of people are formally employed as professional care workers in the care sector: in Germany, in 2007 there were about 236,000 care workers employed by outpatient care services. In

the UK in 2008, 1.5 million people were formally employed as care workers.

Migrant Caregivers

Migrants are a key resource for domiciliary care, as professional care workers and as informal caregivers employed by families and family carers. Within this group, women constitute the vast majority.

In the UK, in particular, the health and social care sectors have over the years become an important destination for foreign workers. Estimates based on the Annual Population Survey 2006 indicate that 16% of the UK's 640,000 care workers (some of whom work in residential care) were born outside the UK. In London, this figure was far higher, at 68%. In Spain, in a survey of 25,000 households receiving home assistance services, around 40% of the care workers involved were foreigners, with Ecuadorians (13% of all care workers) and Columbians (7%) representing the two largest groups from migrant backgrounds. In Germany, the share of care workers from migrant backgrounds in outpatient care services is estimated at 5-10% of the total, with substantially higher numbers in regions with a higher overall migrant population.

Most significantly, family care assistants informally employed by care recipients and their families tend to be of migrant origin, especially in Germany, Italy and Spain, among informal caregivers employed by families to supplement and complement care provision at home. Since these caregivers often do not have formal, declared contractual agreements or, in many cases, legal residency in the host country, their number is unknown.

In Italy, the very high reliance of families on privately-contracted caregivers, is a distinctive feature of LTC provision at home: 13% of all families with dependent people contracted family care assistants privately, compared to less than 2% in Germany and the UK. It is estimated that in 2006-2007, over 740,000 immigrant caregivers were employed as *badanti* by older people or their families, representing 90% of all home care employees. In Spain, different sources estimate that the number of migrant care assistants lies between 200,000 and 600,000 people. The majority of these migrant caregivers are from Latin America and Eastern European Countries. In Germany, the number of migrants employed as caregivers by old people in need of care and their families is estimated to exceed 100,000 and could well be substantially higher. By contrast, the UK does not seem to rely on migrant 'grey' or 'black' labour for help at home and our research did not reveal any trend indicating a possible evolution in this direction.

In general, migration flows reflect language, proximity, and historical links between destination and origin countries. Enlargement of the EU to Eastern Europe has led to an increased flow of migrant caregivers from this area and its neighbouring countries (e.g. Ukraine and Moldova), especially to Germany. Caregivers from Spanish-speaking South or Central American countries are predictably more present in Spain and also in Italy. Pay differentials and lack of adequate employment and career options in the countries of origin drive people with both low and high qualifications to migrate and look for jobs as caregivers. The level of formal education of migrant care assistants is often high and some, albeit a minority, are well-trained nurses. However, specific qualifications and experiences in health or social care are limited, as are training opportunities.

Furthermore, due to ageing migrant and ethnic minority populations in the UK and Germany, the number of old people of migrant origin in need of care and, correspondingly, the number of family carers of migrant origin has lately been rising. In 2007-2008, clients from ethnic minority groups represented 10% of the 510,000 clients receiving community-based services in England. Home care is of special importance for people

from migrant backgrounds, who use residential services less compared to the native population, and an increasing number of migrants are reported to receive help from outpatient care services. In Germany, in response to this rising demand, there is a growing number of private nursing care services which specialise in outpatient care for immigrants, in particular for Turkish and Muslim immigrants and for immigrants from the former states of the Soviet Union.

Caregivers' Needs

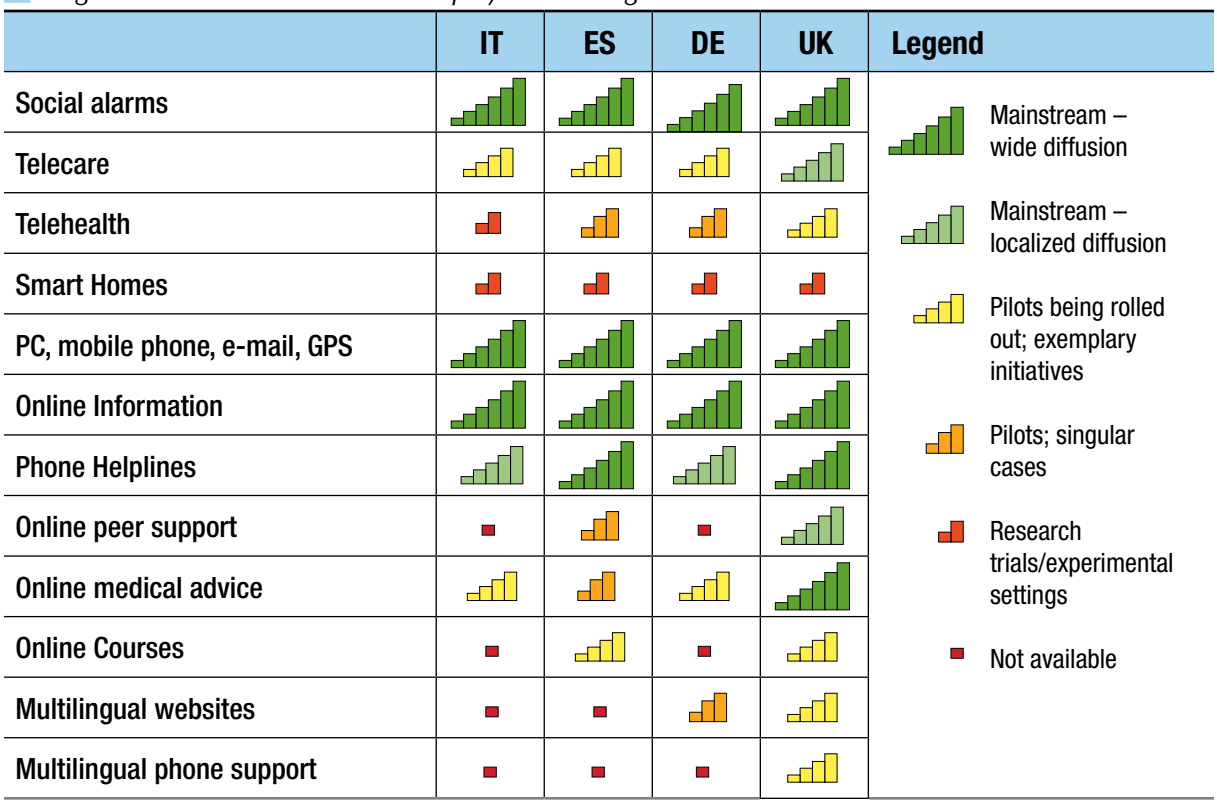
Family carers and care assistants may devote extensive amounts of time to care, up to the point of being engaged 24 hours a day, 7 days a week. Full-time carers and family care assistants in live-in arrangements are prone to experiencing social isolation, psychological distress including anxiety, depression and loss of self-esteem. Opportunities for them to break their isolation, communicate with others and share experiences are called for. They also need specialized psychological support. Limited experience and skills in Long Term Care, the lack of training opportunities and poor knowledge of existing services, put further stress on their situation. Balancing work and caring functions is possibly the most important challenge for carers who work. These represent 40% of family carers on average across the EU (Huber et al., 2009), reaching 50% (2.2 million) of carers of working age (4.4 million) in the UK (Yeandle & Fry, 2010), compared to just above 20% in Spain (in 1996).

The Use of ICT in LTC

In spite of a relatively well-developed market supply, very limited deployment of ICT-based solutions to support the person cared for can be observed. The only solution deployed on a large scale is the first generation tele-alarm.

ICT bring significant opportunities in several dimensions of the work and lives of domiciliary carers in general and of migrants

Figure 1 - The current state of ICT deployment in long-term care



in particular: for information and training, for easing communication, coordination and collaboration among healthcare and care actors, for improving the working conditions of the carer by enabling platforms for emotional and professional support, and for easing social integration of carers through on-line applications (web sites, fora, email, etc). In spite of these opportunities, little deployment can be observed in the four countries analyzed.

Long-term Care Policies

In general, across the different countries studied, little attention, if any, has been paid so far to the role of carers in general and to migrant personal care workers in particular. The use of ICT for enhancing domiciliary care delivery in this context has not been considered either. While in the UK, the valuable contribution of carers has been recognised for some time and a growing set of measures to support them are being deployed, in the three other countries studied, the importance of informal care has not yet entered public awareness. New LTC policies adopted in Spain and Germany in recent years do in fact promote domiciliary care provision, but measures to support the carers involved are still at an embryonic stage.

Challenges

Key challenges for the deployment of ICT-based solutions include the lack of policies aiming to support informal carers and the lack of consideration of ICTs as tools to help them. Additionally, carers lack knowledge and awareness of the available ICT-based solutions that could help them in their job, have limited ICT access (at the older people's homes) and ICT skills, and have privacy and security concerns about exchanging online private information. For the latter, exchange of information inside online settings is particularly delicate when it refers to data on health, dependency or other aspects regarding the mental and physical well being of a person. Disclosure of information on the care recipient is indeed a challenge and ICT can play a key role here.

For migrant carers in particular, the ICT access barrier is exacerbated by the fact that frequently, the carer lives at the older person´s home, and that often, the care recipient's family is not supportive in letting the migrant use the home computer and other ICT facilities as they do not perceive it as a useful activity for care work. In addition, on-line information is usually in the host country language and for migrants, the language barrier can be considerable. Finally, carers' uncertain legal circumstances also constitute a barrier to them disclosing their identities on-line.

Policy Recommendations

To address the barriers described above, policy action is needed. This could comprise awareness raising campaigns on carers´ needs and on available ICT-based tools and their benefits; targeted and focused digital inclusion measures; and measures supporting the development of solutions that are trust and privacy enhancing. Additionally, for migrant caregivers, the deployment of multi-lingual information, training and support services is crucial.

1. Introduction

The eInclusion Ministerial Declaration signed by EU Member States in Riga in June 2006 (European Commission, 2006), identified as two of its priority areas for eInclusion, (a) independent living initiatives and ICT-enabled services for integrated social and healthcare, which are designed to realised increased quality of life, autonomy and safety, while respecting privacy and ethical requirements; and (b) the promotion of cultural diversity in relation to inclusion by improving the possibilities for economic and social participation and integration of immigrants and minorities by stimulating their participation in the information society. The research presented in this report focuses on the interface of these two priority areas by addressing the question:

What is the potential and actual use of ICT-based applications by migrants as caregivers in domiciliary care delivery?

To answer this question, four exploratory research studies were undertaken: a pilot study in 2007/08 assessing the situation in Italy, and three parallel studies in 2008/09 covering England, Germany and Spain. This report summarises and synthesizes the findings of these studies. It is structured as follows. In the remainder of Chapter 1 the general framework and overall challenges for long-term care in Europe will be discussed and the policy background which prompted the development of this study will be outlined. The research questions are then presented, along with the method of investigation and the partners involved at country level.

Chapter 2 gives an overview, with available quantitative figures and other evidence, of the situation of long-term care in the four countries, starting with demographic trends and related care needs and moving to the core topic of the chapter: informal caregivers. A definition of caregivers is given, followed by evidence, country by country, of the number and role of informal caregivers, including those from migration backgrounds; and by a snapshot of the challenging work and life conditions of these caregivers. Chapter 2 ends with a country by country overview of the policy context, mostly at national level, focusing on the attention paid to informal caregivers by LTC policies and by policies which promote ICT use for LTC.

Chapter 3 starts by highlighting how ICT opportunities in long-term care at home can be looked at from three different perspectives –of the care recipient, of care service providers and of informal caregivers– which have actually been developing, rather independently and at different deployment paces in these three domains. Based on this important finding of our study, the chapter moves on to explore the situation with ICT in home care from the perspective of informal caregivers in general and then of informal caregivers from migration backgrounds. A summary is then provided of the opportunities and barriers of ICT use in support of informal caregivers identified throughout this chapter, along with suggestions of priority measures to improve the current situation.

Chapter 4 closes with an outline of the study's conclusions and also identifies further research needs.

1.1 The challenges of long-term care

This report is concerned with the challenges that the growing demand for long-term care (LTC) is creating in Europe, together with people's preference to remain in their own living environments as long as possible and the need to maintain high quality care provision. Two likely components of any supply-side attempt to address these challenges include, on the one hand, migrant labour and, on the other, the use of information and communication technologies (ICT).

Box 1 - Definition of long-term care

Within the EU different definitions of long-term care (LTC) coexist and do not always concur.[1] A comprehensive definition proposed in recent OECD reports[2] sees LTC as:

"… a range of services required by persons with a reduced degree of functional capacity, physical or cognitive, and who are consequently dependent for an extended period of time on help with basic activities of daily living (ADL), such as bathing, dressing, eating, getting in and out of bed or chair, moving around and using the bathroom. This is frequently provided in combination with basic medical services such as help with wound dressing, pain management, medication, health monitoring, prevention, rehabilitation or services of palliative care. Long-term care services also include lower-level care related to help with instrumental activities of daily living (IADL), such as help with housework, meals, shopping and transportation.

Long-term care can be received in institutions or at home. A long-term care institution is a place of collective living where care and accommodation is provided as a package. It refers to a specially designed institution or a hospital-like setting where the predominant service component is long-term care. Long-term care at home is provided to people with functional restrictions who mainly reside at their own home. It also includes institutions used on a temporary basis to support continued living at home, such as community care and day care centres and respite care facilities. Home care also includes specially designed or adapted living arrangements for persons who require help on a regular basis while guaranteeing a high degree of autonomy and self-control and adapted/supportive living arrangements".

In this report, we use home care and domiciliary care as synonyms. For a definition of caregivers, see Section 2.2.1.

1.1.1 Ageing of the population and dependency trends fuel the demand for long-term care

Life expectancy at birth rose by some 8 years in Europe between 1960 and 2004 and is projected to rise by a further 6 years by 2050. A similar trend has occurred throughout the OECD countries, leading to a growing share of population aged 65 and over and 80 and over (see Figure 2). In particular, people over 80 years old in the EU25 are projected to rise from 18.2 million in 2004 to nearly 50 million in 2050 (European Commission, 2008).

The impact of these demographic trends on LTC needs is not direct. It will crucially depend upon the functional capabilities of older people in the future, especially of those over 80 years old, since significant deterioration of health does not usually come before the age of 75 to 80 (Huber et al., 2009). Evidence about trends of disability and dependency in the age group of 80+ is mixed (Lafortune & Balestat, 2007), and in fact few countries collect data on chronic disease incidence, which is a major cause of dependency and disability.[3] However, even under an optimistic scenario of healthy ageing of the European population, the number of dependent persons is projected to increase by 31% in the EU25,[4] from

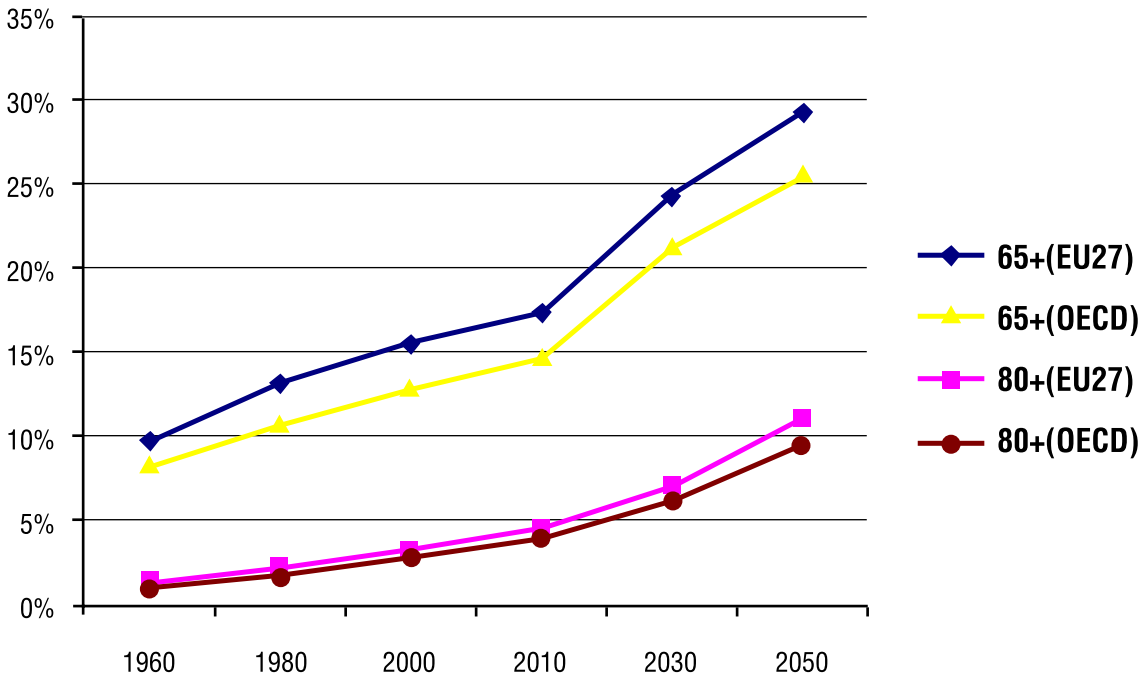
1 Variation in definitions concerns several aspects, in particular: length of care period; identification of the care recipient; the services provided, including the demarcation between healthcare (medical component) and social care (non-medical component). These in turn reflect differences in approaches to hospital discharge and rehabilitation; evaluation of 'dependency' and its coverage; organisation and role of the public sector, the private sector and the family in health and social care provision (European Commission, 2008).

2 This definition was first proposed by the OECD (2005) and later consolidated by Fujisawa & Colombo (2009).

3 "Advances in medicine as well as changes in lifestyles and greater focus on prevention and rehabilitation are all likely to play a role in future dependency in old-age, as are increased obesity and diabetes prevalence, adding to the uncertainty of predicting future demands for long-term care" (Huber et al., 2009, p.32).

4 The reported values exclude Greece, France, Portugal, Cyprus, Estonia and Hungary for which no data was available at the time of these calculations.

Figure 2: Share of population aged 65+ and 80+, OECD and EU countries, 1960-2050



Source: Fujisawa & Colombo, 2009.

12.6 million in 2004 to 16.5 million in 2050. In the worst case scenario, the figure for 2050 would be 26 million (European Commission, 2008).

1.1.2 Demographic and social trends reduce the availability of caregivers

The ageing of the population and a fertility rate below replacement level mean that the working age population (aged 15 to 64) will shrink by a projected 16% by 2050 and the current old-age dependency ratio of four people of working age for every elderly citizen will be halved to a ratio of two to one (European Commission, 2008). This has critical implications for the availability of both informal caregivers and formal care workers.

In Europe, on average more than twice as many elderly people receive care in their own home than in care institutions (7.6% vs. 3.3% of total 65+ population) (Marin, Leichsenring, Rodrigues, & Huber, 2009). Home care is the preferred option of care for most EU citizens (Eurobarometer, 2007). Since home care is in general cheaper than residential care, Member States are also firmly focused on enhancing tailor-made home and community care services and are moving away from institutional care, which is reserved for those with severe disabilities/ conditions (European Commission, 2008).

In this context, care provided by family members (spouses and adult children, especially daughters), friends or other informal carers represents today the bulk of care provision to the elderly. The patterns of informal care provision and the profiles of informal carers differ across Europe, varying according to cultural preferences; living arrangements; availability of formal care services; and the design of benefits (Marin et al., 2009). The role of relatives and friends remains nevertheless crucial even in countries where formal home and residential care systems are available, such as Sweden. In Chapter 2, figures will be provided for the four countries addressed in this report.

However, the prospective reduction of the working-age population, a higher participation of women in the labour market and the increase

in lone-elderly households, with relatives often living further apart, indicate that, in the future, family members might not be readily available to care for their parents or partners. These trends are expected to increase the demand for formal care, and hence public and private spending on it, along with the demand for formal care workers.

1.1.3 Many factors make it difficult to attract and retain long-term care workers

Besides the already mentioned expected decrease of age cohorts entering the labour market, other factors are already making it difficult to match the demand for care and are likely to contribute to reducing the supply of workers for long-term care in the coming decades. Fujisawa & Colombo (2009) provide evidence from many OECD countries about the following difficulties. The rise of educational attainment of the population reduces the availability of workers for less skilled jobs. Wages and other work-related benefits of LTC workers, albeit sometimes higher than in many low-skilled professions, are lower than the average levels in the economy. Additionally, care giving is mentally and physically hard work; and working conditions tend to be precarious as part-time and short-term employment contracts are common. Career progression is nearly absent in most countries and LTC work is generally perceived as unattractive. Difficulties with recruiting and retaining workers for LTC are therefore widespread, as shown by high annual worker turnover in this sector (over 50% in some countries) and high vacancy rates.

Based on the above elements, also confirmed by other sources (European Commission, 2007; World Health Organisation, 2008), the current and prospective situation of LTC in Europe can be characterised in terms of ageing population, increasingly long life expectancy, increasing demand for high quality LTC provision, shrinking numbers of health professionals, LTC workers and informal caregivers, and growing costs for national budgets.

The provision of adequate LTC services in qualitative and quantitative terms will thus be a major challenge for the national welfare systems and for the society. This challenge will have different patterns across Europe, partly due to the different models of LTC systems and the societal approaches to care. Already, however, it is becoming clear[5] that the response to this challenge will entail, amongst other measures: increasing the supply of LTC workers – also by recruiting foreign-born workers; supporting family and other informal care giving arrangements; an improved coordination of care provision across settings (residential, community and home care) and sectors (health and LTC); and using ICT devices and applications to enable and support the above processes and to directly perform some care functions (e.g. monitoring and surveillance).

The research presented here was launched to explore these factors – in particular the role of migrants and the use of ICT in the context of informal domiciliary care provision – and the interrelations among them.

1.2 Policy context and research questions

This research has been carried out in support of the EU eInclusion policies. The eInclusion Ministerial declaration signed by EU Member States in Riga in June 2006 (European Commission, 2006) identified among its six priorities:

1. The use of ICT for the independent living of elderly people and anyone suffering from some form of disability.

2. The promotion of cultural diversity in Europe, through the greater participation of immigrants and ethnic minority people (IEM) in the information society.

5 See for instance, Fujisawa & Colombo (2009) and Eurofound (2009).

IPTS has been studying the potential of ICT applications for Independent Living and for healthcare since 2004.[6] In 2007, in response to a specific request by Directorate General Information Society and Media (Unit H3, ICT for inclusion), IPTS launched a range of studies addressing the new cultural diversity priority set in Riga.[7] In particular, as part of the investigation of ICT's contribution to the labour market and economic participation of IEM in Europe, the decision was made to look at examples in both high- and low-skilled professions.[8] For the latter, the long-term care sector was chosen, given the relevant role played in it by migrant workers in many countries and its importance as a pull-factor of migration into Europe in recent years. Awareness of the current and expected diffusion of ICT in the health and social care sectors also contributed to this choice.

The broader research question addressed originally was: *what is the actual and potential use of ICT-based applications by migrant caregivers in domiciliary care delivery*? Given the high propensity showed by many IEM people in the use of ICT, contrasted with the low ICT adoption typical of elderly people in many European countries, an ensuing question was: *Can migrant care assistants act as mediators or facilitators for the diffusion of ICT-based tools and services among elderly care recipients?*

This question was initially explored in a pilot study on Italy which revealed a situation characterised by (a) a very low ICT adoption in elderly people's households, regardless of whether it was used for care or other purposes; (b) the lack of any policy promoting home care-related technological innovation, except for some local, small-scale experimental and pilot projects; and (c) an extremely widespread and very high reliance on informal, often undocumented migrant caregivers, poorly trained or supported in their care work. Given this situation, unsurprisingly almost no evidence was found of care-related ICT use among IEM informal caregivers at home. However, both the key informants and IEM caregivers interviewed for the study saw considerable potential in this direction.

