

Executive summary:

The ANCIEN project studied long-term care (LTC) for the elderly in Europe and made projections of future LTC use and expenditure. Work Package 1 (WP1) described the variety of LTC systems in Europe in 22 country reports and collected data on their organizational, financial and other characteristics. It developed typologies specifically for LTC systems that were the basis for the selection of four representative countries: Germany, the Netherlands, Spain and Poland. Individual responsibility for LTC turned out to be an important factor to characterise LTC systems: how large is the role of informal care and private funding versus public expenditures? WP2 analysed for the representative countries the need for LTC by making models for the number of persons with limitations in basic activities of daily living (ADL). It used Eurostat population projections as basis for its need for care projections. The impact of smoking and obesity on the future need for LTC was also studied, but it turned out that demographic developments dominated the projections. WPs 3 and 6 studied the use of care, including the choice between formal and informal care, and the choice between care at home and in an institution. The supply of informal and formal care was also analysed. The numbers of care users are projected to increase in all countries, but with large country differences, different trends for formal and informal care, and important effects of alternative needs and socio-demographic scenarios. As the projected trends in supply of formal and informal care do not keep pace with the projected increases in LTC use, policy measures to increase LTC capacity will be needed in all countries if the current level of LTC intensity is to be maintained. WP4 studied the potential impact of technology on LTC provision and use. Technological solutions that are likely to affect LTC were identified from the literature. Economic, cultural, regulatory and organizational factors were identified that may influence the impact of technology on LTC.

The potential impact of key technologies on LTC provision and use has been analyzed for dementia, diabetes and obesity. This impact turned out to be very dependent on the nature and the stage of the condition. WP5 analysed LTC quality assurance by comparing quality policies of different EU-countries. This WP collected data for 15 countries on quality indicators and quality policies. These data were used to cluster countries according to quality policies and to compare these quality typologies with the general LTC system typologies developed in WP1. WP7 assessed the performance of LTC systems. As part of this assessment, it analysed the quality of life of (potential) LTC users in 13 European countries using SHARE and the equity of the LTC systems of four representative countries. It disentangled the effects of demography and the disability level from other effects on the use of care. There turned out to be large differences in care use among countries for a given age, gender and disability composition of the population. Thus differences in the projected level of LTC use among countries are to a large extent determined by these country-specific patterns of care use. WP7 carried out an overall evaluation of the quality of life of LTC users, the quality of care, the burden of LTC and the equity in the four representative countries. Inclusion of informal care giving in the evaluation had an important impact. This made countries with high public spending and relatively low informal care giving score better on the burden of care. Such countries also score higher on equity, because informal care giving and private funding are less equitable ways of funding LTC, while these sources keep the public expenditures lower.

Project Context and Objectives:

The post-war baby boom is turning into a grandparent boom, putting a triple stress on long-term care (LTC) provisions: increasing numbers of elderly, increasing survival of the elderly and increasing survival of frail, disabled elderly through improved care and health care. Epidemiological trends such as smoking cessation and obesity may increase care dependence. At the same time the supply of labour is affected by the ageing of the EU population. This is likely to cause a widening gap between the numbers of care-dependent elderly people and their caregivers. It also puts a strain on the financial sustainability of LTC systems. These developments call for an analysis of the factors that determine the need for care and of the systems that provide it.

The project's main objectives are to analyse:

- (i) the effect of demography and lifestyle on the need for care;
- (ii) developments in the supply and demand of informal and formal care, and the choice between the two;
- (iii) the potential role of technology in solving LTC problems;
- (iv) efforts to improve the quality of LTC;
- (v) and project the use of LTC on the basis of developments in needs and supply; and
- (vi) the performance of different types of LTC systems.

To achieve these objectives, which correspond to Work Packages 2 to 7 of the project, the first work package was designed to gain insight into the characteristics of currently existing LTC systems in Europe.

After compilation of EU-wide data on LTC in WP1, 22 country reports describing the existing European LTC systems and a typology of LTC systems were published. These reports provide information on organization, funding, demand and supply of formal and informal care, and LTC policy. Two typologies of European LTC systems were derived. They serve two purposes: they extend existing classifications of LTC systems found in the literature and they allowed us to select representative countries for further analysis (The Netherlands, Germany, Spain and Poland).

WP2 estimated the effects of demography and lifestyle factors on care needs, using the estimated model to project future numbers of elderly persons by age, gender and severity of need. Spain, Poland, Germany and the Netherlands were chosen as representative of European epidemiology and of different systems of long-term care. A model was linking demographic and lifestyle variables to mortality and disability using multistate life tables. It was found that growing populations of elderly are the most important determinant of future disability; the effects of BMI, smoking and quitting smoking on disability are small, compared to demographic growth.

