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**ANCIEN**

Assessing Needs of Care in European  
Nations

**ASSESSING NEEDS OF CARE  
IN EUROPEAN NATIONS**  
**ESTHER MOT AND PETER WILLEMÉ (EDS)**  
**ENEPRI POLICY BRIEF No. 14**

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**Abstract**

This Policy Brief presents the research questions, main results and policy implications and recommendations of the seven Work Packages that formed the basis of the ANCIEN research project, financed under the 7th EU Research Framework Programme of the European Commission. Carried out over a 44-month period and involving 20 partners from EU member states, the project principally concerns the future of long-term care (LTC) for the elderly in Europe and addresses two questions in particular: How will need, demand, supply and use of LTC develop? How do different systems of LTC perform?



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# ASSESSING NEEDS OF CARE IN EUROPEAN NATIONS

ESTHER MOT AND PETER WILLEMÉ (EDS)\*

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## Introduction

Launched in January 2009, ANCIEN is a research project financed under the 7th EU Research Framework Programme. The project was carried out over a 44-month period and involved 20 partners from EU member states. The project principally concerns the future of long-term care (LTC) for the elderly in Europe and addresses two questions in particular:

- 1) How will need, demand, supply and use of LTC develop?
- 2) How do different systems of LTC perform?

The project consisted of seven work packages aimed at collecting and analysing information and projecting future scenarios on long-term care needs, use, quality assurance and system performance. State-of-the-art demographic, epidemiologic and econometric modelling is used to interpret and project needs, supply and use of long-term care over future time periods for different LTC systems.

This Policy Brief presents the research questions, main results and policy implications and recommendations of these work packages. The reader is referred to the policy briefs of the separate work packages and the research reports available on the website for more detailed information on the data collection, methods of analysis and conclusions. In particular, interested readers are invited to read:

- Kraus, M., M. Riedel, E. Mot, P. Willemé, G. Röhring and T. Czypionka (2010), “A Typology of Long-Term Care Systems in Europe”, ENEPRI Research Report No. 91.
- Bonneux, L., N. Van Der Gaag and G. Bijwaard (2012), “Demographic Epidemiologic Projections of Long-Term Care Needs in Selected European Countries: Germany, Spain, The Netherlands and Poland”, ENEPRI Research Report No. 112.
- Jiménez-Martín, S., R. Vegas Sánchez and C. Vilaplana Priet (2011), “The Relationship between Formal and Informal Care in Europe and its Implications for the Number of Caregiving Hours”, ENEPRI Research Report No. 100.
- Pickard, L. (with an appendix by S. Jiménez-Martin, R. Vegas Sánchez and C. Vilaplana Prieto) (2011), “The Supply of Informal Care in Europe”, ENEPRI Research Report No. 94.
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# 1. How European nations care for their elderly: A new typology of long-term care systems

## 1.1 Introduction

Expected future demographic and societal shifts have put the improvement of quality and efficiency of long-term-care (LTC) systems on the agenda of virtually every EU member state, not least in order to support its long-term financial sustainability. Research to support the reform process, however, suffers from the scarcity of reliable and comparable data to work with, and the extent to which the process can be generalised is further complicated by large differences in the design of national LTC systems. Work Package 1 of the ANCIEN (Assessing Needs for Care in European Nations) project collected data on national LTC systems in 21 European countries and produced national reports describing the structure of these systems. The collected material allowed the project team to derive a typology of LTC systems in European countries. The creation of empirically founded system ‘types’ should serve to make research in this field more easily generalisable within groups of this typology and thus to improve the efficiency of further research on LTC.

## 1.2 Evidence and analysis

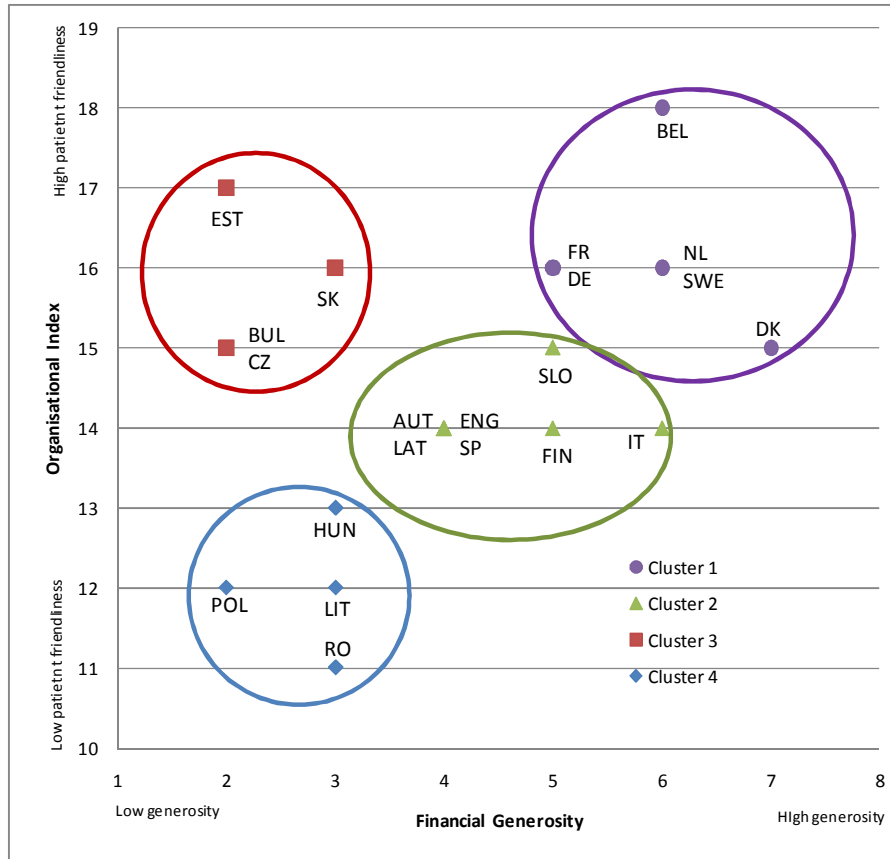
Two typologies of LTC systems were developed. The first approach, which focuses on organisation of care, relies on qualitative information and includes 21 EU member states. The second approach uses quantitative information on the use of care and is limited to 14 EU member states for which data are available.

### *Approach 1. Typology focusing on organisation and financing of care*

In the course of the project, an index relating organisational characteristics of LTC systems to patient friendliness was developed and combined with an index on the generosity of public LTC systems. The two indices depict (almost) a continuum of possibilities of how developed LTC systems and how generous public financing for those systems can be (see Figure 1.1). Both indices, organisational depth and financial generosity, are to be read in a similar manner: high values represent system characteristics that are preferable from the patient’s or client’s point of view, with low values being less preferable. The index for organisational depth is constructed from information on means-testing, entitlements for services, availability of cash benefits, provider choice, quality assurance and integration of care. The index on financial generosity uses public expenditures for LTC as a share of GDP and the presence of cost-sharing.

Four groups of countries can be identified: Nordic countries, but also France and Germany share highly developed systems and quite generous public funding. New member states of the EU usually devote less funds to long-term care, but their systems are far from similar regarding the organisational depth of their systems: the project team finds a country group with highly developed systems (Bulgaria, Czech Republic, Estonia, Slovakia) and a group with less patient-friendly system characteristics (Hungary, Lithuania, Poland, Romania). The remaining group of countries is in an intermediate position and characterised by moderate financial generosity and moderate organisational depth. This group is geographically very diverse and includes Austria, England, Finland, Italy, Latvia, Slovenia and Spain.

Figure 1.1 Organisation and financing typology



Source: Markus Kraus, Monika Riedel, Esther Mot, Peter Willemé, Gerald Röhring and Thomas Czipionka, “A Typology of Long-Term Care Systems in Europe”, ENEPRI Research Report No. 91, Centre for European Policy Studies, Brussels, August 2010 ([www.ceps.eu](http://www.ceps.eu)).

**Approach 2. Typology focusing on use and financing of care**

The following four variables turned out to be essential in characterising LTC systems: public expenditure on LTC as a share of GDP (corrected for the population share 65+), private expenditure as a share of LTC spending, informal care recipients 65+ as share of the population 65+, and support for informal care givers. The results are illustrated in Table 1.1.

Table 1.1 Use and financing typology

Nature of the system	Countries	Characteristics
<b>Cluster A</b> Informal care oriented, low private financing	Belgium,* Czech Republic, Germany, Slovakia	Low spending, low private, high IC use, high IC support, cash benefits modest
<b>Cluster B</b> Generous, accessible and formalised	Denmark, the Netherlands, Sweden	High spending, low private, low IC use, high IC support, cash benefits modest
<b>Cluster C</b> Informal care oriented, high private financing	Austria, England, Finland, France, Spain	Medium spending, high private, high IC use, high IC support, cash benefits high
<b>Cluster D</b> High private financing, informal care seems necessary	Hungary, Italy	Low spending, high private, high IC use, low IC support, cash benefits medium

Notes: IC = informal care.

\* Denotes a medium spender.

Source: Markus Kraus, Monika Riedel, Esther Mot, Peter Willemé, Gerald Röhring and Thomas Czipionka, “A Typology of Long-Term Care Systems in Europe”, ENEPRI Research Report No. 91, Centre for European Policy Studies, Brussels, August 2010 ([www.ceps.eu](http://www.ceps.eu)).

The results give rise to a typology of LTC systems that can be interpreted in terms of ‘spending-related’ and ‘informal care-related’ systems:

- In terms of the role of spending, cluster B is characterised by countries with a highly developed and ‘generous’ public LTC system. This group represents the so-called ‘Scandinavian’ model. On the opposite side, the project team finds clusters C and D, characterised by low- or medium-spending countries with considerable private financing. There is no clearly discernible geographical pattern, as this group includes Mediterranean, Central European and Scandinavian countries, as well as England. Cluster A is an intermediate case, comprising less generous systems with a low share of private financing.
- In terms of the role of informal care, there are two opposite and two intermediate systems. The opposites are clusters B and D. The former is characterised by low informal care use but relatively substantial support for informal care givers, while the latter has high informal care use despite the lack of support. This outcome can be interpreted in terms of the degree of development of the LTC systems: the ‘Scandinavian’ cluster has a highly developed system with generous funding, where the relatively low use of informal care (despite the financial support) can be explained by the availability of and probably the preference for formal services. Conversely, cluster D has a relatively poorly developed formal LTC system, with heavy reliance on informal care despite the relatively poor support (out of necessity, one might say). Clusters A and C combine high informal care use with substantial support, which can be viewed as the ‘expected’ outcome of countries that favour informal care, and support it accordingly.

### 1.3 Recommendations

**The project team recommends** setting up an international database on provision and use of long-term care or putting effort into the improvement of an existing one, because well-known databases such as *OECD Health Data* or *WHO Health For All* primarily cover health but long-term care only to a lesser extent. A prerequisite for such a database would be a common understanding of the definition of key variables. This endeavour could build upon work done by the OECD in the course of the SHA project, where international definitions for key characteristics on financing long-term care are being developed. The project team does not see any advantage in constructing another thematic database separated from related existing databases, but rather expects that it might be more efficient to extend an existing data collection like *OECD Health Data*. Recognising the sometimes close connection between health and long-term care calls for close coordination of data collection and definition issues. Availability of international comparable quantitative data would significantly improve the effectiveness of further research activities in the field of long-term care.

The analysis has shown that characterisation of LTC systems on the basis of simple characteristics (like insurance-based or tax-funded) is incomplete and can be misleading. An LTC system is a complex interplay of many factors that need to be taken into account to assess its performance. The cluster analyses indicate large differences between European LTC systems. These differences are based on historical developments and diverging preferences (e.g. formal vs. informal care orientation), as well as on the national economic situation (e.g. low vs. high public spending). Even countries that seem very much alike in economic background and culture can end up with very different LTC systems. The new member states are practically all constrained in their funding of long-term care, but the differences in organisation are considerable. The goal of this work package was to derive a typology of systems of care; the even more relevant question of how system characteristics relate to performance was analysed in Work Package 7 of the ANCIEN project.

**The project team recommends** directing research efforts towards the desired results of LTC systems. The different and complex systems that have evolved in the EU may be much more comparable regarding the outcomes that they strive for. Unfortunately, there is no general proxy for the outcomes of LTC systems available that could perform the role that life expectancy or healthy life expectancy plays in the assessment of health care systems. Work Package 7 made some progress in answering the question of outcomes. Considering the historical and cultural differences, it is unrealistic to expect that countries could copy each other’s systems, but they can still learn from each other about what works and what does not.