Given these initial findings, the research questions were partly adjusted and the study was extended to other countries. While the attention to migrant caregivers remained present and ultimately drove the investigation, we acknowledged that better information and understanding of the LTC context in which migrant caregivers operate were essential, in particular:

- Which policies and other factors are driving innovation in the LTC sector, and affecting ICT diffusion in particular in the home context?

- What is the actual diffusion of different types of ICT-based tools and applications addressing the different actors involved in LTC at home, in particular informal caregivers?

In the light of these broader issues, the questions on actual and potential use of ICT in LTC by IEM caregivers were reformulated and specified as follows:

- Are there already signs of migrant caregivers using ICT for care delivery at home?

- Beyond possibly a direct usage in the care delivery process, are ICT tools and applications used to provide work-related information and support to migrant caregivers?

- Do caregivers use ICT at the workplace (which is where many of them also live) for work-related or other purposes?

6 See for instante, Cabrera et al. (2004) and Malanowski et al. (2008).

7 The research activities performed and resulting publications on this topic can be found online at the URL http://is.jrc.ec.europa.eu/pages/EAP/eInclusion.html.

8 The case of IT professionals from a Turkish background working in the German ICT industry was chosen for the study of a high-skilled sector. See: Hepp, Welling, & Aksen (2009).

- What are the drivers, barriers and opportunities with respect to ICT use in these different circumstances?

1.3 Research methodology and partners involved

When we started this research, very limited systematic information was available on all of the domains that we wanted to investigate: the use of ICT by IEM people;[9] LTC itself, especially care provided at home and the role of migrants working in formal and informal LTC activities; and the diffusion and use of ICT in the LTC sector in Europe.

Most research and technological applications addressing older people's care needs tend to focus on health-related aspects, rather than on reduced functional capacity in activities of daily living (ADL), which is the core of LTC. The only systematic research project in Europe to date on ICT for LTC recipients (which gives some attention to caregivers), *ICT & Ageing – European Study on Users, Markets and Technologies*[10] has been developed in parallel with our study and is frequently quoted in this report.

To our knowledge, no previous research existed on the specific topic of ICT use by informal caregivers and migrants in Europe. Our research had therefore to be exploratory, in terms of scope, method, and field work.

Our study eventually covered four countries – Italy with the first pilot research and then Germany, Spain and the UK (mostly England) – with supposedly important numbers of migrant caregivers and representing different forms of organisation and cultural attitudes towards LTC of older people at home across Europe. Italy was chosen for the large number and crucial role of migrant caregivers in domiciliary care.[11] Spain was selected for comparison with Italy, given the similarities as concerns the care model, mainly family-based and reliant on migrant caregivers, but with a presumed wider presence of new ICT-related initiatives. Germany and the UK (ultimately England) were selected for the greater role of professional care organizations in their welfare system and for the wider use of ICT both at societal level and presumably in care provision. In the latter three countries (DE, ES, UK), research was designed and implemented as follows:

First, desk-based analysis was carried out of existing official statistical sources and recent studies about the main features of LTC provision, organization and related policies (specifically on ICT-based innovation) and about the presence and role of migrant labour in this sector. Second, web searches and interviews with key informants[12] were conducted to identify and briefly assess representative ICT-based initiatives and services targeting domiciliary care. Third, a total of 40 migrant informal care assistants were randomly selected and interviewed in Milano, Italy (24 women); Malaga, Spain (12 women and one man); and Bonn, Germany (4 women). In Italy and Spain reaching even this small

9 An overview of the few available statistics in European Countries is provided in Codagnone & Kluzer (2010).

10 The ICT & Ageing study was funded by the European Commission, DG Information Society and Media, ICT for inclusion Unit. The core study team comprised three research organisations: empirica Gesellschaft für Kommunikations- und Technologieforschung mbH (Berlin); Work Research Centre (Dublin); and Institute "Integrated Study", Vienna University of Technology (TUW). The project was developed in 2008-2009. See http://www.ict-ageing.eu/ for more information.

11 As we shall see later, in Italy foreign workers are estimated to account for around 90% of caregivers employed by dependent old people or their families. Other countries with very high values are Greece, with about 70% of foreign-born among caregivers employed in private households; and Austria, where about half of total paid caregivers are undocumented and undeclared migrants, usually providing home care (see Fujisawa & Colombo, 2009).

12 These have been found among public and private care providers (including charities and voluntary organisations); job agencies; experts and suppliers of ICT solutions for home care; and providers of support and training services for carers and care workers. The mix of key informants varied across countries. In each country, 10-15 interviews (by phone or face-to-face) were held with the key informants, including deeper ones on some relevant initiatives (5-10 in each country, except Italy). In Germany, a questionnaire was also e-mailed on a larger scale.

number of interviewees was not easy, as many migrants were reluctant to be interviewed due to their often undocumented legal status and/or employment condition. Interviews explored their knowledge, use and expectations regarding ICT in LTC at home.[13] These aspects were also discussed with experts and other key informants with close contacts with migrant caregivers.

IPTS outsourced the research in each country to local research actors: in England, to CIRCLE (Centre for International Research on Care, Labour and Equalities) University of Leeds; in Germany, to the Association of Senior Citizens' Organisations (BAGSO); in Italy, to Istituto per la Ricerca Sociale (IRS); and in Spain, to Consultores Euroamericanos Asociados (CEA) and Innnovation Institute for Citizen Welfare (i2BC).

The studies in all countries were carried out over a 4-5 month period in early 2008 (Italy) and in early 2009 (the other three countries).

13 Interviews also briefly registered the main characteristics (age, education, previous jobs etc.) and working conditions of the respondents.

2. Long-term Care Provision at Home

2.1 Facts and figures on old people in need of care

Throughout Europe and in the four countries analyzed, domiciliary care concerns a large and growing number of people, both as care recipients and caregivers. No precise figures currently exist however on the overall population of LTC recipients and on all those providing care to them. This lack of data can, at least partly, be attributed to the only partial recognition of people in need of care by formal LTC systems and authorities, and the significant involvement of informal caregivers –by definition more difficult to identify and measure– in filling this gap. Information on this complex world is thus available only by approximation, especially as concerns quantitative aspects.

The following tables provide key data for the four countries of our study (and EU27 average) on older age groups of the population and dependency ratios, their health and living situation, all of which contribute to determining LTC needs.

Table 1 shows the current younger age profile of the population in the UK and Spain (roughly in line with the EU27 average) compared to Italy and Germany, which already have a much larger share of people aged 65 and over. Italy, in particular, already has the highest share of 80+ people in Europe (currently along with Sweden). According to demographic projections, Italy will maintain top position in 2050 when, as in Germany, the share of 80+ people reaches 13% and 14% of the respective populations. The table also highlights the projected convergence

Table 1: Current size and projected evolution of older age groups in selected countries and EU27 (various years)

	DE	ES	IT	UK	EU27
Current population (2007)					
Total population (in million.)	82.22	45.28	59.62	61.19	497.48
Age group 65+ (% of tot. pop.)	19.8	16.7	19.9	16	16.9
Million people 65+	16.28	7.56	11.86	9.79	84.07
Age group 80+ (% of tot. pop.)	4.6	4.5	5.3	4.5	4.3
Million people 80+	3.78	2.04	3.16	2.75	21.39
Old-age dependency ratio[14]	29.9	24.2	30.2	24.1	25.2
Projected population (estimates)					
Age group 80+ (% of tot. pop.) - 2020	7.1	5.4	7.3	5	5.7
Age group 80+ (% of tot. pop.) - 2050	14	11.3	13.1	8.9	10.1
Old-age dependency ratio - 2020	35.3	27.4	35.5	28.6	31.1
Old-age dependency ratio - 2050	56.4	58.7	59.2	38	50.4

Source: ICT&Ageing project. See http://www.ict-ageing.eu/?page_id=248 (accessed 08/12/09) based on Eurostat data, see Giannakouris, 2008.

14 In fact, as reported by Huber et al. (2009) more older people are living as a couple for a longer period due to increases in the life expectancy for both sexes over the last decades, which in turn has led to the increase of men in providing informal care over time.

Table 2: Health and functional conditions of older people (selected countries and EU27), 2006

	DE	ES	IT	UK	EU27
People having a long-standing illness or health problem (in % of pop. 65-74)	63.7	46.5	37.7	62.7	55.4
People having a long-standing illness or health problem (in % of pop. 75+)	69.5	56.3	53	69.7	63.3
Activity restriction in the past 6 months (in % of population 65-74)	18.4	15.4	14.8	14	13.9
Activity restriction in the past 6 months (in % of population 75+)	26.2	27.1	24	21.5	24.3

Source: ICT & Ageing project. See http://www.ict-ageing.eu/?page_id=248 (accessed 08/12/09) based on EU-SILC (Statistics on Income and Living Conditions).

by 2050 of Spain (but not of the UK) to the high old-age dependency ratios of Italy and Germany. Given that functional limitations are concentrated among the oldest people (aged 75 to 80 years and over), the above figures underline already high and growing LTC needs in these countries.

As already mentioned, the actual demand of LTC, rather than reflecting ageing as such, depends on the health conditions and functional impediments of older people, which are difficult to predict. Table 2 below shows that in 2006 Italy and Spain had a lower share of elderly people with long-standing illness or health problems compared to Germany and the UK (and to the EU27 average). However, the share of elderly people suffering from some activity restriction in the past 6 months was more homogeneous across these countries.

Living arrangements are also crucial for LTC as they indicate whether an older person can potentially receive support at home from a co-resident (e.g. from a spouse) or must be attended by somebody else or somewhere else (residential solution). Evidence reported in (OECD, 2005)

Table 3: Living conditions of people aged 80+, selected countries and EU27 (2001)

	DE	ES	IT	UK	EU27*
Share of people 80-89					
living in institutions (%)	9	5	4	10	8
living at home (%)	91	95	96	90	92
of which alone (%)	59	30	41	54	46
as couple (%)	30.5	36	34	33	32
with children (%)	2.5	9	7	6	6
other (%)	8	25	18	7	15
Share of people 90+					
living in institutions (%)	28	9	10	30	22
living at home (%)	72	91	90	70	78
of which alone (%)	68	27	45	64	51
as couple (%)	10	12	14	14	13
with children (%)	3	18	10	9	9
other (%)	18	43	31	12	27

** Without Sweden and Malta*

Source: DIW Berlin, 2007, based on 2001 Census data.

Table 4: Beneficiaries of formal LTC services[17] among population aged 65+ (various years)

	DE		ES		IT		England		EU	
	Mid-90s	2006	Mid-90s	2006	Mid-90s	2004	Mid-90s	2006	Mid-90s	Most recent
Share of people 65+ receiving formal care (%)	10.6	10.5	3.9	8.3	4.0	4.8	18.1	16.1	10.2	10.8
at home (%)	7.3	6.7	1.1	4.2	1.8	2.8	14.2	12.6	7.2	7.6
in institutions	3.3	3.8	2.8	4.1	2.2	2.0	3.9	3.5	3.0	3.3

Source: various national and OECD sources reported in Table 5.1 (p.72) of Huber et al., 2009.

shows that older dependent people who live with their partner/spouse or other relatives are more likely to receive informal care than those in a single person household.

Table 3 shows that in 2001 across the EU27, over 92% of people aged 80 to 89 and about 78% of those aged 90+ (for a total of around 15 million people) were living in private households.

Of those living at home, 46% of 80-89 year olds and 51% of those aged 90+ were living alone; respectively 32% and 13% as a couple;[15] 6% and 9% with their children; 15% and 27% in some other living arrangement. The situation however differed across countries, both in terms of levels and trends.[16]

The share of people living at home alone (among those living alone) was lower in Italy (41% of those aged 80-89; 45% of those aged 90+) and even more so in Spain (30% of those aged 80-89; 27% of those aged 90+), compared to Germany (59% and 68%)and the UK (54% and 64%). While the longevity of the partner seems to be an important factor, the possibility of living with children rather than in institutions also plays a role. In Germany, only about 2% of the 80+ lived with their children, and among the very old (90+), 28% lived in institutions. Spain offers the opposite case, with a high frequency of co-residency with children (16.4% among 90+) and a marginal role of institutions (5% for 80-89 year olds and 9% for 90+). Italy and the UK show a similar situation regarding children (in line with the EU average), but a striking difference in the role of institutions for the very old, when care needs are more acute. This is very high in the UK (30% of the 90+), in line with other Central European countries (Belgium, the Netherlands, France and others), and very low in Italy, as in Spain (9-10%). The large share of 'other' living arrangements in Spain and Italy, already high for those aged 80 to 89 and almost doubling in the 90+ group, probably reflects the strong reliance found in these countries on co-resident care assistants employed by families to continuously attend to their dependent relative (more on this later).

As mentioned already, the actual numbers of dependent elderly people is unfortunately not known in a systematic way, across countries. Available statistics provide information about the beneficiaries of formal LTC services among people aged 65+, either at home or in institutions, but this leaves out of the picture all those who only benefit from informal LTC, which are known

15 In fact, as reported by Huber et al. (2009) more older people are living as a couple for a longer period due to increases in the life expectancy for both sexes over the last decades, which in turn has led to the increase of men in providing informal care over time.

16 For instance, according to figures reported by Huber et al. (2009) earlier trends towards higher levels of solitary living slowed down or halted in the 1990s in some countries in Europe – including Germany and the UK, but not Italy and Spain – as a consequence of multiple factors.

17 Figures for the four countries in the table mostly reflect beneficiares of in-kind benefits and not of cash allowances.

to be many especially in Southern Europe (Spain, Italy, Greece and Portugal).

Evidence on formal LTC in the EU given by Huber et al. (2009) shows that:

- the share of the 65+ population receiving formal LTC services has been growing slightly overall, including those who receive services at home (Table 4). This is seen to reflect improved health and living conditions, which mean that an increased share of older people can now be cared for at home, along with policy measures adopted in many countries that explicitly favour such a solution;
- there are significant cross-country variations in the share of beneficiaries (see Table 4), although in recent years numbers have been converging.[18] Nordic countries and a few others including England, Austria and the Netherlands reach over 15% of the 65+ population; Germany and Spain have held a middle position in recent years (8-10%); while Italy is in the group, with most Eastern European countries, where LTC arrangements are not as formalised and less than 5% of the 65+ population receive formal care.

Box 2 - People in need of care from migration backgrounds

Our country studies in Germany and England found that among those in need of care an increasing share is represented by older people from migrant backgrounds.

The presence of long-established, large migrant communities explains this finding. In **Germany** in 2006, 19% of the population was reported to be from a migrant background. German official care statistics do not distinguish between natives and immigrants, neither for people in need of care nor for caregivers, so that figures on them are not available. However, studies found that in the migrant population the risk of long-term care dependency is much higher compared to natives and the number of people in need of care is thus expected to increase significantly.

Home care is of special importance for people from migrant backgrounds, who use residential services less compared to the native population, and an increasing number of migrants are reported to receive help from outpatient care services.[19] Overall, however, compared to natives, immigrants in need of care rely more on informal care, mainly from female family members. Language barriers and cultural distinctions, information deficits and the lack of culture-sensitive offers are likely reasons for this. In light of limited professional support, our study on Germany raised the concern that home care in immigrant families is loaded with special risks concerning the quality of care and special stresses and strains for both the people in need of care and their family carers.

In **England**, people from minority ethnic groups made up 9% of the total population already in 2001/02 and are likely to represent an even larger share of the population today. While this segment of the population tends to have an average younger age profile, according to our country study on England, higher incidence of illness and disability is reported in some minority ethnic communities (in particular Bangladeshi and Pakistani), which tend to be concentrated in areas of socio-economic deprivation. This is one of the likely causes of the higher incidence of caring responsibilities found in those same groups (see Appendix 2 of the England report). On the whole, in 2007-08 clients from ethnic minority groups represented 10% (52,000) of all clients (510,000) receiving community-based services in England (see Table 4 of the England report).

18 The concentration of support on fewer older people with greater care needs is often an explanation for the decreasing coverage, especially in delivery of care at home, which can be noticed in some countries starting from higher shares of beneficiaries, like Sweden or England (see Table 4 and footnote 44 for further evidence).

19 A study in Bremen and Bremerhaven (Lotze & Hübner, 2008) found that among recipients of outpatient care services from migrant backgrounds (increased by 111% between 2004 and 2008) most (62.2%) were from the CIS states (i.e. the former Soviet Union), 17.3% were from Turkey and 10.7% from Poland.

Fujisawa & Colombo (2009) note that in the few countries for which data is available, the average share of formal LTC recipients among the oldest age cohort (80+) is over five times that of the 65-79 aged cohort, and has a strong female over-representation (one and a half times the male share). This reflects a generally higher prevalence of disability among elderly women (Lafortune & Balestat, 2007).

2.2 Actors in domiciliary long-term care provision

Countries have different approaches to providing formal LTC support at home (Huber et al., 2009). In the four countries analyzed here, in spite of local differences that will be highlighted later, the general framework of formal LTC provision is quite similar. People in need of care can apply to one or more local, regional or national public authorities for domiciliary care services to be provided in kind or for 'cash for care' allowances that give beneficiaries the means to finance either the use of in-kind services, or to serve as compensation for informal caregivers. Among the four countries, England also provides direct support to carers. The services or allowances are awarded by the designated public bodies depending on care needs, dependency and other factors (e.g. income). While there are differences in eligibility criteria; in the conditions for using the cash benefits; in the way domiciliary care is organised and in the type and amount of services provided or covered by LTC schemes, the scope of formal LTC in the four countries includes support to activities of daily living (ADL), to instrumental activities (IADL) and basic medical help.

Publicly-supported LTC schemes, especially in terms of provision of in-kind benefits (see Table 4), tend to cover only the people in the most severe dependency conditions and are insufficient to cater for all the care needs of elderly people. Hence, in all countries informal caregivers play a crucial role for meeting those needs.

The role of informal caregivers in fact can be seen to compensate for the deficiencies of formal care services, but also reflects, at least in some countries, the wish of almost 50% of potential care recipients. When a special Eurobarometer on *Health and Long-term Care*[20] asked respondents about their preferences for assistance should they become dependent and need regular help, very few (8% on average in EU27) chose a care institution and 81% wished to be cared for in their own home, either by relatives (45%) or by professional services (24%) or a personal carer (12%).

Table 5: In which way you would prefer to be looked after?

	DE	ES	IT	UK	EU27*
In own home by relative (%)	48	48	44	44	45
In own home by professional care service (%)	24	19	19	28	24
In own home by personal carer privately hired (%)	12	9	16	10	12
In home of close relative (%)	6	5	4	7	5
In care institution (%)	7	11	8	5	8
Don't know (%)	3	8	9	6	6

Source: Eurobarometer, 2007, question QA20b.

20 See Eurobarometer, 2007, *question QA20b.*

The answers for the four countries of this study are provided in Table 5. While the preference for a relative as carer is shared in a similar way across all of them, the lower importance of professional services in Spain and Italy might also reflect the scarcity of formal care services in these countries. The higher reliance of Italian respondents on personal carers clearly reflects, on the other hand, the current prevalence of this solution for care provision in Italy.

2.2.1 Who are the caregivers: a definition

For the purposes of this report, *caregivers* is used as the overarching category encompassing all individuals providing help to a dependent person, in activities of daily living and related instrumental activities, frequently in combination with basic medical services (see Box 1 - Definition of long-term care). Referring to the definitions proposed by Fujisawa & Colombo (2009), Table 6 summarizes the main characteristics of different categories of caregivers and the correspondence between the definitions used in this report and those used by the OECD. In this report, we distinguish between:

a) *Care workers*. They provide care as employees of public social (or health) care services and private care organisations or on the basis of a formal contractual obligation directly with the person receiving care, his/her family or an intermediary agent. The employment contract would normally specify tasks to perform, annual leave rights and pay, and be declared to the social security system. Care workers generally possess some kind of recognized qualification, typically in basic nursing.

b) *Carers*. They are informal caregivers who are typically spouses/partners, other family members, friends and neighbours or volunteers. Carers do not have a formal contractual agreement with the care recipient and provide LTC for free. Given the rise of support programmes for carers and consumer-choice programmes for care recipients, we also include here informal caregivers (family and friends) who get some compensation for their care activity in terms of benefits, cash payments or allowances provided by these programmes. In general, carers are not professionally trained or qualified to provide care.

c) *Family care assistants*. These are caregivers receiving a salary or pay by the care recipient or his/her family on an informal basis, i.e. without a work contract and/or without social insurance coverage (we will refer to this as *illegal employment*), or, when they do have a contract, without the contract or the hours worked being (fully) declared to social security (*undeclared* condition). Family care assistants tend not to be professionally trained or qualified to provide care, and, because of their employment situation, they tend to have less access to training and opportunities for career development than care workers.[21]

In the countries that we studied, privately hired care assistants are called household assistants in Germany, family assistants or badanti in Italy, home care workers or personal assistants in the UK and informal carers in Spain. It should be noted that the degree of 'informality', which distinguishes the 'care worker' status from that of 'family care assistant' varies both in aggregate terms across countries, reflecting broader employment regulation and practices and the specific organisation of LTC in a country (especially the development of formal care services), and often in the life of the individual caregiver herself. So, for instance, in the UK home care workers and personal assistants are more frequently registered and declared, while in the other three countries privately hired care assistants are more frequently in the grey or black labour market. Also, as happened twice in Italy, new legislation adopted to legalize large numbers of undocumented migrants working as caregivers caused a shift of employment status for many of them from informal to formal. On the other hand, care workers, especially if in part-time employment, are reported to take undeclared, temporary domiciliary care jobs offered by families to top up their income (the extent of this phenomenon is unknown).

21 The implications of the informal employment condition for remuneration are less clear, as sometimes, being de facto self-employed brings greater opportunities for higher pay.

Table 6: Caregivers definitions and main characteristics

IPTS definition	Formal job contract/ declared to social security	Payment	Recognised qualification/ certification in nursing	Documented (if migrants)	Description	OECD definition[22]
Formal LTC care workers						
Care workers	Yes	salary/pay	Yes	Yes	Practicing nurses usually with lower nursing qualifications than professional nurses. They are qualified and authorized to practice in the country where they work.	**Practicing nurses**
	Yes	salary/pay	No	Yes	Nursing aids/assistants and other care workers, without recognised qualification/certification in nursing.	**Personal care workers**
Informal caregivers						
Carers	No	No	No	Yes /No	Family members, friends and volunteers not receiving any monetary compensation.	**Uncompensated informal caregivers**
	No	cash benefits / allowances	No	Yes	Family and friends who receive some monetary compensation for their care activities.[23]	**Compensated informal caregivers**
Family care assistants	No	salary/pay	Yes /No	Yes	Caregiver receiving a salary/pay by care recipient or his/ her family but without a formal contract declared to social security	**Undeclared caregivers**
	No	salary/pay	No	No	As above but without residence and work permits	**Undocumented migrants**

22 See Fujisawa & Colombo, 2009.
23 We refer here to benefits, cash payments or allowances provided to informal carers as part of cash benefit programmes and/or to care recipients under consumer-choice programmes.

