



MORE YEARS

BETTER LIVES

## Joint Programming Initiative

More Years, Better Lives

The Potential and Challenges of Demographic Change

# Data Mapping Project



Main Findings and Policy  
Recommendations



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## 1. INTRODUCTION

European governments, social planners and policy-makers have identified demographic change as one of the major challenges in the 21st century. According to Eurostat population projections, in 2050 about one-third of the population in most European countries will have reached the age of 65 and over, and in some countries, nearly every second citizen will be aged 50 and over. The situation of the old and the oldest-old (a term used to refer to those aged 80 and over) is of a particular relevance when dealing with the challenges and opportunities of demographic change.

The new demographic realities at the European and national levels require policy reforms, e.g. in terms of retirement schemes and pension systems, the labour market and health care. Evidence-based advice and decision-making depend greatly on the availability and access to reliable and validated data. Scientific studies and policy consultancy cannot provide well-informed advice unless they are based on sound knowledge and a solid interpretation of the most recent and high-quality survey and register data.

## 2. THE DATA MAPPING PROJECT

The governments of the European member states that are partners in the framework of the Joint Programming Initiative “More Years, Better Lives – The Potential and Challenges of Demographic Change” have recognised the great importance of data access and quality in commissioning an in-depth analysis of the data infrastructure in those countries. As a result, the research ministries and organisations of 11 countries (Austria, Belgium, Denmark, Finland, France, Germany, Italy, Netherlands, Spain, Sweden, United Kingdom) and Croatia, with an observer status, have contributed to this evaluation.

The Data Mapping Project sought to map the range of data sources for the study of demographic change due to ageing processes at the European and national levels, to examine whether there are major gaps in the currently available data infrastructure, as well as to provide data producers with user-driven feedback on standard data sources. It provides both scientists and policy-makers with a comprehensive overview of where to find appropriate data for cross-disciplinary approaches and evidence-based policy consultancy in an ageing context. The Data Mapping Project also helps to inform the development of the JPI’s Strategic Research Agenda, and any calls or research proposals that will follow from it, by identifying relevant sources and data gaps. Moreover, it will help to avoid the repetition of work by individual projects, and to ensure that researchers are well informed about possible data sources. A total of 337 national and European-wide data sources have been described and evaluated by experts who have been commissioned by their governments. The catalogue of these European databases can be found at [www.jpi-dataproject.eu](http://www.jpi-dataproject.eu). This website also provides access to summarizing country reports.

The results of this first in-depth analysis show that while the provision of data on ageing populations has been improving through the (partially combined) efforts of national and international statistical offices, non-governmental data providers, and the research community throughout Europe and abroad, there is still a dearth of high-quality information in a number

of areas. These shortcomings are related to access to data, to the sub-populations and the topics covered, and to the methodological underpinnings of the data sources, and particularly of the existing surveys.

#### Access to Data

One key limitation that was identified within this project is related to access to registry data; that is, microdata that are in or originate from a database that is continuously updated—often for administrative purposes—such as population registers. Registry data are particularly important in population research, as in many instances they represent a source of high-quality records that provide excellent coverage of the resident population. In some cases, register data could be used for both cross-sectional and longitudinal analysis, as well as for studying regional differences. Nevertheless, access to register data is often limited due to strict data protection laws, complicated procedures of access, or low levels of user-friendliness. Moreover, restrictions and procedures differ between countries and institutions, which creates an additional barrier to generating a cross-national register or a survey-linked-to-register database. For example, in Belgium the need for understanding local regulations was accentuated, while in other member states—such as Austria and Sweden—difficulties and restrictions related to technical access were highlighted. In light of these problems, initiatives such as the Danish Centre for Survey and Survey/Register Data (CSSR) seek to provide researchers with access to survey data and survey-linked-to-register data in a relatively user-friendly manner.

Moreover, in the emerging European Research Area the absence of information in languages other than that of the country should be addressed. The access problem applies particularly to the international accessibility of register data, and thus poses a challenge to comparative research, which undoubtedly offers the opportunity not only to learn from the living conditions and experiences of the elderly in diverse societal contexts, but also to identify best practices in societies facing the challenges of demographic change. There-

fore, providing at least the basic information and the metadata in English would support international efforts for data preparation and analysis.

Thus, we recommend:

1. Increasing efforts to provide open access to anonymised register data in online databases or research data centres, particularly for international users;
2. Providing exhaustive and user-friendly documentation on how to use register data; and
3. Promoting international networks of research institutions and data providers for comparative studies which could jointly benefit from data exchange.