## 2. Demographic Epidemiologic Projections of Long-Term Care Needs in Selected European Countries: Germany, Spain, the Netherlands and Poland

### 2.1 Introduction

The large post-war baby boom began in 1946 and its cohorts reached the retirement age of 65 starting in 2011. A ‘baby crash’ (a sharp decline in fertility) followed the baby boom. Policy questions related to the provision of health and long-term care services in an ageing population need reliable forecasts of the numbers of disabled elderly persons. In WP2, we used demographic models to project the future need for long-term care in four countries of the EU: Germany (DE), Spain (ES), the Netherlands (NL) and Poland (PL), based on the EUROPOP 2008 mortality forecasts. The methods developed are generic and easily applicable to all countries that can produce mortality data and prevalence data on limitations in activities of daily living (ADLs) and selected risk factors.

Disability and morbidity are descriptions of health states with many dimensions. We are most interested in severe disability, leading to a loss of independence and the need for help in self care. This is operationalised as having at least one limitation in basic activities of daily living (subsequently referred to as an ADL disability), defined as self-reported difficulty with any of the following actions: a) bathing, b) dressing, c) eating, d) indoor transfers and e) toileting and continence. The prevalence of disability is determined by incidence and survival in that state. To assess dynamic changes in populations, we need information on dynamic change – how people flow into disability and out of life. Projections of disability are based on the future numbers of persons entering old age (demographic change), the length of time they will live as elderly individuals (mortality and life expectancy), the probability that they will become disabled and the length of time they will survive being disabled (epidemiology of disability).

We seek answers to three questions. First, what will be the consequences of the demographic increase of elderly cohorts? Second, what will be the consequences of the life extension of these cohorts (sometimes called ‘double ageing’)? And third, what will be the consequences of a changing epidemiology with the known effects on disability of smoking and obesity?

### 2.2 Evidence and analysis

The EUROPOP 2008 forecasts are the basis of our demographic and mortality forecasts. The first question is answered by baseline demographic projections assuming constant mortality and incidence after age 55, projecting the forecasted increase of populations reaching age 55 in the period 2008–60. Information on the numbers of the disabled elderly currently living in the community is taken from the large European study, SHARE (the Survey of Health, Ageing and Retirement in Europe), complemented with estimates of the numbers of the elderly living in institutions, derived from WP 1 of the ANCIEN project.

The second question is answered by the forecasted mortality at age 65 and older, and by the relation between disability and mortality. This relation is determined by ageing: age since birth as a proxy of wear and tear (or chronology, ‘Chron’ in our scenarios) and age before death as a proxy of biological age, characterising the resilience of the organism against the ageing process (‘Biol’, from biology in our scenarios). The effect of increasing life expectancy is assessed by three scenarios studying different morbidity scenarios. A chronological scenario (Chron) assumes increasing life expectancy but a constant incidence of age-specific disability. This is an “expansion of morbidity scenario”, predicting longer life by increased survival of the diseased. The biological scenario (Biol) assumes equal trends in mortality and disability. A similar but more conservative scenario assumes that the incidence of disability is delayed similar to mortality (‘Delay’). The former socialist countries of Europe, here exemplified by Poland, are lagging behind in life expectancy. The EUROPOP scenarios (and most scholars) assume that these countries will catch up: mortality scenarios assume convergence. Therefore, we have also added a scenario of future convergence in terms of disability in Poland (‘Convergence’).

The third question is answered by epidemiologic scenarios. We modelled the effects of lifestyles (smoking and obesity) as categorical variables. Gender- and age-specific mortality by disability were identified by using data from the Rotterdam Study Project and the prevalence conditional on risk factors was defined by the SHARE study.

In Germany, life expectancy for women at age 65 was 20.1 years and for men it was 16.8 years in 2008. This life expectancy is split into two parts: disabled and not disabled. German men were expected to live 3.3 years with an ADL disability and German women 4.8 years (reflecting the higher prevalence of disability among women). Women experience disability more often than men; also, the prevalence of disability is very low among Dutch men and a bit higher among Spanish women. Poland is characterised by a high mortality rate, particularly among men, and a high prevalence of disability. Such a rapid age-related decline in physical function has also been documented in Russia.

The EUROPOP 2008 scenario assumes that in 2040, more than three years of life expectancy are added by lowered mortality (somewhat more than a year per decade). In a biological scenario, the increase in the duration of disability would be close to nil (data not shown): this scenario assumes that late-age disability is timed by the date of death, not by the date of birth, so life extension postpones both death and disability and solely adds healthy years. In a chronological scenario, half of the gained life expectancy is spent in disability (data not shown). This reflects the high prevalence of disability at older ages, but assumes that disability at old age and mortality are independent processes. In the less extreme Delay scenario (see Table 2.1), the increase in the duration of disability is more moderate. The scenario of Poland's convergence with Germany on disability incidence shows that even a strong assumption of convergence (with an equal disability incidence in 2040) will still have a limited effect on disability prevalence (not shown): reducing flows (incidence) has a slow effect on the remaining shares (prevalence).

*Table 2.1 Life expectancies at age 65, by period (2008 and 2040), gender and disability status*

	<b>F</b>			<b>M</b>		
	<b>e<sub>65</sub></b>	<b>nDe<sub>65</sub></b>	<b>De<sub>65</sub></b>	<b>e<sub>65</sub></b>	<b>nDe<sub>65</sub></b>	<b>De<sub>65</sub></b>
<b>Germany</b>						
2008	20.10	15.35	4.75	16.87	13.56	3.32
2040 Delay	23.34	17.78	5.56	20.37	16.25	4.12
<b>Spain</b>						
2008	20.96	14.87	6.09	17.14	13.79	3.35
2040 Delay	23.89	17.02	6.87	20.48	16.37	4.11
<b>The Netherlands</b>						
2008	19.94	15.64	4.30	16.59	14.39	2.20
2040 Delay	23.25	18.26	4.99	19.99	17.26	2.73
<b>Poland</b>						
2008	18.56	10.85	7.71	14.50	9.91	4.59
2040 Delay	22.37	12.89	9.48	18.77	12.45	6.31
Convergence	22.62	14.47	8.14	19.05	13.44	5.61

*Notes:* F is female, M is male, e<sub>65</sub> is life expectancy, nDe<sub>65</sub> is life expectancy free of disability and De<sub>65</sub> is life expectancy with disability, all at age 65. For scenarios, see text.

*Source:* L. Bonneux, N. Van Der Gaag and G. Bijwaard (2012), "Demographic Epidemiologic Projections of Long-Term Care Needs in Selected European Countries: Germany, Spain, The Netherlands and Poland", ENEPRI Research Report No. 112, CEPS, Brussels.

To the individual life expectancies of Table 1, we have added the population effects of demography, in order to obtain the developments in the number of the disabled elderly. If incidence and mortality remain constant, all increases will be caused by demographic increases alone. In Germany, the increase in the elderly caused by the baby boom will be low (+44%), while it will be high in the Netherlands (+82%) and intermediate in Poland and Spain (respectively +57% and +65%). A constant



disability incidence (or prevalence) but lowered mortality rate would be a ‘worst case disability scenario’ (Chron). In most countries, the prevalence of disability would double. In the Netherlands, the number of the disabled elderly would even increase by an additional 140%. The somewhat more optimistic Delay scenario shows the effect of a modest decline in the disability incidence. In Germany, the Netherlands and Spain, the increase in disability by life extension combined with a delay in the onset of disability would be between 7 and 11%, caused by ageing. In Poland, this figure would be 22%, a consequence of the high prevalence of disability and more pronounced increases in life expectancy. If mortality converges, however, it is not reasonable to assume no convergence of disability. Convergence with Germany would limit the effects of life extension on disability by 5 percentage points, mostly as a consequence of a historically high prevalence of disability. But it would never fall under a demographic scenario.

Table 2.2 shows the consequences of differences in the risk factors of obesity and smoking for the cohorts in the German life table. With risk factor-specific prevalence of disability, we are able to calculate the risk factor-specific incidence of disability. For reasons of brevity, only Germany is shown.

*Table 2.2 Healthy life expectancies at age 65 by risk factor status in 2008*

2008	Women			Men		
	$e_{65}$	$nD e_{65}$	$D e_{65}$	$e_{65}$	$nD e_{65}$	$D e_{65}$
<b>Germany</b>						
EUROPOP	20.07	–	–	16.82	–	–
ANCIEN	20.10	15.35	4.75	16.87	13.56	3.32
nS	20.33	15.49	4.84	17.33	13.87	3.46
S	16.47	13.13	3.34	13.66	11.49	2.16
nO	20.22	15.88	4.34	16.92	13.59	3.33
O	19.73	13.39	6.33	16.56	13.09	3.47

*Notes:*  $e_{65}$  is life expectancy,  $nD e_{65}$  is life expectancy free of disability and  $D e_{65}$  is life expectancy with disability. NS and NO and are non-smokers and non-obese persons, respectively, while S is smokers and O is obese persons. All data are in years.

*Source:* L. Bonneux, N. Van Der Gaag and G. Bijwaard (2012), “Demographic Epidemiologic Projections of Long-Term Care Needs in Selected European Countries: Germany, Spain, The Netherlands and Poland”, Enepri Research Report No. 112, CEPS, Brussels.

Smoking decreases the duration of disability by a high mortality rate. Obesity increases the risks of disability, particularly among women. Smokers’ life expectancy is nearly 4 years shorter. The lives of obese individuals are not much shorter, but those of obese women are nearly 2.5 years shorter in which they are free of disability, and two years longer with a disability. The scenarios assume that future mortality and incidence are risk factor-dependent, but that the changes over time in mortality and incidence are risk factor-independent (the forecasted changes, in % per year, are equal among the obese and non-obese).

But even these extreme scenarios, with large consequences for the individual life course, have a rather limited impact on the prevalence of disability. Every individual born before 1975 will contribute to the prevalence of disability among those aged 65+ in 2040, while only the obese fraction in that population can contribute to the excess prevalence of disability, caused by obesity.

Smoking trends are implicitly taken into account by the EUROPOP 2008 forecast methodology. These have been a major cause of the mortality decline among men in European democracies since the 1970s, but not among European women, born before the Second World War: by societal consensus, these generations of girls were not allowed to smoke. This changed after the War. The female baby boom generation took up smoking in large(r) numbers, and will pay the price with increased mortality. In general, this means that the future decline of female mortality is overestimated by the EUROPOP mortality scenario, while the future decline of male mortality is underestimated.

The scenarios show the overriding influence of demographic change on future disability. The demographic projections for 2040 are robust: in the life table, 95% of babies will survive until age 55. Life extension is the second most important force driving the increase in disability. The simple linear forecasts of the EUROPOP scenarios project a period of unprecedented decline in mortality among those aged 55+ from the second half of the 20<sup>th</sup> century to the future. Yet the predicted life expectancy among women aged 65 in 2040 is still lower in the EU than the actual female life expectancy in Japan at age 65 in 2009 (24.0 years); thus, this is not an unreasonable scenario.

Assuming a constant disability incidence with sharply decreasing mortality (the chronology scenario) would be pessimistic and not consistent with theories of ageing. For the time being, and for severe disability, there is strong support for more biological scenarios. At the same time, assuming sharply decreasing disability while little progress is observed in cognitive causes of disability may be too optimistic. Still, the numbers of life years lived with disability remained surprisingly constant in the Netherlands as in other countries. The intermediary Delay scenario is a somewhat more conservative estimate of the biological scenario, which is a safe basis for projections used in policy preparation.

The effects of changing risk factors on the prevalence of disability are surprisingly small. First, there is demographic inertia: it takes many years to replace populations. People start smoking as teenagers and they will die as smokers or quitters six decennia later. Second, every person born between 1943 and 1975 will add to the population of the elderly at risk of disability, but only a fraction of that population is at an increased risk by disabling lifestyles. If one-sixth is disabled when not obese but one-third is if obese, and 20% are obese, the attributable risk is 3%. If the prevalence of obesity doubles, from 20% to 40%, the attributable risk doubles to 6% and the prevalence of disability increases from 20% to 23%. If for instance in the Netherlands the population aged 65+ were to double from 100 to 200, there would be 47 disabled individuals among these 200 persons: 20 would be added because of the doubling of the population and 7 would be added because of doubled obesity. The numbers are relatively limited compared with the demographic increase. Note that the assumptions of both change (a doubling of the prevalence of obesity) and risk (a doubled risk) are extreme, and true increases in attributable risk would be smaller.

The effects of quitting smoking are associated with life extension. Smoking shortens life and shortens life with disability. Many smokers improve the prognosis of their disease considerably by quitting and extended survival by lifestyle modification can hardly be called a disadvantage. Yet even extreme scenarios would not add many disabled elderly persons.

A most important conclusion is that the future numbers of the disabled elderly can be forecasted robustly and will be determined for a large part by demographic change. Lowered mortality rates increase life expectancy, but being a result of progress, it is predominantly a life expectancy free of disability. Obesity increases disability, but only the added obese are at a higher risk. Successful anti-obesity policies will lower the number of disabled elderly persons only modestly. Smokers suffer more from lethal diseases – but the population effects are small and mostly caused by smokers who do not quit. Successful policies that help smokers to quit will increase life expectancy, with the consequence of only a very moderate increase in the number of the disabled elderly.