Migrants are found in any of the above caregiver categories. However, they tend to be overrepresented, especially in some countries, among the family care assistants. Besides frequently lacking a formal, declared contractual agreement, migrants are often also *undocumented*, as they do not have a residence permit authorising them long term stay in the country where they live, usually because they may have been unsuccessful in the asylum procedure, have overstayed their visa or have entered the country illegally.

In this report, both b) *carers* and c) *family care assistants* will be referred to as *informal caregivers*. When referring to paid caregivers, both groups a) and c), the term *care labour* is used, and the services provided by them are referred to as *paid care*.

From the supply perspective, *(professional) care services providers/organisations* are public or private (commercial or non-for profit) organizations which employ *care workers* (b) and provide institutional-residential or outpatient services. Given the focus of this report, we shall mostly speak of (*professional*) *home care services providers*.

2.3 Facts and figures about informal caregivers

Comparable, up-to-date statistics on informal caregivers across Europe are extremely limited. Two important reasons for this are the lack of commonly agreed definitions and the fact that care is mostly delivered at home through informal arrangements which are not even recognised as such (a spouse caring for her/his dependent partner) and are inherently difficult to measure. The involvement of (mainly female) migrants in this process, albeit significant in Europe and elsewhere and widely acknowledged, is even less explored and raises further measurement complexities.

Figures in Table 7 were gathered by the OECD in the pilot data collection exercise on the long-term care workforce carried out in 2008. They only cover three of the four countries that we studied and they concern all caregivers, not just those attending older dependent people. Significantly, this exercise managed to find data on foreign-born caregivers only for a few countries not covered by our study[24] and only with respect to formal LTC workers.

Below, we summarize additional information, both quantitative and qualitative, drawn from our

Table 7: Number of formal and informal LTC workers, selected OECD countries, 2006 or latest year available

Countries	Formal LTC workers	Informal LTC caregivers
Italy (1)	126,000	4,035,000
Spain (2)	11,000	2,709,000
England & Northern Ireland (3)	92,000	5,062,000

Note: (1) 2003. Data on formal LTC workers refer to nurses and caregivers in institutions. (2) Data on formal LTC workers refer to nurses in institutions. (3) 2001. Data on formal LTC workers refer to caregivers providing services in institutions and at home.

Source: Fujisawa & Colombo, 2009.

24 Figures were found for Australia (25% of all LTC workers), Canada (26%), the US (18%) and the Netherlands (8.2%).

country reports which in turn mostly draw on national sources, concerning LTC recipients and their caregivers, especially informal ones and those from migration backgrounds.

2.3.1 Germany

In Germany in 2007, 2.25 million people (2.7% of the 82 million inhabitants) were in need of care and benefited from the Social LTC Insurance system,[25] i.e. had been assessed for their care needs and acknowledged to fall within one of the three grades of dependency (I to III) covered by the system.[26] Of these people, 68% (1.54 million) were cared for in domiciliary settings, while the rest (709,000) were in institutional-residential care.

Of those assisted in their homes, one million (or 65%) were cared for exclusively by (an unknown number of) family members and other informal caregivers[27] and the remaining half million by about 236,000 care workers employed by outpatient care services.

Box 3 - Care workers with migrant backgrounds in formal care in Germany

Our study on Germany could not find any systematic information about the nationality and/or origin of the 800,000 care workers employed in Germany in 2007 in residential and outpatient care services. Interviews revealed, however, that employees from migrant backgrounds are becoming more and more important in institutional care, especially for older patients who have a migrant background themselves. In outpatient services, the main focus on nursing functions and the legal restrictions concerning employment in nursing make it less likely to find employees from migrant backgrounds. According to information received from expert questionnaires in our study, the share of care workers from migrant backgrounds in outpatient care services amounts to 5-10% of the total. Studies at local level provide further evidence on this.

In North Rhine-Westphalia,[28] 97 inpatient and 16 outpatient care facilities had on average 30% of their employees from migrant backgrounds, with a considerably lower rate (11%) in outpatient care services. The immigrant population in the region is 23% of the total. Above 90% of the staff from migrant backgrounds were women and 58% came as Spätaussiedler (late repatriates, i.e. immigrants of German origin from Eastern European states). Other large groups are from Turkey or from the former Yugoslavia (first and second-generation immigrants). Half of the staff from migrant backgrounds are skilled employees with vocational qualifications in general nursing or geriatric nursing. The others are mostly nursing assistants. The proportion of qualified migrants was higher in outpatient care than it was in inpatient care facilities.

In 49 outpatient care services studied in Bremen and Bremerhaven[29] (representing almost half of all domiciliary care providers in the Federal State of Bremen), 22.1% of total staff was found to have migrant backgrounds (89% of them being women). This level was twice that of the other study.

Our study on Germany also reports a growing number of private nursing care services which specialise in outpatient care for immigrants, in particular for Turkish and Muslim immigrants and for immigrants from the former states of the Soviet Union.

25 See: Pflegestatistik 2007. Pflege im Rahmen der Pflegeversicherung. Deutschlandergebnisse. Statistisches Bundesamt Wiesbaden, 2008.

26 The threshold for admission in the system is to have care needs for no less than 90 minutes per day. Based on this and other criteria, our study on Germany reports that about 25% of all applications for benefits is rejected, leading the authors to state that the real number of people in need of care or at least needing substantial help in their daily life activities is much higher (p.9).

27 This one million care recipients are those covered by the LTC insurance system who received care allowances (Pflegegeld) to be used for compensating or paying family members and/or other caregivers assisting them. The number of final beneficiaries of the care allowances (i.e. the compensated/paid caregivers) is however unknown. See Section 2.5.1 on Germany for more information about care allowances.

28 See Friebe, 2005.

29 See Lotze & Hübner, 2008.

In the case of formal care at home, non-profit institutions from the non-statutory social welfare (six very large ones in particular) play an important role. In 2005, these organisations looked after over 50% of the recipients of outpatient care services; a slightly smaller share of home care recipients was served by private commercial organisations; and only 2% by public, municipal institutions.

Workers with migrant backgrounds are found throughout the formal care sector, both in residential and outpatient services (see Box 3).

In the context of informal care provision, in Germany as in Italy and Spain, families ever more frequently fall back on migrant caregivers to assist with care tasks in older people's homes. The main reasons reported from other studies are the growing limitations on the side of families in providing an adequate answer to increasing care needs and the high costs of professional care services in both outpatient care and nursing homes.

Reflecting the growing number of people in need of care from migrant backgrounds (see Box 2), our study on Germany found that there are also families from migrant backgrounds who employ care assistants from their country of origin. When the family member in need of care has poor German language skills, the possibility to communicate with the caregiver in the common mother tongue is an important benefit.

The number of migrants privately employed, legally and illegally by families to act as household and care assistants in Germany is not known. Conservative estimates range between 50,000 and 100,000 people. Some experts[30] estimate that the number of undeclared migrants (mainly from Eastern European countries) employed as care assistants alone amounts to 100,000 people. The overall figure could indeed be higher, given that outpatient care providers interviewed in another study[31] had found, in approximately two thirds of the households they served, a migrant care assistant complementing care provision.

In order to support and regulate the recruitment of care assistants from the Eastern European EU Member States,[32] the German government has established specific rules and procedures, including the appointment of the Central Placement Office ZAV (*Zentrale Auslands- und Fachvermittlung*) of the Federal Employment Agency as a 'matching' agent for the employment of foreign care assistants. This official system, however, often does not seem to meet the demands of many people in need of care and their families. Thus, while it is used by an increasing number of people to legalise an existing employment relationship with a migrant care assistant, currently the vast majority of people in need of care fall back on other ways of recruiting migrant care assistants, most of them in the 'grey market'.

Our study on Germany mentions new employment approaches which involve care service providers located in Eastern Europe operating directly or in partnership with German providers. Direct recruitment by families through informal channels, albeit illegal, is also known to be widely practiced, when alternative solutions are not available, also in view of the financial constraints faced by the employers (see Table 8).

Illegal working conditions are associated with high uncertainties and risks for all the parties involved: employment contracts, if they exist, are often unclear; additional costs are not anticipated or well defined; and the quality of care is not ensured. At the same time, illegality reduces the possibility of integration, which is already limited for migrant care assistants by factors related to their work (lack of free time, isolation etc., more on this in Section 2.4).

30 See Neuhaus, Isfort, & Weidner (2009) and Fussek (2008).

31 See again Neuhaus, Isfort & Weidner, 2009.

32 In Germany, access to the national labour market is still restricted by interim regulations, until 30 April 2011, for workers from Poland, the Czech Republic, the Slovakian Republic, Hungary, Slovenia, Romania and Bulgaria.

Table 8: Cost of different arrangements for care assistance in Germany (various years)

	Euro / month
Regular German outpatient care services for assistance around the clock (only few providers offer this arrangement)	2,700 – 3,200
Migrant care worker recruited through official agencies	1,200 – 2,500*
Illegally employed migrant care worker (without social security insurance, etc.)	500 -1,000*

** Meals and accommodation and in some cases reimbursement of travel costs must be added*

Source: various sources referring to years from 2005 to 2009 reported in Lamura et al., 2009; Mollenkopf, Kloé, Olbermann, & Klumpp, 2010, p.27.

2.3.2 Italy

In Italy, the presence of migrants in LTC settings has been growing significantly over the last years. Three areas have been identified where migrant care workers are increasingly present in residential and other formal care settings (Lamura et al., 2008): migrants have gradually started to fill the many vacancies which exist in nursing and other care positions within health care facilities (2% of all nurses in Italian hospitals in 2005, up from 0.8% in 2002).

Due to lack of nursing staff, many families (20% in a study on the North-East and Central Italy) resort to privately (and often illegally) employed care workers to ensure that their older relatives receive proper night assistance during their hospital stay. With a pay of 50-80 Euro per night, this job niche attracts both Italian (70% of the total) and migrant care workers.

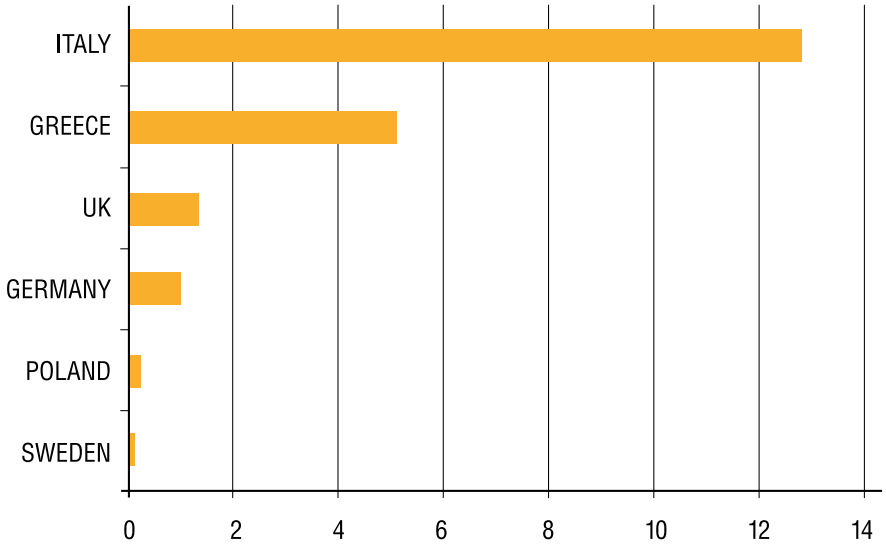
Although no aggregated data is available on the nationality of the staff employed in residential settings, some local studies show that the migrant care workers' presence in residential settings is rapidly increasing, in order to relieve national staff shortages, and due to less complicated hiring procedures than in the healthcare sector.

The distinctive feature of informal care giving in Italy is undoubtedly the very high reliance of families on privately contracted caregivers. Even if the disability ratio among the community-dwelling older population in Italy is decreasing, the ever larger cohorts of older people result in an increase of the absolute number of dependent older Italians living at home in the last years, reaching 2.1 million people in 2005 (Lamura & Gori, 2009). In addition, about 160,000 dependent older people live in residential facilities.

It is known that less than 8% of all people aged 65+ (about 940,000 out of 11.9 million) are reached by publicly-funded (home or residential) formal care services, which are available mostly in Northern regions: 4.9% at home (580,000) and 3% in residential care facilities (360,000[33]) (ibidem). Hence, at least 1.5 million old dependent people must somehow be assisted at home, more or less exclusively by informal caregivers. Since informal caregivers in Italy have no specific rights or entitlements, for which they would be registered or otherwise accounted for, they are particularly 'invisible' and their actual number is unknown. The OECD reports approximately 4 million of them (see Table 7).

33 This percentage includes both dependent and independent old people living in institutions.

Figure 3: Prevalence of privately paid caregivers in households caring for older people (2004)



Source: Lamura et al., 2009.

Figure 3 above shows that 13% of all families with dependent people contracted privately family care assistants, compared to less than 2% in Germany and the UK. Table 9 shows how the number of domestic workers,[34] including caregivers, contracted by Italian families and declared to social security has grown significantly over the past two decades. This has been done by relying on migrant labour, mostly women, whose share reached 73% of all domestic workers in 2005 (Lamura et al., 2009).

In fact, estimates for 2006-07 of *badanti* alone (i.e. caregivers), including in this case also the undeclared ones, counted over 740,000 immigrant caregivers employed by older people or their families, representing 90% of all home care employees. Of these workers, 42% were estimated to be undocumented; 25% to be documented, but without a declared job contract; and only 33% were documented and with a declared job contract (Boccagni & Pasquinelli, 2008).

Table 9: Domestic workers in Italy by nationality (1991 -2004 selected years)

Year	Total	With foreign nationality	%
1991	181,000	36,000	19.9
2001	269,000	140,000	52.0
2002	541,000	409,000	75.6
2003	543,000	411,000	75.7
2004	503,000	372,000	74.0
2005	471,000	342,000	72.6

Source: Lamura et al, 2009, based on INPS.

34 Domestic workers include people who cook, clean, take care of children, the elderly, the disabled, or even domestic animals, the garden and other household's elements. On domestic work and the role of migrants, see International Labour Office (ILO), (2010).

A deeper analysis (Lamura et al., 2008) has identified some drivers of this situation in Italy. Reliance on migrant caregivers grows in the more demanding care conditions: for instance, over 25% of Italian families with family members suffering from dementia and over 33% with severely disabled family members employ migrant caregivers, in most cases in a live-in solution. This is coherent with the finding that the possibility to 'guarantee constant care' is the main motivation (almost 90% of respondents) given by families for employing migrant caregivers. Also, 'getting help at the time you need it most' is, according to carers, the most valued characteristic of the service provided by paid migrant caregivers.

Predictably, income and the overall socio-economic status of the employers also play a role. The richest carers are six to seven times more likely to employ migrant caregivers (40% do) than the poorest ones (6%). But the relationship and work status of children and daughters-in-law providing care are also important: over 25% of daughters-in-law and somewhat fewer of the sons contract migrants if they work; only between 5-10% do, if they are not employed. On the other hand, daughters – who are traditionally expected to be the main care provider – tend to rely less on external help, but still those at work do so in 15% of cases, compared to 10% for those without jobs.

From a financial point of view, besides public care allowances (see Section 2.5.1), the costs born by Italian families in privately hiring migrant caregivers are kept low by several factors: co-residence (which reduces costs for both parties); the wage differentials between Italy and the migrants' countries of origin;[35] the fact that migrants in most cases are undeclared to social security or are declared for a lower number of working hours (also at the request of the worker herself, for fiscal reasons); and that, when they are legally hired, fiscal incentives have been recently introduced to reduce overall costs and fight against undeclared work (Lamura et al., 2008). All these factors make hiring a migrant a more convenient choice compared to residential care arrangements that are only limitedly available and cost 1,500-2,000 Euro/month at least, further reducing the demand and the supply for this solution.

The lack of a legal migration status for many migrants, due to the very low number of officially admitted annual entries established by the government's labour immigration quotas, also contributes to the continuation of grey/black labour market arrangements. For instance, the overall number of new entries approved by the government for 2008 was 170,000 labour migrants. Of these, 65,000 were for *badanti* and other domestic workers. Facing this opportunity, almost 730,000 applications were submitted, 412,000 of which were from *badanti* formally still in their home countries, but almost always already working in Italy. In 2009, after widespread complaint and pressure from over 300,000 families left in the illegal condition of hiring an undocumented migrant, the government finally agreed to also process their requests. A similar legalization process had already occurred in 2002, involving at the time over 200,000 migrant workers.

2.3.3 Spain

In Spain, as in Italy, informal care provision at home is overwhelmingly the dominant approach to meeting the care needs of dependent elderly people. The application of new legislation known as the Dependency Law (*Ley de la Dependencia* 39/2006, see Section 2.5.1) is expected to increase the role of formal providers of 'home help', but this is occurring gradually and at different paces across regions.

As reported in our study on Spain,[36] long-term care in residential settings reached in 2004 just over 10% of dependent 65+ old people

35 Facing an average salary of 800-1,000 Euro net per month for a full-time migrant caregiver employed in a private household in Italy in 2004, the average wage in 2006 was about 150 Euro in Ukraine and 300 Euro in Romania, two of the main countries of origin of badanti working in Italy. (Lamura et al., 2008).

36 Original sources are Jiménez- Martín et al. (2007): Aspectos económicos de la dependencia y el cuidado informal en España. Barcelona: Universidad Pompeu Fabra http://www.fedea.es/pub/otros/librodependencia-FAZ-Sergi.pdf and Jiménez-Martín, Sergi. Viliaplana Prieto, Cristina. (2008) Trade-off between formal and informal care in Spain [online]. Universitat Pompeu Fabra, Universidad Católica San Antonio de Murcia y FEDEA, ftp://ftp.cemfi.es/pdf/papers/pew/Tradeoff.pdf.

(almost 14% among those dependent for ADL). The remaining 90% were cared for at home. Almost 75% of older people in need of care received exclusively informal help (80% among those dependent for IADL and 65% among those dependent for ADL). In addition to informal help, another 10% received also support from public domiciliary care services (known as 'home help' services[37]) or bought in private home help.[38] Only 5% of older people in need of care relied exclusively on private (4%) or public (1%) home help. Altogether, therefore, 85% of dependent people aged 65+ received in Spain almost exclusively informal care.

According to some estimates (IMSERSO, 2005b) those providing care in Spanish families were 1.6 million people in 2004: about 600,000 of them on a continuous basis and 1 million irregularly. The profile of the carer in Spain is a woman between the age of 45 and 65 years; 43% are daughters, 22% are wives and 7.5% are daughters-in-law of the cared person. The majority of carers are married (75.2%) and are not in gainful employment (73.1%) (IMSERSO, 2004).

Roughly in line with the above estimate on continuous informal care provision,[39] the 2005 White Book on *Care of dependent people in Spain* (IMSERSO, 2005a) reports 726,000 informal caregivers who were co-residents, caring for a 60+ years old person: 634,000 of them were carers (family members, friends etc.), while 92,000 (about 13% of the total) were informal care assistants employed by the family.

Among care assistants, migrant women have become increasingly common. Their number is unknown, but our study found estimates by different sources ranging from 200,000 to 600,000 people. The majority of these migrant caregivers originate from Latin America and Eastern European Countries. Domiciliary care positions are often the only opportunities for an immigrant woman arriving in Spain in search of a better life and to enter into the Spanish labour market. The lack of studies on immigrant caregivers reflects however the 'invisibility' of this phenomenon.

Migrants are increasingly present also in the provision of formal home help services. In a survey of 25,000 households across Spain receiving such services around 40% of the care workers involved were foreigners, with Ecuadorians (13% of all care workers) and Columbians (7%) representing the two largest groups from migrant backgrounds (IMSERSO, 2005b).

2.3.4 UK - England

In England, social care provision –including home care- is the statutory responsibility of 150 local authorities referred to as *councils with social services responsibility* (CSSRs). The social care reform which started twenty years ago (with the *NHS & Community Care Act* of 1990) has in fact promoted a 'mixed economy' approach. This means that the CSSRs must arrange social care services for eligible clients – including home care and residential care for older and disabled people – but are discouraged from providing these through their own employees and must purchase part of them from the independent sector, consisting mostly of private companies and charities. Over time, this has led to a significant development of the sector, which provides care both to people in need covered by council-supported community-based services (outsourced to this sector), and to those who can afford to buy care services on the market. In 2008, about 4,900 domiciliary care 'agencies' were registered with the Commission for Social Care Inspection (CSCI), up from 3,700 in 2004. Most of the home care agencies were small outlets with fewer than 100 people using their service and over 75% of them were privately-owned.

37 Public home help is organised at regional level and delivered by Municipalities through social care centres. Typically, it includes personal support (physical and emotional help), domestic help (household chores) and other support. Depending on the region, in 2006 these services reached in most cases between 2% and 6% of 65+ older people (10% only in Extremadura). See IMSERSO, 2006.

38 The very old (80+) and dependent lone people (single, widowed, separated/divorced) were found more prone to have professional help along with informal care solutions.

39 Co-residency can be assumed to be strongly associated with intensive, continuous care in the case of employed care assistants. On the other hand, relatives, especially partners, live together regardless of levels of dependency and related care needs.

Out of a total adult social care workforce of 1.5 million workers in 2008, just over 1 million were employed in the independent sector (a growing figure over the years); 220,000 were employed by councils (a gradually shrinking figure) and 150,000 were self-employees working as personal assistants (+34% over the previous year). The increase of personal assistants reflects the extension of the Direct Payment Scheme[40] to a larger number of older and disabled people and also their carers, who can use that money amongst other things to employ professional caregivers.

As illustrated in Box 4, the formal home care sector which has developed in England relies also on care workers from migrant backgrounds, both long-established and newly arrived, with a particular incidence in specific localities. High and persistent staff vacancy and turnover rates, especially for care workers in domiciliary settings[41] are clearly a powerful pull factor of migration in this sector.

Box 4 - Care workers with migrant backgrounds in England[42]

The analysis of the 445,000 domiciliary care workers (care assistants and home carers) recorded in the 2001 Census in England reveals that 90% were women, over 50% were aged 25-49 (but with a higher than average presence of women aged 50-59[43]) and about equally split between full-time and part-time jobs (Yeandle et al, 2006).

Among women, just over 10% of all care worker positions were held by women from ethnic minority groups. This figure rises to over 30% in some areas and was highly variable between different localities, in part reflecting the size of the ethnic minority population in each area.

In some localities, women from ethnic minority groups (considered together) were more concentrated in care work than in all other jobs, but this was not true everywhere and depended upon the precise composition of the ethnic minority population in each locality. Black African and Black Caribbean women were more concentrated in care work almost everywhere, and in some places the 'White Other' group (which includes people from other European countries, as well as a number of other categories) was also highly concentrated in this occupation. By contrast the Indian, Pakistani and Bangladeshi population groups of women tended to be under-represented in care work, irrespective of the locality in which they lived. Ethnic minority men, especially from the Black and Black British groups, were also overrepresented in care work in most localities.

A more recent and specific study of immigration in the social care sector (Moriarty et al 2008; p 26) found strong demand for migrant labour as a way of dealing with recruitment problems in social care, and evidence of increased recruitment from the European Economic Area (EEA), especially Poland. Data from the Annual Population Survey 2006 shows that 16% of the UK's 640,686 workers employed as care assistants and home carers (some of whom work in residential care) were born outside the UK. In London, this figure was far higher, at 68% (Moriarty et al., 2008).

