# COURAGE in EUROPE – Collaborative Research on Ageing in Europe

## Background

The increase in the proportion of older people in Europe is the result of unprecedented economic, social, medical and technological changes that have made it possible for Europeans to live a long and active life. In Europe, the percentage of persons older than 60 was 20.3% (3.0 for 80+) in 2000, and will rise to 28.8% (5.2% for 80+) in 2025, and the median age will rise from 37.7 to 45.4: the old age dependency ratio (i.e. the number of persons 65+ per one hundred persons 15-64) will rise from 21.7 to 33.2 (UN, 2002).

If, on one side, these demographic trends are fairly well understood, the huge political and social changes that they will produce, are less well understood. Should we expect that future populations will live long and active lives, with severe disability occurring only at the very end of life – a phenomenon called 'compression of morbidity'? (Fries, 2003) Or should we rather expect that the ageing population will experience increasingly high prevalence of mild and moderate disability for a longer period – a phenomenon called 'expansion of morbidity'? (Scheider and Brody, 1983) Both these ageing scenarios have huge, but very different, political and social consequences. If compression of morbidity is true, then we should expect cost savings (as older populations work longer), reducing pension costs and contributing through income taxation to help pay health and other social expenses. If, instead, expansion of morbidity is true, then the overall health and social costs will be far higher as cross-the-board costs will increase in health, rehabilitation and assistive technology services, in employment, transportation and communication accessibility modifications and in other accommodations designed to decrease the burden of disability. The evidence concerning the different ageing scenarios is conflicting. Certainly the prevalence of most chronic diseases (neurological and psychiatric conditions, arthritis, heart problems, diabetes, hypertension and obesity) and their associated risk factors has increased in developed countries (Lafortune, et al. 2007).

## EU Context and Priorities

For this amount of facts, in 2006 the European Commission identified ageing of population as one of the challenging policy issues of the 21st century (EC, 2006). Valid and reliable outcome measures for good statistics, and innovative measurement instruments for cross-population comparative analyses are needed. Current ageing studies involving persons aged 50+ tend to confuse the relationships between a person's health state, his/her quality of life and well-being, relying on measures with limited validity. This confusion is due to overlapping research questions and a conflation of subjective and objective perspectives and evidence. So there is a need to measure these elements independently and against the background of the clear conceptual framework of health provided by WHO's International Classification of Functioning, Disability and Health – ICF (WHO, 2001; Leonardi et al., 2006), that defines disability as the interaction of a health condition with contextual factors. This is the main objective of COURAGE IN EUROPE – Collaborative Research on Ageing in Europe.

In 2007, the OECD released a Health Working Paper on trends in severe disability among the elderly. Severe disability was defined in terms of dependency and presence of one or more limitations in ADLs, therefore relying on a proxy measure of severe disability which was not consistent across countries. Though there is clear evidence of a decline in disability among elderly people in five of the 12 countries, in other countries rates are increasing or stable (Lafortune et al, 2007). However, the policy question (long-term care needs in the future) is used to define the phenomena (severe disability) under investigation, but it is preferable to define the phenomena that generate these needs independently of the needs themselves, and to develop methodologies in which data are collected on the basis of fit for purpose assessment tools.

Some problematic issues arise when methodologies applied in these projects are considered critically. Most of these problems lie in a lack of conceptual clarity and others in practical problems researchers encounter while planning these projects.

**COURAGE IN EUROPE project**

COURAGE in Europe is a three-year project coordinated by Neurological Institute 'Carlo Besta' of Milan and with eleven partners from Italy, Spain, Finland Poland and the WHO. The project is going to develop an instrument to evaluate health and disability determinants in ageing with a comprehensive newly developed protocol. Reliable and valid instruments that measure health outcomes (both physical and mental), quality of life, and well-being in an ageing population are needed. Current studies do not clearly address the mechanisms that purport to explain the linkages between health, quality of life and well-being, because they rely on measures that do not discriminate these constructs, dramatically undermining their validity. This fact underscores the necessity to measure health, quality of life and well-being independently and against the background of ICF model. The ICF makes it possible to define individual levels of health in terms of objective states of capacities to function in a given set of domains, whereas a person's quality of life is entirely a matter of their subjective appraisal of those states irrespective of the actual level of health; well-being is a function both of a person's subjective satisfaction with various aspects of life as well as his/her current affective state measured as a time-weighted metric of amount of negative or positive emotions.