WP3 focused on demand and supply of LTC. Starting from a descriptive overview based on the results of WP1, several micro-econometric models have been developed to shed light on the socio-demographic and economic determinants of LTC use and informal care provision. The main trends in the formal care workforce have been studied using a simple stock-flow cohort model. Age, ADL disability and living arrangement are found to be the main determinants of the use of different types of LTC, although the choice between residential and home care and between formal and informal care is also substantially influenced by differences in the organization

of national LTC systems. The results contribute to the literature on LTC demand and supply and form the basis of the projections of future use and provision of LTC in WP6.

WP4 studied the potential impact of technology on LTC provision and use. Technological solutions that are likely to affect LTC were identified from the literature. Economic, cultural, regulatory and organizational factors were identified that may influence the impact of technology on LTC. The potential impact of key technologies on LTC provision and use has been analyzed for dementia, diabetes and obesity.

This impact was analysed separately for different stages of these three conditions:

- 1) prevention and the initial stage;
- 2) moderate conditions;
- 3) severe conditions.

WP5 aimed at analysing LTC quality assurance by comparing quality policies of different EU-countries. After a desktop review of existing LTC quality systems, a survey was developed to gather data for 15 countries on quality policies and indicators. These data were used to cluster countries according to quality policies and to compare these quality typologies with the general LTC system typologies developed in WP1.

WP6 provides projections of future LTC use and supply based on the results of WP3. Specifically, the micro models developed in WP3 have been used to build (cell-based) macro simulation models. Projections of future use of formal and informal care were obtained combining projected needs (from WP2) with available national socio-demographic projections on household composition and educational attainment for four representative countries. The numbers of care users are projected to increase in all countries, but with large country differences, different trends for formal and informal care, and important effects of alternative needs and socio-demographic scenarios. As the projected trends in supply of formal and informal care do not keep pace with the projected increases in LTC use, policy measures to increase LTC capacity will be needed in all countries.

WP7 analysed the performance of different LTC systems. A performance framework was developed according to which the assessment of LTC systems will take place. Many elements of this performance framework will be scored using the information collected in the previous WPs. In addition, WP7 included separate analyses of the experiences of individual LTC users in different countries using the Share database. Furthermore, equity was analysed for the four selected countries along several dimensions. National partners gave feedback on the performance results for the systems of their countries. Finally, the results of these analyses were brought together in a report on systems' performance.

Project Results:

Description of the main research results

1. New typologies of long-term care 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 two typologies of LTC systems in European countries: one typology of organisation and financing of care, and another typology focusing on use and financing of care. Unlike existing typologies, the ANCIEN typologies focus on LTC rather than a broader definition of social, health or welfare services, and include old as well as new EU member states. Furthermore, the ambitious data collection process allowed the project team to apply formal methods in deriving the typology, which is another novelty in this field. The first approach, which focuses on organisation of care, relies on qualitative information and includes 21 EU member states. The second approach characterises use of care and therefore needs quantitative variables. Due to data limitations in the area of metric variables, only 14 countries could be included into the latter typology.

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. 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.

Approach 2. Typology focusing on use and financing of care

This approach uses quantitative information on the use of care and is limited to 14 EU member states for which data are available. 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 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.

Comparison of the two approaches

Making assumptions on preferences, the typologies resulting from the two approaches can be ordered according to attractiveness of their systems for elderly in need of care. Despite the differences in explanatory factors, the two typologies yield the same result for 10 out of 14 countries for the attractiveness ordering. Denmark, the Netherlands and Sweden have a very clear profile of paying a lot of attention to the interests of LTC users. It is not surprising that they end up in the most preferred category in both typologies. Other countries, like Hungary, are clearly less attractive to LTC users. Some other Eastern European countries do not spend a lot of money on LTC, but their organisational depth is quite high, which leads to a higher ranking in both typologies. Examples are the Czech Republic and Slovakia. The ordering is really dependent on the approach only for Belgium, France, Germany and Italy.

Compared to existing typologies, the results are based on richer datasets. This can lead to a different clustering of countries. The clustering of the Nordic countries Denmark, the Netherlands and Sweden seems to be the most robust under different clustering approaches.

The ANCIEN team used the use and financing typology as a basis to select representative countries for further analysis.