The health and social care sectors have over the years become an important destination for foreign workers in the UK. The proportion of work permits issued to foreign workers in the health and medical services sector has risen from 7% of all permits in 1995, to 22.5% in 2000, reaching 26.1% in 2005. In that year alone, over 17,000 permits were issued to 'nurses and carers' and 1,350 to 'care assistants and home carers'.

40 The Direct Payments scheme is a cash for care system introduced in the mid 1990s for sick and disabled people under state pension age, and a later made available to other categories of beneficiaries. In 2007-08, 4.4% of all those receiving community-based services in England were using Direct Payments.

41 The 2008 State of Social Care Report (see Box 8 of our England report) give a turnover rate of 17.9% for all staff in the independent sector and a vacancy rate of 3.8%. These figures increase respectively to 20.7% and 5.2% for staff in home care settings.

42 Ethnic categories used in official surveys in the UK are the following: White British, White Irish, White Other, Mixed Ethnic group, Indian, Pakistani, Bangladeshi, Black Caribbean, Black African, Chinese and Other groups.

43 In England as a whole, women aged 50-59 held only 9% of all jobs in the economy, but occupied 22% of all care worker jobs.

While the supply of formal care services has increased, the number of people covered by council-supported community-based services has fallen over the years. They were 577,000 in 2007-08, 82% of whom (473,000) were people aged 75 or older. This represented only about 1 in 8 people in that age cohort in England (half that share if only users of publicly funded home care services are counted). Eligibility and contribution criteria for council-supported services – reflecting care needs, income and other variables – have become stricter over time to the benefit of older people and households with the most critical care needs. This shows up clearly in the falling number of beneficiaries paralleled by the increasing hours of care per household.[44] Still, users of council-supported care services may also have to pay something: in 2006, 40% of them either paid a charge to their councils towards the cost of the care they received or had to 'top up' their care package privately, or did both.

Given the rationing of council-supported care supply and the cost of care services provided on the market, informal carers remain a crucial actor in LTC provision also in England and the UK. Almost 6 million people (11% of the population) in the UK (4,855,000 in England) were recorded to provide unpaid care in the 2001 Population Census. About 4.4 out of the 6 million carers (73%) were men and women of working age and 1.3 million (22%) were over state pension age (at that time, 60 for women and 65 for men). The incidence of caring rises with age until men and women reach their 50s, remaining a common experience until well after state pension age. Women are more likely than men to be carers in all age groups under 75 years. In particular, a quarter of all women aged 50-59, and about 1 in 6 men, provided unpaid care. Men are more likely than women to be carers only when they are over age 75.[45]

Considering people of working age only, 10% of men and 14% of women provided unpaid care and respectively just over 70% and 60% of these carers also worked. Male carers who work in 90% of the cases were in full-time employment, while female carers who work in 50% of the cases had a part-time job.

Interestingly, among people of working age from migrant backgrounds, the incidence of caring varies significantly across ethnic groups: 12% of men and 14-16% of women were carers among Indian, Pakistani and Bangladeshi people, compared to 6-8% men and 7-11% women among Black Caribbean, Black African and Chinese people. In the case of Pakistani and Bangladeshi women of working age, less than 20% actually worked. Among all other ethnic groups, the percentage of female carers who also had a job was higher (above 45%), but below the average for all women (just over 60%), except in the case of Black Caribbean women (on average).

Compared to the other countries that we studied, cared people and carers in England do not seem to rely on migrant 'grey' or 'black' labour[46] for help at home and no trend was found by our research indicating a possible evolution in this direction. Three main reasons are given in our study on England of the marginal presence of migrant informal care assistants in that country: the development of a large independent home care sector, which itself employs new migrants and care workers from ethnic minority groups already living in the country, bringing them into the formal care sphere; the strict enforcement of immigration laws leading to fewer undocumented migrants living in the UK compared to other countries;[47] and a cultural reluctance of English families to resort to live-in care solutions. In other countries we have seen that this possibility (co-residency) is an

44 In 1997, households receiving home care were 479,000; in 2007-08 they were 328,000. The average care time per household in 2007-08 was however 12.4 hours per week, over twice the 1997 figure. The total amount of hours of home care provided had thus increased from 2.6 million per week in 1997 to over 4 million in 2007-08.

45 From that age, women are much more likely than men to be widowed, hence without a spouse to care for.

46 We refer here to the different degrees of informality in work arrangements, often coupled with different legal status conditions of migrant care workers found in the other countries.

47 For statistics and analyses on the situation in Northern Europe, see http://clandestino.eliamep.gr.

important reason for recruiting migrant caregivers and employing them informally, given that formal continuous care at home, if available at all, would be extremely expensive.

2.3.5 Common characteristics of migrant family care assistants

Across the four countries studied some common characteristics of formally and informally employed migrant caregivers emerge:

Origin

In general, migration flows of LTC workers reflect language, proximity, and historical links between destination and origin countries. Enlargement of the EU to Eastern Europe has led to an increased flow of migrant caregivers from within this area and its neighbouring countries (e.g. Ukraine and Moldova), especially to Germany, but also to the other countries. Caregivers from Spanish-speaking South or Central American countries are predictably more present in Spain and also in Italy.

Background and motives

Pay differentials and lack of adequate **employment and career options** in the countries of origin drive people with both low and high qualifications to migrate and look for a job as caregiver. Typical profiles of migrant paid caregivers, as established in the case of Germany, but similarly relevant also in the other countries studied include:

- Young unemployed women, aiming to broaden their professional competencies through a new language proficiency, to study in Germany, or earn money to later study in the home country;
- Divorced women or single mothers who want to earn their living and support children's education;
- Women with personal/family financial problems they hope to solve by taking a job abroad;
- Women who need money to build a house, set up a business or similar ventures.

The envisaged **length of stay** reflects also their motivations. In Germany most migrant care assistants do not strive for permanent settlement, but rather migrate for a limited time[48] in order to solve pressing problems. **Employment status** also plays a role on this decision. In Italy, according to Lucchetti et al. (2004) over 50% of migrant care assistants employed by a family without a contract plan to stay less than 3 years; while over 50% of those regularly employed by a family or working in a care organisation plan to stay for ever, or at least for 4 or more years. The intention of returning back to the home country is widespread also among migrant women in care jobs in Spain.

Qualifications and skills

In Germany, the level of **formal education** of migrant care assistants is often high and some are well-trained nurses. In Italy, a study of 220 women migrant care assistants found that the majority of them possesses a relatively high educational level: 12% had a university degree, 23% a secondary school title and 16% attended a vocational school, whereas 15% had only reached elementary school and only 1% had no title at all (Lucchetti et al., 2005).

However, based on other studies and our own, the vast majority of migrant care assistants, especially those in undeclared work conditions, seem to have very limited or no specific **training and experience** in health or social care; **information** on the situation they will face in dependent people's homes and on the tasks they are expected to perform.

48 Our study found that migrant care assistants in Germany often stay in the households for two to three months. In order to ensure continuity, some care agencies try to organise teams of two or three people who rotate. However, some care assistants stay longer than originally intended, taking up different employments over several years.

Despite this **training opportunities** are very limited. In Spain our study found that apart from few traditional nursing courses for Spanish-speaking immigrants, no training programs on LTC were available. Similarly, the study on Italy found training courses for migrant family care assistants to be a 'quite marginal' phenomenon (with no attention paid to ICT opportunities). Training initiatives promoted by local authorities have however been growing in the last few years aiming at better qualifying immigrant paid caregivers.

Language barriers emerged as an issue in our country studies, but the few statistics available show that they are not too widespread. In Germany, language barriers do not seem to be a problem for most people or families employing a migrant care worker.[49] In Italy, 'problems of communication and understanding' were indeed the most frequent difficulty with the cared person's family felt by migrant care assistants, but it was mentioned by only 28% of the respondents in the study by (Lucchetti et al., 2005).[50]

2.4 Work conditions and needs of informal caregivers

All four country studies, in line with other research on this topic, underline the many difficulties that informal caregivers face. We list the major ones below, highlighting in each case the additional or specific aspects which concern informal caregivers with a migrant background.

Long time devoted to care

Family carers and care assistants may devote an extensive amount of time to care, up to the point of being engaged 24h a day, 7 days a week. For instance, statistics from the UK 2001 Population Census show that most carers provided their unpaid support for between 1 and 19 hours per week, but one in 20 women aged 60-64, and almost one in 30 men of the same age provided more than 50 hours of care per week.

In particular, supporting older people to perform activities of daily living (ADL) such as eating, bathing, dressing, toileting, continence or transferring (from bed to chair and back) most often requires continuous care and therefore close proximity to or co-residency with care recipients. As reported in Huber et al. (2009, p.64-65), this support is given mostly by informal caregivers in Southern European countries such as Spain and Italy, where co-residency is also more frequent. According to Huber et al. (2009), in Spain, informal caregivers were in 80% of cases the source of support for personal care on ADL to older people (75+), compared to 70% for support on IADL such as transport/shopping and nearly 60% on household chores. In Germany and the UK, informal caregivers were overall less important and, in particular, contributed to a lower share of personal care (respectively 45% and 35% of cases), while they did engage, albeit also less, in transport/shopping and household chores (50% and 40%).

As we have seen, migrant care assistants are often employed precisely to reduce the burden on carers, by ensuring 24 hour availability and taking up caring and household tasks. Consequently, they are particularly present in co-residency care arrangements and tend to be involved in the most demanding care functions. In Italy, a study found that almost 50% of 220 female migrants interviewed worked more than 9 hours a day, although the relative majority (28%) worked 5-8 hours a day (Lucchetti et al., 2004).

49 In a recent study (Neuhaus, Isfort & Weidner, 2009, p. 63), 78% of households reported that their migrant care assistants had sufficient German language skills.

50 In the groups of 220 women migrants, over 40% in fact declared to have no difficulty in the relationship with the cared person's family. Other problems mentioned were: lack of respect (16%), excessive claims (13%), payment problems/exploitation (7%). Several other issues were however listed with respect to the most burdening aspects of providing care (see Section 2.4).

The amount of time devoted to care and surveillance of dependent people and/or the almost permanent availability requested to many informal caregivers create problems and needs in many areas. Balancing work and caring functions is possibly the most important challenge for carers who work. The percentage of carers who are in gainful employment is about 40% on average across the EU and varies across countries (Huber et al., 2009). In the UK, in 2001, about 50% (2.2 million) of carers of working age (4.4 million) combined their care, with other paid work, 1.5 million in full-time jobs, and the remainder in part-time employment (Yeandle & Fry, 2010). In Germany, in 2000 (Huber et al., 2009), the equivalent share of carers at work was below 40% (with the majority in part-time employment). In Spain, in 1996 the share of main carers working was just above 20%.

Many caregivers end their professional career or reduce their hours of work as a result of caring and, overall, the higher the needs of the dependent person, the higher the rate of non-working carers. At the same time, any solution that can make it easier for carers to remain in paid work is important, because work provides an income and pension rights; helps to maintain social networks; offers a temporary relief from the caring role; enhances self-esteem; and offers the opportunity to share concerns with colleagues in a similar situation (see below).

Another challenge is to make it easier for caregivers to involve in full-time caring, by, for example, making basic IADL services such as shopping and banking more easily available, e.g. through online or phone based services. In this case, informal family care assistants may face confidence problems in being entrusted to act on behalf of the cared person or his/her family and authentication problems on the side of the service providers. These problems might be compounded for family care assistants with a migrant background with an undocumented status.

Isolation, emotional and physical stress

Caregivers, and in particular full-time carers and family care assistants in live-in arrangements are likely to experience some degree of social isolation, psychological distress including anxiety, depression and loss of self-esteem. For instance, a report by the Alzheimer's association in the US (cited in Fujisawa & Colombo, 2009) found that about one-third of family members providing care for people with dementias have symptoms of depression and other health problems. In the US, care workers such as nursing aides, orderlies and attendants have the highest nonfatal occupation injury and illness rates in the country (Fujisawa & Colombo, 2009, p.22), a finding that is likely to apply also for informal caregivers.

These conditions generate among other things a strong need for caregivers to have more opportunities to communicate with others, to share emotions, experiences and requests with other caregivers, and to receive specialized support to address any psychological distress they may suffer from.

These problems and the related needs were found in our country studies to be even more serious among paid migrant caregivers, who are separated from their friends and families and often do not have a social network to turn to when they are overwhelmed with their tasks, need help or advice, or simply someone to talk to.[51] Intercultural and language barriers increase the feeling of isolation. The often undeclared working situation and undocumented status can lead to excessive demands on the migrant caregiver, augmenting their stress. Also, their precarious working condition prevents migrants from being recognised by formal LTC providers as partners in the caring process and from receiving support and training.

51 In fact, to fight isolation migrant caregivers are found (especially in Germany and Italy) to connect with other workers from the same country of origin through an intense use of mobile phones, and in some places to gather in specific meeting points for migrant caregivers and spend their leisure time together.

Limited experience and skills in long-term care, poor knowledge of existing services and support

The complexity of care tasks and the required skills to support dependent people vary significantly, and can be deemed to be higher for dependency in ADL rather than IADL, when medical aspects become more prevalent. Thus, the growing absolute number and share of 80+ people among LTC beneficiaries entails a growing complexity in care provision and in general the need for caregivers to know and be able to address the specific needs of older people who are dependent in ADL.

Facing this situation and its likely evolution, all studies, including ours, underline the fact that informal caregivers, especially carers, but also care assistants tend to have limited, and, in perspective, increasingly inadequate knowledge and skills for care provision, especially concerning dementias and the organisation of LTC services. They know little about the rights of care recipients and the attached conditions; the providers of support, including of technology-based solutions and services; and, where it exists, the support that might be available for informal caregivers themselves, especially carers who also work.

In the case of carers, this situation reflects the fact that they often deal with caring tasks for the first time, at least of older people (while they may have cared for children earlier in their life) and that not much is done in our society to prepare people for performing this function, even though this is gradually changing, at least in some countries. In the case of paid informal caregivers, except those professional care workers who choose to be 'informal' (usually part-time) for their own convenience, limited skills and experience tend to reflect the overall low expectation of those employing them, i.e. care recipients and their families, who look at the grey labour market in the first place for a low cost 'solution'. Other factors are also at play, such as the educational background,[52] the lack of training opportunities in LTC, the high turnover and possibly only temporary occupation in LTC for many of them.

All these problems tend to be more acute with migrant family care assistants, especially those newly arrived and those from culture-linguistically distant countries, who also face intercultural and/or language barriers and lack even the basic understanding of the care context (players, rules, expectations etc.) both inside and outside the household.

Also family caregivers from migrant backgrounds face additional problems. Our study on Germany, for instance found that with the first generation of Turkish immigrants now slowly reaching old age, prior experiences with care in Germany are scarce and the informal, inter-generational knowledge transmission which traditionally occurs in the home society is missing. Consequently, the knowledge about care needs in old age and the respective possibilities for information and support are especially low in Turkish families. The Turkish community and Turkish media in Germany have rarely dealt with issues such as dementia. Hence there is much need for awareness raising, information, support and guidance.

The study on Spain provides an example of problems arising from cultural differences: a family care assistant from Maghreb did not understand the need of some hygienic procedures for her terminally ill patient and, following her tradition, constantly used henna on the patient's skin. Although the importance of hygiene was explained to her, according to the carer who had hired her, she would not see it as a priority.

The particular needs arising for caregivers with migrant backgrounds comprise more

52 Fujisawa & Colombo (2009) state in fact that there are few data on educational attainments of informal caregivers. However, according to the 2005 American Community Survey about two-thirds of the (informal) personal and home care aides in the US had secondary school diploma or lower educational attainment.

reliable, easy to reach and understandable information; training; and timely direct guidance and support on how to manage personal care and in particular medical aspects, especially in case of emergencies, but also in performing everyday tasks, which become, as said before, more complex with 80+ care recipients.

Managing sensitive personal data

Another challenge for caregivers in general, and especially informal ones, that emerged from our country studies, has to do with information management and privacy issues. Much of the relevant information that the actors involved in the care process deal with, or even simply are concerned about and exchange among themselves, is based on sensitive data on personal health and dependency conditions of the care recipients, but also on work, life, emotional and other personal conditions of the caregivers themselves. This issue came up not by chance when exploring the opportunities and risks of ICT use in LTC, as these technologies significantly increase the risks of breaking privacy requirements of care givers and recipients, but also offer solutions to address them.

2.5 Policies and measures in support of informal caregivers

In view of the evidence presented in the previous sections about the important role played by informal caregivers in LTC at home and the range of significant problems and needs they face in that role, three[53] of the country studies performed for our research were requested to explore in general terms the presence, if any, and main features of: LTC policies and measures in support of informal caregivers, in particular carers; ICT policies and measures addressing LTC at home, highlighting again any specific attention paid to informal caregivers.

2.5.1 Long-term care policies and carers

As illustrated in Huber et al. (2009), a series of policy developments aimed at increasing the share of people receiving care at home, rather than in institutions, were introduced in a number of countries in the 1990s, including Germany, Italy and the UK and later Spain. These measures provided cash benefits or a mix of cash and in-kind benefits to care recipients at home. In some cases, the cash benefits might be used to pay for informal carers. In parallel with these developments, policy-makers have in some cases started supporting informal carers directly with money or other means.

The main finding from our exploration of this domain is that the importance of family carers for LTC is at this stage formally acknowledged by the national policies of all the countries examined in this report, which however address their needs still almost exclusively in terms of (indirect) financial support. The only exception among the four countries is the UK, with a longer record of policy attention directed towards carers, and an overall more articulated range of financial[54] and in-kind support measures for them. The fact the UK is also the only country among the four with robust data on carers,[55] both reflects and likely contributes to such enhanced policy attention.

UK: a long established and articulated focus on carers

Also in response to pressure from carers' organisations who have been very active in the UK for many years, the incoming Labour Government

53 As mentioned before, the first pilot study on Italy had a narrower focus and the policy context was addressed only with respect to technology in LTC.

54 Huber et al. (2009) (see Table 5.3, p. 83) show that besides England, the only other European countries which have introduced some form of so called 'care allowances' and may give other benefits to carers (pension credits, respite care, leave and support services and others) are: Ireland, Luxembourg, Norway, Sweden and Finland, Slovenia and the Slovak Republic.

55 The official State of Social Care annual reports, published by the Commission for Social Care Inspection (CSCI) in relation to the system in England (since 2005) provide an important example of this.

passed in 1999 the initial National Carers' Strategy (*Caring about Carers: a national strategy for carers*) that played a key role in raising the profile of carers; introduced a special Carers Grant for the 150 councils with social services (statutory) responsibility, to develop innovative, high quality carers' services; and among other things identified telecare as relevant to carers' situation.

A number of subsequent legislative and policy developments,[56] including the *New Deal for Carers* announcement in 2007 have given to carers limited but enforceable rights, placing new statutory obligations on local authorities, employers and others. These new rights include: the right to unpaid leave from work to deal with emergencies and caring crises; the right to request flexible working arrangements; the right to a Carer's Assessment (which acknowledges their desire to work as well as to care); and the right to access education, training and employment. Besides the services made available directly by local councils or by outsourced independent providers, at national level, carers can (if they can establish eligibility), claim Carers Allowance (currently a very modest weekly sum expected to be reviewed), and some other carers' benefits available through the national social security system.

Overall, the England report found that these valuable developments are very far from an adequate response, given the scale and range of carers' needs. For instance, at present, only a minority of carers have had their own needs assessed (less than 5% in 2007/08), very likely resulting in an extensive amount of unmet demand. Similarly, while some local authorities also thanks to the Carers Grant have been innovative, resourceful and imaginative in developing new support for carers, these examples of excellence are far from universal and still reach a limited number of carers.[57] Local services remain variable, patchy and insecure and many carers remain isolated, unaware of their rights and entitlements, and cut off from the services and support to which they are entitled.

The government's revised national strategy for carers was presented in June 2008, in *Carers at the Heart of 21st Century Families and Communities*. This document set out a 10-year 'vision' for an enhanced support system for carers and made commitments in relation to: information and advice; breaks; better National Health System's support, including annual health checks for carers; employment support; protection from inappropriate caring roles for young carers; training for carers and for professionals in contact with carers (see *Caring with Confidence* programme in the 'ICT policy section below); and improvements to information about carers.

Two important additional elements stand out in the England report on LTC policies for caregivers. First, the above efforts towards carers are paralleled in the UK by other initiatives aiming at strengthening the formal LTC workforce, the latest of which is the *New Strategy for a 21st century social care workforce*[58] presented in 2009. Second, as already mentioned, third sector carers' organisations have played a significant role in raising and steering the policy agenda towards carers. At national level, they also achieved, through effective lobbying, the development of research and information activities on and for carers. At local level, they have been involved in the development of carers' centres, services and support, through a constant dialogue with local authorities and with the independent domiciliary care agencies.

56 The main legislative and policy developments in England affecting carers are summarized in Box 5- ICT applications for LTC provision at home, p. 12 of the England report.

57 Specific carers' services, funded by the Carers' Grant and by the local authorities' core budgets for Adult and Children services, reached 9% of carers in 2005/06 according to the CSCI.

58 Aiming among other goals to raise the status of social care careers, this strategy includes: CareFirst – a scheme to support 50,000 long-term unemployed people to access employment in social care; additional 1,300 apprenticeships in social care; a new Management Trainee Scheme to encourage graduates and 'top quality executives' to enter the sector; and a new voluntary registration scheme for home care workers.

Germany: attention to carers growing

The key legislation affecting long-term care in Germany is Code of Social Law SGB XI of 1995. This established the Social Long-term Care Insurance system which privileges care delivery at home and defined: the criteria for the attribution of benefits to people in need of care; the amount and types (in kind, in cash or both) of the benefits according to three levels/grades of dependency; and the type of care/support covered by the insurance. The system has been reformed in 2008 by the Federal Ministry for Health with the *Long-term Care Further Development Act (Pflegeweiterentwicklungsgesetz)* with several measures aiming in particular to improve the situation of older dependent people and their informal caregivers.

As a way to incentivise domiciliary care provided by family members and their helpers, the Social LTC Insurance system envisages a Cash Attendance Allowance[59] (*Pflegegeld*) that can be used to pay informal caregivers. These are also entitled to specific additional benefits: free training; breaks (now a care-leave up to 6 months) and substitute care; special unpaid leave for acute situations; pension and accident insurance; support in returning to the labour market. Besides this, the reform also strengthened some special measures to help the families in their caring role such as support for volunteer work (training, volunteer companionship, establishing volunteer groups) and improved counselling through LTC advisers and new regional Support Centres (*Pflegestützpunkte*).

Other policy measures mentioned in the report – the *Round Table for Long-Term Care* of 2003, which led in 2005 to the *Charter of Rights for People in Need of LTC and Assistance* and the establishment in 2007 of the *Coordinating Office LTC* at the German Centre of Gerontology – all make reference to people in need of care and their relatives, thus showing awareness of the importance of informal caregivers on a larger scale. The German report did not find, however, dedicated policy measures addressing carers, like they exist in the UK, or any official statistics about informal care in domiciliary settings beyond those covered by the Social LTC Insurance system. In the light of the positive impact of carers organisations in the UK in raising the awareness and efforts of public policies towards informal caregivers, the establishment in March 2008 of the first national carers association in Germany *Wir pflegen* (*We Care*) might lead to changes in the above situation.