### 3. SUB-POPULATION COVERAGE

A second particular weakness of the existing data infrastructure pertains to the population sub-groups included in samples. A number of population sub-groups—such as the oldest-old, residents in institutions, people with disabilities, people with chronic diseases, elderly people with immigrant backgrounds, and people with very low or very high socio-economic status—are not sufficiently included or represented in many survey samples. The reasons for the under-representation of these groups could be related to the following: (1) these individuals are difficult to reach (be it by the interviewer, by phone, or online) and, in some cases, (2) they have a limited capacity to answer questions because they are in poor health or have limited language proficiency. Hence, there is a lack of data for the most vulnerable population groups.

This applies particularly to the population aged 80 and over, as most of the surveys do not include them by design. Thus the coverage of ageing in these surveys is restricted to the responses of middle-aged adults and the younger elderly.

In seven of the countries covered by this project, an under-representation of institutionalised older people was reported. Important questions cannot be answered, such as questions related to how older people who receive formal care experience ageing, and about their wellbeing and their living conditions. As a general rule, only the population censuses provide information about the institutionalised population, regardless of age.

Individuals with disabilities at all ages are also frequently excluded from survey samples, making it difficult to identify the relationships between disability on the one hand and work, environment, retirement etc. on the other hand.

For migrant populations and ethnic minorities, it was acknowledged that their diverse origins would make it difficult to select representative samples for each group. Yet it is also recognised that the presence of the foreign population as a whole—even as the dan-

ger of oversimplification that such a merger of migrant groups might lead to is acknowledged—is neglected in the samples. Thus, little is known about migrants' living and working conditions, civic engagement, wellbeing and health. This holds true not only for third-country nationals, but also for citizens of the member states themselves.

A particularly important group that is excluded from survey samples and design is the population with very low (and very high) socio-economic status, or those beyond the socio-economic “mainstream” (e.g. those who are socially isolated), who are again a major target group for policy interventions in general, and within Europe 2020 in particular. Census data are the most important source for analysis with respect to this sub-group, as participation is compulsory.

As these groups are often the focus of social policy-making, we should collect more specific data on them.

Thus, we recommend:

4. Developing and supporting surveys with a more representative sample of the vulnerable and dependent populations in general, and especially of people 65, 80 and older, the institutionalised population, people with disabilities, immigrants, and people outside the socio-economic “mainstream”;
5. Providing better access to aggregated data from official statistics, data from health care institutions, and other institutions that deal with people from the above-mentioned sub-groups; and
6. Developing new strategies for improving the participation of the above-mentioned groups in micro-censuses and censuses.

## 4. THE TOPIC COVERAGE

In terms of thematic coverage, this project focused on 10 demography-relevant policy fields:

- Health and Performance;
- Social Systems and Welfare;
- Work and Productivity;
- Education and Learning;
- Housing, Urban Development and Mobility;
- Public Attitudes towards Old Age;
- Social, Civic and Cultural Engagement;
- Uses of Technology;
- Wellbeing; and,
- Intergenerational Relationships.

Within the fields covered, the evaluators of the data project identified shortcomings in the following areas.

There was a lack of data that pertain to living arrangements, not only of the elderly, but also of the aggregate population, which limits the ability to study social and familiar networks. In terms of social policy, this lack of data makes it difficult to analyse and identify the support provided by these networks. Families, friends and social networks often serve as substitutes or at least complements to institutional care. However, it is important to note that identifying the living arrangements per se would not provide sufficient information on the direction and type of support provided. It is therefore important that the forms and directions of intergenerational transfers become the focus of survey design and data collection. The lack of data on living arrangements and on social support provision is especially problematic when the very old, who are often excluded from survey samples, are considered. We therefore know very little about where and how they live, with whom, and who is providing their support or care. These issues are not only relevant in terms of care needs, but also with regard to proactive instruments to minimise the environmental risk factors of the elderly. These topics are gaining in importance as the number of people aged 80 and over increases.

Very little data are available about the mobility of the elderly across countries within and outside of Europe. Mobility may include residential moves—which in some cases may be related to care needs—as well as work-related commuting and mobility. Nevertheless, this lack of data affects not only the elderly. The number of countries offering a reliable source for the study of mobility at population-representative levels is still small. Thus, the study of the living conditions and mobility patterns of Europeans has been severely restricted by a lack of data, which leaves much room for developing and improving data sources, in terms of both registers and surveys.

A further shortcoming is found with regard to the level of participation of those aged 50 and over in education and training programmes. Surveys rarely examine the involvement of older people in lifelong learning and training activities, notwithstanding the growing importance of (further) education and training for achieving the goal of increased labour market participation in particular, and active ageing in general.

In terms of the use of technologies, data regarding assisted living are also scarce. How ICT might contribute to decreases in age-related costs, to improving elderly care, and to increasing the quality of life among older people are questions with a high degree of policy relevance. However, little empirical evidence to support policy-makers and researchers exists.