2. Demographic epidemiologic projections of long-term care needs

Work Package 2 of the ANCIEN project assessed the actual and future numbers of elderly care dependent people in four selected countries: Spain, Poland, Germany and the Netherlands. These countries were representative of European epidemiology and of different systems for the provision of long-term care. WP2 produced two types of scenarios: 1)

scenarios according to several assumptions about how disability and mortality are related; 2) risk factor scenarios on the effects of smoking and BMI. The demographic scenarios used the mortality forecasts of the EUROPOP 2008 scenarios as a basis for projections of the number of disabled elderly people.

The following scenarios without risk factors were used:

Constant incidence and mortality scenario (CONST)

To be able to assess the potential of demographic change, independent from changes in mortality, we postulated a (pessimistic and unrealistic) scenario with no mortality change: CONST, from constant mortality. The change in both incidence and mortality is 0%. CONST therefore reflects the demographic change introduced by the cohorts that entered at age 55, and reached 65 in the years 2008-2060 (or more or less the birth cohorts 1943-1995). All subsequent scenarios add decreasing mortality to this scenario.

Constant prevalence scenario (PREV)

The prevalence scenario (PREV) applies constant age-specific prevalence ratios of disability to the changing populations. This is a much used and simple technique to assess future care needs. The technique makes implicit assumptions that are made explicit by multi-state simulation.

Chronological ageing scenario (CHRON)

The chronology scenario (CHRON) assumes that age-specific incidence rates are dependent on age, which is the period since birth. Incidence is kept constant. The difference with the PREV scenario is caused by explicit assumptions about survival in disabled or non-disabled states. Indeed, in the prevailing scenario of decreasing mortality, prevalence will increase as decreasing mortality among the disabled extends their survival.

Biological ageing scenario (BIOL)

The biological scenario (BIOL) assumes that age-related disability is determined by biological (or prospective) age: the remaining years of life before death. This assumes a biologically plausible similar decline of disability incidence to that of mortality. The EUROPOP 2008 mortality forecasts assume a close interaction of the mortality decrease with age: mortality declines sharply at younger ages, but less at older age and close to nothing in the oldest ages. This is reflected in the biological forecasts. In general, biological scenarios predict the expansion of healthy life, but no expansion of disabled life. Up to now, this is most consistent with observations of severe disability in the available literature.

Delayed ageing scenario (DELAY)

The delayed ageing scenario is a conservatively modified ageing scenario. DELAY assumes that the disability is delayed in the life course to older ages, similar to mortality. While the biological scenario assumes close interaction of mortality decrease with age, the delay scenario postpones disability, similar to mortality, avoiding this interaction. Incidence is then declining less at younger ages (avoiding the very large disability declines of the multiplicative biological scenario), but declines more at older ages (more consistent with a hypothesis of postponed disability). As incidence decline at younger ages prevents more disability at older ages, the DELAY scenario is a biological scenario, but which is more conservative than the biological scenario BIOL.

The DELAY scenario has been used as a base case scenario throughout later work packages within the ANCIEN project.

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.

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. Smoking decreases the duration of disability by a high mortality. 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).

The 'Lean' scenario assumes that the prevalence of obesity will halve (and reach the levels of the 1960s again). The 'Fat' scenario assumes that the prevalence of obesity will double (and reach the levels of the US). These scenarios are extreme, as we assume the change to have occurred in 2008. 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. The table also shows that the impact of different smoking scenarios on the development of disability is not very large.

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 20th century to the future. Evidence shows that life extension is correlated with life extension free of (severe) disability; this will limit the increase in the prevalence of disability in populations living to older ages. Lower smoking rates increase

survivorship, but have only a small effect on the prevalence of disability. A higher prevalence of obesity increases the prevalence of disability attributable to obesity, but this increase is relatively limited compared with the demographic growth in the numbers of the elderly.

3. Availability and Choice of Care

Work Package 3 of the ANCIEN project aims 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.

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 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.

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 follow the procedure proposed in Bourguignon et al. (2007), and 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 (see Gabriele et al., 2011), 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.

4. INFLUENCE OF TECHNOLOGY ON THE FUTURE OF LONG-TERM CARE SYSTEMS

New technologies may have a beneficial impact on LTC systems by improving the quality, effectiveness and efficiency of LTC provision and by decreasing the need for LTC in the first place. WP4 studied the potential impact of technology on LTC provision and use. Technological solutions that are likely to affect LTC were identified from the literature. Economic, cultural, regulatory and organizational factors were identified that may influence the impact of technology on LTC. WP4 developed a framework to analyse the impact of technology on LTC. The functioning of this framework is illustrated for a number of specific long-term conditions: dementia, obesity and diabetes.