Concerning cultural diversity aspects, our study on Germany found that in recent years, long-term care patients from migrant backgrounds have become a growing customer group in the field of outpatient care (see Box 2). This has led to increased efforts in developing and implementing culture-sensitive offers, but still no nationwide culture-sensitive care system can currently be deemed to exist in Germany. An interesting policy initiative in this direction is the *Active Ageing of Migrant Elders across Europe* (AAMEE) project (www.aamee.de) launched by the Ministry of Intergenerational Affairs, Family, Women and Integration of the State of North Rhine-Westphalia and supported also by the European Commission. The project focuses on the promotion of active ageing and full integration of immigrant and ethnic minority older people, but attention is also placed on their care needs and caregivers.

Spain: implementation of the new dependency law

Law 39/2006 for the Promotion of Personal Autonomy and Care for Dependent People (Promoción de la Autonomía Personal y Atención a las personas en situación de Dependencia) enacted since 2007, has brought an important novelty in the rights and entitlements of dependent people and their families in Spain.

59 With the reform of 2008, payments which remained fixed for years are now adjusted every two years. For example: Grade I rate for Pflegegeld was € 215 per month in 2008; in 2010 it will be € 225 and € 235 in 2012.

The law acknowledges the right of elderly or disabled people to carry out their basic activities of daily living (ADL) and entitles those accredited as dependent to receive care and attention by means of services (home help, day centres, night centres or residences and remote care) corresponding to their degree of dependency. When the competent administrations are unable to offer these services, the more dependent beneficiaries are entitled to receive a cash benefit. Such financial assistance can be used to obtain care from private providers (allowance for services, Prestación económica vinculada al servicio) or from family carers (Prestación económica para cuidados en el medio familiar y apoyo a cuidadores no profesionales). Family members, when they have to assist a highly dependent relative, can thus now be paid for their help as informal carers and are also entitled to respite care and counselling. The family has also the option to contract a care worker from outside the family circle.

Reflecting the decentralized responsibility for social care and health care in Spain, and in particular the mandate to autonomous regions to organize caring networks for disabled people according to local needs and conditions,[60] the application of this law relies on the initiative of the 17 autonomous regions and the lower tiers of the local public administration (more than 8,000 municipalities). Changes brought by the new Dependency Law are consequently taking place at different pace and in different ways across the country.

Beyond the aspects related to new Dependency Law, our study on Spain has not identified other significant changes or policy measures at national level addressing carers and other informal caregivers. At regional level, however, many studies of carers' conditions in view of devising policy action have been found, along with some policy initiatives addressing carers and voluntary caregivers. The study on Spain in fact identified also the presence of important third sector organisations established by carers and families of dependent people to promote awareness of their needs and support members. For instance, CEAFA the Confederation of Associations of Relatives of Patients with Alzheimer disease and other dementias represents about 200,000 families throughout Spain.

Italy: poor recognition of informal caregivers in the welfare debate[61]

The Italian welfare system in support to citizens in need of care is characterized by an almost exclusive orientation towards a 'cash-for-care' approach, with a marginal role of in-kind services. Dependent people can receive care payments by different authorities,[62] currently adding up to 800-1000 Euro per month. Little or no control is exerted over the use made by recipients, officially free to use this money as they wish. Facing the limited supply of formal care opportunities and growing constraints on the availability of informal care by family members,[63] the above financial support has been translated, as we have seen, into an increasing reliance on migrant labour.

The lack of any specific policy attention and support to carers, beyond providing them with financial support through the care recipients and some leave rights for those who also work, can be seen to reflect the broader way in which care has been addressed in Italy. According to Saraceno

60 This occurred with the Second Action Plan for Disabled People (II Plan de Acción para las Personas con Discapacidad (2003-2007) passed in 2003 by the Ministry of Labour and Social Affairs.

61 The pilot study on Italy did not address the broader situation of carers, as it was only focused on migrant caregivers. Information provided in this section, except for the section's title, is thus based on other sources.

62 The State provides a disability pension (means tested, 238 Euro/month) and a care allowance (universal, 450-700 Euro/month, received by 7.7% of all 65+ people). An increasing number of regional and municipal authorities introduced additional cash benefits, of 300-500 Euro/month, usually means tested and sometimes controlled in their use. In recent years, the average income of older Italians living alone was slightly above 1000 Euro/month.

63 The reasons are the same as elsewhere: demographic (reduced potential support ratio), social (reduced support from social networks) and economic, increased/longer labour market participation of women and older workers.

(2008) care is viewed "as an issue which only concerns the family and the women in it, which does not imply any right for the care recipient or for the caregiver, and which does not require any competence, even though the caregiver is expected to provide an uncommon amount of relational capability and affection".

Within this general context, support initiatives launched by local authorities towards carers and the migrant care labour that they now employ on a large scale can increasingly be found at regional and municipal level, but mostly in the Centre-North of Italy.

2.5.2 ICT policies for long-term care at home and carers

In the next chapter, we provide a more articulate view –for the four countries examined by our research– of the main features and of the deployment situation of ICT-based devices and services for LTC at home, especially from a caregivers' perspective. Here we anticipate some of these elements and illustrate the public policies which promote technological development and deployment in this field. In particular, we look at if and how LTC policies address ICT opportunities for domiciliary care delivery and informal caregivers, and vice versa, if and how ICT-related research and innovation policies dealing with applications in health and social care pay attention to the home context and to informal caregivers. The findings summarized below come from our country studies, integrated from those of the *ICT & Ageing* study (see footnote 10).

The main result from our exploration of policy action and awareness concerning the use of ICT in LTC in the four countries examined is that only in the UK one can find at the moment a strategic initiative to mainstream ICT use in LTC, broadly shared by the different policy actors involved, and resulting in concerted actions to turn this drive into reality on a large scale. Obstacles such as the separation of health and social care services nevertheless still limit the wider and more effective ICT deployment also in the UK. Carers, on the other hand, are increasingly considered and addressed also in publicly promoted ICT initiatives, and –more than in the other countries– are exploiting ICT opportunities on their own incentive as a response to their needs and those of the person they care for.

In the other three countries, albeit with differences in the amount of resources and other aspects, research and innovation policies at national and regional level, often with help from European programmes, have promoted a number of R&D projects, pilots and trials on ICT use in all the three main application areas for LTC at home (telecare, telehealth, home automation and assistive technologies, see Box 6. However, what seems to be missing in all three countries is a clear commitment to promote a more systematic use of ICT in LTC at home and a policy framework coherent with that goal (e.g. on reimbursement aspects). These are necessary to promote holistic and concerted actions for a wider use of ICT in LTC and to address integration issues across health and social services. An integrated, holistic approach to respond to the multiple needs of dependent people is indeed increasingly found also in these countries, but only in pilots and small-scale trials. Carers and other informal caregivers, on the other hand, are still mostly overlooked or poorly addressed across the board: in the most recent technological projects (see for instance the observations in the report on Germany from the latest AAL congresses), but also in the only currently mainstreamed ICT-based service in LTC at home, i.e. social or tele-alarms.[64]

64 With regards to social alarms and how the response is delivered (by the family or by social care staff) once an alarm event has been alerted to the call centre, Cullen & Kubitschke (2010) notice that "This aspect is clearly an important factor for cost-benefit assessment and also, more generally, in relation to how the market can/will develop, but does not yet seem to have received much visible attention in either the research and policy contexts" (p. 82). The evidence shows that some countries (e.g. Nordic countries and Hungary) rely mostly on formal care staff (at least during working hours), whereas in others (Spain, Italy, Ireland, France and Poland) there is reliance on family carers, and in others (including Germany, UK and the Netherlands) some mixture of the two can be found.

Our study did not aim to explain policy differences across countries. However, the fact that all three countries witness a much stronger regional autonomy compared to England, may play a role.

England: a broad ICT strategy for LTC, with specific attention to carers

In England telecare initiatives have existed for well over a decade, with a number of local pilots and projects put in place in the 1990s, and telecare already mentioned in the first National Strategy for Carers (1999). The major official impetus to these developments has however unfolded only in the past 5 years, in particular with the *Preventative Technology Grant* and with the launch of the *Whole System Demonstrators*. At least a dozen major policy reports have highlighted the potential of telecare and telecare is relevant today to a range of policy initiatives. The report on England concludes that on the policy level today, ICT and telecare are generally expected to emerge as central to the sustainable development of the social care system. There has been a *Green Paper* (July 2009) and a *Personal Care at Home* Bill (2009), indicating that, whichever party wins General Election in 2010, will become active in this sector. On the other hand, the scientific evidence base on ICT benefits for LTC is still in development, but not yet viewed as sufficient to support major reallocation of social and health care budgets.

In 2004, the government announced a new funding stream for local authorities, the *Preventative Technology Grant*, and following this, in July 2005, the Department of Health published *Building Telecare in England*. This policy document provided local authorities and their partners with guidance in developing telecare services for their communities and set out expectations for the use of the Preventative Technology Grant.

The England report illustrates how over £80 million of the *Preventative Technology Grant* were made available to all English CSSRs over 2006-08 to 'pump prime' telecare projects that should become sustainable in the long term. Besides reaching at least 160,000 older people with telecare, one of the projects' objectives was also that of reducing the burden placed on carers and providing them with more personal freedom. Support to service redesign and knowledge dissemination (about challenges, solutions, results etc.) from and across local telecare and telehealth initiatives has been organised to aid the delivery of housing, health, social care and support services for older and vulnerable people. This has been done under the *Building Telecare* agenda by the Department of Health in particular through the Telecare LIN (Learning and Improving Network).[65] The three *Whole System Demonstrators,* which started in the counties of Kent and Cornwall and the London borough of Newham in April 2008, are an additional key component of this articulated strategy. Designed as large-scale pilots testing new models of care (ultimately with over 7,000 telecare and telehealth installations in individuals' homes), these projects were set up to understand the complexity and assess the real benefits of integrated health and social care supported by advanced technology.[66]

While the above programmes usually mention carers as important actors and potential beneficiaries of their initiatives, the England report also lists some policy measures which address specifically carers and use ICT to achieve their goals. For instance, under the revised national strategy for carers launched in June 2008, the new *Caring with Confidence* initiative was started in 2009 and is investing £15 million to develop and deliver, also

65 See http://www.dhcarenetworks.org.uk/IndependentLivingChoices/Telecare/.

66 Cullen & Kubitschke (2010) state that "early reports suggest implementation has proven complex and thrown up a variety of unexpected challenges. One aspect is the lack of direct overlap between the social care and healthcare populations in terms of need/eligibility for both telehealth and telecare. Drop-out rates by users have also proven higher than expected and practical problems have been experienced in relation to technology supply (e.g. product recall). Integrating data sharing between multiple organisations has also proven challenging. Lessons learned from the demonstrator programme can be expected to be very helpful for informing the process of wider mainstreaming of integrated telecare/home telehealth over the coming years" (p.67).

through online systems, an 'expert carers' training programme to 37,000 carers in 2009-2011 (more on this in Section 3.2). Significantly ensuring that carers from ethnic minority communities are well represented among the programme's beneficiaries is a key objective, and among the providers delivering this support at local level, some are expected to be specialists in outreach and support for these groups. Also, the Department of Health's official website hosts a Carers' Discussion Forum[67] for carers to exchange views and information. This website also has a restricted access area to enable Carers Lead Officers (personnel with lead responsibility, in each CSSR, for developing local carers' strategies and for implementing policy on support for carers) to discuss existing and proposed care-related projects and to share ideas and information. Finally, having acknowledged that carers need better information and have difficulties in finding out about the support available, the government's *New Deal for Carers* (2007) launched a new (free) national telephone helpline for carers called 'Carers Direct', which went live on 1 April 2009 (see again Section 3.2)

It is important to underline that, reflecting the active role that carers' organisations have played in the progress of public policies in their support, the England report found an active role of those organisations also in developing ICT-based services that cater for carers' needs and that complement those directly promoted and run by public organisations. Some of these and other ICT-based initiatives for carers developed by other third sector organisations and by local authorities will be referred to in the later chapter providing examples of ICT use for/by carers.

Germany: many recent initiatives for ICT in LTC, but still limited attention to carers

Social alarms have been available in Germany for over two decades and are used, with different intensity, throughout the country. More advanced ICT applications – e.g. telecare based on passive sensors and enhanced alarms, home telehealth, assistive technologies and smart homes – have attracted increasing attention following the explicit policy goal of enabling people in need of care to live at home as long as possible, clearly reaffirmed in 2008 with the *LTC Further Development Act*.

The German government has thus supported several research and piloting activities for telecare, initially with 30 million Euro under the research programme *Assistive Systems for Healthy and Independent Living in Old Age (Altersgerechte Assistenzsysteme für ein gesundes und unabhängiges Leben),* in the framework of the *High-Tech Strategy for Germany* (2006), coordinated by the German Federal Ministry of Education and Research (BMBF), and later with125 million Euro over three years in the framework of the European "Ambient Assisted Living Joint Programme" (2008-2013). Home telehealth initiatives also benefit from these programmes (and from the support of health insurers), leading to a considerable amount of trial activity and pilot projects. In home technology, while a range of stand alone home automation products are available on the German market (e.g. electric shutters, home security systems, intelligent lighting systems, energy management systems, air conditioning systems), networked smart home solutions specifically geared towards the needs of older people have up to now only been implemented in experimental settings (Cullen & Kubitschke, 2010). *The Intelligent Home (Das intelligente Heim)* programme, launched by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth in 2006, is supporting further demonstration projects in this area.

Besides national programmes, the German study found a range of initiatives and programmes supported by the Federal States, such as the *GAL – Gestaltung altersgerechter Lebenswelten,* the Lower Saxony Research Network Design of Environments for Ageing.

67 See http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Carers/DH_079500.

The significant resources spent in this area have contributed to build up research capacities and expertise in ICT based services and products for older people and have also. produced outcomes which have started to be successfully mainstreamed (e.g. the SOPHIA telecare services described in Box 6 of the Germany report). However, there is so far no dedicated policy strategy directed towards facilitating wider implementation of available ICT solutions (Cullen & Kubitschke, 2010). Our German study found behind this situation: "segregation of competences among Federal Ministries; segregation of responsibilities between Healthcare and Long-term Care; a segregated view in projects and programmes of older people needing care, on the one hand, and technology on the other, without considering the everyday context of domiciliary care" (Mollenkopf et al., 2010, p.47).

Carers and families of people in need of care are routinely mentioned in policy documents and projects promoting ICT use for LTC, but compared to the concentration on care recipients and the growing attention on using ICT to support care workers in their professional outpatient care activity, "family carers, legally or illegally employed migrant care assistants and other informal carers play –if at all– only a minor role" (ibidem, p.47). Opportunities have multiplied in recent years for informal caregivers to find information and various forms of support on the Internet, thanks to the initiative of all kinds of mostly private organisations.[68] Yet, referring to a previous IPTS study (Malanowski et al., 2008), the authors of the Germany report conclude that "no fundamental changes have taken place since 2001 when Germany was classified as a country without an explicit policy or initiatives for the use of ICT as an empowering tool for family carers in any policy area" (p.59).

Spain: efforts to coordinate local level ICT initiatives

The inclusion of social alarms (known as tele-alarms in Spain) as an explicit element of social care policy already for many years, and their public provision and financing through municipalities and Autonomous Communities has significantly contributed to their diffusion.[69] The new Depedendency Law of 2006 has renewed the right of dependent people to receive tele-alarm services and, in the cases of greatest need to receive more advanced telecare support.

There is however no focused national policy for the provision of telecare and home telehealth services, as this is left to the initiative of Autonomous Communities. Significantly, the Spain study found that the main Spanish institution in charge of social care, dependency and elderly people, IMSERSO,[70] had only one report out of 89 published since 2003 relating to ICT. Efforts to coordinate and support actions at national level are mostly focused on research and technological developments.

For instance, the national information society programme *Plan Avanza 2006-2011* includes a telehealth area which funds projects to improve the quality of life of patients, to reduce costs, to develop teleconsultation and diagnosis in under-resourced areas and to connect primary and specialist care. The *Plan Avanza* is co-ordinated in each Autonomous Region in accordance with their own regional strategy for the development of these services.

68 This likely reflects the overwhelming role for LTC delivery in Germany of the non-profit sector and private institutions, which roughly equally share among themselves 98% of persons looked after by outpatient services (see Table 7 of the Germany report).

69 Take up was estimated in 2006 at 3-3.5% of people 65+ years old (up to almost 10% in the Madrid region). See also Section 3.1

70 IMSERSO is the branch of the social security system whose role is to assess the needs of families with dependent members and to determine the ensuing financial contribution to the dependent person's pension or allowances.

Also to promote coordination of efforts developing at regional level, the Spanish Ministry of Industry has charged the Association of Electronic, Information and Telecommunications Technologies Enterprises of Spain (AETIC) to run *eVIA*, the *Spanish Technological Platform of Technologies for Independent Life and Accessibility* (*Plataforma Tecnológica Española de las Tecnologías para la Vida Independiente y la Accesibilidad*). The platform comprises national stakeholders from the industry, national and regional administrations, consultancy companies and research centres. It is a forum, organised in working groups, to share information on developments in the field, discuss key issues and possibly identify and implement joint projects, with funding from national and European programmes. One of the nine (in 2009) working groups was devoted to telecare/ teleassistance and another one to eHealth.

Overall, the actual availability and take up of telecare services and home telehealth services in Spain is still limited, with many pilots, and localised mainstreaming only in some regions.[71] Also in the realm of internet-based services for information, training and support, our study on Spain found various projects, also funded by public institutions, for disabled and elderly people, sometimes with a section addressing caregivers. Very few web projects are however dedicated to caregivers (formal and informal) and the resources that are available are inefficient and of poor quality. Two exceptions promoted respectively by the regional governments of Galicia and Andalusia are the *Coidanet* and the *Cuidadoras en Red* online networks (see Box 9).

Italy: small, local initiatives but no structured ICT policy for LTC and carers

In the Italian case, neither our study nor the survey by Cullen & Kubitschke (2010) could identify any specific legislation or policy at national level, and in many cases not even at regional level, covering the full range or even single areas (like social alarms, which are more developed on the ground) of ICT applications for LTC at home. As bluntly stated in the report on Italy, "the Italian experience amounts to a patchy and diverse combination of single local initiatives, mostly experimental, out of any nation-wide strategic design" (Boccagni & Pasquinelli, 2008). The charging or reimbursement situation for social alarms and telecare services (mostly offered by commercial service providers and third sector organisations at the local level) also shows a considerable geographic variability and the lack of any clear policy at national level.

The decentralisation of responsibilities for health care at regional level and the lack of a national framework for LTC services (reflecting the 'cash-for-care' orientation of the Italian welfare system) are important factors behind this situation. The launch in 2008 of a *National Observatory for the assessment and monitoring of the e-Care networks* is seen as a positive step to start overcoming the fragmentation in this field and to move towards some form of network model across Italian regions (Cullen & Kubitschke, 2010).

In this context, there seems to be no policy attention to the opportunities that ICT bring to carers and other (mostly migrant) informal caregivers. Such attention can be found occasionally only in specific local level projects.[72]

One ICT application has indeed been developed at national level that is of interest for this target group. The Ministry of Interiors launched in December 2008 the web-based system that families and other employers, directly or through intermediaries, must use to submit applications to hire migrants

71 Cullen & Kubitschke (2010) found that in Catalonia, some hospitals have developed hospital-in-the-home services and there is also some telemonitoring available through public health centres in Castile and Léon, Extremadura and Castile-La Mancha.

72 Cullen & Kubitschke (2010) report that in Trieste, Milan and other areas in Lombardy dedicated policies (and associated service) have been implemented to support people with dementia and their families, but similar offerings do not seem to be available in other parts of the country.

according the annual quotas for different types of jobs established by the national government.

In the Italian report's discussion about why no one case has been found of an initiative or project using ICT in domiciliary care involving migrant care assistants, despite their widespread presence in Italian families, Boccagni & Pasquinelli (2008) make a conclusive statement which likely explains much of the missing relationship between ICT and informal caregivers more broadly in that country:

"Backwardness in technological applications to elderly care in Italy, is a common denominator, along with a generally poor interest – and even lesser incentives – to invest more in the area. Insofar as care workers' contribution is perceived as a merely 'emergency-covering' one, with no further scope for a professional development in its own right, perspectives for greater ICT application will be scarce – let alone care workers' active involvement with them. As long as domiciliary care is approached by families, and even by welfare agencies, as a sheer matter of 'behaving well' and displaying attitudes and gestures supposedly 'natural for any woman' (although some migrant groups by national origin are perceived as much fitter than others), all the stakeholders involved will hardly see any reason for investing more in ICT".

3. ICT in Domiciliary Care

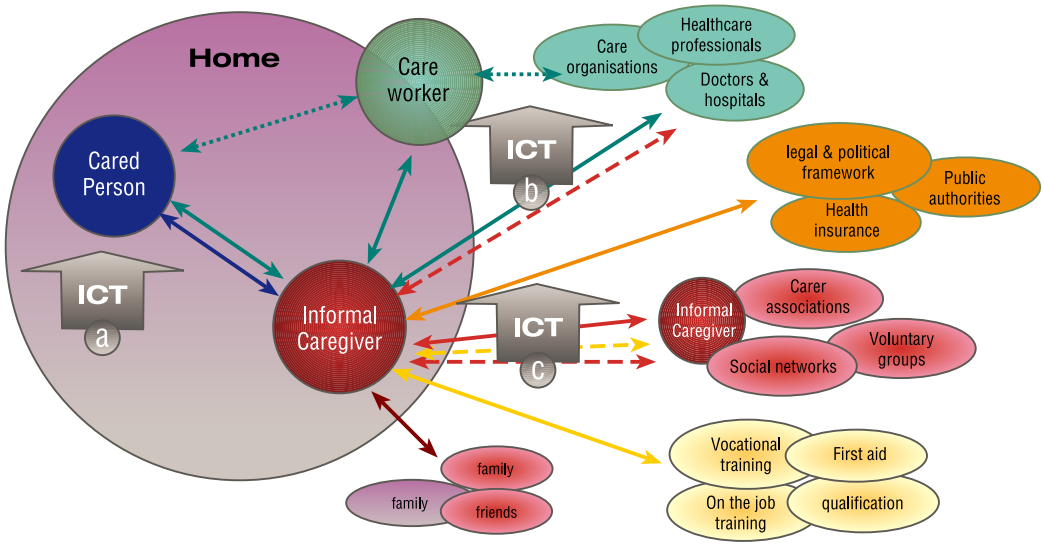
3.1 Overview of ICT for long-term care at home

ICT-based applications addressing domiciliary care provision have been available for quite a few years, in some cases as relatively widespread services (e.g. telealarms) and in other cases still at a pilot stage (e.g. more advanced telecare and most telehealth applications). Recently, at research and experimental level, more complex and comprehensive approaches have started to be developed such as Ambient Assisted Living[73] and Personal Health Systems.[74] All these applications focus primarily on the person in need of care.

In our study, we have taken a different perspective and focused our attention on the use of ICT to address the needs of the caregivers, in particular carers and other informal caregivers. The caregivers' needs, as we have seen in Section 2.4, may relate to care provision functions (e.g. knowing how to best perform a given care task or coordinating assistance with professional caregivers attending the same dependent person), but may also relate to the challenges brought by care giving, e.g. coping with emotional stress and fears or balancing care functions with work.