Within the topic of wellbeing, data are available at the national and the international levels. Yet these data are often fragmented and stem from surveys that differ in scope and time. Very few if any surveys are specifically focused on and extensively study the wellbeing of the elderly. However, there are a few datasets that simultaneously include both objective and subjective indicators of wellbeing. As the definition of wellbeing and the variables that would allow for its measurement are still being discussed in the scientific community, reaching a common understanding on these issues might be useful, as the concept is still used differently by each discipline.



Finally, a shortcoming that was highlighted by the authors evaluating Austria, Denmark, France, the Netherlands, Spain and Sweden, and which also holds true at the European level, is the absence of data pertaining to individual attitudes towards and societal images of old age. In this context, it is not only necessary to understand how society views elderly people and what types of discrimination are exhibited among age groups, but also how the elderly see themselves and what future expectations with regard to ageing and retirement they might have. As those attitudes, images, and expectations strongly affect how individuals and communities deal with the consequences of ageing, we should devote more effort to gaining a better understanding of the underlying socio-psychological and cultural determinants.

Thus, we recommend:

7. Increasing available funding opportunities for collecting register and survey data on less-explored topics (see above);
8. Supporting further research lines and research projects on the above-mentioned topics, which will also serve as a motor for more and better data availability; and
9. Encouraging public institutions in related fields of activity to allow for access to related data.

A number of methodological shortcomings were identified in this project. First, important databases and surveys with a high degree of international recognition remained incomplete and fragmentary, and can thus be only partially used or will soon become out-dated. In a number of cases, the preparation and the harmonisation of data can take a protracted period of time, which may result in a delayed release of data, thus limiting the policy-relevant use of the data. To address this problem, we recommend that the time that elapses between data collection and release should be shortened without compromising data checks and cleaning to ensure data quality. Thus, the data should become available for research and policy design as soon as possible.

A further shortcoming of the existing data infrastructure is its methodological diversity. Data are not always homogenous and thoroughly comparable due to the use of various definitions, methodological concepts, and analytical instruments. The harmonisation and conceptualisation problems, along with differences in the timing of data collection periods, limit comparative research and options for linkage across databases and countries.

Another concern relates to the great variety among the member states in terms of the geographical coverage of the available register and survey data. More specifically, the multiple administrative levels of data collection—from the national level to the level of regions and municipalities—could be later reflected in fragmented data sources. In countries where autonomous or linguistically diverse regions exist, register and survey data seem to be frequently collected at the regional level. However, these data are often not harmonised, and might therefore be neither comparable nor compatible.

More harmonised data collections for comparative studies are not only relevant for research, but are also essential for policy-making. As harmonisation processes affect the development and release of cross-national collections, these processes often determine the

timeliness of data sources. Therefore, we recommend that the existing data harmonisation processes be improved, not only in terms of the methods applied, but also in terms of comparability to other surveys. In this regard, the successful experience of official surveys and research infrastructures, as well as final users could contribute to the improvement of the methodological processes behind the data production processes. This would lead to recommendations regarding definitions, methodological concepts and common understandings, which would contribute to the harmonisation data work.

Ageing is a dynamic process that affects more than one generation, thus its effects are experienced not only at a specific point of time, but from a life-course perspective. Therefore, we suggest promoting and continuing the funding for longitudinal data collections, particularly those that follow a single sample over time, such as the Survey of Health, Ageing and Retirement in Europe (SHARE), the English Longitudinal Study of Ageing (ELSA) and the Swedish Longitudinal Occupational Survey of Health.

Finally, while the importance of cross-national studies should not be neglected as they provide rich, comparable data, we also recommend that the national collection of data be further developed and improved. National and international data are not substitutes for either policy-making or research, as both provide data to cover different needs. Therefore, their complementary roles should be further developed.

Thus, we recommend:

10. Improving existing incomplete database and survey infrastructures;
11. Strengthening and contributing to the sustainability of well-established structures;
12. Strengthening the dialogue between scholars and policy-makers through regular meetings and workshops, where scientific output and policy-relevant initiatives are discussed; and

13. Involving researchers in decision-making procedures in the creation of datasets and data availability, e.g. by internationally-composed research data councils.

## 6. CHALLENGES AND OPPORTUNITIES

There are a number of additional challenges and opportunities that warrant attention. First, there are several ethical considerations. Because microdata report individual information, data disclosure is an issue that has become increasingly important, and will continue to be so. In addition to the firm and complex data protection rules at the European and national levels, a number of data protection techniques have been developed to ensure the privacy of the respondents. The most common data protection technique is the anonymisation of data. Other techniques used across Europe include, for example, masking and synthetic data generation, which, while being very useful in terms of data protection, might also result in a decreased statistical power of the data and an increased risk of bias. An emerging challenge regarding data protection is the collection of biological, genetic and medical samples. Complicated legal regulations in that area can, however, be a serious burden for researchers trying to publish the data they have collected, even when the standard procedures of data protection, e.g. anonymisation, are applied. In some cases, data ownership results in collections not being available to the broad scientific community for a prolonged period of time. Instead, these collections may be used only by the research group who have collected the data.