The potential impact of key technologies was analysed separately for different stages of these three conditions:

- 1) prevention and the initial stage;

- 2) moderate conditions;
- 3) severe conditions.

This summary focuses on the framework to analyse the impact of technology. All other results of this work package can be found in Mazzeo, M., P. Agnello, A. Rossi Mori (2012), Role and Potential Influence of Technologies on the most Relevant Challenges for Long-Term Care, Enepri Research Report No. 113.

4.1. A scheme to explore the influence of technology on a LTC scenario
The 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 progresses of healthcare 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. The intent was to formulate a comprehensive and systematic scheme to allow the policy makers to produce informed decisions about technologies in relation to the other priorities of intervention in a jurisdiction.

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

A. The LTC needs susceptible of technological assistance, with criteria focussing on:

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

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

- 1 The opportunities increased by the technologies;
- 2 The ways of potential impact of domotics, equipments and home devices;
- 3 The potential impact of domotics, equipments and (remote) devices on ADLs;
- 4 The potential impact of domotics, equipments 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;
- 7 The potential impact of information systems.

Source Mazzeo, M., P. Agnello, A. Rossi Mori (2012), Role and Potential Influence of Technologies on the most Relevant Challenges for Long-Term Care, Enepri Research Report No. 113., CEPS, Brussels

4.2. The analysis of three case studies: dementia, diabetes, obesity

To tune the concepts and to show the large variety of the mechanisms that may apply to a situation, the scheme was explored in nine situations: three different stages (namely: initial stage, mild situation with a stable care plan, severe situation with a complex combination of multiple complications) related to three long-term conditions (namely: diabetes, dementia and obesity). For each criterion, the degree of effect was expressed qualitatively, either as "null" (feature not relevant or not

applicable), or as one point (negligible effect), two points (mild effect) or three points (strong effect). The assessments were then rendered also as colours in synthetic tables.

The case studies indicate the expected variety and provide a qualitative appraisal to raise questions and guide a comparison among a set of scenarios. The field experts in each jurisdiction will need to customise the scheme through various cycles of discussions and assessments, in order to express joint consolidated and repeatable judgements and to inform the decisions of the local policy makers.

With respect to the needs for LTC in the different phases of the three case studies, the following notes apply about 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 the minor consequences of the disease (if there aren't severe complications), the persons in advanced stages of obesity or dementia are unable to perform self-care and remain completely dependent. About the demand for healthcare activities, social activities and continuative 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 the severe stage the complications of diabetes ask for a good coordination among the various specialists. About obesity, in the first stage the GP with the nurse could be able to manage the care plan, including the education of the individual about the diet and the lifestyle. In later stages, more professionals will be involved. About dementia, the clinical problems aren't the most relevant ones with respect to the other issues.

The technologies could permit more effectiveness or reduce the need for the different types of services: hospitalization, nursing care, home care, informal care, self-care. In the initial and moderate stages of diabetes and obesity, technology may play a good role in delaying the progress of the conditions by increasing prevention and integrating the activities performed by different carers. In the most severe cases, technology may help in reducing the need of hospitalization. Medium and severe stages of obesity may be managed in nursing facilities or at home with an informal carer supported by technology. However the technology cannot replace professional care in keeping the patient at home in case of severe cases of dementia and diabetes.

About domotics, equipments and home devices, the routine data acquisition may be improved by technology in case of obesity and diabetes, where patients may collaborate in the process. Technology may have a great impact on dementia in terms of surveillance 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 the IADLs, a large number of mature technological solutions are already in use and -apart from some particular activity for each case study- a further impact will be generally moderate or irrelevant.

Technology could already have an important role in remote monitoring and remote visits that can be beneficial to patients in terms of increased clinical effectiveness, patient-centeredness, and efficiency. Some further advance may be envisaged in the future about the remote visits by

formal carers on 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 assist the patient to be educated, trained, informed by carers, and to stay in contact with his/her own social network.

Finally, the 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.

5. Quality policies and indicators for long-term care in the European Union

WP5 aimed at analysing LTC quality assurance by comparing quality policies of different EU-countries. After a desktop review of existing LTC quality systems, a survey was developed to gather data for 15 countries on quality policies and indicators. These data were used to cluster countries according to quality policies and to compare these quality typologies with the general LTC system typologies developed in WP1.

Clusters based on quality policies

WP5 identified four clusters based on quality policies across countries.