Looking from this broader perspective, the findings of our study indicate that ICT-based applications can contribute to long-term care at home in three areas (see related ICT 'arrows' in Figure 4):

Figure 4: Where ICT can support domiciliary care and caregivers



73 See http://www.aal-europe.eu/ for the AAL joint programme implemented by the funding authorities of 20 European Member States (and three associated countries), with substantial financial support of the European Commission. Malanowski et al. (2008) provide a general overview of the potential of ICT for active ageing and independent living services.

74 http://ec.europa.eu/information_society/events/phs_2007/index_en.htm.

a) in care provision, either for chronic or acute episodes, focussing on the cared person. The digital technologies at play here and their main current applications are described in Box 5 below. They include simple and advanced types of telecare (alarms, sensors etc.), home telehealth (telemonitoring and other medically-oriented care services) and smart homes. These applications provide elderly and dependent people with the care and reassurance needed to allow them to remain living in their own homes, avoiding or delaying the transfer to hospital and/or institutional care. These solutions can also alleviate the burden of carers and other informal caregivers, by allowing them to delegate certain monitoring tasks and ensuring the safety and well-being of the person cared-for in times when they cannot personally be around;

Box 5 - ICT applications for LTC provision at home[75]

The main ICT deployment domains for care provision at home, with technologies and applications relatively mature and already on the market can be distinguished as follows[76]:

- **'Social alarm'** is the term used to describe a service (and associated equipment) that enables help to be called by a dependent person when needed. The service typically involves a special telephone or portable alarm device that can be used to make a call to an alarm centre in the event of a need arising (e.g. a fall). Social alarms have frequently been called 'first generation telecare'. Often, but not always, more advanced telecare services are developed as add-ons to the basic social alarm services and are implemented over the social alarm infrastructure. In Spain, social alarms are referred to as 'telealarms'; in England also as 'community alarms'.

- **'Telecare"** is used to describe a range of enhancements to the basic social alarm service concept. Telecare is mostly concerned with the provision of social care (i.e. non medical services) to the home. Typical examples include the provision of various sensors in the home (e.g. fall detectors, bed/chair occupancy sensors, smoke, gas and flood detectors, and so on) that alert social care services in the event of a problem arising in the home. In addition, videophone-based or other remote social care to the home can also be considered to be forms of telecare. Such applications have frequently been called 'second generation telecare', whereas the term 'third generation telecare' has been used to describe ICT-based solutions of more preventative nature such as extensive sensoring in the home for the purposes of 'lifestyle monitoring'. In Spain, telecare is known as tele-assistance.

- **'Telehealth'** is mainly used to refer to the use of ICTs in the delivery of medically-oriented care services to older people in their homes. It can include a variety of somewhat different services or applications, including telemonitoring (e.g. blood pressure, blood glucose, ECG, etc.), teleconsultation (e.g. online, by videophone, by telephone) and telerehabilitation (e.g. by videophone), as well as self-care devices to be used by people in their own homes to help them monitor and manage their health by themselves. They are often, but not always, developed and implemented independent of telecare solutions, in part because of the traditionally separate organisation of and demarcation lines between medical care and social care.

- **'Smart homes'** is the term now commonly used to describe a range of environmental control, home automation and home network systems that can help older people to remain living independently in their own homes. In addition to such 'systems', there are also a variety of more standalone ICT-based assistive technologies that can help older people to remain independent, including computer-based or other electronic communication aids, object locators, reminder systems and so on.

75 These definitions have been developed by the ICT&Ageing project (see footnote 10) and are available at the URL: http://www.ict-ageing.eu/?page_id=248 (accessed 08/12/09).

76 At research and experimental level, more complex and comprehensive approaches have started to develop in this field, such as Ambient Assisted Living (see http://www.aal-europe.eu/) and Personal Health Systems (see http://ec.europa.eu/information_society/events/phs_2007/index_en.htm.

Figure 5: The current state of ICT deployment in long-term care

	IT	ES	DE	UK	Legend
Social alarms					Mainstream – wide diffusion
Telecare					
Telehealth					Mainstream – localized diffusion
Smart Homes					Pilots being rolled out; exemplary initiatives
PC, mobile phone, e-mail, GPS					Pilots; singular cases
Online Information					Research trials/experimental settings
Phone Helplines					Not available
Online peer support					
Online medical advice					
Online Courses					
Multilingual websites					
Multilingual phone support					

b) in care provision also, but in support of the management, communication and coordination needs of the different professional care actors. Here, ICT-based applications rely on PCs and increasingly on mobile phones and other handheld digital devices, on Internet-based systems and often 'office-type' software. They are used by front-line care workers, back-office staff (administrative and technical), medical doctors and other care professionals. Access to these applications can be granted also to informal caregivers and the very care recipients, but our study found that this occurs very seldom;

c) in support of the carers' and other informal caregivers' needs for information, emotional and specialised help, training, socialisation and others. This has been provided already for some time through information web portals, and more recently through online training services and online social networks. Several examples of these will be provided later in the chapter.

3.1.1 Deployment situation of ICT for LTC at home

The current deployment of ICT along these three areas varies across the four countries studied, with the UK/England at a more advanced stage in most domains. Figure 5 below attempts to summarize the state of the art of deployment of different ICT-based application and services in LTC in those countries,[77] based on our own research

77 In Figure 5 the term 'mainstream' refers to applications/services which have moved into 'normal' day-by-day operation by established or new service providers, likely after having gone through a pilot phase, where their full functionality and everyday operation were still being tested, fine-tuned and assessed. We distinguish between two types of 'mainstream' deployment levels with respect to market penetration/scale of diffusion of the application/service, rather than to its maturity as a viable operational/commercial solution. In the world known as the web 2.0, where applications/services tend to be made public and operational when they are still in 'beta test', the distinction between pilot and mainstream in terms of maturity looses much of its significance, and is kept to refer to the number of online services and/or of their users. In the context of LTC, this applies mostly to 'Online Information' and 'Online peer support'.

results and those of the *ICT & Ageing* project coordinated by Empirica (see footnote 10).

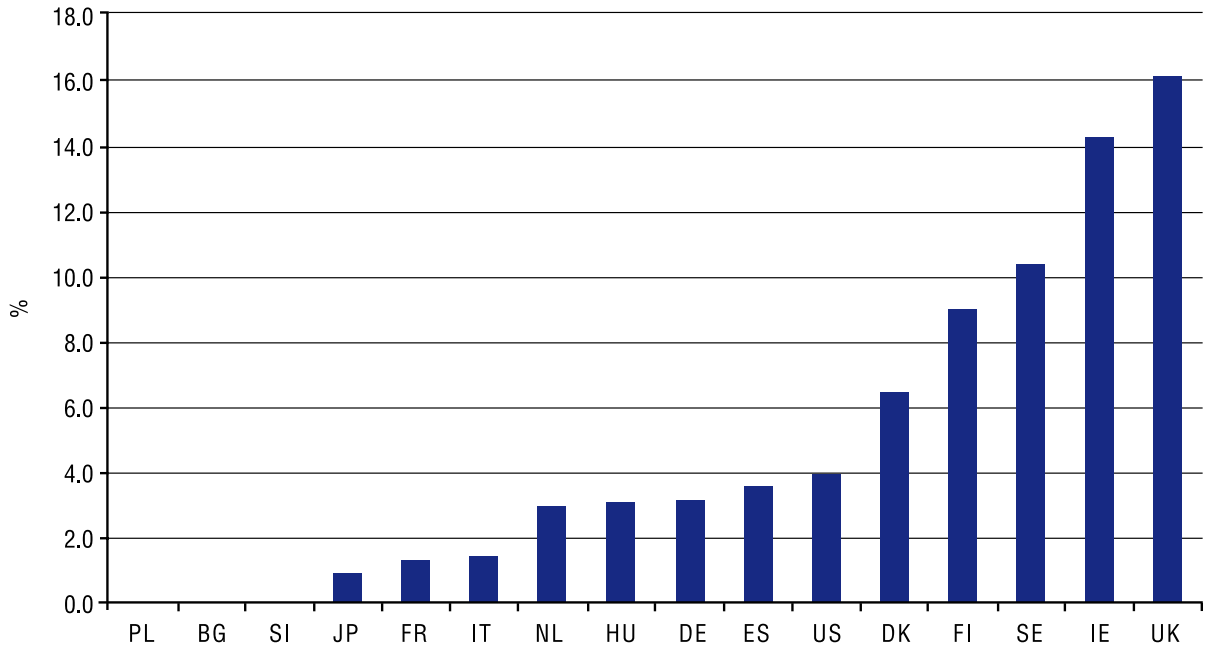
One of the main conclusions of these studies is that the potential of ICT for long-term care is, as yet, not fully realised anywhere. As pointed out by Cullen & Kubitschke (2010, p. 1): "Although a considerable range of promising devices and systems has emerged from RTD efforts pursued in Europe and beyond for more than a decade, wider mainstreaming of ICT-enabled solutions within real world service settings has to a large extent yet to occur". Furthermore, policy-driven ICT initiatives for LTC (see Section 2.5.2) tend to focus on strictly technological and/or medical aspects, while paying little attention to the care recipient as a person with complex needs and concerns, and even less attention – except again in the UK – to the role and needs of informal caregivers.

In this respect, however, our study found a growing number of initiatives, falling in particular within the above area 'c', where already available Internet and web-based tools and applications are witnessing a sort of 'autonomous self-development' process, with an important role of carers' organisations and informal groups, and are used to support several dimensions of the work and life of the domiciliary carers and, albeit still occasionally, of migrant caregivers as well. We shall illustrate some of these initiatives in Section 3.2 below.

3.1.2 Deployment of ICT solutions for care recipients

Concerning the deployment of ICT solutions in support of care recipients (area 'a' above), our four country studies confirm the findings of the *ICT & Ageing* project. First generation telecare devices, i.e. push button or 'social' alarms, have by now become mainstream, and are widely known and used by many elderly people (not only dependent ones), albeit with significant variation across countries (see Figure 6). For second generation telecare (i.e. passive or automatic alarms), solutions are currently being deployed on a wider scale only by few care providers and/or in specific regions. Only the UK, 2nd generation telecare devices have a level of take-up that might reach or even exceed 1% of the population aged 65+, and most of the other countries have very low levels of provision and take up (Cullen & Kubitschke, 2010). Third

Figure 6: Estimated penetration of social alarms (% of people aged 65+, 2008)



Source: Cullen & Kubitschke, 2010.

generation telecare services, i.e. advanced sensors, life style monitoring, mobile alarms or video-based telecare, are still mainly in an experimental stage.

Home telehealth services, i.e. medical care from a distance, chronic disease monitoring and management supporting the early discharge from hospital etc., are in different phases of experimentation and piloting, with some projects being rolled out on a larger scale in some regions. However, our study on England found that in 2009 the number of telehealth installations remained quite small, at approximately 5,000 compared with the much larger number of some 1.5 million, telecare users (mostly community alarms). Smart home technology, i.e. automated/intelligent home environments, is still under development and has not yet reached market maturity.

Besides technological 'immaturity' in some areas, several barriers have been identified to a wider deployment of the above assistive technologies.[78] Resistance to adopt ICT-based solutions by elderly people, but sometimes also by care workers and family carers, is an important obstacle. The low level of digital experience and skills among mature adults, especially women, in their late 40s and among older people – the age groups which most care givers and recipients belong to – is a crucial factor in all the four countries considered here (and beyond). Studies report also fears of the 'big brother' effect, i.e. excessive control and loss of privacy over the care recipients (Mair et al., 2005).

The risk of technology replacing entirely face-to-face contacts is also a frequent concern, since LTC is seen primarily as a matter of directly delivering personal care, in particular to those with the most critical care needs. The opportunities offered by ICT to complement, support or alleviate, rather than substitute direct personal care efforts – to the benefit of caregivers in the first place – are still little explored and most often simply not known by care givers and recipients. Evidence of the very benefits of ICT solutions for domiciliary care exists, but it is still being enriched (also thanks to the multiplication of cases) and is not disseminated widely.

Cost of technology and services is a problem for many, and reimbursement schemes are often unsupportive (for various reasons) of these solutions. Care recipients and their families often lack the know how to find ICT-based solutions and financial support (if available), to implement and operate them at home, and where to seek for help when needed. Limited awareness and knowledge are reported also among local level decision-makers, who usually have responsibility for home care services and related investment decisions. Finally, the involvement of a plurality of public and private organisations in domiciliary LTC delivery is known to lead to coordination and interoperability problems among health, care and other actors.

3.1.3 Deployment of ICT in professional care organisations and ICT use by care workers

Concerning ICT in support of care workers and the organisations they work for (area 'b' above), our study gathered some evidence[79] on Germany and England, where professional care providers play a significant role in domiciliary LTC delivery and are increasingly involved in ICT projects.

In Germany, (mobile) phones, different types of computers and GPS/navigation systems are quite commonly used by care providers, especially the large third-sector organisations, for better communication with their employees and volunteers[80] and to enhance the organization of care delivery. Modern telephone systems and

78 For a wider discussion of these issues see the ICT & Age project's final report (Cullen & Kubitschke, 2010).

79 The use of ICT by professional long-term care organisations in institutions or at home was not investigated as such in our country studies. Nevertheless, some information about this topic was gathered through the analysis of scientific literature and through experts' interviews during field work. We are not aware of any specific study on this topic at European level.

80 Most of the non-statutory welfare organisations rely also on large numbers of volunteers who contribute in various ways to care provision.

mobile phones are systematically available[81]. E-mail is seen as an indisputable means of communication between internal staff, outpatient care workers and volunteers. Communication and networking through Internet sites also seems to be common and well accepted. For this, care workers use both services provided by their umbrella organisations and professional associations[82] and general public sites, such as http://www.xing.com/de/.

A partly similar picture holds true for the use of common communication and internet based services also in England. However, some of the cases investigated there for our study highlight also the presence of people reluctant to use ICT among social and healthcare staff in local authorities and charities.[83] This seems mostly due to a lack of confidence in using technology coupled with a lack of knowledge of the opportunities offered by ICT both to care recipients and caregivers. However, ICT can also assist in overcoming these barriers to deployment, as is illustrated by the case of *City and Guilds*, a leading provider of vocational qualifications in the UK, who launched the first accredited course for care workers to learn how to assign appropriate telecare packages to clients in need of them.[84] City and Guilds runs from 2003 an online facility called SmartScreen (http://www.smartscreen.co.uk/) with a range of resources and tools for tutors and learners working on social care qualifications. Initiatives were also found of local authorities and charities training their care staff on how to use computers and other ICT to work better and to meet the needs of their clients.[85]

Several of the barriers to a greater ICT use in LTC at home discussed in the previous section seem in fact to be relevant also in the formal care context, in particular: age and possibly gender-related aspects associated with low digital experience of care workers; concerns about technology replacing or negatively affecting direct personal care delivery; and obstacles to the effective use of ICT in processes that cross organisational boundaries, including those that might reach informal caregivers. Two such cases were identified in our study, both in Germany (see later: LifeSensor and Sophia).

3.1.4 Deployment of ICT for informal caregivers

Finally, concerning carers and other informal caregivers (area 'c' above), ICT based products and services already available today to a larger market – email services, information web sites, blogs and wikis, online social networking services, free phone lines, mobile phones and others – have started being used to address many of their needs: to gather useful knowledge about care functions; to maintain contacts with the family and other social support networks; to coordinate care provision; to communicate with professional health and care personnel; to participate in social and economic life, including retaining work.

This development is in many ways a reflection of the broader move towards greater user empowerment enabled by recent ICT trends[86] and of the increase of digital literacy among older age cohorts and elderly people, who are the vast majority of informal caregivers and who tend to

81 But other portable devices such as notebooks, personal digital assistants (PDA) and smart phones were found, in 2009, to be still 'an exception'.

82 such as www.diakonie.de, www.caritas.de, www.kfd.de, www.bpa.de.

83 For instance, an interview to the Home Farm Trust, a national charity providing long-term support for people with learning disabilities and their families, found that engaging care workers with ICT-based facilities was viewed as 'a constant challenge'. The explanation given was that this approach is not yet part of the core requirements made by regulators and key agencies, such as Skills For Care (the employer-led authority on the training standards and development needs of social care staff in England).

84 The course, called the Certificate in Supporting the Users of Assistive Technology, was found in a very early stage of development and with little take-up at the time.

85 For instance, Nottingham County Council uses Tunstall's online training tool (see report on England p.43) to train its own social healthcare staff on how to assess carers' ICT needs effectively. Refresher training is also offered regularly to encourage staff to remain mindful of the potential of ICT in social care.

86 We refer here to the growth of the new online social media and of new Internet-based technologies and services known as web 2.0, characterised among other things by much enhanced user friendliness and enabling users to become active content producers. For an overview of this evolution and its social impact see IPTS (2009).

have more limited ICT skills and experience than younger people. As indicated in Figure 5, online information services and telephone-based help lines are quite common and are reported to witness growing numbers of users, among informal and formal caregivers and care recipients themselves. All the other types of applications and services, based on our findings, seem on the whole to be still at an early stage of development. Also, as we shall see in the next sections, very few of these online services are tailored to the needs of informal caregivers from migrant backgrounds, for instance, by providing multilingual support.

3.2 ICT in home care from the perspective of informal caregivers

In this section we present a number of examples of initiatives and services which illustrate how ICT are used to address the needs of informal caregivers, in particular carers but also care assistants. Table 10 below clusters these examples into five broad categories of initiatives, based on the type of needs they address. Underlined cases in the second column are those where attention is devoted to cultural diversity issues, in terms of multilingual content provision or in other ways. All the cases are briefly illustrated in the boxes in this section.

3.2.1 Involving informal caregivers in ICT-based professional care services

LTC at home, even when care service providers are involved, implies the contribution of different actors taking responsibility for different care tasks. Family members and other informal caregivers are almost always involved, even if it is just to be informed about the status of their

Table 10: Cases of ICT-based initiatives and services addressing informal caregivers

Needs and type of initiative	Cases in the four countries studied
Communication with care recipient; access to her status, assistance planning etc.	• Sophia (DE) • LifeSensor (DE)
Information and guidance on LTC, referral information on LTC services, online consultation	• Pflegewiki (DE) • *Carers Direct Helpline (UK)* • Telephone Befriending Scheme (UK) • Carers in Hertfordshire's website (UK) • *Sercuidador (ES)* • Un cuidador, dos vidas (ES) • CEAFA, Website of Spanish confederation of Alzheimer families associations (ES)
Peer support, mutual assistance, information exchange (online forums, blogs, social networks)	• Carers UK's Discussion Forum (UK) • *SEKIS Berlin (DE)* • Seniorlotse Bremen (DE) • Forums and personal blogs on the web site of the German Alzheimer Society (DE) • *Cuidadoras en Red (ES)*
Training on care giving (through multimedia, online tools)	• *Caring with Confidence (UK)* • *City & Guilds – Learning for Living (UK)* • Coidanet (ES) • Spain's Alzheimer Foundation, FAE (ES) • *Aspasia (IT)*
Information and training on using ICT to support/enhance care functions (addressing care workers and informal caregivers)	• List of local authorities' websites devoted to telecare opportunities in England (UK report p.68) • *Nottingham City Council's telecare project (UK)* • TATE (Through Assistive Technology To Employment) project (UK) • Home Farm Trust's CTEC Centre (UK)

relative and the occasional visit. Often, however, their role is more demanding: being available for an emergency does not require any active function, but may entail a number of adjustments and constraints on one's personal and work life. Enhancing communication, coordination and information exchange among the actors involved at various levels in care provision should thus be beneficial to all of them.

We mentioned before that informal caregivers, including carers who are close relatives of the dependent person tend not be considered as potentially active subjects in the use of ICT-based systems designed to support people in need of care[87] and/or used by professional care workers. Our study, however, found two exceptions to this rule, both of them in Germany. In the case of SOPHIA, informal caregivers (family members and volunteers) have access to a video-based communication system used by the service provider to support the cared person. In the case of LifeSensor authorised caregivers have access to information about the cared person and care services which concern her, via the Internet.

Informal caregivers, especially those in live-in arrangements, have a continuous observation of the cared person's conditions and needs, and of the contextual factors that might affect them. They may thus be a valuable source of insight on these aspects, integrating in qualitative terms data collected through some monitoring system or during the visit of a professional. They could also contribute by performing relatively simple telemedicine tasks, e.g. measuring and transmitting blood pressure. For these functions to be effective, the key informants interviewed in Italy underlined that well designed communication systems would be needed, in terms of simple use by the caregiver, respect of the privacy of the cared person, and fast and direct transmission of the information to the professional/s in the health and social care services who could best act upon

Box 6 – Cases of informal caregivers' access to ICT-based professional care services

SOPHIA GmbH & Co. KG (report on Germany) is a care service working as a franchise system, selling services and products directly to older people or through housing organisations. SOPHIA offers safety and other services 24 hours a day, 7 days a week, addressing a wide range of needs: emergency calls; organisation of outpatient care and assistance in finding and contracting repair services for the household, personnel for daily household tasks, escorts for visits to the doctor, or social companions, etc. Every participant has a 'godfather', a personal contact person who calls at least once a week to chat and to check whether something has to be done in the household or for the older people themselves. 'Godfathers' are volunteers recruited and trained by the non-profit SOPHIA foundation. In some of the six different service packages offered on a commercial basis by SOPHIA, the screen-/TV-based system used by the cared person to communicate with the service centre can also be used to communicate with the 'godfather', with other SOPHIA users or with family members, as long as specific software is installed on their PC.

LifeSensor (report on Germany) is also commercial service, available since June 2000. It uses personal computers and Internet for collecting information about the health status of a person and relays this information to everyone involved in the medical treatment and care of this person. The LifeSensor member chooses who is authorised to access the information, for example, care professionals, doctors, informal caregivers, relatives and others. Authorised professionals are responsible for keeping the information up to date. For people in need of care and their families or other informal caregivers, LifeSensor offers the possibility of maintaining an overview of the health status and care needed. LifeSensor can also be used like an electronic calendar with a reminder function for appointments, medicine etc. Access via internet enables relatives – if they are given access – to be informed at any time.

87 See footnote 64 about the uncertainty still surrounding the role of carers in social alarm services.

it. Additionally, of course, some training of the informal caregivers would be needed.

3.2.2 Online information and guidance on long-term care

We have seen that carers and other informal caregivers have manifold information needs as they very often face situations which are new to them and for which they lack any preparation. With the growing acknowledgment of the crucial role they play for LTC at home and in response to this need, a wide range of ICT-based initiatives have been launched to provide informal caregivers with: information and guidance on LTC problems; referral information on LTC services; and even professional consultation. Several such initiatives were found in all the countries we studied.[88] These initiatives are promoted by national or local authorities,[89] professional associations, commercial care service providers, senior citizens' and carers associations, foundations, non-statutory welfare organisations and other types of voluntary sector entities.

In terms of technology, the initiatives that we investigated use different solutions to disseminate information and communicate with customers: simple websites, e-mail, telephone-based systems. A multi-channel approach, i.e. combining different solutions, is in fact adopted by the most advanced services. Also, web sites increasingly tend to incorporate Web 2.0 functionality, i.e. blogs, wikis, forums and other tools which support content production and horizontal interaction among users.

Some examples of the different approaches drawn from our country studies are illustrated below.