Ageing will cause sharp increases in the numbers of the disabled elderly, but these increases are easily foreseeable over several decennia and planning for future resources can be initiated in a timely manner.

### **3. Availability and Choice of Care**

#### **3.1 Introduction**

The ageing of the population in the EU member states in combination with the cuts in national budgets have led to the emergence of important challenges for both citizens and governments. The number of caregivers who need to balance paid employment with caring responsibilities can substantially increase as a result of other institutional and cultural changes that are taking place simultaneously in Europe, most of them related to an increase in female labour force participation.

From the point of view of caregivers, providing care often diminishes their results in the labour market in terms of wages. And, as is well documented in the literature, it can also have an adverse effect on their personal well-being, in terms of the quality of life, happiness, personal fulfilment and achievement of personal and family goals.

The provision of informal care is an important source of long-term care (LTC) for older people in Europe. According to the SHARE database,<sup>1</sup> between 21% and 43% of the population living in Europe aged 65 and older are receiving informal care. Given fiscal constraints on public budgets in most of the EU countries and the ageing of the population, it is likely that in the very near future informal care providers will represent the most important source of care for disabled and older people in Europe. In this context, we need to analyse the determinants of the provision of care to understand the determinants of receiving this type of care and to design adequate policies to support caregivers in a sustainable and efficient way.

Following this aim, it is necessary to understand 1) how the share of informal and formal care varies between the EU countries and 2) the underlying reasons for the observed differences between European countries, both in the propensity to provide formal and informal care and in the probability of receiving both formal and informal care. To this extent, among the factors considered in the analysis to explain the observed cross-country differences in the EU are: dissimilarities in the structure and characteristics of the formal care provision and the number of institutionalised dependents in the country; differences in the characteristics of the citizens within each country that determine their propensity to provide informal care, e.g. the level of education and income, the role of women in the family and household chores, family structure, etc.; We also seek to understand 3) the interdependence between formal and informal care, since the demand for formal care will evolve depending to a great extent on whether they are complementary or substitutes and, finally 4) the potential dependent's unmet needs and the burden suffered by the informal caregivers.

### **3.2 Evidence and analysis**

The structure of LTC systems differs considerably from one country to another, as a result of the different nations' structure, history and culture as well as their economic performance. The analysis reveals that both a centralised and shared decision-making structure can be found in Europe with a roughly similar frequency: in about half of the LTC systems the main responsibilities for regulating LTC reside at the national level, while in the other half this responsibility is shared between national, provincial and municipality levels. This proportion holds true for both institutional and home-based care. In contrast to our expectations, not all Eastern European LTC systems are organised in a centralised way. In the Bulgarian, Estonian, Latvian and Slovakian LTC systems, decision-making is the responsibility of both the central and local levels.

Regarding the demand for formal care, we find that women, people with ADLs (Activities of Daily Living and/or IADLs (Instrumental Activities of Daily Living), people living alone, and persons with higher/university education have a higher probability of receiving formal care. The probability of using formal LTC is higher in countries where the provision of formal LTC is more developed. Within the EU, the Netherlands is the country with the highest probability of formal care usage while Spain has the lowest probability and German and Italy are in an intermediate position.

As regards informal care, irrespective of the country considered, the demand for informal care is determined mostly by the limitations and inabilities, and the characteristics of the caregivers and dependent people. We find that men have a higher probability of obtaining informal care from inside the household and women from outside the household. In most countries, age and physical limitations are the leading factors that determine the use of informal care: care is provided to the "older among the elderly". Persons with higher/university education have the lowest probability of receiving informal care in Spain and Poland, while income is positively related with receiving informal care from people

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<sup>1</sup> SHARE is the acronym used to refer to the Survey of Health, Aging and Retirement in Europe, which collects information on the health, lifestyle and financial situation of individuals aged 50 and older in a majority of European countries.

living in the household in Germany and the Netherlands. The analysis reveals, contrary to common belief, that informal care provided regularly from non-family members is more common in the Netherlands and Germany than in Eastern European and Mediterranean countries.

Moreover, according to the evidence obtained from Eurobarometer data, differences in socio-demographic factors as well as differences in long-term care systems between the countries determine the supply of informal care.

On the other hand, as illustrated with Finnish data, older, poorer, single and less healthy individuals are more likely to be institutionalised. According to results obtained from the Finnish data, after controlling for health status, demographics and income, we find that individuals living in old-age homes report higher levels of happiness than those living at home.

Finally, we provide an evaluation of the supply of formal care in representative countries. Using a simple stock-flow cohort projection method, care employment is projected to evolve very differently in the countries considered. High net inflows of workers into the LTC sector are projected in Spain for all age categories considered, due to changes in the family model, growing income for middle-class households and the ageing population. As a consequence, the number of LTC workers projected by 2031 is double the current level. In Germany it is projected that the total number of people working in LTC will decrease slightly, with net inflows projected only in the share of workers aged 30-44. In the Netherlands, LTC employment is projected to remain constant, with an increase only in the share of workers aged 40-49. In Poland, the share of workers in LTC is projected to halve during the same period.

### ***The interdependence between types of care***

The previous section summarised the results obtained from the analysis about the probability of supplying formal or informal care using the information available for the countries considered. The statements are based on an econometric analysis concerning the supply of care where different sources of available care are seen as if they were independent. In that setting, the amount of informal care received by an individual does not depend on the amount of formal care that s/he receives.

In the real world, however, the decision about the supply of informal care is taken within the family, and obviously the quantity of formal care supplied determines the amount of informal care provided to dependents and *vice versa*. Therefore, the amounts of informal and formal care provided should be considered as intertwined decisions, where the quantity provided of each one determines the amount provided of the other. The main methodological challenge in addressing this question is to deal with the endogeneity problems related to the labour supply decision and the allocation of time into care responsibilities.

There are different hypotheses to explain the relationship between the different sources of care provision chosen by families:

- *Compensatory hypothesis*. Care recipients resort to formal care as a last resource once other possibilities are exhausted.
- *Substitution effect hypothesis*. Care recipients substitute formal care with informal care and vice versa.
- *Complementary hypothesis*. Both types of care complement each other.
- *Task-specific hypothesis*. Each type of care is specific to some determinate type of caring needs.

To shed some light on how these different sources of care interrelate, we estimate a two-equation model for the choice of the type of care and the number of hours of care used/received (one for each type of care: formal, informal as well as the combination of both), with the aim of analysing the trade-off between formal and informal care, in a set of countries considered representative of different regions within the EU. The model allows us to test competing hypotheses regarding the complementarities/substitutability of formal and informal care, conditional on family characteristics and socioeconomic variables from the SHARE database. The analysis was performed separately for Germany, the Netherlands, Spain, Italy and the Czech Republic, which are the countries chosen to

represent each of the clusters that are defined within the EU regarding the countries' characteristics of their long-term care systems.

According to the results, there is evidence in favour of the task-specific model and complementary model in Spain and Italy. (The same results were also obtained in the Czech Republic, although there are some identification problems in this country due to the small number of observations.) On the other hand, we found no evidence in Germany or the Netherlands of any kind of interrelationship between the different sources of available care.

Finally, we have analysed the sample of countries available in SHARE, grouping them under three different criteria: geography, the generosity of their LTC system and the characteristics of their LTC systems. The evidence indicates that, if any, the 'task-specific' model, in which each task is covered by using a specific type of care, best characterises the experience of the European countries as a whole.

### ***Labour market implications of caring for caregivers***

Informal care can be a cost-effective way of providing care to disabled people, but, at the same time, reliance on informal support can have adverse consequences for the informal caregivers, such as stress, isolation and loneliness. Moreover, caring for a family member can result in the loss of economic opportunities, since caregivers often must end their labour participation or reduce the hours of paid work.

In order to determine the importance of all these factors on the burden of informal caregivers, we analyse the probability of being an informal caregiver, the probability of having labour problems due to care-giving tasks and the probability of suffering unmet needs in formal care, using data from the Eurobarometer. In an alternative exercise we evaluate, using data from the European Community Household Survey, a model of the probability of a caregiver being constrained in the amount or kind of paid work because of care duties. We use a probit model where the dependent variable is being constrained in the amount or kind of paid work because of being a caregiver. We find that women who are not working and the people who are caring for adults in the household are the ones with a higher probability of being constrained (the probability increases with age and with intensity of care responsibilities) in the labour market.

### **3.3 Policy implications**

Given the ageing of the population in the EU and the increased participation of women in the labour force, it is unquestionable that we will experience a substantial increase in the demand for long-term care services in the very near future. Year by year, more persons with disabilities will need assistance and support to enjoy a good quality of life and be able to participate in social and economic activities.

Although informal care could be an efficient and less costly procedure to satisfy the increasing need for long-term care services, relying exclusively on this source of care cannot be considered a solution, at least in the long run. This is further analysed in Work Package 6 of the ANCIEN project. Firstly, even if an increasing use of this type of care will help to reduce the long-term care government expenditures, it is also required that governments ensure that informal care provision evolves accordingly with certain quality standards. This responsibility will become more expensive and unattainable the higher the size of the informal care sector. Secondly, specifically for the case of Finland, we have found evidence that dependent people who receive formal care in institutions report higher levels of satisfaction and happiness than those that are not institutionalised. Although this evidence cannot be generalised, it points to a venue for future improvement of the LTC system.

Secondly, the results obtained with Finnish data on residential care suggest that there are limits to further de-institutionalisation of long-term care (the current policy stance in many countries). The severely disabled elderly in particular might be better off in residential care than in a home care environment. Thirdly, the fact that many informal carers feel constrained in their career possibilities is an additional argument for ensuring sufficient formal care provision, both at home and residential.

Moreover, as shown by our analysis, when clustering countries, the task-specific model appears as the most appropriate paradigm to characterise the experience of the European countries. Policy should be oriented to improve the formal care provision and at the same time to provide the necessary support to informal caregivers, either by means of financial support or by the development of new regulation and support actions in the labour market that allows caregivers to balance active lives and caring responsibilities, especially in those countries (Greece, Spain, the Netherlands, the United Kingdom, Austria, Hungary, Malta, Slovakia, Slovenia, Romania and Croatia) in which the conflict between labour market participation and caregiving is more evident.

As a final remark, policy-makers should enable caregivers to remain in paid work if they want to, as this helps them to have an independent life, to avoid burn-out and to sustain the caregiver's role. Many countries have deployed market labour policies that make it easier for informal caregivers to juggle working and caregiving responsibilities. We have appreciated that the lower probability of having labour problems in certain countries (Germany, Denmark) is associated with the implementation of measures aimed at reconciling labour and care.

## 4. The Influence of Technology on Long-Term Care Systems

### 4.1 Introduction

Typically, the provision of LTC has been reactive and episodic, causing an avoidable use of hospitals and residential facilities. The innovative organisational models that are being introduced to prevent, alleviate and control the consequences of compromised functional autonomy are intended to better meet the holistic health and well-being of citizens.

The meaningful use of Information and Communication Technology (ICT) and advanced home equipment may be crucial in the offer of more services. They need to be more targeted and effective to reduce the fragmentation of interventions by social and health operators, and the geographical dispersion of citizens and professionals on the ground.

The greatest impact on the future of LTC will not be due to the ad hoc and scattered diffusion of certain tools among individual citizens-consumers, but rather to large-scale organisational changes of the entire welfare system, supported by enabling technological services aimed at chronic diseases, fragility and healthy ageing. In fact, ICT and domotics may deeply influence the rise of new models of care by shifting the focus from residential care to home, thereby reducing hospitalisations, changing the roles of formal and informal carers and of citizens-patients, reducing functional limitations, frailty and its related risks and lessening the burden on informal carers.

Future coordinated care models with a proactive citizen role may be successfully deployed with appropriate technological support at an increasingly accessible cost, improving both the quality of life of affected individuals and their families, and the economic sustainability of the overall system.

The effects of technology on the LTC sector will be combined with socio-demographic developments, i.e. the increase in the number of elderly people, the reduction in family size, and changing lifestyles. To this end, two contexts should be considered:

- the **direct opportunities** to better adapt individuals to their daily activities and social context, living with long-term conditions and recovering as well as possible from the related loss of functionality, with the resulting chances to alleviate the burden on informal carers and restore their productive role in society to some extent; and
- the **indirect effects** that prevent or delay the need for LTC, e.g. by a focus on the risks for frail elderly people, timely interventions to avoid or reduce the consequences of health-threatening events and improve the care for chronic diseases.

The European Union has implemented numerous initiatives in this area, including: AAL-Ambient Assisted Living, ICT for Health and e-Inclusion, now integrated into the framework of the Digital Agenda and of the European Innovation Partnership on Active and Healthy Ageing.