COURAGE in Europe will create a valid and reliable scientific evidence base on determinants of health and disability in ageing, that is comparable across countries in Europe and internationally.

COURAGE in Europe will validate the research protocol in the general population of Spain, Finland and Poland – countries selected to give a broad representation across different regions, taking into consideration their population and health characteristics (median age, life expectancy and sex ratio). Should further EU or national funds be available, other countries could be added to this research. The differences in socio-economic gradients between Poland and Spain and Finland will also provide opportunities to compare the effects of social security mechanisms and ageing outcomes. Spain represents a country that is ageing very rapidly, with very low institutionalisation rates for the elderly and self-reported health and well-being in population surveys that is lower than Northern European nations. Spain, as a Southern Mediterranean country, still represents a culture in which families play a key role in taking care of individuals with disabilities. Spain has also experienced great demographic changes, with a flow of immigrants which has increased the population. Finland presents an interesting opportunity to examine whether earlier reported trends on declining severe disability amongst the elderly are indeed continuing. Also, since Finland possesses registries that go back over a century, it may be possible to empirically examine the relationship between health and well-being outcomes in older ages and early childhood adversity. Finally, Poland is the largest of the newer member states and has a very rapidly ageing population, comparable to most of Western Europe.

**COURAGE IN EUROPE objectives**

Four main objectives will be pursued by COURAGE

1. The first objective is to develop valid assessment instruments to measure key health and health-related outcomes in the general population (from age 18 to end of life). Previous and on-going surveys and research projects on ageing in Europe (and internationally) will be evaluated for coherence and best practices and linked to the ICF framework. The aim is to build linkages with existing national and cross-national ageing studies in (or including) Europe, such as the Study of Health, Ageing and Retirement in Europe (SHARE), WHO's Study on Global Ageing and Adult Health (SAGE), Measuring Health and Disability in Europe: supporting policy development (MHADIE), European Community Health Indicators (ECHI), and the Mental Health Disability: An European Assessment Study

(MHEDEA). The outcomes of these projects, where available, will be used to build the components of the COURAGE in Europe tools and methodology. A key activity in this first objective is the analysis of existing longitudinal (and other) ageing data sets in Spain, Poland and Finland.

2. To validate with a survey in Poland, Spain and Finland the COURAGE protocol, an instrument which will be mindful of the need to create a scientific evidence base for health and disability determinants in ageing. Substantive analysis of this survey will reveal the relationships between these outcomes and determinants to establish further face and construct validity. This baseline cohort will be carefully documented so that possible future follow up may demonstrate predictive validity.
3. To produce substantial innovation in disability and ageing survey methodology. COURAGE protocol will include two additional and innovative elements that might have substantial bearing on ageing: the Built Environment and Social Networks. The assessment of disability, through activity limitations and participation restriction, and its relationship with environmental factors' effect are fundamental in determining people's health, quality of life and well-being. Many studies have shown that poor self-rated health is associated with structural factors in the built environment (Subramaniam, 2006). Understanding how the built environment can facilitate a person's performance means to enhance everyone's experience of better participation, health, quality of life and well-being. The built environment directly impacts on persons' daily life and, as people age, there is an increasing importance of social networking as often there is an increasingly dependency on social networks for a level of support that can facilitate active living. The relevance of social cohesion and social networks has also been recently explored showing that the lack of social network contributes to increasing mortality (Berkman et al., 2004). The existence of good social networks has been demonstrated to be a protective factor for dementias (Fratiglioni et al, 2000; Berkman, 2000). The nature of the social network as an indicator of the attitudinal environment needs to be defined and operationalised in terms of relationships, social support and attitudes. The indicators for social networks and social cohesion, as they apply specifically to an ageing population, need to be defined as there is considerable evidence that the nature and extent of an individual's social network strongly influences health outcomes. The built environment has a considerable impact on how individual capacities in functioning translate into actual performance in real life environments. This in turn is likely to influence individual quality of life and well-being.
4. To provide cross-population analysis and a baseline for longitudinal data collection. The methodology will enable to produce comparable cross-population analysis of non-fatal mental and physical health outcomes, quality of life, and well-being. The project will incorporate state-of-the-art analytical methods so that self-report responses may be calibrated to adjust for reporting biases. Though a longitudinal study is beyond the scope of this project, the testing is intended to provide a baseline and prepare the ground for potential future longitudinal studies in Europe.