The use of multiple channels, including the telephone, is important at the moment to reach the current generation of carers and care recipients, who often do not use computers and the Internet. With the natural ageing of younger ICT users who become caregivers and with the gradual increase of digital literacy and use also among elderly people, web-based services are expected to reach ever more people. In fact, the very availability of useful online services can be seen as a potential driver to break digital exclusion barriers among caregivers and care recipients alike.[90]

Concerning the content of online services, many of the websites found in our country studies are perfectly suited to meet the needs of persons in need of care, of caregivers in general and of carers in particular, and provide valid and high quality information. However, problems were reported from the point of view of non-expert users, such as: the difficulty to judge the quality, validity and seriousness of information given in web sites; and the diversity in the way information is organised online and the fragmentation of websites. Problematic issues from a cultural diversity perspective, in particular the very limited presence of multilingual services, will be discussed later.

With respect to the presence of migrants in domiciliary LTC provision, it is worth mentioning here that our study also found a few websites with information and guides to the recruitment and employment of migrant care assistants.[91]

88 In Spain, a systematic online search performed for our study found a total of 25 websites which were fully dedicated or hosted sections for carers and other caregivers (including professional ones).

89 Our study on England found, in fact, that local authorities have been more active in promoting telecare opportunities, also thanks to the stimulus and support of the national Preventative Technology Grant (see Section 2.5.2), than in using ICT to provide carers and other informal caregivers with support, advice and training, or to engage them in mutual help initiatives.

90 Our study did not investigate to what extent digital inclusion initiatives addressing the older segments of the population exploit the growing amount of online services available for carers as a motivational resource for using technology within this target group. Such an investigation would undoubtedly be interesting and might bring useful suggestions both for digital inclusion and long-term care policy measures.

91 For instance, in England, the Social Care Institute of Excellence (SCIE) provides a 'best practice guide' for employers on its website and the agency Skills for Care provides an Internet accessible 'Manager's Guide' to the international recruitment of health and social care workers. Online information on these matters is also provided in relation to the official procedures for hiring a foreign care worker (see 2.3) in Germany by the Federal Employment Agency's ZAV and in Italy by the Ministry of Interiors.

Box 7 - Cases of online information and guidance for caregivers

Pflegewiki (DE) is an information website launched in 2004 on caregiving. It currently publishes over 5000 articles and had 13.000 unique visitors per day in 2009. The site also has an English version and contains a rich picture database.

Carers Direct Helpline (report on England) is an online information service and a telephone helpline for carers[92] (who can also email their queries or use the postal service). The service became operational in April 2009 and is run by the National Health Service. The website also hosts a carers' blog and an online community (forum). Carers Direct helpline uses advanced tools and trained interpreters to enable helpline advisers to communicate with carers whose first language is not English (about 100 languages are supported). Tools are also available to communicate with deaf, deafblind, hard of hearing and speech-impaired customers.

Telephone Befriending Scheme (report on England) is a service that gives advice and reassurance by phone to mostly older carers who have demanding caring roles. It is supported by the Leicestershire County Council, but is run almost entirely by volunteers, often carers themselves. The scheme also produces a newsletter, but very few carers chose to receive it in electronic format.

Sercuidador[93] 'Being carer' is the website for carers launched in 2006 by Cruz Roja (Spanish Red Cross). It also hosts an online TV training service for care workers and blogs specializing in caring. Acknowledging the important role of migrant care assistants in Spain, Cruz Roja has cross-linked Sercuidador with its www.migrar.org portal, the most popular website for migrants in Spain, with a matching function for people giving or looking for a care job.

Un cuidador, dos vidas[94] 'One carer, two lives' is the initiative, launched by La Caixa Foundation (Spain) in 2009, to provide support services and workshops for dependent people and their caregivers. This is done through a website, a guide on paper and DVD, and a telephone service. The initiative is carried out in collaboration with several Spanish regional governments, with Fundación Alzheimer and CEAFA (Spanish confederation of Alzheimer families associations).

3.2.3 Peer support, mutual assistance, information exchange

We have seen that care giving can be emotionally very stressful, that caregivers often suffer from isolation and that other caregivers' experience can be a precious source of practical and moral support. As new tools for online interaction are becoming ever more easy to use and available, unsurprisingly our country studies found a number of online forums and communities, blogs and even one case (*Cuidadoras en Red*, see below) of a dedicated social networking service,[95] providing opportunities for personal expression, exchange of information and mutual help among carers themselves. These services are increasingly integrated in the information and support websites just discussed before and are often initiated by the same types of entities that support them, possibly with a greater role in this case of third sector organisations.

Being mostly quite recent, these initiatives have not yet been thoroughly assessed. A discussion of the Carers UK's online forum experience (report on England) highlights however a number of interesting insights: the role and limitations

92 As a telephone helpline, the service is available 7 days a week, from 8 am – 9 pm Monday to Friday and from 11 am to 4 pm at weekends. The online site is at http://www.nhs.uk/Carersdirect/Pages/CarersDirectHome.aspx.

93 See http://www.Sercuidador.org.

94 See http://obrasocial.lacaixa.es/personasdependientes/uncuidadorguia_es.html.

95 Our study did not explore the online communities of carers and other people involved in care which are likely emerging (spontaneously) within general social media and social networking sites such as Facebook. This is another potentially interesting line of further research on ICT and long-term care givers.

of anonymity in the forum; the importance of moderation; balancing public posts and private message exchanges; the difficulty of involving 'external' participants (in this case, care workers representative of public social care services).

These issues are present in most online communities, but tend to become more critical when very private and sensitive issues are discussed and mutual trust must be built and constantly nurtured. This kind of initiatives, unless they grow out spontaneously, must therefore be developed and accompanied with much attention and without too many expectations of short-term results. Nevertheless, our country studies repeatedly underline the potential of ICT to enable 'self-help' processes and empower caregivers through horizontal support and exchange.

3.2.4 Training to provide care

Learning to care for almost all informal caregivers is mainly a matter of 'learning by doing'. Even when opportunities to learn in more organised ways exist (e.g. through training courses), access to them is often limited by the lack of time and by mobility restrictions stemming from the very care activity. In line with the shift of LTC policies towards promoting home care delivery and the acknowledgement of the need to support carers and other informal caregivers, training opportunities for these target groups are indeed growing. These are also gradually incorporating ICT to enable distant learning (usually 'blended' with face-to-face teaching sessions) and/or to enrich teaching/learning process thanks to multimedia solutions (e.g. video demonstrations of specific care practices).

Box 8 - Cases of online support and information exchange services for informal caregivers

Carers UK Online Discussion Forum (report on England) has become the UK's most popular online discussion group specifically aimed at carers. Launched in 2005 by the national charity Carers UK, it is a moderated forum with (in 2009) over 1500 members (more than half of which had posted at least a message) and 66,000 page views per month. The forum enables primarily peer support, information exchange and networking.

SEKIS[96] (report on Germany) serves as a Self-help Contact and Information Exchange system for all those living in and around Berlin who need to deal with care problems. SEKIS is run by a citizens association and is supported by various public and semi-public bodies. SEKIS website provides information in German, English, Polish, Turkish, French and Russian, thus catering also for the needs of local immigrant communities, including paid caregivers.

www.alzheimerblog.de (report on Germany) is an online space for self-help, available to people with dementia, their relatives and all people engaged in dementia or Alzheimer, hosted on the website of the Deutsche Alzheimer Gesellschaft (German Alzheimer Society). Besides much information for people who are concerned or interested in Alzheimer issues, the website offers a forum where they can exchange experiences, tips for coping in every day life etc. The German Alzheimer Society also provides at a price (9 cent/minute) information and advice from consultants through a phone service.

Cuidadoras en red[97] is an online social network specializing in caring for/by women launched in late 2008 in Andalusia (Spain) by I2BC, the Institute of Innovation for Human Wellbeing and the Nursing Department of the University of Málaga. The network also hosts an online community called 'Immigrants in family care'. This is the only online community initiative dedicated to this target group that was found in all four country studies. At the time of our research (May 2009), the network and the migrant caregivers community were still at an initial stage of development, with respectively 72 and 6 members.

96 See www.sekis-berlin.de.
97 See http://www.cuidatel.es.

The potential of ICT-enabled distance and self-learning for caregivers with significant time and mobility constraints to attend regular face-to-face courses has been acknowledged by all the experts interviewed for our country studies. Two obstacles, however, were also systematically mentioned: the lack of digital skills and confidence in using ICT among most members of the current generation of potential beneficiaries; and, partly related to this, the lack of access to computers and the Internet in the homes of older dependent people. Both barriers refer back to the need of adequate digital inclusion measures for older people in general and specifically for those involved as recipients or providers of LTC.

As we shall see in Section 3.3.2, migrant care assistants are reported, at least in some countries, to suffer from additional restrictions to use the ICT equipment that might be available in the cared person's home.

3.2.5 Information and training on ICT opportunities in care provision

Lack of awareness and information at all levels of society on the opportunities offered by ICT to enhance care provision and to support the caregivers has been reported in all the countries addressed by our study. A partial exception concerns social alarm services, which

Box 9 - Cases of ICT-supported training for care giving

Caring with Confidence (report on England) is the initiative of the UK government delivering an 'expert carers' training programme to 37,000 carers in 2009-2011. Along with local group sessions, 10,000 carers are expected to use the online and self-study versions of the programme. As mentioned in Section 2.5.2, a key objective of the programme is to ensure that carers from ethnic minority communities are well represented among its beneficiaries.

Learning for Living[98] (report on England) is the Internet-based course on everyday caring functions for carers by City & Guilds, the leading provider of vocational qualifications in the UK. The course leads to a nationally recognised (level 2) formal qualification called 'Certificate in Personal Development and Learning for Unpaid Carers'. Besides the online modules the course offers: DVDs with video and audio recordings; tutors for instruction and feedback via email and a helpline for technical assistance. Launched in 2004, by 2009 approximately 700 carers had engaged in the course.

Coidanet is an online network and portal for caregivers and dependent people developed since 2006 by the regional government of Galicia (Spain) with support from the national information society program Plan Avanza. Along with online information and community support to people in need of care, their carers and other caregivers, the portal provides online training workshops on topics such as 'Bioethics and dependency', 'Burn out Syndrome' and 'Dependency legislation'.

Alzheimer Foundation of Spain, FAE. The foundation offers different services to people suffering from Alzheimer and their professional and informal caregivers. Among them, it provides to third parties (care organisations, local associations and others) an online platform (Moodle) to develop and deliver online courses and other learning material.

Aspasia[99] is a project developed in Emilia-Romagna (Italy) since 2006 (originally under Equal – European Social Fund) whose full name is Homecare to the elderly: an integrated system of personal and enterprise services. While addressing informal caregivers in general, the project's main focus is on migrant caregivers. The project used some basic multimedia tools to facilitate the self-training of migrant care assistants on the fundamentals in personal homecare. The project also provides a range of training packages for professional and informal caregivers accessible through an e-learning platform (see http://campus.anzianienonsolo.it/) and introductory information for newly arrived migrants on life and working conditions in home care in Italy.

98 See http://www.learning-for-living.co.uk/.
99 See http://www.equalaspasia.it/.

are relatively well known by the wider public, also thanks to advertisements and information campaigns on the media.

To overcome this shortcoming, the suppliers of ICT-based devices and services have started to provide caregivers with information and training opportunities about what they offer, often using ICT themselves for delivery (websites, PC-based learning tools etc.). We found this to be happening primarily in England.

The prevalence of these initiatives in England can be seen to reflect various factors: the more advanced stage of deployment of telecare services in that country, with suppliers ready and better organised to promote their offer; the positive impulse and financial support given to this evolution by the national *Preventative Technology Grant* (see Section 2.5.2); and the acknowledgement by the home care service providers of the important role that carers play in domiciliary care, hence the need to inform and even train them on telecare opportunities.

In the other three countries that we studied, these conditions seem to be missing (a national scheme promoting telecare initiatives at local level) or to be at an earlier stage of maturation (telecare deployment and recognition of carers' role).

3.3 ICT in home care from a cultural diversity perspective

In the previous sections we already highlighted, across the three domains of ICT opportunities/ applications in LTC at home and especially in support to carers (area c), some instances where the presence of people from migrant backgrounds in our society is somehow considered. In this section, we first summarize and integrate those findings which are referred to ICT use for migrant care recipients and caregivers. We then report the evidence that we gathered in our field work on the use of ICT by migrant caregivers (most of them employed informally as family care assistants) and the difficulties they face.

Box 10 - Cases of ICT-based information and training on ICT solution for home care

Local authorities' websites in England (report on England). Over twenty such websites with sections devoted to telecare opportunities are listed in the report's Appendix 1, showing the telecare providers' awareness of the need to undertake promotion efforts.

Nottingham City Council's telecare project (report on England) is using on-line training and computer-based guidance to improve the understanding and use of its second generation (sensor-based) telecare services among its own staff, the users (people in need of care) and the carers. Telecare promotion is also done via carers' events, Day Care Centres, local media, council newsletters, a short video, display stands at libraries, the Internet, general practitioners and health surgeries and via social care staff. Immigrant and ethnic minority carers have been specifically targeted via literature translated into relevant languages.

TATE, Through Assistive Technology To Employment (report on England) is an Equal project (2004-08) which addressed how assistive technology[100] can support people with learning disabilities and their carers. The project developed various ICT-based tools to assess care needs and potential assistive technology applications; to train care recipients and caregivers; and to disseminate information on these opportunities.

Home Farm Trust's CTEC Centre (report on England) has expanded on the work of the TATE project and provides on a regular basis courses to caregivers, both professional and informal ones, and to care recipients on how they can use ICT to improve the living conditions and address the needs of people with learning disabilities. These courses are accredited by City and Guilds and the Leaning Disability Awards Framework.

100 Assistive technology comprises a wide range of digital devices and solution that help people whose activities are limited by physical and other impairments to operate equipment in their home for security, communication within and outside the home, comfort and control of environment, entertainment and work.

3.3.1 Cultural diversity in ICT initiatives and services

Cultural diversity in LTC provision at home arises from two complementary trends. The first is the growing presence on the supply side of LTC provision at home of paid caregivers from migrant backgrounds. These workers, especially those employed directly by the families of dependent people who often come to Europe with temporary migration prospects, were the original focus of our study and we found large number of them in Germany, Italy, and Spain (see Section 2.3). In England, we discovered that, instead, migrants are formally employed by professional care providers (occasionally by families as well), where they join already established care workers from ethnic minority communities.

The second phenomenon that somewhat unexpectedly emerged from our study is the presence, in England and Germany, of large communities of people from migrant backgrounds with growing numbers of ageing members with care needs. These are becoming customers of LTC services, even though they tend to rely more on informal caregivers than native people in both countries (see Section 2.1). Cultural diversity is thus entering the LTC scene in Europe also from the demand side, as people in need of care from migrant backgrounds and their carers.

We take these two perspectives, from the demand and supply side, on cultural diversity in the domain of LTC at home to look again at the ICT initiatives and services that we covered in our study.

Starting from the demand side, people in need of care from migrant backgrounds and their carers, we can say that in England and in Germany only an incipient attention was found to this potential customer group within initiatives developing or offering telecare, telehealth or smart home solutions and services. Only one pilot in Germany is known to have used the Sophia telecare service communication facilities (see Box 6) to establish and maintain contacts between Turkish service customers resident in Alte Kolonie (North Rhine-Westphalia) and their friends and relatives in home towns/villages in Turkey.[101] The development of culturally sensitive products and services including explicitly also ICT-based ones, in the fields of housing and care (for care recipients and their carers) is publicly called for by the *Active Ageing of Migrant Elders Across Europe* (AAMEE) project promoted by the Government of North Rhine-Westphalia.[102]

In England, no direct involvement of people in need of care from ethnic minority groups was found in any pilot or demonstrator project for telecare and telehealth; and uptake of existing commercial services by this segment of the population was acknowledged by experts interviewed in our study to be extremely low. For this reason, some local authorities which offer these services have adopted specific measures to reach new customers among ethnic minority communities (e.g. the translation in different languages of the information services produced by *Nottingham City Council's telecare project*, see Box 10).

Beyond care recipients, the central government, some local authorities and care providers in England have acknowledged that people in some ethnic minority groups are particularly likely to have caring responsibilities and, at the same time, have less access to the support services provided by the statutory or voluntary sector. Carers from ethnic minority groups have thus been identified as target deserving specific attention and measures in some of the ICT-based programmes and services which address carers in general. As we have seen, the

101 This case is not included in our report on Germany, but was presented at the AAMEE conference in Bonn on October 1 2008 by THS Wohnen GmbH. THS is one of the biggest housing companies in Germany with 150,000 tenants, 25% of which are immigrants. About 12% of THS' 30,000 Turkish tenants are older than 60 years of age. The presentation is available at: http://www.aamee.eu/deutsch/Konferenz_2008/vortraege/forum5/forum5_ref_mense_marie_pre.pdf

102 See http://www.aamee.de/conf_08/memorandum/index.php for the Bonn Memorandum which mentions this.

Carers Direct helpline uses an advanced multi-lingual support system to enable communication with customers in over 100 languages (see Box 7). The *Caring with Confidence* training programme for carers has involved providers at local level who are specialists in outreach and support for ethnic minority groups (see Box 9 - Cases of ICT-supported training for care giving).

Concerning cultural diversity on the supply side of LTC, according to interviews done for our study in Germany and England, migrant care workers employed by home care service providers enjoy the same exposure to ICT on the workplace and the same support for learning to use and incorporate them into the daily work practice as their native colleagues. Differences in how workers deal with these technologies are deemed to reflect personality and interest in technology rather than cultural background.

In England, the provider of vocational qualifications *City and Guilds* (see Box 9) explained that they did not develop any courses or facilities within their online offer specifically for care workers from migrant backgrounds, because diversity issues are already well integrated in their existing courses.

Migrants working as informal family care assistants, on the other hand, despite being hundreds of thousands in the countries that we studied (especially in Italy, Spain and Germany), seem to be almost entirely ignored by the online services that address carers and caregivers in general. They can of course make use, in principle, of the online information, training and mutual support opportunities that are increasingly publicly available to caregivers. In practice, as we shall see later, this seems to occur very little. The lack of adapted or dedicated services for them is likely an important explanation for it.

In Italy, we only found the *Aspasia* project (see Box 9) which offers ICT-based training and information activities addressed specifically to *badanti* from migrant backgrounds. The project website's interface and content are available only in Italian, even though a link is provided to automatic web-based translation services.

In Spain, of the 25 websites found by our study fully dedicated or hosting a section for home caregivers none was available in any foreign language[103] and only two paid some attention to migrant caregivers: *Sercuidador* (with a link to an online care job demand/supply service, see Box 7) and *Cuidadoras en red*, which hosts an online community of migrant paid caregivers (see Box 8). In Germany, no specific attention to informal migrant caregivers, including care assistants, was found in the range of websites dealing with LTC analysed by our study. Only one of them provides multi-language content: the *SEKIS* service in Berlin (see Box 7).

In England, as we have seen above, some ICT-based multi-language services on LTC are available, mostly targeting carers from migrant backgrounds. Migrant paid caregivers outside of the formal care sector seem to be few, compared to the other countries (see Section 2.3) and are barely addressed as such. Some trade unions[104] provide online information and support to all migrant workers regardless of occupation, on general topics such as employment system and conditions, health and safety. Some voluntary organisations –such as Kalayaan's Justice for Migrant Workers[105]– offer migrants online support on rights, employment and related issues specific to the care sector.

103 In Spain many migrant caregivers are Spanish-speakers from Latin America, so language should not be a barrier. However, the use of other national official languages may create problems also for these caregivers. For instance, the online services of Coidanet in Galicia (see Box 9) are entirely based on the Gallego language.

104 TUC (Trade Union Congress) hosts a website with content in Polish designed to support Polish migrant workers (http://www.pracawbrytanii.eu/). UNISON, the largest UK public service union to which many care workers belong publishes a regular newsletter for migrant workers (http://www.unison.org.uk/migrantworkers/).

105 See http://www.kalayaan.org.uk/.

3.3.2 ICT use by migrant family care assistants

Our study gathered some information about ICT access, skills and use among 40 migrant family care assistants interviewed in Italy (24), Spain (12) and Germany (4). In all three countries, the interviewees were women (except one man in Spain); almost all of them coming from Eastern Europe and South America; with a lower average age in Spain (32 years) than in Italy (49 years). Other information on their demographic features, education and length of stay in the host country, along with the list of topics addressed in the interviews, can be found in the text and appendices of the reports on Italy and Spain.

It should be noted that none of the migrant care assistants interviewed in Italy and Spain had ever worked in households where social alarm systems or more advanced telecare or telehealth applications were used.[106] The answers summarized below on ICT access and skills, use and barriers thus mostly refer to mobile phones, computers and the Internet and related services and applications, as they are being used by the caregivers themselves. Only in the final discussion on expectations and aspirations about ICT-support in home care, the answers of the migrant interviewees and of some experts take into account also the broader range of opportunities afforded by ICT for LTC.

Limited PC and Internet access homes and diverse levels of digital skills

All migrant care assistants interviewed seem to own a **mobile phone** and for many of them this is the only available communication technology, both at the workplace (in the home of the people they care for, and where they often live as well) and in their own home. As migrant care assistants use mobile phones intensively and for many purposes (see below) and saving cost is a high priority for them, which is reflected in their extensive knowledge on how to minimize costs and their proficient use of different SIM cards with different rates. SMS are used a lot for private communication.

In general, the interviewees reported that in the older people's households where they work **computers and Internet** are seldom present. The implications of this depend among other things on digital skills and familiarity, which vary significantly among the migrant care assistants interviewed.

In Italy, only 25% of the respondents declared to have some familiarity and to use these tools, but they did not specify in which location.

In the Spanish group, on the contrary, 70% of the respondents claimed to use a computer and the Internet. A third of them had access from their own home; all others usually gained access to the Internet from public places such as cybercafés or telecenters.[107] Respondents in Spain in fact reported that, in the few cases where computers and Internet do exist in the care recipient's home, families do not usually grant permission to use them.

Respondents in Germany gave a different picture with respect to families' attitudes. Those care assistants familiar with computers and Internet reported using these tools from the home of a care recipient's relative (where they were more likely to be available). This corresponds to what Neuhaus et al. (2009) found in a broader study on Germany: most of the families they interviewed (69%) consider care assistants as

106 In Italy, six out of the 24 interviewee had had experience with instruments such as electric beds and lift.

107 These figures on PC-Internet use rates are higher, but close to the results of the Spanish annual survey on ICT use by individuals and households. The 2008 results show that 'foreigners' had on average reached the same levels of PC adoption (61% of all respondents) and Internet access (56%) as Spanish nationals. Access to the Internet by 'foreigners' had occurred from home in 62% of the cases; from work in 20% and from cybercafés in 35% of cases. Therefore, respondents in our group have less access from their own home (possibly because many of them have live-in arrangements with the people they care) and rely more on cybercafés than 'foreigners' in the national survey.

part of their family and support the migrant's connection with relatives in the home country, for instance by providing them with access to Internet and Skype.

Personal reasons driving ICT use: social contacts and job search

Based on the interviews to migrants and key informants dealing with them, and on the observation of websites identified during our study, the use of mobile phones, computers and Internet by migrant care assistants can be summarized as in Table 11 below. Except for the use of mobile phones for communication needs related to everyday care tasks, personal motivations are the main drivers of ICT use, in particular of computers and the Internet.