The technological solutions available today can significantly improve the quality of life of citizens and their informal carers, allowing many of them to resume an active role in the community. The LTC system may improve the optimal management of resources, increasing both the quality and the appropriateness of care. The industry may also benefit the provision of services and the design and marketing of devices and ICT solutions.

Technology can massively impact LTC by altering the existing relations among the various actors. It can empower each member of the ‘virtual team’ built around an individual, by allowing him/her to perform more complex tasks than before, and possibly improving the labour division between players.

Three major benefits for quality may be envisaged: increased adherence to guideline-based care, enhanced surveillance and monitoring, and decreased medication errors. The main area of improvement is preventive health; the major efficiency benefit may result in a decreased utilisation of care.

## **4.2 Evidence and analysis**

Technologies may affect the future of each long-term condition in various ways, depending on several factors, e.g. the type and the stage of the condition, other health problems, the individual social context, the background of the local community, and the progress of health care and technologies. Furthermore, the decisions on LTC models and technologies by the policy-makers of a jurisdiction depend on the demographic, normative and economic factors.

A set of description criteria was developed in order to perform a detailed analysis of the possible influences of the technologies on any particular LTC scenario. Partners involved in WP4 of the ANCIEN project jointly assessed the degree of influence of technology in relation to three chronic conditions: diabetes, dementia, and obesity. The aim of this exercise was to formulate a comprehensive and systematic scheme to allow policy-makers to reach informed decisions about technologies in relation to the other priorities of intervention in a jurisdiction.

The scheme provides a systematic framework to explore an LTC scenario; it therefore allows it to collect and discuss the contributions by stakeholders, to compare various LTC scenarios for the expected evolution of needs and the potential influences of technologies, in order to devise the goals and the milestones of an action plan within a specific local context.

The scheme considers 51 criteria, organised in two sections and a number of sub-sections, as follows:

### **A. The LTC needs susceptible to technological assistance, with criteria focusing on:**

1. *The foreseeable evolution of demographic aspects, lifestyles and health care;*
2. *The limitations on ADL-IADL that may require LTC and*
3. *The required activities of formal and informal carers.*

### **B. A meaningful use of technological solutions, with criteria related to:**

1. *The opportunities increased by the technologies;*
2. *The potential impact of domotics, equipment and home devices;*
3. *The potential impact of domotics, equipment and (remote) devices on ADLs;*
4. *The potential impact of domotics, equipment and (remote) devices on IADLs;*
5. *The potential impact of devices allowing remote communication: role of formal carers;*
6. *The potential impact of devices allowing either the citizen or the informal carer to remotely communicate: reason for contact and*
7. *The potential impact of information systems.*

With respect to the needs for LTC in the different phases of the three case studies, the following notes apply regarding the potential evolution of the prevalence of the condition, the ADL-IADL limitations, and the demand for activities by formal and informal carers.

While the diabetic patient is normally able to cope with the therapy and minor consequences of the disease (if there are no severe complications), the persons in advanced stages of obesity or dementia are unable to perform self-care and remain completely dependent.

As regards the demand for health care activities, social activities and the continual presence of another person (formal or informal carer), diabetes in the initial and moderate stages requires a regular, periodic follow-up by the GP and the specialist. In its severe stage the complications of diabetes demand a good level of coordination among the various specialists. Regarding obesity, in the first stage the GP and the nurse should be able to manage the care plan, including the education of the individual about diet and lifestyle. In later stages, more professionals will be involved. As for dementia, clinical problems are not the most relevant ones with respect to the other issues.

New technologies can allow greater effectiveness and reduce the need for different types of services: hospitalisation, nursing care, home care, informal care, and self-care. In the initial and moderate stages of diabetes and obesity, technology can play a valuable role in delaying the progress of the conditions by increasing prevention and integrating the activities performed by different carers. Medium and severe stages of obesity may be managed with nursing facilities or at home with an informal carer supported by technology. However, technology cannot replace professional care in keeping a patient at home in cases of severe dementia and diabetes.

Regarding domotics, equipment and home devices, routine data acquisition may be improved by technology in the case of obesity and diabetes, where patients may collaborate in the process. Technology may have a considerable impact on dementia in terms of supervision of the patient and management of the environment, but in general it will play a marginal role in further improving and supporting ADLs; notable exceptions are the tools for supporting mobility and controlling continence in patients with dementia and obesity. Concerning IADLs, a large number of mature technological solutions are already in use and – apart from some particular activity for each case study – further impact will be generally moderate or irrelevant.

Technology could already play an important role in remote monitoring and remote visits, which can be beneficial to patients in terms of increased clinical effectiveness, patient-centeredness, and efficiency. Some further advances may be envisaged concerning remote visits by formal carers for complicated diabetes, which will have some indirect influence on LTC, and about the opportunities for tele-rehabilitation with a direct impact on LTC. Remote communication technologies work significantly in most stages of all the three pathologies (except severe stages of dementia) and could help the patient to be educated, trained, informed by carers, and to stay in touch with his/her own social network.

Finally, integrated information systems may play a critical role in supporting the work processes in care organisations, across all the pathologies, also regarding the administrative issues, the allocation of resources and quality control. Their role is less relevant for dementia, in those processes where the patient needs to collaborate. The effect of ICT on the chronic care model for diabetes is high, with an indirect influence on the related LTC.

### **4.3 Policy Recommendations**

The recommendations fall within four lines: the provision of technological support to various actors in a favourable context; the promotion of awareness in a country on the issues at stake and on the opportunities offered by technology; supporting the integration of LTC technologies into care processes, and the progressive production of a corpus of reference information ('infostructure') to foster a pervasive and interoperable development of the sector.

***The right context for the development of technology.*** Many solutions now available are recognised as being effective and sustainable in the international literature. It is also clear that the most important factor for successful implementation is a precise outline of the role of technology within a well-defined path of organisational change, and the presence of leadership to drive the change process. Without an implementation plan clearly redefining the responsibilities, roles, and behaviours of each actor, resistance to change may occur, which hampers the opportunity to get acquainted with technology as an essential component of a new care model and thus to establish a permanent solution.



***Increase awareness of the opportunities offered by technology.*** A major factor that hinders the development of technology in the LTC sector, although the benefits have been amply demonstrated, is the lack of awareness about all the opportunities offered by technology. In order to best use the limited resources available for LTC, various complementary strategies may be put in place to assist decisions in the public system, the insurance schemes, the voluntary organisations and families.

A first form of intervention is the development and coordination of a network of intra- and inter-regional information centres providing assistance on the rights of citizens; help in choosing the most suitable devices for each individual, providing information on the social and health care organisations (including volunteer organisations) and on their available services. The centres could also produce and distribute (multilingual) material to compare different types of devices and manage showrooms to offer the opportunity to test them. The network of centres could have a web portal, on which documents could be made available to citizens in electronic format and where a discussion on the problems in the LTC sector could take place. A set of pre-competitive ‘living labs’ can also be recommended. These centres would be an innovation space where industries, authorities, organisations, gather their experiences, present national and international best practices, and identify new user requirements for the design of new technologies.

Finally, short training modules could be organised to increase awareness among decision-makers, such as the managers in the municipalities, in the local health authorities and in voluntary organisations. This activity would not only have the goal of preparing them to design a roadmap and to monitor its progress, but also to create a network among managers to exchange information and updates and to support policy-makers in setting priorities and strategies.

***Improve the demand for industrial solutions.*** Industry involvement in LTC is still underdeveloped, even considering the inadequacy of the demand side, which is highly fragmented and with specific difficulties in entering into long-term programmes. Technology is often an issue left directly to the patient-consumer. Valid technological solutions, with proven benefits, already exist; however, unlike other technologies (e.g., diagnostic technology in health care), LTC technologies are still not fully integrated into care processes or daily activities. Researchers and decision-makers should investigate how to assess technologies, from the economic and organisational points of view, in order for them to take more informed decisions about how to update care models.

The mechanism and strength of influence of technologies on each long-term condition is very different across the various phases of its evolution and among the different conditions. The activities carried out in Work Package 4 of the ANCIEN project developed a systematic framework with a grid of criteria to analyse the potential influence of technologies on a series of features (related to ADL, IADL and the mutual roles of the individual, the formal and informal carers), and to work out systematically the specifications for technological solutions within each phase of a long-term condition. As a proof of concepts, the framework was applied to three stages of each of three case studies, respectively to dementia, diabetes and obesity, to show the large difference in the requirements within each scenario.

***Develop and maintain the ‘infostructure’ for semantic interoperability.*** A coherent future application of the technologies in the LTC sector may be accelerated by the production and maintenance of a robust infostructure in a computable format, i.e. a systematic definition of the details about the content shared between applications, made coherent at regional, national or international level. That infostructure, specific to the social and health sectors, includes: i) the systematic description of relevant care processes and related exchanges of documentation among the actors, with the criteria to select the information to be included in the various documents; ii) a unique name and an identifier for the main parameters and variables to be collected and exchanged in different contexts, each with a set of the allowed values and their respective codes; iii) a definition of each indicator of process and outcome, useful to build a dashboard for decision-makers; the adoption of clear and explicit definitions for indicators (uniform among health care organisations, municipalities and regions) would allow managers to compare similar realities; iv) the modalities of interaction between the home equipment and the rest of the information system.

The content can be built gradually, starting from processes and data considered as most appropriate by the policy-makers in each jurisdiction; the content can then be extended in accordance with the local

development plans, also considering the relationship with the efforts on an Electronic Health Record (EHR), which is going to be implemented in several countries and regions. In particular, the infrastructure of the EHR may be used for social care processes other than health care.

In addition, a topic certainly useful to managers is the definition of detailed professional profiles for technology managers and related training plans. Technologies, to be successfully exploited, need innovators able to understand how to integrate them into the care processes, and how to manage the relationships among all the stakeholders and players.

## **5. Quality Assurance Policies and Indicators for Long-Term Care in the European Union**

### **5.1 Introduction**

The provision of high quality, long-term care (LTC) is an important policy goal. Yet considering the multidimensionality of the concept of quality, the vulnerability of many LTC recipients, the inevitable scarcity of resources and the importance of informal care, it is difficult to ensure high quality LTC. In this Policy Brief we report on quality assurance policies and indicators for LTC in the following EU countries: Austria, Estonia, Finland, France, Germany, Hungary, Italy, Latvia, Poland, Slovakia, Slovenia, Spain, Sweden, the Netherlands and the UK.

Data were collected in two ways: first, we developed a survey on quality assurance policies and indicators, and submitted it to all the partners involved in WP5 of the ANCIEN project; in a second step, survey data were analysed by LUISS to cluster countries according to their similarity in quality assurance policies. Also, we collected quality indicators used at the national level in each country and categorised them according to different criteria.

This section is structured as follows: we first discuss the main findings of the analyses of survey data; then we derive the main implications for national and EU-level policies and interventions.

According to the World Health Organization (2002), the goal of LTC is “to ensure that an individual who is not fully capable of long-term self-care can maintain the best possible quality of life, with the greatest possible degree of independence, autonomy, participation, personal fulfilment and human dignity”.

Unlike acute care, LTC does not eliminate diseases but aims at alleviating suffering, reducing discomfort, improving the limitations caused by disease and disability, and maintaining the best possible levels of physical and mental functioning.

These aims encompass a broad mix of services, such as personal care, health care and life management (e.g. shopping, medication management and transportation). They also span a wide range of resources, such as assistive devices (e.g. canes and walkers), more advanced technologies (e.g. emergency alert systems and computerised medication reminders) and home modifications (e.g. ramps and hand rails). As for the settings, LTC may be either institutional or home-based, and formal or informal.

Again unlike the acute sector, many LTC professionals are not specialised and are relatively unskilled. The sector is labour-intensive. Most LTC activities are performed by paraprofessionals with a variety of skills (home assistants, housekeepers, nurse assistants, activities staff or informal caregivers). Skilled workers (nurses, physicians, etc.) are involved to a lesser degree than in acute care. Medical devices are also significantly less complex and costly than those used for acute care. Many of the core LTC activities concern help with basic functioning or improving patient autonomy in performing basic or instrumental activities of daily living.

Any approach to assessing the quality of LTC needs to recognise all these differences from acute care, and the following in particular:

- Long-term care is both a health and a social issue. For the health service components of long-term care, judgments about the quality of care may emphasise the medical and technical aspects of care.

For other facets of long-term care, judgments about the quality of care reflect the opinions and satisfaction of consumers.

- The potential and actual role of consumers is an essential element in long-term care. Thus the desired health outcomes depend on the patient's perspective and activation.
- For nursing homes and residential care settings, including assisted living, the physical environment of the facility can contribute to the physical safety and functional mobility of residents and, more broadly, to their quality of life.
- The very essence of LTC, more specifically the persistent nature of the disabilities and of the chronic conditions, has an impact on i) the development of interpersonal relationships among providers, families and patients; ii) the physical adaptation of the home or the infrastructure of facilities to accommodate or attend patients on a longstanding basis; and iii) the greater need for coordination among different types of carers.