What is the relation between the type of LTC system and quality policies and indicators? The results are mixed. Some countries belonging to WP1 cluster A (Germany, Slovakia, Estonia) and others belonging to WP1 cluster C (France and England) correspond in WP5 to cluster 1, which is characterized by quality policies aimed at formal care, quality policies aimed at outcomes, and quality guidelines. These countries, as by description of WP1 clusters A and C, present a high use and high support to informal care. However, in WP5 most of them do not support a similar strategy concerning quality policies and indicators. Apparently, there is a gap to be filled in these countries: since informal care is that important, a quality strategy ought to be developed in this field.

The Netherlands, at the opposite, is perfectly consistent with its strategy. In use and financing typology it belongs to cluster B, which is composed of countries that are generous in public spending and invest a lot on formal LTC (both residential and home care). This is consistent with The Netherlands position in WP5 cluster 1, where quality of formal care is a key factor.

As for their use of informal care, also Austria, Spain, and Finland (WP1 cluster C) would be expected to invest on quality of informal care. This is slightly the case since they belong to WP5 cluster 2 which is mainly characterized by input-process indicators but also by quality policies for informal care.

Based on our data, Poland and Slovenia focus on private spending and consistently have not developed national quality policies and indicators. Italy as well relies on private spending and informal care but has not developed policies about informal care.

Results for quality policies

By analyzing 15 EU countries we identified the following main results for quality policies.

Integration: since LTC is intrinsically a multidimensional activity which needs multiple competencies to be effectively carried out, coordination of LTC providers is key to guarantee a high level of quality. Coordination in fact is related to the following key issues for quality in LTC:

- 1) Timeliness, that is the degree to which patients are able to obtain care promptly. Coordination of care is key for timeliness when a patient needs to go through different stages of care and across providers.
- 2) Continuity, that is the extent to which healthcare for specified users, over time, is coordinated across providers and institutions.
- 3) Integration between primary and secondary care, and between healthcare and social care. Without this coordination quality may be undermined.

In different countries there is a growing awareness that quality of LTC is based on an effective integration of health and social services. On average (see WP 1 data of the ANCIEN project) there is a medium integration of the components of LTC. However, quality indicators about coordination are fewer 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 policies. Consistency is a key issue in some countries because of the lack of integration of responsibilities. LTC policies and LTC quality policies may be developed by different actors. Also, quality policies may not reflect the actual use of LTC.

As discussed above, countries with high scores in the use of formal care and high public spending on LTC have consequently invested in quality policies on formal care. Countries with high co-payments are less prepared as for quality systems. The latter should invest more in quality policies on home-based care and informal care. The latter aspect may also be relevant for countries with high 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. In order 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. However, our results show that most countries do not report to the public data about quality of care of 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 needs. As the bulk of LTC is provided by informal caregivers and dependent upon their health and well-being, caregiver needs must also be assessed and satisfied. Our results show that most interventions deal with financial support for buying devices;

training/counselling of the informal caregivers; assessment of the health conditions and personal needs of patients.

Monitoring. Monitoring systems are needed to support quality evaluation, to promote informed policy and to provide feedback to the various actors in the field. On average monitoring for authorization/accreditation occurs every 3 years (range 1-5).

Education: a competent staff is a key factor for the quality of LTC providers. LTC however needs staff specialised in the care of the elderly. Among the many professional roles that are involved in LTC, the most prepared staff seem to be the GPs. 10 countries report that GPs are provided a specific education for LTC. Fewer countries report the same for other roles. Nurses also play a key role in LTC facilities and home nursing care. Their shortage is a threat for quality of LTC.

6. Future use and supply of long-term care in Europe

WP 6 of ANCIEN studied 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 the four selected representative countries, Germany, the Netherlands, Spain and Poland. 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 harmonized 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. The base DELAY scenario assumes that disability incidence is delayed to older ages with the same amount of time as mortality is delayed.. The risk factor scenarios explore the effect of alternative assumptions about trends in smoking and obesity. Further socio-demographic scenarios take account of the changing household composition and higher levels of education of the future older population. In all scenarios, the probabilities of using different types of care are assumed to remain the same in the future as they are at present, controlling for age, gender, disability and other relevant variables.

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.

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%). Use of both formal home care and informal care is projected to increase most in Spain. For informal care use, an increase of 140% is projected for Spain, while for Germany and the Netherlands the projected increase is much lower.

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 with 162% and use of informal care with 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 prevalences 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.

Sensitivity analyses have shown that the projected numbers of residential care users are very sensitive to alternative assumptions about the incidence of disability and mortality in Germany, but less so in the other countries. The alternative bio-demographic scenarios have strong effects on the projections of formal home care and informal care in all countries considered. Of the different risk factor scenarios, the BMI scenarios generally have little impact - as their impact on the disability projections is low (see results of WP2) while alternative assumptions about future trends in smoking behaviour have a larger effect. Taking account of future trends in household composition generally makes little difference. The impact of the better education scenario differs, depending on the strength of the association of care use and educational level and the magnitude of projected educational changes.