As publishers of books and journals are increasingly forced to provide open access to publications—at least to those that have been created using public funding or support—and to find ways to ensure intellectual property rights and contractual arrangements with authors, agreements could be made with data providers. Of course, there is a principle difference between the publication of research results and the publication of individual data. While the importance of privacy and the protection of ownership rights are acknowledged, it is also essential to accentuate the importance of data availability for research and policy-making. Even if concerns about the potential misuse of data may often be justified, it has to be stated that research data collection has another legitimisation base: unlike in the case of marketing, consumer data and social network data, which are collected through different

channels and are frequently used to increase monetary profit, the collection of demographic data is for scientific purposes only, and aims to create more generalized evidence and should therefore not threaten privacy concerns. The objective of demographic and socio-economic data is to examine people's current situations and identify their needs, and thus to provide decision-makers with evidence-based advice on how to improve the wellbeing and quality of life of the elderly today and in the future.

In connection with these general concerns about potential misuse of data, there is another problem that arises: due to the low level of awareness among the potential participants of the importance of such research, surveys often suffer from low—and, in the case of longitudinal studies, declining—response rates, which limits their usability.

Increasing the awareness of the positive externalities of demographic surveys will also be beneficial in terms of the anticipated EU regulation on the right of individuals to approve any use of their data. This is a particularly important point to keep in mind as the planned EU regulation might endanger attempts to improve the data infrastructure in Europe. Scholars have pointed out that the planned European regulation on data protection and collection will have a negative impact on the social sciences in general. The move to more increased regulation, however, does not appear to be the only possible solution: a Swedish task force is currently examining the options for improving access to data, while the European policy initiatives seem to be moving in the opposite direction.

Thus, we recommend:

14. Starting a debate on open-access data, particularly if it has been collected, sampled or developed using public funding;
15. Making individuals aware that existing mechanisms guarantee the protection of their rights and individual data, as well as improving the

collection methods in order to increase the response rates; and

16. Reconsidering the planned EU legislation on the rights of individuals to approve any use of their data.

In times of economic recession and budget constraints, especially as the pressure on state budgets is increasing due to continuously rising age-related expenditures, there is an increased risk that we will devote fewer resources to research and data collection. Some scholars have expressed concerns that surveys might be dropped from programmes or reduced due to funding limitations. Furthermore, trends towards multipurpose data collection and surveys covering the general population (instead of specifically targeted populations) have been observed. While these changes may save money and use resources more efficiently, they might also jeopardise the level of detail and the explanatory power of the collected data. As a consequence, costs may still increase if information is needed later for research projects or policy interventions tailored to a specifically targeted population sub-group.

Thus, we recommend:

17. Improving the budgetary allocation for research and research infrastructures, especially with the goal of improving access to statistics, as well as developing surveys and research databases.

Despite these shortcomings and challenges regarding the existing data infrastructure, a number of good practices have been identified. It was agreed that the Survey of Health, Ageing and Retirement in Europe (SHARE) is one example of best practices in terms of survey methodology, data availability, and geographical and topic coverage. The survey's ex-ante harmonisation ensures comparable data for all 10 social policy fields of this project, and is specifically targeted at the population aged 50 and over. Other examples of good practices are the Health Data Navigator and the Active Ageing Index, two initiatives in which particular efforts are being made to bring together topic-specific databases. These initiatives are particularly useful as they

provide an overview of the existing health and active ageing-related sources that is otherwise hard to get. Nevertheless, there is still a lack of data sources on other topics such as social systems and welfare.

We acknowledge the need for integrative databases that allow for the collection of information in a single site or instrument, and suggest the further development of a comparative policy database. The Population and Policy Database, which exists as a pilot version, could serve as an example, providing descriptions on an increasing number of social policy interventions, demographic data and contextual indicators, which would allow for a cross-country comparison and analysis over time in multiple policy fields.

Finally, we conclude that the Data Mapping Project of the Joint Programming Initiative "More Years, Better Lives – The Potential and Challenges of Demographic Change" was a useful approach to develop a catalogue of resources for the study of ageing on a European level. This may lead to a more efficient use of currently available sources and the development of new data infrastructures used by policy-makers and researchers.

Thus, we recommend:

18. Promoting knowledge about the databases among user groups in order to avoid the unnecessary duplication of efforts or data analyses that are not grounded on the finest available data; and
19. Continuing the exercise of collecting and evaluating information on existing databases, and keeping the database which has been created in the framework of this project continuously updated.