In WP5 of the ANCIEN project, we took into account all these variables in understanding diverse national approaches to promoting the quality of LTC. A caveat is that having a sound quality assurance policy does not automatically guarantee that a country will have high quality LTC. We defined quality as a multidimensional concept encompassing the effectiveness of care, patient safety, responsiveness (or patient-centeredness) and the coordination of providers. The first three dimensions have been identified by the OECD as the main issues of any approach to quality in health care. We included coordination as a fourth dimension because we believe that quality in LTC, given the complexity of LTC, must also include the coordination of different providers. Continuity of care (across social care and health care, as well as across levels of care) is a key issue in ensuring the quality of LTC.

## **5.2 Evidence and analysis**

By analysing 15 EU countries, we identified the main features of quality assurance policies outlined below.

**Integration.** LTC systems are so complex and involve so many stakeholders and decision-makers that no one is fully responsible for LTC. Furthermore, LTC is intrinsically a multidimensional activity that requires multiple competencies to carry it out effectively, the coordination of LTC providers is crucial to guaranteeing a high level of quality. Coordination is actually related to several key issues for quality in LTC:

- i. *Timeliness*, that is the degree to which patients are able to obtain care promptly. The coordination of care is critical for timeliness when a patient needs to go through different stages of care and across providers;
- ii. *Continuity*, that is the extent to which the health care specified for users, over time, is coordinated across providers and institutions; and
- iii. *Integration between primary and secondary care, and between health care and social care.* Without this, quality in coordination may be undermined.

In different countries there is a growing awareness that the quality of LTC is based on an effective integration of health and social services. On average, there is a medium level of integration of the components of LTC. Yet there are fewer indicators for assessing the quality of coordination than for other dimensions (such as effectiveness and responsiveness). According to country reports, transitions from/to hospitals is an issue to be addressed.

**Consistency between LTC policies and LTC quality assurance policies.** Consistency is a central issue in some countries because of the lack of integration of responsibilities. LTC policies and LTC quality assurance policies may be developed by different actors. Also, quality assurance policies may not reflect the actual use of LTC.

As discussed in the above section, countries with high scores in the use of formal care and high levels of public spending on LTC have consequently invested in quality assurance policies in formal care. Countries with high co-payments are less prepared for quality systems, and should invest more in

quality assurance policies in home-based and informal care. The latter aspect may also be relevant for countries with high levels of public spending that are trying to increase the role of informal care.

**Transparency.** Today, in LTC the role of the user/patient is often very limited. Therefore, it is very important not only to take into account the patients' needs but also their expectations, including the desire for choice. To do so patients need to be informed about the quality of the providers. This can be done by improving transparency and making better information available to users. Our results, however, reveal that most countries do not provide public data about the quality of care in LTC institutions.

**Quality of informal care.** In many countries, informal caregivers sacrifice part of their lives to take care of their elderly family members. A quality LTC system therefore should not only be based on the assessment of the patient's needs. As the bulk of LTC is provided by informal caregivers and is dependent upon their health and well-being, caregivers' needs must also be assessed and satisfied. Our results show that most interventions entail financial support for buying devices, training/counselling of the informal caregivers, and assessing the health conditions and personal needs of patients.

**Monitoring.** Monitoring systems are needed to support the evaluation of quality, promote informed policies and provide feedback to the various actors in the field. On average, monitoring for authorisation/accreditation occurs every three years (ranging from one to five years).

**Education.** Competent staff is a key factor for the quality of LTC providers. Yet LTC needs staff who are specialised in the care of the elderly. Among the many professional roles that are involved in LTC, the most highly qualified staff seem to be GPs. Ten countries report that GPs are provided specific education for LTC. Fewer countries report the same for other roles. Nurses also play a pivotal role in LTC facilities and home nursing care. The shortage of nurses is a threat to the quality of LTC.

### **5.3 Policy options to improve the quality of LTC**

There may be many ways to tackle a certain problem concerning quality and this research may not be specific enough to pinpoint the best. Nevertheless, below we identify some policy recommendations to address specific quality issues in LTC.

#### **Integration**

- Policy-makers should stimulate the development of methods to measure the integration of LTC responsibilities and the collection of more precise data on integration.
- National policy-makers should promote the integration of the currently scattered responsibilities at all levels. LTC should be addressed as a national priority. An integrated strategic plan on LTC (including strategies on quality) should be developed at the national level and implemented by local authorities.
- The European Commission and the national authorities should promote the diffusion of best practices. Examples in this regard are the project "Medtogether" in Austria and Law §92b SCBXI on Integrated Care in Germany.
- National policy-makers should support the use of information and communication technology (ICT) for the integration of all the actors involved in LTC, including patients. The use of ICT has the potential to reduce risks and increase quality by standardising care processes, enabling the remote monitoring of patients and empowering the patient in self-treatment (WP4 deliverables).
- Local health and social authorities could organise the provision of services around the patient by identifying a case manager. In some countries this may be the GP, while in others, such as Estonia, it may be a specialist (gerontologist).

#### **Consistency between LTC policies and those on the quality of LTC**

- Countries with a large diffusion of informal LTC should address the issue by having a quality assurance policy for informal care (to protect caregivers and care recipients) and for supporting

informal caregivers through services (e.g. respite care). (See the discussion above on the quality of informal care.)

### ***Transparency***

- The European Commission and the national authorities should promote/recommend transparency on information about the results of quality assessments. A national commission for the selection of shared criteria for the quality assessment would be needed, to avoid criticism about methodology.
- The European Commission and the national authorities should promote the diffusion of best practices on transparency. In Germany, the quality assessment results of LTC providers have been published online since 2008. In the Netherlands, data about the quality assessment results of LTC organisations are publicly available on a voluntary basis. In 2008, 49% of health care providers were already publishing their data. The long-term target is to reach 100%. In Slovakia, data about the quality assessment results of LTC organisations will become publicly available as the new legislation becomes effective from 2013. In the UK, a system providing quality ratings for providers began operating in 2003 for formal institutional care and 2005 for formal domiciliary care. Since June 2010, however, it has no longer been in operation and there is no news about a replacement programme.

### ***Quality of informal care***

- National and local authorities could promote networking among local authorities, volunteer organisations and families.
- The European Commission and the national authorities could promote the diffusion of best practices in this regard. Examples include the experience of the municipalities in Sweden, the Mezzo association for informal caregivers in the Netherlands and national training programmes, such as “Caring with Confidence” in the UK (even if it has been discontinued).
- Local authorities should assess the needs of informal caregivers to ensure personalised support is provided in terms of caregiver training, statutory visits and prevention campaigns. For instance, in the UK the NHS (National Health Service) website provides informal caregivers lengthy information on medical devices and assisting technologies, on how to move and handle the patients.
- National authorities could promote the diffusion of standard information and communication technologies for remote monitoring, thus alleviating the burdens of informal caregivers.

### ***Monitoring***

- The European Commission should recommend that member states monitor providers according to the different dimensions of quality: the effectiveness of care, safety and responsiveness to patient’s needs.
- Monitoring frequency should be standardised across countries to enable comparisons of the impact of quality assurance policies at the national level on the specific dimensions of quality of care.

### ***Education***

- National authorities should promote the development of a standard curriculum for each LTC role.
- The European Commission should promote research studies on best practices for the training, hiring and retention of geriatric nurses as well as for other LTC roles in LTC systems and providers.

## 6. Projections of Use and Supply of Long-Term Care in Europe

### 6.1 Introduction

Sharp increases in the numbers of older persons and an improved survival of disabled older persons are expected to cause an increase in the demand for and use of long-term care (LTC) in the coming decades in all European countries. At the same time, population ageing is likely to have a profound impact on future availability of both formal and informal caregivers. As Work Packages 1 and 3 of the ANCIEN project and other comparative studies have demonstrated, European countries differ considerably in how they organise, finance and allocate LTC. There is considerable variation not only in levels of formal and informal care use, but also in how care use is related to disability, household composition, and other characteristics of older persons. Supply side analyses have shown large country differences in the prevalence of informal care giving and in formal care workforce participation rates. Furthermore, current and predicted disability levels are much higher in some countries than in others. How population ageing and other societal trends (e.g. changing living arrangements, higher female employment rates) will affect future use and supply of formal and informal care is therefore likely to differ considerably across European countries.

WP 6 of ANCIEN has delved into the issue of how supply and use of LTC are likely to develop in different care systems. Projections of use and supply of residential care, formal home care and informal care have been made up to 2060 for four countries, Germany, the Netherlands, Spain and Poland, identified in WP1 as representative of different LTC systems. The projections focus on personal care, i.e. help with basic activities of daily living (ADLs) such as bathing, dressing, eating and getting in or out of bed.

The future use of LTC has been projected using macro-simulation (cell-based) models. Probabilities of care utilisation by persons aged 65 and over have been estimated using the cross-nationally harmonised SHARE data (home care use) and national databases (residential care use). Due to data limitations, the projections for Poland include residential care only. Numbers of care users have been projected under a range of bio-demographic, risk factor and socio-demographic scenarios, relying on the population projections by age, gender and disability provided by NIDI in WP 2 of ANCIEN, and available population projections by household composition (national databases) and education. Likewise, the future supply of informal care has been projected using cell-based models. The models focus on provision of personal care by persons aged 50 and over. The projections are based on micro models using SHARE data, linking the probability of being an informal caregiver to a number of socio-demographic variables. The models distinguish between help given to people in the older generation (intergenerational care) and help given to spouses or partners aged 65 and over (spouse care). The probability of providing informal care is assumed to remain the same in the future as it is at present, controlling for key socio-demographic variables. The supply of formal care has been projected using aggregate labour supply models, and simple assumptions of constant fractions of LTC workers in the workforce. Trends in demand and use of LTC have been confronted with future LTC capacity, both in terms of the formal care workforce and informal care availability.

### 6.2 Evidence and analysis

#### *Future use of residential care, formal home care and informal care*

In all ANCIEN representative countries, the numbers of users of residential care, formal home care and informal care are projected to increase between 2010 and 2060 under the base DELAY scenario. However, trends differ markedly for different care categories within countries, and there are large between-country differences in trends for similar care categories as well. Relative to the base year, the increase in the use of residential care is projected to be highest in the Netherlands (+ 200%), followed by Spain (+ 162 %) and Poland (+ 152%) (see Table 6.1). The smallest increase in residential care use is projected for Germany (+102%).

*Table 6.1 Projected numbers of residential care users in Germany, the Netherlands, Spain and Poland, 2010-2060, DELAY scenario (in thousands)*

	2010	2015	2020	2025	2030	2035	2040	2045	2050	2055	2060	% increase 2010-2060
DE	648	729	814	906	978	1028	1108	1218	1321	1360	1310	102%
NL	142	160	180	206	245	299	339	375	408	429	426	200%
ES	364	400	426	465	522	593	680	777	858	918	954	162%
PL	59	67	77	88	98	110	121	129	136	141	149	152%

*Source:* Geerts, Willemé & Comas-Herrera (2012), “Projecting long-term care use in Europe”, in Geerts, Willemé & Mot (eds), “Projecting long-term care use and supply in Europe”, ENEPRI Research Report No. 116, CEPS, Brussels.

Use of both formal home care and informal care is projected to increase most in Spain. Under the base DELAY scenario, the numbers of formal home care users are projected to increase between 2010 and 2060 by 150% in Spain, by 79% in Germany and by 116 % in the Netherlands (Table 6.2). For informal care use, an increase of 140% is projected for Spain, while for Germany and the Netherlands the projected increase is much lower (51% and 66% respectively, see Table 6.3).

*Table 6.2 Projected numbers of formal home care users in Germany, the Netherlands and Spain, 2010-2060, DELAY scenario (in thousands)*

	2010	2015	2020	2025	2030	2035	2040	2045	2050	2055	2060	% increase 2010-2060
DE	756	849	940	1014	1095	1180	1275	1364	1410	1403	1357	79%
NL	229	258	296	338	387	436	472	493	502	502	493	116%
ES	417	463	494	532	592	663	751	851	937	1001	1042	150%

*Source:* Geerts, Willemé & Comas-Herrera (2012), “Projecting long-term care use in Europe”, in Geerts, Willemé & Mot (eds), “Projecting long-term care use and supply in Europe”, ENEPRI Research Report No. 116, CEPS, Brussels.