Under the assumption of constant probabilities of care utilisation, for all countries the projections show a considerable increase in the numbers of users of all types of care - residential care, formal home care and informal care - even under the more optimistic scenarios. The key driver of the projected increases is demographic change.

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.

In all four ANCIEN representative countries, the relatively slow projected rise in informal care supply is not primarily due to trends in spousal care, but 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 (not shown here). 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 up 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.

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. The projections of informal (or formal) care-givers assume constant probabilities of providing informal care (or constant rates of LTC workforce participation). These projections of the numbers of care-givers are then compared with the numbers of care-givers that would be needed if the supply of informal (or formal care) were to meet demand in future. These numbers are calculated by assuming that the current ratio of care-givers to care-users remains constant in future years. A potential shortage of care-givers, an informal (or formal) 'care gap', can then be identified.

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.

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. In relative terms, the formal 'care gap' is particularly large in the Netherlands, a country with a high share of formal care users, and in Poland, where use of formal (residential) care is much less prevalent. It is also large in Spain, where use of formal care is low too. While in the Netherlands the formal 'care gap' is almost completely due to an increased demand, in Spain and Poland a combination of an increased demand and a shrinking workforce is at play. In all four countries, the

shares of the workforce in the LTC sector would at least need to double in order to keep pace with demand.

7. PERFORMANCE OF LONG-TERM CARE SYSTEMS IN EUROPE

The aim of work package 7 (WP7) of ANCIEN is to assess the performance of LTC systems. We attempted to make progress with this complex subject to the extent that the available data permit. We selected a set of criteria against which the performance of LTC systems can be evaluated. WP7 gathered information about performance, based on previous ANCIEN work packages, external sources and additional analyses within WP7. These additional analyses concerned: the quality of life of LTC users, equity of LTC systems and projections of LTC expenditures. The research report on WP7 presents an overview of available information on performance criteria for all countries studied in ANCIEN. WP7 ended with a final evaluation of LTC systems that concentrates on the four ANCIEN representative countries, for which we have more complete information on performance.

Performance framework

WP7 used the following set of core criteria for the evaluation:

1. The quality of life of (potential) LTC users.
2. The quality of care
3. The total burden of care: financial burden and the burden of informal caregiving
4. Equity of the LTC system
5. 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.

Below, we describe how European countries score on several 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.

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.

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

To assess the quality of care, WP7 used data from the Eurobarometer 67.3 survey. The values for the quality indicators can be found in the WP7 research report.

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 total expenditures on residential and formal home care relative to GDP in 2040. 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.

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 (not shown here) 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.

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. 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.

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.

Two aspects are particularly important for equity in revenue-raising: the extent of risk pooling and the progressivity of funding. The Netherlands scores best on both aspects, so it has the highest equity in revenue raising of these four countries.

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. 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

WP7 found 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.

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. We assume equal weights for the different aspects of a dimension (such as the financial burden and the burden of informal care as aspects of the total burden). 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. We also ensure that higher values always imply better performance, thus we reverse the sign of the total burden indicator.

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. Over the four dimensions taken together, the Dutch system seems to score relatively well. The German system has somewhat lower scores than the Dutch on all four dimensions. The high burden of care consists for a considerable part of the burden of informal caregiving in Germany, and this is a less equitable way of organising the LTC system. The Polish system excels in having a low total burden of care. We see a clear trade-off between this burden of care and the other dimensions, as the Polish system scores lowest on quality of care and equity. The Spanish system has few extreme scores. 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.

Potential Impact:

The potential scientific impact of ANCIEN The project's potential scientific impact derives from our efforts to conduct research beyond the state of the art regarding several aspects of long-term care modelling. The innovations we have proposed were either new analyses or resulted from a novel combination of existing models into a more comprehensive modelling framework. Our new typology of LTC systems extends the traditional distinction between the 'Beveridge' and 'Bismarck' organisational models of social security, and also paints a more subtle picture than the simple geographical 'Scandinavian'/'Central European/Mediterranean model. Our use of formal cluster analysis was an innovation that allowed us to combine several quantitative dimensions of LTC systems in a multivariate analysis. The four types of LTC systems that emerged from our analysis were instrumental in selecting four countries that were deemed representative of these systems, allowing the development of separate projection models for each system. ANCIEN partners developed a dynamic epidemiologic/demographic model capable of projecting the future elderly population by age, sex and disability status. The main innovation of this approach is that the model can be built using relatively few data on the prevalence of disability and that it incorporates the effect of risk factors on future disability. The advantage of our approach over projection models that have been reported in the literature is that our method can be used for many countries in a standardized way, including for countries that lack detailed data on the incidence of disability. The results, given suitable assumptions about future lifestyles, are compatible with the Eurostat population projections. A micro-model of informal care provision was developed that distinguishes between intergenerational and spouse care. While this distinction is often overlooked, it has important consequences for future potential informal care availability due to the particular demographic evolution of intergenerational caregivers. We developed a novel framework to analyse the impact of technology on LTC. The functioning of this framework was illustrated for a number of specific long-term conditions: dementia, obesity and diabetes

The potential impact of key technologies was analysed separately for different stages of these three conditions:

- 1) prevention and the initial stage;
- 2) moderate conditions;
- 3) severe conditions.

Our analysis of quality assurance integrated the various criteria of quality assessment reported in the literature and applied it to a large set of European countries.

A macro simulation model was developed based on a set of micro behavioural models that incorporate the determinants of formal and informal care, the choice between home and residential care, and the availability of informal caregivers. While the various components of this model have been described in the literature, our model is, to the best of our knowledge, the first attempt to specify a comprehensive projection model of LTC use for representative countries of different LTC systems. The main contribution consists of combining epidemiologic/demographic projections of future care needs with a detailed model of LTC use and an independent projection of formal and informal care provision. This approach results in a detailed picture of the future use, availability and cost of LTC in European countries. The detail of information

substantially improves the typical projection output of models with similar aims, such as the Ageing Working Group model. Of course, the simplicity of the latter is the price that has to be paid for applying it to all 27 member states. A new and comprehensive framework was developed to evaluate LTC systems, taking into account all available dimensions of LTC system performance.

A new analysis was carried out to get more insight into the effect of different LTC systems on the quality of life of (potential) LTC users. Furthermore, horizontal and vertical equity of LTC systems of the four representative countries were analysed. As far as we know, we carried out the first quantitative evaluation of LTC systems of European countries according to a structured format. The potential policy impact of ANCIEN The new typologies developed in the ANCIEN project that are specifically aimed at LTC systems, have the potential to change the way policy makers look at LTC systems. The key defining characteristics may be different from what was traditionally expected. Factors such as informal care use, private financing and support for informal care givers provide new insights about the type of system and its impact. Looking at LTC systems on the basis of traditional and more general typologies is not always as informative. An example is the distinction between tax-financed and premium-financed systems that does not say a lot about the functioning of the system. Different scenarios for future ADL disability made in the project were based on explicit assumptions about changes in mortality and incidence of disability. This can give policy makers a much sharper insight into the potential impact of healthy ageing on future disability. Though healthy ageing is important for older persons and society and mitigates the rise in the future number of disabled, underlying demographic factors such as the ageing of the baby boom generation are dominant. In a traditional scenario with constant age-specific prevalence rates of disability, the number of disabled older persons increases by 80 to 130% between 2008 and 2040 in the four representative countries. The mitigating effect of the ANCIEN base scenario with delayed disability is limited to 10 to 30 percentage points of the increase.

Even though it is very welcome, health ageing has only a limited impact on the projected increase in disability. In policy discussions, prevention is often mentioned as a possible way to limit the increase of future health care costs. However, successful prevention policies that increase the lifespan, such as anti-smoking policies, may lead to more disability over the lifetime and higher costs in later years. Although there are sound public health arguments to pursue anti-smoking policies, the strength of the cost argument is unclear. The risk factor scenarios support public health policies aimed at quitting smoking. It turns out that even wildly successful anti-smoking policies will only increase the future number of disabled elderly in a very limited way. The ANCIEN results show that obesity mostly has an impact on disability and not on mortality. Thus anti-obesity policies can be expected to improve public health and mitigate future increases in care costs at the same time. Unfortunately, the effect of very successful anti-obesity policies on future disability is also small: the decrease in projected disability is limited. Naturally there are many other reasons to promote a healthy weight for the population. Future research into the potential of technology to solve LTC problems may be facilitated by the framework that was developed in the ANCIEN project.