Migrant care assistants use mobile phones intensively to handle the various organisational and communication **tasks associated with their job**. Job-related functions are performed much less frequently with computers and the Internet, even though in Germany, migrant care assistants who are familiar with these tools were reported using them to communicate and exchange information, e.g. with relatives of the person in need of care, medical personnel, and their employer or agent. Two migrant interviewees in Italy (out of the six who use computers) declared using the Internet to look for information related to their job (caring people suffering from Alzheimer and other topics). This is the only reference made by migrants in our interviews highlighting their knowledge about the existence and their use of web-based resources on care topics, like those illustrated before (see for instance Box 7).

Mobile phones are also very important to break **social isolation** in the host country by maintaining social contacts and organising meetings with other migrants from the same country of origin. People who do not use computers and Internet use mobile phones also to communicate back home.

Keeping in touch at low cost with **family and friends in the country of origin** is in fact the main motivation to use computer and Internet among those with digital skills and access to them. Another important use of these tools is to **search for job opportunities** and in general to gain a better knowledge of the care labour market, e.g. where demand for care services is stronger, which tasks are required by families and so on. The analysis of some online forums and blogs on websites for migrants (e.g. *Migrar.org* in Spain or *Stranieriinitalia*[108] in Italy) confirms this priority.

Also mobile phones are used to look for work and exchange labour market information through the migrants' social networks. In fact, they are also used in support of **informal recruitment** chains. In our study on Spain, it emerged that there are networks of migrant care assistants that establish contacts between migrants and local families in need of assistance. These networks are mostly maintained through word of mouth and mobile phones.[109]

Finally, migrant family care assistants and care workers are found very active online in Italy, **commenting news and participating to forums** devoted to the ever changing government policy

108 See for instance http://www.stranieriinitalia.it/ (Foreigners in Italy - the portal of the new citizens) which offers also information in several languages.

109 Similarly in Italy the bulk of migrant care assistants' recruitment was found to still develop along informal networks, mediated by local acquaintances and ethnic ties, or possibly by charitable institutions, with a still marginal role of public welfare agencies or private companies. The role of technology in this processes in Italy has not yet been investigated. In the UK, on the contrary, a recent study found that recruitment methods of foreign workers in low wage employment have changed and the use of the Internet, among other factors, has reduced dependence upon formal recruitment agencies (see (Anderson, Rush, Rogaly, & Spencer, 2006)). It may be worth mentioning here, with respect to recruitment processes, the European project C.A.S.A. (Care Assistants Search Agency) which aims to create and test a model for national agencies which will provide support for migrant carers and those who most need their assistance. The model will initially be tested in three European countries, Italy, Germany and Greece. The project started in January 2009 is supported by the European Fund for the Integration of Third-country Nationals. See www.casa-project.eu.

Table 11: Motivations and patterns of ICT use by migrant care assistants

Domain of need/ purpose for ICT use	ICT use: frequency, solution and services
Job-related needs	
Organise care and communicate with others involved (care recipient, family members, care professionals etc.)	Very frequent, mostly through mobile phones Few cases use the Internet (e-mail and VoIP services)
Search information on care issues	Few cases use information web sites
Help families in informal recruitment processes	Cases reported, mostly through mobile phones
Personal needs	
Break social isolation, maintain local contacts with other migrants in host country	Very frequent, mostly through mobile phones
Maintain contact with family and friends in home country	Very frequent, first main use of the Internet (e-mail and VoIP services) Mobile phones by non-Internet users
Search for job opportunities and exchange of other labour market information	Frequent, second main use of the Internet (job-related web sites, online forums) Frequent also through mobile phones
Gather information and debate on host country's labour migration measures	Some cases (in Italy), web sites for migrants and related forums

towards migrants in general and those working as carers in particular.

Barriers to enhanced computer and Internet use, also for care-related tasks

The **lack of time to learn and practice** seems to be the most important constraint on migrant care assistants' chances to become computer and Internet users or to enhance their ICT competences, also with respect to care functions (e.g. learning to search for information on the web). This is especially the case when they are in co-residency arrangements, also due to the very limited presence, as seen above, of digital tools in care recipients' homes.

The **lack of adequate online content** for information and training purposes is another frequently mentioned problem. Adequacy here is typically referred to lack of content in the migrant's own language or content in the host country language which is not adapted on language complexity, presence and detail of explanations and other features which might make it easier to understand by a foreigner. In this respect, a migrant interviewee mentioned as a problematic aspect the very basic or shortened language used for private posts and comments on web forums, blogs and social networking sites by native people, including carers and cared people exchanging experiences and feelings about their situation.

The need to have keyboards and software apt to support different alphabets is a specific **technical barrier** to the use of computers and other devices which was mentioned by the Home Farm Trust in the UK.

Both experts and migrant care assistants consulted in our study tended to agree also on a broader obstacle. The **illegal and/or undocumented work and residence status** of many migrant care assistants in Italy, Spain and

Germany, creates objective barriers for instance to attend publicly-supported training courses; to subscribe to communication services; to use online services which require payments through credit cards etc. Uncertainty about the conditions and length of stay in the host country also reduce motivations to make a learning investment. Exploitative working arrangements put further restrictions on the free time available.

Expectations and aspirations concerning ICT-based support in home care provision

As mentioned before, the migrant care assistants interviewed in our study had never heard of or knew very little about the use of ICT in care provision, except for social alarms. According to our report on Italy, the interview resulted in a sort of 'disclosure' experience for many interviewees, as it raised their attention to issues potentially of interest for them and their employers, but in fact completely marginal, in their own current everyday practice. However, once presented with a brief description of ICT opportunities for domiciliary care, most interviewees expressed opinions about them and related them to their needs.

In Italy, interviewees valuated positively all devices that can help moving heavy people (electric lifts, recline chairs, electric wheelchairs and so on) and increase older people's autonomy. Computers were seen as potentially useful for planning care tasks and drugs dispensation, and to carry out activities online (e.g. banking) without leaving home. Alternatively, social alarms and similar devices were seen positively, as they could allow the carer to leave the assisted person safely alone for some time. Also in Spain, all the interviewees, except one, expressed the opinion that ICT could facilitate care tasks.

Migrant caregivers interviewed in Germany confirmed the desire for suitable emergency call systems and other solutions that could increase safety and security in care delivery. They also expressed an interest for: easy to use ICT solutions to support communication with all those involved in the care process; web portals with trustworthy and comprehensive information on legal, health and care issues; e-learning training programmes for improving their caring capabilities (e.g. emergency management) and, possibly, leading also to professional qualification (e.g. as geriatric nurse). In all these domains, the possibility to fall back on one's mother tongue for interfaces and content was considered very important, in order to minimize risk of errors, with potentially serious consequences, due to misunderstandings and poor proficiency in the host country's language. The use of photos, short movies, interviews and so on was also mentioned as important to make websites and training tools easier to understand and more inviting.

Home care experts in Germany with knowledge of migrant caregivers' specific conditions and needs also suggested using icons and other solutions independent of language skills to enhance the user-friendliness of devices and applications icons. They recommended that ICT-supported learning should include face-to-face training sessions near to the migrants' work and living places. This would provide opportunities to meet other people living in the same region, better contributing to migrant's integration than remote e-learning courses alone.

3.4 Breaking barriers and seizing ICT-related opportunities for informal caregivers

Figure 7 below summarizes at a general level the findings illustrated so far regarding the opportunities and benefits that ICT can bring to informal caregivers involved in domiciliary care provision and the barriers that limit a wider or more effective exploitation of these opportunities (including some that are specific to migrant caregivers).

3.4.1 ICT opportunities for informal caregivers

As mentioned before, telecare, telehealth, assistive technologies and others solutions

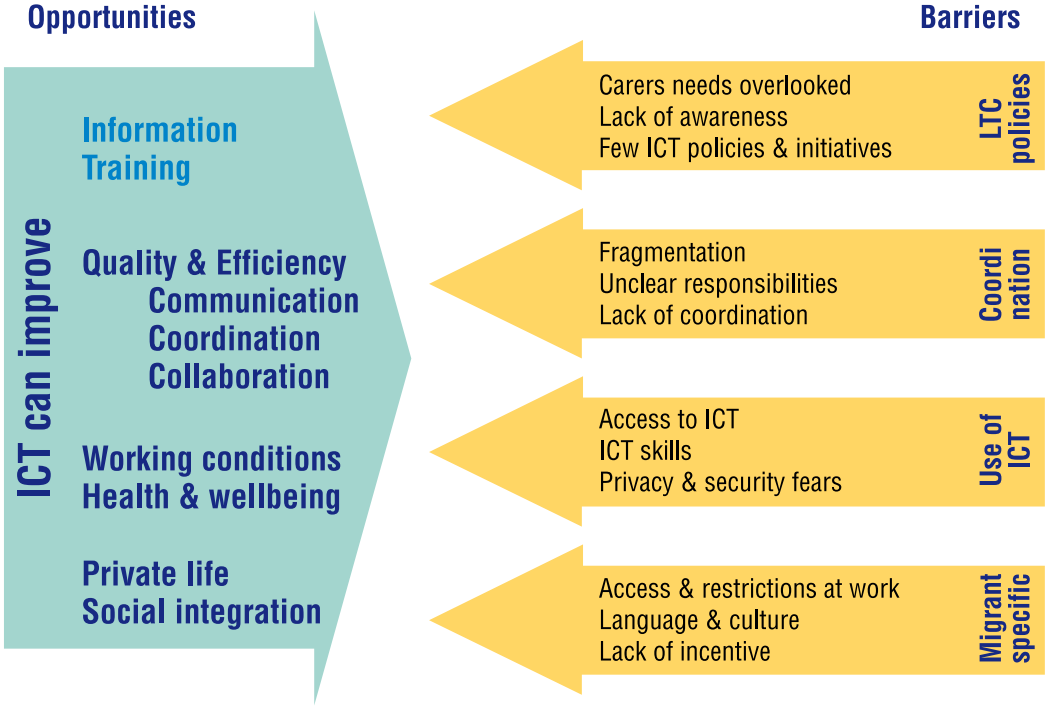
which primarily address people in need of care have an important, as yet untapped, potential in alleviating the burden of carers and other informal caregivers, by allowing them to delegate certain monitoring tasks or perform them at a distance, and by ensuring the safety and well-being of the care recipient at times when they cannot personally be around. This in turn is expected to help carers in gainful employment to better cope with their job demands, and carers in general to reduce stress factors which affect their health and wellbeing.

However, more significantly, even simple computers, the Internet and other modern communication technologies are already opening up unprecedented opportunities for facilitating the work of informal caregivers and improving their personal situations. In this respect, we have seen that ICT can be used to:

- Provide online and telephone-based information and advice on all kinds of issues and aspects related to LTC at home, to address both emergency situations and everyday care challenges;
- Provide training opportunities entirely online or combined with face-to-face courses, which can be entirely self-administered or supported by a tutor or teacher, and so on;
- Support communication, coordination and collaboration with all those involved in home care provision, thus contributing to the quality and efficiency of care;
- Enable the formation and smooth operation of online communities and informal exchanges among caregivers sharing similar conditions and needs. Again, these can be a source of information, advice and peer support for the caregivers, and they can contribute to at least partially reducing isolation and alleviating the ensuing stress.

These opportunities can also be exploited to address the additional, specific needs of caregivers

Figure 7: ICT opportunities and barriers for informal caregivers



Source: Cullen & Kubitschke, 2010.

from migrant backgrounds, such as social integration; learning and understanding the institutional context and the dominant culture of home care in the receiving country; accessing ICT-based content and services in their mother tongue and/or learning the host country language (see later).

3.4.2 Barriers to ICT deployment and usage by informal caregivers

Facing these opportunities, Figure 7 lists a range of barriers that were already mentioned in other parts of this report and are summarized and grouped here into four sets.

First, with the partial exception of the UK, we have seen that LTC policies in the countries we studied, despite the growing attention devoted to home care provision, have largely overlooked the needs of carers and informal caregivers in general. Besides this, policy makers and other stakeholders seem to lack awareness and/or to be unconvinced of the opportunities that ICT bring to all the actors involved in home care provision. In fact, systematic support to ICT use for care recipients is itself still missing. The lack of adequate evidence of ICT usage experiences in LTC (in terms of scale, duration and other aspects) and of cost-benefit analyses probably contribute to this situation. Again except for the UK, relatively few initiatives are thus currently exploring and testing the use of ICT in support of carers and other informal caregivers, and when they do so, it is mostly thanks to the efforts of third-sector organisations and carers themselves. The growing presence of migrant caregivers, their need for support and the opportunities that ICT bring to address them are almost entirely ignored also at this level.

The second set concerns features which seem to characterize the LTC sector in many countries. We refer to the large number of actors involved in LTC provision, typically at the local level; the division between health and social care services, and the lack of coordination between them; and the multiple, usually unclear responsibilities with respect to who should lead actions which must cross organisational boundaries. These are often given as an explanation of the difficulties in developing important, systemic changes, such as the large scale and holistic application of ICT in support of home care provision. But they also concern the development and later the quality assurance of innovative services which go beyond strictly care functions, such as providing online information and training for care recipients and informal caregivers.

The third set of barriers concerns mostly weaknesses on the adoption side. We mentioned before that among the majority of informal caregivers there is also a profound lack of awareness and information of the opportunities offered by ICT, typically accompanied by low or no digital skills and experience (especially among older people), and serious worries about privacy and security issues both for the care recipient and the caregiver.

Migrant care assistants, who are often found to intensively use computers, Internet and mobile phones mostly for communication reasons, face some barriers which are the same as those of other caregivers (e.g. lack of knowledge of care-related ICT opportunities), but they also have additional problems. We refer to restrictions in computers and Internet access in the care recipient's home, where they often live, but also at public internet access points.[110] There is also the paucity of adequate online resources (information, training, social networks) on LTC tasks and challenges, available in their mother tongue and/or in a language and format that are accessible to them. Finally, we refer to the vulnerable work and residence status of many migrant care assistants, which puts constraints on their work and personal life, and also affects their motivations and chances of using ICT for care-related purposes.

110 The use of computers and Internet in free or commercial public internet access point, phone shops and the like suffers almost inevitably from time constraints, limited privacy and interruptions of concentration.

3.4.3 Priorities for policy action

In order to seize ICT opportunities to support informal caregivers in an ever more culturally diverse European society, the barriers we just discussed could be addressed through various measures which concern policy makers and other actors in different fields.

Awareness and information on ICT opportunities for informal caregivers should be improved at all levels: policy makers, LTC sector organisations and professionals, care recipients and informal caregivers themselves. Our study on Germany, in particular, underlined the widespread resistance of people who start having dependency problems and those close to them to openly admitting, discussing and facing these problems, which is a pre-requisite to start looking for support solutions, including technology-based ones. Public information campaigns are thus needed that de-stigmatize the issues of old age, care, illness and dementia and increase knowledge about all support opportunities afforded by ICT (and other means) for longer independent-living, care delivery and coping with caring functions. The crucial role and needs of informal caregivers should be emphasized, given their current poor visibility and recognition.

A crucial way of supporting these awareness and information efforts and generally improving policies on ICT for LTC must come from *more research and documentation* of what is happening in this field. Again, specific attention should be paid to the issue of informal caregivers, which our study showed to be dramatically under-researched.

Related to these points is the suggestion to set up, at country level, a well organised, easy to search and high quality *information system devoted to ICT for LTC*, with a 'section' dedicated to support for informal caregivers. This information system could bring together content from multiple sources as a way of compensating for the current fragmentation and diversity of information in the field. It would target the general public and specialist advisors, such as the support centres on LTC (or disability, dependency, etc.) already active or being set up at regional level in all four countries that we studied, since currently their knowledge of, and promotional activities for, ICT opportunities appear to be limited.

Another range of measures pertain to what are known as *digital inclusion policies* (Timmers, 2009). Digital inclusion measures providing non-ICT users with generic access opportunities, for instance through public internet access points, and basic training (typically use of standard computer software, e-mail and Internet navigation) are found increasingly inadequate for many target groups.[111] Measures thus need to be better targeted, in this case by identifying specific caregiver types with likely specific digital exclusion problems, e.g. older carers who have never used computers; younger carers who left employment, with some ICT experience; migrant caregivers expert in using only a specific Internet communication service and so on. Measures also need to be more focused, in terms of content, on the needs of the new users. They should thus help users to use applications and access online content which are immediately relevant to them, such as the online services for caregivers that we illustrated in Section 3.2, and develop a critical understanding of their potential and limitations. For instance, given the privacy concerns of many carers, training measures should point to the risks of disclosing personal information on online forums and social networks and to the ways to reduce them.

Targeted and focused digital inclusion measures for migrant care assistants, given lack of or restricted access to computers and Internet in the households where they work and the shortcomings of Internet/phone shops, cybercafés etc. (see footnote 110), entails promoting such access in locations where the caregivers already meet (e.g. a migrants association's centre, a local library close to the weekly meeting point in town,

111 See on this: Rissola (2007) and Groeneveld, Haché, & Kluzer (2008).

and so on). Measures to overcome trust and other barriers to ICT use from the care recipient's home could also be explored.

Another priority towards this target group is the development of *reliable, transparent and multilingual information* to be made available online on the legal, organisational and medical context of care and on care practices in the particular country. *Training material* and modules in different languages also have to be produced and made known. A complementary measure to the above is to promote and support ICT-enabled learning of the host country language in a functional way for caring activities.[112]

Finally, for all informal caregivers, regardless of their origin, it is very important that the ICT industry and LTC service providers develop devices for care delivery and in support of caring functions that are accessible and simple to use, following the '*design for all*' approach.[113] The use of icons (avoiding having to read and understand written text) and multiple languages are probably crucial to achieving this result.

Having said this, the most salient finding of our four studies is that far *more research* is needed to establish a reliable knowledge base on the issue of IEM working as informal caregivers and their needs.

112 The French government has in fact chosen domiciliary paid caregivers as one of the first categories of migrant workers who will be offered the possibility to use a distant learning platform specifically designed for the functional learning of French in a work-related perspective. The contribution of ICT to second language education of adult migrant is a line of research that IPTS has been developing since 2009. For online publications and materials on this see http://is.jrc.ec.europa.eu/pages/EAP/ICT-IEML2.html.

113 The UN Convention on the Rights of People with Disabilities defined design for all or universal design as "the design of products, environments, programs and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design."

4. Conclusions

This study, carried out in four EU countries (Germany, England, Italy and Spain), shows that informal caregivers, i.e., family, friends, volunteers and other caregivers employed by the care recipients or their families, provide most of the care to the elderly today, and their number could reach 10% of the population. Furthermore, demographic ageing trends and policy trends towards granting stronger care rights to citizens and a greater emphasis on domiciliary care provision, are likely to increase their role and number. In spite of this, little policy attention has been paid to the situation and needs of carers and those who help them.

Policy intervention is needed to increase support to informal care givers, in particular to raise policy and public awareness of the concerns and needs of informal caregivers and to inform caregivers of their rights and the support available to them. Furthermore, across the different countries studied, little policy attention, if any, has been paid so far to the role of informal care givers in general, and migrants in particular, or to the use of ICT for addressing the challenge of making socio-health care provision sustainable in the long term in the context of an ageing society. Policies which aim to make use of ICT to enhance the quality and efficiency of LTC will have to integrate the vital role played by informal caregivers, whether they be family members, volunteers or care assistants employed by the family. Policymakers will have to take into account the fact that more and more informal caregivers are from migrant backgrounds.

ICT entail significant opportunities in several dimensions of the work and lives of domiciliary carers in general and migrant carers in particular: for information and training; for easing communication, coordination and collaboration among health care and care actors; for improving carers' working conditions by enabling platforms for emotional and professional support; for easing carers' social integration through on-line applications (web sites, fora, email, etc); for facilitating participation of multiple actors in caring and for supporting specific migrant integration needs. There is a general and broad agreement concerning the usefulness of ICT in improving the quality of care provision, relieving informal caregivers, assisting them in their care tasks and improving their well-being. However, currently this potential remains largely untapped.

Specific targeted measures and incentives are needed to unlock the potential offered by ICT, namely:

- actions aiming to raise awareness and provide information on ICT opportunities for caregivers across stakeholder groups, such as, for example, the collection, documentation and dissemination of good practices;
- targeted digital inclusion policies addressing the specific profile, conditions and needs of caregivers in terms of access, training and content provision;
- the development of reliable, transparent and multilingual information and training material to be made available online on the legal, organisational and medical context of care and on practices in the particular country;
- the promotion and support of ICT-enabled learning of the host country language for migrants;
- the development by the ICT industry and LTC service providers of services for care

delivery following the "design for all" principle; and finally

- actions aiming to improve collaboration between the different players involved in providing home care, needed for large scale and holistic application of ICT in support of home care provision.

Changes are needed to improve the precarious situation in which migrant family care assistants live, in particular in relation to residency and work permits, employment conditions and access to services. Migrant family care assistants are unanimously acknowledged as crucial for meeting care needs in most European countries. However, legal and administrative frameworks have not yet recognized social reality in this field and need to adapt to respond to recent and future challenges in home care. Modifications are also needed to create the necessary (albeit not always sufficient) preconditions to develop effective (ICT-based) training and support actions that can improve the quality of care provision, and enable those who want it the transition to professional qualifications in this or related areas.

Finally, in order to support the implementation of the above policy recommendations, **more research is needed in order to provide**:

- comparable, reliable, comprehensive statistics on the role of informal care givers in general and of IEM in particular in care jobs will have to be provided;

- better knowledge of the profile of formal and informal caregivers, work conditions, tasks, caregivers' needs and the potential of ICT;

- a better understanding and evidence of the impact of current ICT-based products, applications and services in improving the quality and efficiency of care, on the well-being of the care giver and in supporting an increased availability of caregivers;

- a better understanding of how policy can support development, scalability or replicability of existing good practices in other contexts within the EU; and

- the identification of sustainable business models to finance ICT infrastructure, applications, devices and services across actors.

Acronyms

AAL	Ambient Assisted Living
ADL	Activities of Daily Living
AT	Assistive Technology
CCSR	Councils with Social services (statutory) Responsibility (in England)
CSCI	Commission for Social Care Inspections (in UK)
IADL	Instrumental Activities of Daily Living
IMSERSO	Instituto de Mayores y Servicios Sociales, Institute for the Elderly and Social Services (in Spain)

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Abstract

This report synthesizes and discusses the findings of a series of studies on the use of ICT to support caregivers providing Long-Term Care at home, with particular attention to migrant caregivers.

The use of Information Communication Technologies (ICT) for health and social care is playing an increasingly important role in the context of the demographic changes. As, on the one hand, people are getting older and the need for care is increasing, and, on the other hand, the number of formal and informal caregivers is decreasing, technical devices are seen as a possible solution to this dilemma. At the same time, people in need of care and their relatives have a tendency to informally employ private care assistants, often from migrant backgrounds, to assist those in need of care in their homes with daily tasks, so as to avoid and postpone their transferral into institutional care.

To better understand the current and prospective use of ICT to assist informal caregivers, and in particular those of migrant origin, JRC-IPTS conducted a series of exploratory studies, assessing the situation in Italy, Spain, Germany and the UK. This report gives an integrated overview on the situation of domiciliary care in each of these countries and related policies; investigates the state of deployment and the opportunities for ICT in home care and identifies drivers and barriers for the deployment of ICT by caregivers with a particular focus on migrant care assistants. Finally, it discusses potential policy options.

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