*Table 6.3 Projected numbers of informal care users in Germany, the Netherlands and Spain, 2010-2060, DELAY scenario (in thousands)*

	2010	2015	2020	2025	2030	2035	2040	2045	2050	2055	2060	% increase 2010-2060
DE	2700	2846	3102	3364	3710	3975	4070	4133	4197	4198	4075	51%
NL	93	107	123	138	150	161	167	165	159	155	154	66%
ES	1176	1280	1376	1486	1635	1841	2080	2343	2577	2747	2825	140%

*Source:* Geerts, Willemé & Comas-Herrera (2012), *ibid.*

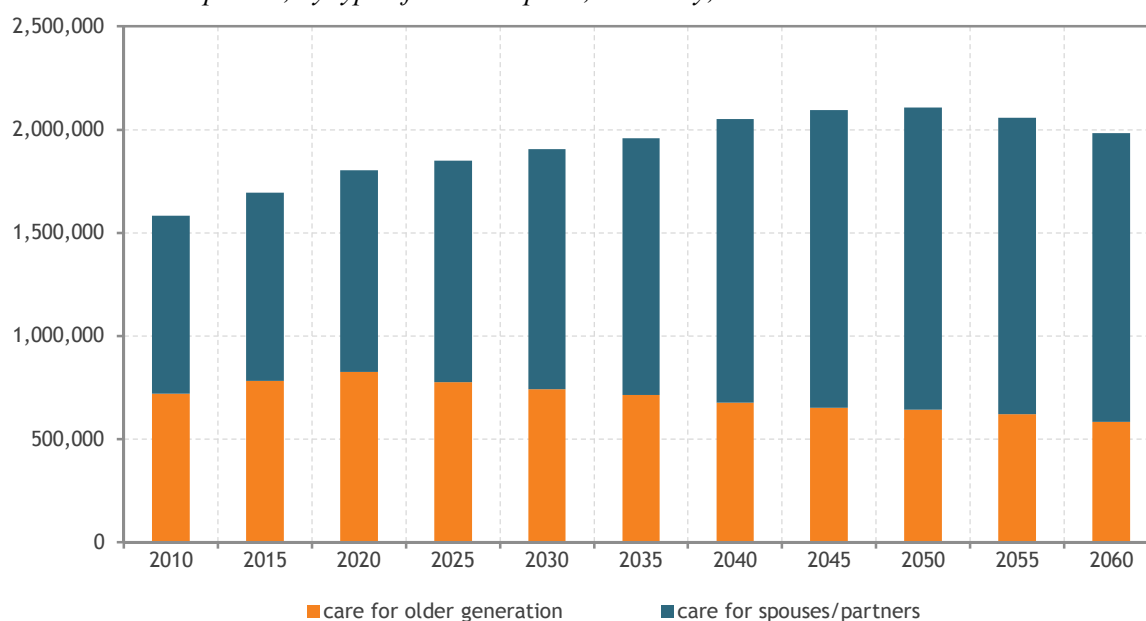
For all countries, the percentage increase in the numbers of residential care users is projected to be higher than the percentage increase in the numbers of formal home care users. The smallest increases are projected for informal care use. While for Spain the differences between care categories are rather small (under the base scenario use of residential care is projected to rise by 162% and use of informal care by 140%), differences are much larger for the Netherlands (a 200% increase for residential care but an increase of only 66% for informal care).

These differences in care utilisation trends can be related to demographic, epidemiological and care system factors. Among European countries, the timing, extent and speed of population ageing varies considerably. Furthermore, age-specific prevalence of disability also differ, as does the extent to which formal and informal care use is related to care needs, potential informal care availability and other characteristics of older persons.

### *Future supply of informal and formal care*

In all the ANCIEN representative countries, informal care supply, by people aged 50 and over, is projected to increase both in the shorter term, over the next 30 years, and in the longer term, over the next 50 years. The projections for Germany show an increase in the numbers providing personal care to older people over the next 50 years, with numbers rising from approximately 1.6 million in 2010 to approximately two million in 2060 (Figure 6.1). This increase is solely due to an increase in spouse care. Care for the older generation is projected to fall in absolute terms.

*Figure 6.1 Estimated numbers of people aged 50 and over providing informal personal care to an older person, by type of care recipient, Germany, 2010-2060*



*Source:* Pickard & King (2012), “Modelling the future supply of informal care for older people in Europe”, in Geerts, Willemé & Mot (eds), “Projecting long-term care use and supply in Europe”, ENEPRI Research Report No. 116, CEPS, Brussels.

As shown in Figure 6.2, the projections for the Netherlands show an increase in the estimated numbers providing informal personal care to older people over the next 50 years, with numbers rising from approximately 75,000 in 2010 to approximately 105,000 in 2060. As in Germany, the projected increase in the numbers providing informal care is solely due to an increase in spouse care. Care for the older generation is projected to fall in absolute terms, though the decline is not as great as in Germany.

In Spain, there will be an increase in the numbers providing personal care to older people over the next 50 years, with numbers rising from approximately one million in 2010 to approximately 1.5 million in 2060, an increase of 40%. In Spain, this increase is a result of increases in both spouse care and care for the older generation.

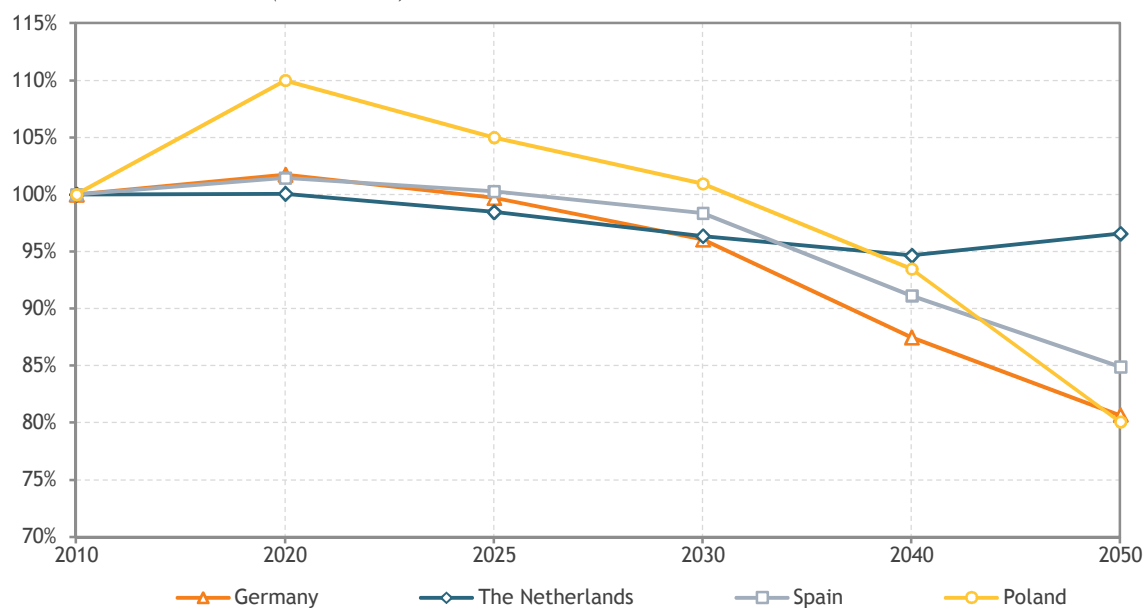
In Poland, there will be an increase in the numbers providing personal care to older people over the next 50 years, with numbers rising from approximately 500,000 in 2010 to 600,000 in 2060, an increase of nearly 15% (Figure 6.2). As in Germany and the Netherlands, the increase in provision of care for older people in Poland is solely due to an increase in spouse care, which rises by over 50% between 2010 and 2060.

In all four ANCIEN representative countries, the relatively slow projected rise in informal care supply is not primarily due to trends in spousal care, which is projected to rise in all countries. The relatively slow growth in informal care supply is due to projected trends in care for the older generation, which are, in turn, driven by underlying demographic trends in the numbers of people aged 50 to 64.



Projections of the LTC workforce show a rather similar trend until 2025 for the ANCIEN representative countries (Figure 6.2). All countries stay at a more or less stable number of LTC workers, with the exception of Poland, where the number of LTC workers will increase between 2010 and 2020. After 2030 the countries split into two clusters. The first cluster, consisting solely of the Netherlands, will experience only a very small decrease of LTC workers until 2040 and a final increase in the number of LTC workers between 2040 and 2050. The second group, consisting of Spain, Germany, and Poland, will experience a much stronger decrease and lose 15% to 20% of its LTC workforce between 2010 and 2050 if current patterns persist.

Figure 6.2 Projections of the LTC workforce for Germany, the Netherlands, Spain and Poland, 2010-2050 (2010=100)



Source: Wittwer & Goltz (2012), "Projections of the future long-term care workforce", in Geerts, Willemé & Mot (eds), "Projecting long-term care use and supply in Europe", ENEPRI Research Report No. 116, CEPS, Brussels.

### **Growing care-gaps**

Drawing on a methodology originally developed in relation to projections of informal care supply and demand in England, the results of the projections of use of informal care under the base DELAY scenario are compared with the projections of informal caregivers, and a similar comparison is made for the projections of formal care use and the projections of formal care workers.

In the methodology, a comparison is initially made between projected numbers of informal (or formal) caregivers and projected numbers of informal (or formal) care-users, with the projections of informal (or formal) caregivers assuming constant probabilities of providing informal care (or constant rates of LTC workforce participation). These projections of the numbers of caregivers are then compared with the numbers of caregivers that would be needed if the supply of informal (or formal care) were to meet demand in future. The estimate of the number of caregivers that would be needed if supply were to meet demand is calculated by assuming that the current ratio of caregivers to care-users remains constant in future years. A potential shortage of caregivers, an informal (or formal) 'care gap', can then be identified.

*Table 6.4 Informal care-users, informal caregivers at constant ratio of caregivers to care-users, informal caregivers at constant probability of providing care and informal ‘care gap’, Germany, the Netherlands, Spain, 2010 and 2060 (in thousands)*

		Care-users (A)	Caregivers at constant ratio of care-givers to care-users (B)	Caregivers at constant probabilities of providing care (C)	Informal ‘care gap’ (B)-(C)
Germany	2010	2,700	1,583	1,583	0 <sup>a</sup>
	2060	4,075	2,389	1,984	405
Netherlands	2010	93	74	74	0
	2060	154	123	103	19
Spain	2010	1,176	1,042	1,042	0
	2060	2,825	2,504	1,461	1,043

*Note:* It is important to note that a zero care gap does not imply adequacy of current levels of care.

*Sources:* Pickard & King (2012), “Conclusions – Informal care supply and demand in Europe”, in Geerts, Willemé & Mot (eds), “Projecting long-term care use and supply in Europe”, ENEPRI Research Report No. 116, CEPS, Brussels.

Table 6.4 shows that the projected numbers of informal caregivers, based on constant probabilities of providing care, are lower in 2060 than the numbers that would be needed if supply were to meet demand. By 2060, the ‘care gap’ between the numbers of caregivers projected to be available and the numbers needed to meet demand amounts to approximately 400,000 caregivers in Germany, approximately 20,000 caregivers in the Netherlands and over a million caregivers in Spain. The key conclusion of the comparison of informal care supply and demand is that the supply of informal personal care to older persons in representative European countries is unlikely to keep pace with demand in future years. The reason why informal care does not keep pace with demand is primarily to do with trends in intergenerational care, which are themselves based on underlying demographic trends in the numbers of people aged 50 to 64. The informal ‘care gap’ is particularly large in Germany and Spain, and this in turn reflects the heavy reliance on informal care in the long-term care systems in these countries.

*Table 6.5 Formal care-users, formal care workers at constant ratio of care workers to care-users, formal care workers at constant fraction of workforce and formal ‘care gap’, Germany, the Netherlands, Spain, Poland, 2010 and 2050 (in thousands)*

		Care-users (A)	Care workers at constant ratio of care workers to care-users (B)	Care workers at constant fraction of workforce (C)	Formal ‘care gap’ (B)-(C)
Germany	2010	1,405	631	631	0 <sup>a</sup>
	2050	2,731	1,227	509	718
Netherlands	2010	371	236	236	0
	2050	911	581	228	353
Spain	2010	781	430	430	0
	2050	1,795	988	365	623
Poland	2010	59	18	18	0
	2050	136	42	15	27

*Note:* It is important to note that a zero care gap does not imply adequacy of current levels of care.

*Source:* Geerts & Willemé (2012), “Conclusions – Formal care supply and demand in Europe”, in Geerts, Willemé & Mot (eds), “Projecting long-term care use and supply in Europe”, ENEPRI Research Report No. 116, CEPS, Brussels.

As Table 6.5 shows, in all four countries, in 2050 the projected numbers of formal LTC workers based on constant workforce participation rates are lower than the numbers that would be needed if supply of formal care were to meet demand. The resulting formal ‘care gap’ amounts to approximately 700,000 LTC workers in Germany, 350,000 care workers in the Netherlands, 625,000 care workers in Spain, and 27,000 care workers in Poland.