The framework encourages very specific analyses, because it makes a clear distinction between different disorders or limitations and the stage of

the disorder. This may shed much more light on technological opportunities than just the use of general principles. Furthermore, the analysis shows that governments can play an important role in creating the right conditions for technological developments in LTC, by increasing awareness and supporting knowledge. The projections of supply and use of LTC show clearly that both an informal care gap and a formal care gap will open up if no action is taken. This analysis has the potential to alert societies to this danger and to stimulate the thinking about possible solutions. The analysis also makes it clear that future developments in intergenerational care are for a large part determined by basic demographics (the development in the number of persons aged 50-64 years). Even if children (in law) will be equally inclined to take care of their parents despite increasing labour market participation and more geographic scattering of families, policymakers still have to realize that developments in the number of persons in the relevant age brackets are unfavourable. This is an argument in favour of policies to increase the formal care supply. The equity analysis that was part of the evaluation of systems shows other disadvantages of relying too heavily on informal care. In societies with a strong public coverage of care risks, the funding is shared by everybody, not just those who have someone close to them who needs LTC. Relying largely on informal care (or private financing), is a comparatively unfair way to distribute the burden of LTC. It is important to support informal care givers and make access to formal care possible.

An increase in the supply of formal care is important to close the expected care gap that will open up given the current pattern of care use, but for countries with generous systems the ANCIEN analysis draws attention to the relatively intensive pattern of care use. The analysis showed that countries with a generous LTC system, such as the Netherlands, will spend a relatively large part of GDP on LTC in the future under conditions of ageing with the current pattern of care use. ANCIEN did not include a complete sustainability analysis, but such countries have to keep in mind that they may be confronted with sustainability problems in the future. In this respect, a very relevant result is that the high LTC expenditure in the Netherlands is not caused by an unfavourable composition of the population regarding age, gender and disability. On the contrary, the composition is favourable compared to the other representative countries, but the pattern of care use is very intensive. The analysis makes clear that one policy option is to make the pattern of public care use less intensive. It turned out that the differences in the pattern of care use among European countries with a different level of economic development can be very large (such as the difference between Poland and the Netherlands). This may be food for thought for policy makers at both extremes of the distribution. Not only may countries with generous systems encounter sustainability problems in the future, countries with rudimentary formal care systems that usually lean heavily on the availability of informal care, may have to consider a future increase in formal care supply. The results and policy implications of the ANCIEN project are of particular importance to women, as they play a large role both in providing informal care and as users of formal care.

ANCIEN Dissemination Activities:

The main dissemination channel is the website of ANCIEN that was formed at the beginning of the project (see <http://www.ANCIEN-longtermcare.eu> online). ANCIEN website has provided information on project activities and findings with links to the participating institutes. The results of

each work package are published as research reports and policy briefs. All publications are available through the ANCIEN webpage. ANCIEN project results were presented at the Final Conference that was held in Brussels as well as two Clustered Seminars in Rome and Paris. The final conference was organised at CEPS on 24th October 2012 where almost 80 people from scientific community (higher education and research), members of various European institutions and EC officials, industry representatives, civil society and media were present. Rome and Paris clustered seminars also served for wider dissemination platform of ANCIEN findings. LUISS organised the first clustered seminar in Rome on 4th October 2012. More than 50 people including academia, policy making, patient and LTC associations, local health units, association financial companies and companies interested in long term care insurance joined to the first ANCIEN clustered seminar. Family TV -a web TV owned by Federanziani which is the largest association of elderly people were also present and LUISS gave an interview to Family TV. The second clustered seminar was organised by University Paris-Dauphine in Paris on 9th October 2012. The audience was mainly from the scientific community and policy makers. The ANCIEN project also benefits from the already active dissemination channels of the CEPS webpage, where all reports have been published as part of the ENEPRI Research Report series (see <http://www.ceps.eu/faceted/books/results/taxonomy%3A101> online).

The ENEPRI Research Reports series are also accessible through the European Network of Economic Policy Research Institutes (ENEPRI) website (see <http://www.enepri.org> online). CEPS and ENEPRI web pages provide additional dissemination channels and will ensure continuity in access to ANCIEN publications. The partner institutions also ensure a wider diffusion of the country reports at the national level as well as other publications through their own web pages and their own publications. After compiling EU-wide data on LTC for the elderly, 22 country reports describing the existing LTC systems and a typology of LTC systems were published. 28 research reports were published to disseminate the project methodology and results. These reports are mainly targeting academic community. The major findings and policy implications of all work packages were published in 8 separate policy briefs. These policy briefs give a short overview about each WP and policy recommendations which aim to ensure wider dissemination of project's results to policymaking community. In addition to ANCIEN publications individual partners published articles in peer review journals as well as articles or working papers in their own institutes' publication series.

List of Websites:

<http://www.ancien-longtermcare.eu/>