**Questions for Consideration by Policy Makers**

Although the most recent European data suggests that morbidity does not necessarily increase in the oldest old (Christensen, 2008), informed policy decision-making will critically depend on which, if either of these ageing scenarios is more likely to occur. Some core questions are still unanswered. Among them:

- Is it possible to measure and compare the determinants of ageing across populations?
- What is the connection between ageing and decrements in quality of life and well-being? What is the role-played by some key environmental factors?
- Is ageing a major driver of disability?

- What is the burden caused by neuropsychiatric conditions?

**What works: solutions and action**

The potential ethical and social aspects raised by population ageing – in light of WHO's definition of healthy ageing as 'the process of optimising opportunities for physical, social and mental health to enable older people to take an active part in society without discrimination and to enjoy an independent and good quality of life' – will be also addressed in COURAGE

Current ageing studies generally focus on the impact of specific diseases, or on some genetic markers that are connected to ageing, as well as the complex mechanisms that underline the inflammatory pattern. Unfortunately, the majority of these findings are not likely to be immediately transferrable into intervention procedures. An aspect which is particularly interesting in COURAGE research is that targeted environmental factors, such as built environment and social network, can be modified through appropriate interventions. The connection between such factors, objective health status and subjective dimensions, such as quality of life and well-being, will enable policy makers to expand the range of possible actions that address the problem of ageing in Europe.

Producing innovative instruments for health and disability data collection, COURAGE in Europe will try to respond to the need of clear data for development of rights-based policy, as expressed in the Article 31 of UN Convention on the Rights of Persons with Disability and will provide the common protocol for the first European Disability Survey.

**COURAGE in Europe Consortium**

Neurological Institute 'Carlo Besta' IRCCS Foundation, (Milan, Italy);
World Health Organization (Geneva, Switzerland);
Institute for Health and Welfare (Helsinki, Finland);
Universidad Autonoma de Madrid (Madrid, Spain);
Sant Joan de Déu - Serveis de Salut Mental (Barcelona, Spain);
Provincia Lombardo Veneta Ordine Ospedaliero di San Giovanni di Dio Fatebenefratelli (Brescia, Italy);
Agenzia Regionale Sanità, Friuli Venezia Giulia (Udine, Italy);
IRCCS Eugenio Medea - Ass.ne La Nostra Famiglia (Conegliano, Italy);
Jagiellonian University — Medical College (Krakow, Poland);
PBS DGA Spolka z o o. (Sopot, Poland);
IPSOS Operaciones SA (Barcelona, Spain);
CF Consulting Finanziamenti Unione Europea (Milan, Italy).

**Key references**


1. United Nations. Dept. of Economic and Social Affairs. Population Division (2002) World Population Ageing 1950-2050. New York, UN
2. Fries JF (2003) Measuring and monitoring success in compressing morbidity. Ann Intern Med 139:455-59
3. Schneider EL, Brody JA (1983) Aging, natural death and the compression of morbidity: another view. N Engl J Med 309:854–7
4. Lafortune G et al (2007) Trends in Severe Disability Among Elderly People: Assessing the Evidence in 12 OECD Countries and the Future Implications. OECD Health Working Paper 26.
5. European Commission (2006). The demographic future of Europe – from challenge to opportunity. (COM(2006)0571). Brussels, EC
6. World Health Organization (2001) International Classification of Functioning, Disability and Health. Geneva, WHO
7. Leonardi M et al (2006) The definition of disability: what is in a name? Lancet 386:1219-21

8. Subramanian SV et al (2006) Neighborhood effects on the self-rated health of elders: uncovering the relative importance of structural and service-related neighborhood environments. J Gerontol 61:S153-60.
9. Berkman LF et al (2004) Social integration and mortality: a prospective study of French employees of Electricity of France-Gas of France: the GAZEL Cohort. Am. J Epidemiol 159:167-74.
10. Fratiglioni L et al (2000) Influence of social network on occurrence of dementia: a community-based longitudinal study. Lancet 355:1315-9.
11. Christensen K et al (2008) Exceptional longevity does not result in excessive levels of disability. PNAS 105:13274-79.

**COURAGE IN EUROPE is a European Commission project funded within the Seventh Framework Programme Number HEALTH-F2-2009-223071**