### **6.3 Policy implications and recommendations**

The inevitable rise in the numbers of elderly persons in Europe as a result of the ageing of the baby-boom generation and increased life expectancy are expected to lead to a corresponding increase in the demand for LTC in the coming decades. The challenges that this increased demand will raise are threefold. First, the projections of use and supply of informal and formal care of the ANCIEN project have shown that the supply of care is unlikely to keep pace with demand in future years. Given that the informal ‘care gap’ is attributable primarily to trends in intergenerational care, if more people are to provide care, they are likely to be people of ‘working age’. There is pressure in all European countries for people of ‘working age’ to be in employment, in order to maximise the tax base in the context of population ageing. It seems unrealistic to expect people to combine regular personal care for an older person with high rates of employment. It seems likely that, in response to the informal ‘care gap’, more formal services will need to be provided. However, at current LTC workforce participation rates, the supply of formal personal care, in turn, is unlikely to keep pace with demand. The key driving factor of the projected shortages, both informal and formal, is demographic change: smaller birth cohorts after the baby boom generation resulting in lower numbers of available carers, both professional and informal. If this ‘care gap’ is not filled, the available care will not suffice to meet growing demand.

A second challenge that the future demand will present is the associated rise in LTC expenditure and the increasing burden on social security or government budgets, if growing needs are partially met by growing formal care supply. This will be a major problem in countries that rely heavily on formal care.

Third, the projected shortage of informal caregivers will further increase the already substantial burden the carers are facing (such as labour market problems, physical and mental health problems due to workload and stress, etc. If, due to budgetary constraints, the projected additional demand would be shifted towards informal care, this will further exacerbate the situation of elderly spouses and adult children. Alternatively, if informal carers will not be able to increase their supply of care further because of labour market obligations and other obstacles, the situation of disabled elderly people will deteriorate. Meeting the required care capacity, even regardless of budgetary constraints, raises the problem of maintaining an adequate level of quality of care.

The diverging trends in future LTC demand and supply raise the question of whether technological advances could help reduce the care gap, essentially by boosting the productivity of formal and informal care workers or by reducing the need for care in the first place. While it is hard to answer this question in any definite way, technology certainly has the potential to help in a variety of ways, some of which have been documented in Work Package 4 of the ANCIEN project. Examples include improved independence of disabled elderly people due to remote monitoring systems, assistive devices etc., but also the potential improvements offered by information and communication technology in coordinating and organising LTC. Furthermore, technology can support improvements in the diagnosis and treatment of chronic conditions that may slow the increase in the need for LTC. Whether these efficiency gains will suffice to bridge the care gap is impossible to assess, so it is probably wise to anticipate an increasing care burden in European countries and to start making plans to deal with its consequences.

## 7. Performance of Long-Term Care Systems in Europe

### 7.1 Introduction

Evaluation of long-term care (LTC) systems is a relatively underdeveloped but important subject. Countries such as Sweden, Denmark and the Netherlands were already spending around 4% of their GDP on LTC in 2010. While many new member states spent less than 1% of GDP in 2010, all European countries expect a large increase in LTC expenditures over the coming decades because of population ageing. Ageing will not only make expenditures rise, it will also increase the importance of having a well-organised LTC system.

The aim of Work Package 7 (WP7) of ANCIEN is to assess the performance of LTC systems. We attempt to make progress with this complex subject to the extent that the available data permit. The ANCIEN project selected a set of criteria against which the performance of LTC systems can be evaluated. The information about performance is based on previous ANCIEN work packages, external sources and additional analyses within WP7. This Policy Brief describes the performance criteria and summarises the results of the additional analyses regarding: the quality of life of LTC users, equity of LTC systems and projections of LTC expenditures. It also presents results for other important aspects of performance (such as quality of care and the burden of informal caregiving). The research report on WP7 presents an overview of available information on performance criteria for all countries studied in ANCIEN. This section summarises the final evaluation that concentrates on four representative countries, for which we have more complete information on performance. The selection of these countries took place in WP1, where typologies of LTC systems were developed. We selected Germany, the Netherlands, Spain and Poland to represent each of four types of LTC systems.

### 7.2 Evidence and analysis

#### *Performance framework*

We studied the criteria that international organisations and national governments use for the performance of LTC systems. From those criteria, we selected criteria that are strongly affected by the LTC system and capture all important aspects of these systems without too much overlap. Also considering data availability, this yielded the following set of core criteria for the performance framework:

- i. Quality of life of (potential) LTC users
- ii. Quality of care
- iii. Total burden of care: financial burden and the burden of informal caregiving
- iv. Equity of the LTC system
- v. Choice

The total burden of care consists of two aspects: expenditure on paid care (the financial burden), but also the resources that are supplied by unpaid informal caregivers. These caregivers spend time and effort on LTC. Depending on the circumstances, informal caregiving can lead to labour market problems and mental health problems. It is thus important not to neglect the burden of informal caregivers in determining the total burden of care.

We describe below how European countries score on these criteria, followed by the overall evaluation.

#### *Quality of life of LTC users*

To study the impact of LTC systems on the quality of life of users, we analyse the experience of users on three aspects of the LTC system on which we have data via the international SHARE database. These aspects are the probability that a person receives help in case of limitations (in mobility, iADL or ADL), the probability that this help is sufficient and the difference between the life satisfaction of people with and without limitations in different countries. Via this latter aspect, we aim to measure the properties of the LTC system on which we do not have data, such as control over daily life and the dignity of older persons with limitations. The main idea is that the difference in life satisfaction of

people with and without limitations is an approximation of these unobserved properties once we control for the health status of people, the country of residence, whether people receive help and the sufficiency of this help (we also control for many other characteristics and the reporting style of respondents). An important caveat to keep in mind is that the SHARE database only includes persons who live at home.

Table 7.1 summarises the results. It presents groups of significantly differing countries for each of the three aspects. The table shows that many countries score high on some aspects and not so high on others. Germany, for example, scores very high on persons with limitations getting help, but the scores for the help meeting the needs and the unobserved properties of the LTC system are much lower. The Netherlands scores high on the sufficiency of the help, but the results are mediocre for the other aspects. Poland scores low on all aspects except the unobserved properties of the LTC system, where it scores medium high. It is important to note that Poland has a high number of people with a limitation and this may impact the results. Spain scores low or medium-low on all aspects. However, Spain carried out LTC reforms since the data were collected in 2006-07, which on the one hand had the potential to improve the score, but on the other hand were severely hindered by budget cuts because of the economic and financial crisis. Switzerland, Belgium and France score consistently high on all three aspects.

*Table 7.1 Relative experience of LTC users for groups of countries*

Country name	Level of help	Level of sufficiency	Unobserved system properties
Austria	medium high	medium	medium low
Belgium	medium high	medium	medium high
Czech Republic	medium high	medium	low
Denmark	medium	medium	medium
France	medium	medium	high
Germany	high	medium	medium low
Greece	medium low	low	medium
Italy	medium low	high	medium low
Netherlands	medium high	high	medium low
Poland	low	low	medium high
Spain	medium low	low	medium low
Sweden	medium	low	medium low
Switzerland	medium high	high	medium
Number of groups	5	3	5

*Source:* R. Faber and E. Mot (2012), “The experience of LTC users”, in Mot, Faber, Geerts and Willemé (eds), “Performance of Long-Term Care Systems in Europe”, ENEPRI Research Report No. 117, CEPS, Brussels

We reach several conclusions. For receiving help with their limitations, older persons living at home are best off in Germany out of the 13 countries in our sample. Given that help is available, the sufficiency of the help is best ensured in Switzerland, Italy and the Netherlands. The unobserved properties of the LTC system are most favourable in France. An older person who considers all three aspects of the LTC experiences important might be best off living in Belgium, Switzerland or France.

### ***Quality of care***

The Eurobarometer 67.3 survey provides a general measure of the quality of LTC services for a wide range of European countries. The respondents were asked to evaluate the quality of care services for dependent people in their home and the quality of nursing homes. Based on these indicators, only a relatively small variation can be observed in the quality of services across the analysed countries. According to these statistics, the quality of services is generally low in the new member states, whereas it is relatively high in Austria, Germany, France, the Netherlands and Sweden.

### *The total burden of care*

**The burden of formal caregiving.** The predicted financial burden of care in 2040 is an indicator for the sensitivity of the LTC systems to ageing. We measure this burden by the predicted expenditures on residential and formal home care relative to GDP in 2040. These projections are produced by multiplying the projected numbers of care users (from WP6 of ANCIEN) with average costs per user.

Table 7.2 shows the predicted *public* expenditures, based on the DELAY scenario. The table also shows the results of a simulation exercise designed to disentangle the effect of demographic factors (differences in age and gender composition) and disability from other influencing factors. Thus we apply the population structure of the “country depicted in the row”, but use the usage probabilities and unit costs of care of the “country in the column”. Missing simulation results in the tables are due to the lack of appropriate data.

*Table 7.2 2040 public LTC expenditures as percentage of GDP (row country: demography)*

Usage and unit cost country		DE		ES		NL	PL
	Formal home care	Residential care	Formal home care	Residential care	Formal home care	Residential care	Residential care
DE	<b>0.6</b>	<b>0.932</b>	0.191	0.467	1.526	4.794	0.035
ES	0.497	0.854	<b>0.165</b>	<b>0.383</b>	1.285	3.885	0.03
NL	0.391	0.532	0.126	0.339	<b>1.014</b>	<b>3.325</b>	0.028
PL	1.231	2.64	0.427	0.762	2.829	10.01	<b>0.087</b>

*Source:* A. Bíró (2012), “Overall evaluation of performance”, in Mot, Faber, Geerts and Willemé (eds), “Performance of Long-Term Care Systems in Europe”, ENEPRI Research Report No. 117; simulation results supplied by FPB.

On the basis of these calculations, the projected Dutch public expenditures on residential and formal home care are the highest among the four analysed countries (4.3% of GDP). The second highest expenditures are projected for Germany (1.5% of GDP in 2040). However, the simulated expenditures are considerably higher if the Polish demographic structure and disability are applied to the usage rates and unit costs of the Netherlands (12.8% of GDP). The predicted public expenditures in the Netherlands are high because of the high utilisation of formal LTC services, but still these expenditures are tempered by the relatively favourable demographic structure of the country.

The predicted private expenditures on residential and formal home care are lower than the public expenditures, but the pattern of the differences among the countries is similar to the public expenditures. The main difference is that the predicted total private expenditures relative to GDP are similar with using the German or the Dutch usage rates and unit costs. Again, applying the Polish demographic structure and disability strongly increases the predicted expenditures.

Although due to the lack of appropriate data we do not have predictions for the expenditures on formal home care in Poland, based on the available evidence we can still assume that those expenditures are of similarly small magnitude as the expenditures on residential care. Based on these considerations, the Netherlands is estimated to face the highest expenditures on formal LTC within the next 30 years, followed by Germany, Spain and Poland. The Polish demographic structure and disability rates increase the predicted expenditures to a high extent, but this effect still leaves the public and private expenditures small in Poland, mainly due to the small usage rates.

**The burden of informal caregiving.** To give an idea of the burden of informal caregiving under conditions of ageing, WP7 generates an indicator of the demand for informal caregivers in 2040. This is based on the number of informal caregivers giving personal care in 2010. We assume that the ratio of informal caregivers relative to the disabled people aged 65 and above remains constant. Using the projections of the WP2 DELAY scenario, we can thus generate an estimate of the future number of caregivers needed and relate it to the predicted 50+ population in 2040 (see Table 7.3). The demand for informal caregivers relative to the 50+ population will be highest in Spain and Germany. In comparison, the demand in the Netherlands for informal personal care will be relatively very low.

Table 7.3 Predicted demand for informal caregivers in 2040

Caregivers per 50+ population	
Constant ratio caregiver/disabled (%)	
Germany	7.14
Netherlands	2.07
Poland	5.92
Spain	7.77

Source: A. Bíró (2012), “Overall evaluation of performance”, in Mot, Faber, Geerts and Willemé (eds), “Performance of Long-Term Care Systems in Europe”, ENEPRI Research Report No. 117, CEPS, Brussels.

### **Equity of the LTC system**

WP7 of ANCIEN analyses equity in the LTC systems of the representative countries using two equity concepts: horizontal and vertical equity. Horizontal equity requires the like treatment of like individuals. For example, persons with the same resources should contribute to the funding of LTC to the same extent. Vertical equity requires the unlike treatment of unlike individuals. An example is that persons with higher needs should receive more LTC services. These concepts of horizontal and vertical equity were applied to two dimensions of LTC systems: revenue raising and resource allocation.

**Revenue-raising.** Two aspects are particularly important for equity in revenue-raising: the extent of risk pooling and the progressivity of funding. The degree of risk pooling (or level of coverage of the dependency risk) is a key determinant of the performance of the system in terms of horizontal equity. The lower the degree of risk pooling, the more likely it is that people with higher levels of need (and possibly lower levels of resources) have to contribute higher resources to their care. Countries with a low degree of risk pooling tend to rely greatly on informal care. The degree of progressivity of the way in which resources are raised will affect the performance of the system in terms of vertical equity. Where most resources are raised as informal care, or with forms of payment that are regressive, the system will perform worse in terms of vertical equity.

Applying these attributes for the four representative countries reveals that the Netherlands scores best on both aspects, so it has the highest equity in revenue-raising of these four countries, followed by Germany, Spain and Poland

**Resource allocation.** Important aspects affecting the equity of resource allocation are equity of access to the care system and equity in the level and mix of services that persons receive relative to their needs. These two aspects were analysed for the four countries, both concerning horizontal and vertical equity. Access based on needs and not on means testing promotes horizontal equity. Both Germany and the Netherlands score high in this respect. However, national eligibility criteria with strict thresholds for entry to the system, as used in Germany, lower the vertical equity, resulting in Germany scoring less well on vertical equity. Both Poland and Spain score relatively low on equity in resource allocation compared to the Netherlands and Germany.

Of the four countries, the Netherlands performs well in terms of equity, both horizontal and vertical. Germany’s system performs well on horizontal equity but less so on vertical equity. The Spanish system’s reforms of 2006 introduced new features that potentially increased the equity of the system, but the system has not been fully implemented and major cuts have undermined its potential to deliver in terms of equity. The Polish system is characterised by a very small formal care sector and universal care-related cash benefits to everyone over 75 (regardless of the need for care) which does not perform well in terms of vertical equity.

### **Choice**

Information on choice in the ANCIEN countries can be found in Mot et al. (2012). This information was collected in WP1 and concerns the choice of provider (in institutions and at home) and the availability of cash benefits. As an indicator of choice we simply add up the available information on

the freedom of choice of providers and on the availability of benefits in cash. This gives an equal choice score for all four representative countries, and thus we cannot differentiate them according to this dimension in the final evaluation. Due to the equal values, omitting this category from the final ranking does not influence the results.

### 7.3 Overall evaluation

We evaluate the LTC systems of the four representative countries using the core criteria from our performance framework (excluding choice because of the equal scores). Due to the complex nature of the LTC systems, such an overall evaluation exercise is necessarily based on a set of simplifying assumptions. An important simplification is that we have to make assumptions on the weights of the different performance dimensions in the overall evaluation, since there is no research that we can base those weights on.

To give an overall evaluation of the performance of the LTC systems, we construct aggregate indicators for the selected five performance criteria that are directly comparable. For quality of life, quality of care, equity and total burden, we start by aggregating the sub-dimensions (e.g. the three aspects of quality of life) to one indicator per performance criterion, assuming equal weights for each of the sub-dimensions. Following that, we standardise the values for each indicator (with a mean of zero and standard deviation of one). We also ensure that higher values always imply better performance, thus under standardisation we reverse the sign of the total burden indicator. Table 7.4 presents the original indicator values for the four countries as described above, as well as the standardised values.

Table 7.4 Evaluation of LTC systems in the four representative countries, based on the core criteria

Original values	Quality of life		Quality of care (1-4)	Equity (1-5)		Total burden		Choice (0-4)	
	AME on help	AME on help meets needs		Unobserved properties	Revenue raising	Resource allocation	Formal (% GDP)		Informal (% 50+)
DE	0	0	-0.275	2.699	3.5	3.5	2.186	7.14	3
NL	-0.096	0.068	-0.206	2.855	5	5	4.84	2.07	3
PL	-0.374	-0.057	0.27	2.33	1	1.25	0.1	5.92	3
ES	-0.311	-0.124	-0.207	2.772	2	1.5	0.805	7.77	3
Standardised values (higher score - better performance)									
	Quality of life	Quality of care	Equity	Total burden	Mean score	Mean score, burden of informal caregiving excluded			
DE	0.494	0.151	0.374	-1.044	-0.006	0.23			
NL	0.851	0.825	1.229	0.106	0.753	0.385			
PL	0.078	-1.442	-0.98	1.324	-0.255	-0.361			
ES	-1.423	0.466	-0.624	-0.382	-0.491	-0.255			

Source: A. Bíró (2012), “Overall evaluation of performance”, in Mot, Faber, Geerts and Willemé (eds), “Performance of Long-Term Care Systems in Europe”, ENEPRI Research Report No. 117, CEPS, Brussels.

The Dutch system has the highest scores on all dimensions except the total burden of care, where it has the second-highest score after Poland. The Dutch score on total burden is based on a relatively very high future expenditure on formal care combined with a low burden of informal caregiving. In the performance of the Dutch system we see to some extent the trade-off in action between the total burden of care and the other dimensions: equity and quality can be relatively high because the Netherlands spends a lot on publicly financed formal care. The high reliance on formal care, combined



with the ageing of the large post-war baby boom generation in the Netherlands, leads to high expenditure projections compared to other countries. However, the total burden of care is lower than in Germany and Spain because of the relatively low use of informal care. Over the four dimensions taken together, the Dutch system seems to score relatively well.

If we just take a simple average over the four key dimensions despite the fact that we have no information on the preferences, we see that the Netherlands scores first, despite the high total burden of care. It is followed by Germany in second place, Poland in third place and Spain in the fourth place. If the burden of informal caregiving is omitted from the overall evaluation, then Germany performs relatively better, and Spain performs better than Poland. Thus, our results are sensitive to the inclusion of the burden of informal caregiving.

Naturally, we cannot conclude from these overall scores that every country would be better off by implementing the highest scoring system. This is not just because the weights are unknown and preferences differ among countries, but also because a system as a whole is unlikely to be transferable to other countries. Its functioning will depend in part on a shared history and culture in a country and specific institutions. It is more reasonable not to attempt to copy other national systems, but to be inspired by them, especially concerning aspects where they score well. The lessons learned from other systems can be used, for example, to adapt aspects of a national system that are seen as unsatisfactory within the country itself.

#### **7.4 Policy implications and recommendations**

A number of lessons emerge from our research. First of all, the performance of a LTC system is a complex multi-faceted concept. The experience of people with limitations has many relevant aspects, which in turn have different dimensions. An example is the fact that a LTC system can score differently on horizontal and vertical equity. To complicate matters further, the performance of the system is not just important for people with limitations, but also for their families, potential caregivers in general and society at large. Ideally, all such aspects are included in an evaluation. The impact of informal caregiving on the caregivers and on society (e.g. the labour market) should not be forgotten. In the evaluation for the four representative countries, inclusion of informal caregiving considerably impacts the results.

The second lesson follows from the simulations where we disentangle the effects of demography and the disability level from other effects on the use of care. This lesson is that differences in the projected *level* of LTC use among countries are to a large extent determined by different patterns of care use and – to a smaller extent – by differences in disability levels. Demography (composition of the populations over age and gender) plays a limited role. There are huge differences in care use among countries for a given age, gender and disability of the population. In countries with generous LTC systems, changing the care-use pattern may be a powerful way to control costs (but at a price). In countries with more rudimentary LTC systems, a possible development towards a more average care-use pattern will lead to a much larger formal burden of care.

A third lesson of the simulations is that whereas demography is not much of a determinant of the *level* of care use, demographic developments are indeed important determinants of the *growth* in the future need for LTC. In countries where ageing plays an important role, the demand for LTC will increase considerably in any case, even when future elderly are going to be healthier than the current elderly. Both demography and prevalence rates have an important impact on the growth of disability.

Fourth, countries tend to organise their LTC system in very different ways. Despite the differences in organisation, basic characteristics of the system such as the probability of receiving help for older persons with limitations may be comparable under very different systems. The role of the state in funding and organising LTC versus individual responsibilities is one of the most important differences among countries. A large role for individuals and families means high private funding and/or a large role for informal care. These choices concerning private funding and the role of informal care have a large effect not only on public expenditure but also on the fairness of the system. With informal care and private funding, risk-sharing is limited. Family members have to supply informal care (or pay for private care) because they have someone near them who needs it, independent of their capacity to

contribute to funding of care. And for elderly persons with limitations, their chances of receiving help depend to a lesser extent on their needs and to a larger extent on the coincidence of having access to informal carers or not or being able to pay for private care. This makes the funding of the system less equitable.

Thus, more publicly oriented LTC systems tend to be more equitable, but there is a price to be paid. Because such systems depend more on public funding, the financial burden is generally higher and may increase a lot when ageing plays an important role. However, we should not conclude that countries with a large dependence on informal care are safe from future problems with the sustainability of their LTC system. The research in WP6 showed that both informal care and formal care will be confronted with a gap between demand and supply given the current propensity to supply informal care and to work as a formal care worker.

Fifth, we found that there is a lack of internationally comparable data on LTC. If countries consider it important to learn from each other's systems, the collection of comparable data would have to receive more attention. This is especially the case for data on the quality of care. Another difficulty with comparing systems is that these systems are clearly multidimensional and the weights for the different performance dimensions are unknown. Research into these weights, especially internationally-oriented research, would be very useful.

Finally, we can conclude that information about other national systems can provide inspiration for adapting a country's own system. Using the performance framework, policy-makers can identify the weak points of their own system and in the next step, select some countries where the LTC system scores well on those dimensions. They can see how those countries manage to score better on those particular aspects and this may inspire them to improve their own system. Sometimes other countries have found unexpected 'solutions' for certain problems. But policy-makers would still have to consider carefully how well the solutions found in other countries would work in their own country and which trade-offs are involved.

**L**aunched in January 2009, ANCIEN is a research project financed under the 7th EU Research Framework Programme. It runs for a 44-month period and involves 20 partners from EU member states. The project principally concerns the future of long-term care (LTC) for the elderly in Europe and addresses two questions in particular:

- 1) How will need, demand, supply and use of LTC develop?
- 2) How do different systems of LTC perform?

The project proceeds in consecutive steps of collecting and analysing information and projecting future scenarios on long-term care needs, use, quality assurance and system performance. State-of-the-art demographic, epidemiological and econometric modelling is used to interpret and project needs, supply and use of long-term care over future time periods for different LTC systems.

**Work Packages.** The project started with collecting information and data to portray long-term care in Europe (WP 1). After establishing a framework for individual country reports, including data templates, information was collected and typologies of LTC systems were created. The collected data form the basis of estimates of actual and future long term care needs in selected countries (WP 2). WP 3 builds on the estimates of needs to characterise the response: the provision and determinants of formal and informal care across European long-term care systems. Special emphasis is put on identifying the impact of regulation on the choice of care and the supply of caregivers. WP 6 integrates the results of WPs 1, 2 and 3 using econometric micro and macro-modelling, translating the projected needs derived from WP2 into projected use by using the behavioral models developed in WP3, taking into account the availability and regulation of formal and informal care and the potential use of technological developments.

On the back of projected needs, provisions and use in European LTC systems, WP 4 addresses developing technology as a factor in the process of change occurring in long-term care. This project will work out general principles for coping with the role of evolving technology, considering the cultural, economic, regulatory and organisational conditions. WP 5 addresses quality assurance. Together with WP 1, WP 5 reviews the policies on LTC quality assurance and the quality indicators in the EU member states, and assesses strengths, weaknesses, opportunities and threats of the various quality assurance policies. Finally WP 7 analyses systems performance, identifying best practices and studying trade-offs between quality, accessibility and affordability.

The final result of all work packages is a comprehensive overview of the long term care systems of EU nations, a description and projection of needs, provision and use for selected countries combined with a description of systems, and of quality assurance and an analysis of systems performance.

#### Principal and Partner Institutes

CEPS is responsible for administrative coordination and dissemination of the general results (WP 8 and 9). The Belgian Federal Planning Bureau (FPB) and the Netherlands Bureau for Economic Policy Analysis (CPB) are responsible for scientific coordination. Other partners include: German Institute for Economic Research (DIW); Netherlands Interdisciplinary Demographic Institute (NIDI); Fundación de Estudios de Economía Aplicada (FEDEA); Consiglio Nazionale delle Ricerche (CNR); Università Luiss Guido Carli-Luiss Business School (LUISS-LBS); Institute for Advanced Studies (IHS); London School of Economics and Political Science- Personal Social Services Research Unit (PSSRU); Istituto di Studi e Analisi Economica (ISAE); Center for Social and Economic Research (CASE); Institute for Economic Research (IER); Social Research Institute (TARKI); The Research Institute of the Finnish Economy (ETLA); Université de Paris-Dauphine-Laboratoire d'Economie et de Gestion des organisations de Santé (DAUPHINE- LEGOS); University of Stockholm, Department of Economics; Karolinska Institute-Department of Medicine, Clinical Epidemiology Unit ; Institute of Economic Research, Slovak Academy of Sciences (SAS-BIER); Center for Policy studies (PRAXIS). Most of the ANCIEN partners are members of the European Network of Economic Policy Research Institutes (ENEPRI).