UNECE

Recommendations for Measuring Older Populations in Institutions

UNITED NATIONS

UNITED NATIONS ECONOMIC COMMISSION FOR EUROPE

Recommendations for Measuring Older Populations in Institutions

Prepared by the Task Force on Measuring
Older Populations in Institutions

UNITED NATIONS

Geneva, 2020

Preface

As populations across the UNECE region and throughout the world grow older, it becomes increasingly important both to produce statistics on topics of specific relevance to ageing and older people, and to ensure adequate, representative coverage of older people in the production of statistics on all topic areas. With this in mind, a UNECE Task Force produced the *Recommendations on Ageing-related Statistics*, published in 2016. Among the priority areas identified for future work in those recommendations was the issue of how to approach the inclusion in statistics of older people who are not part of a private household, but who instead live in an institution.

Statistics on social and demographic topics are typically produced from surveys of private households. For many statistics this is suitable, especially when balanced against the additional costs that the coverage of institutional populations would entail. In ageing populations, however, it becomes necessary to consider how bias might be introduced into statistics as a result of excluding the older populations living in institutions; by virtue of the absolute size of such populations, their size relative to the total population, and the degree to which their characteristics vary systematically from those of the population of older people in private households. While such bias is recognized, views on what to do about it vary widely, as evidenced by strongly-expressed and polarized comments received during consultation on the *Recommendations on Ageing-related Statistics*.

In view of this evident need for guidance on the subject, in 2017 the Conference of European Statisticians (CES) established a Task Force on Measuring Older Populations in Institutions. The objectives of the Task Force were to consider the definitions and classifications of 'institution' and 'institutional populations' *as they pertain to older people*; and to provide guidelines for statistical offices on whether, when and how to include such populations in the production of statistics on ageing-related topics. The Task Force was asked to review current approaches and identify good practices; to provide estimates of the extent to which exclusion of institutional populations biases ageing-related statistics; and to formulate recommendations for the treatment of institutional populations of older persons in social surveys and other data sources to produce ageing-related statistics.

The Conference of European Statisticians endorsed the *Recommendations for Measuring Older Populations in Institutions* at its 67th plenary session in June 2019.

Acknowledgements

Contents

List of tables

List of figures

Acronyms

ADL . . . . Activities of Daily Living

AAT . . . . Ambient Assisted Technologies

CAAS . . . . Social Assistance Accommodation Census (Mexico)

CES . . . . Conference of European Statisticians

CHARLS . . . . . . China Health and Retirement Longitudinal Study (China)

CRELES . . . . . . Costa Rican Longevity and Healthy Aging Study (Costa Rica)

ELSA . . . . English Longitudinal Study of Ageing (United Kingdom)

EU . . . . European Union

GESIS . . . . German Social Science Infrastructure Services

HSE . . . . Health Survey for England

HRS . . . . Health and Retirement Study (USA)

ILQ . . . . Institutional Living Quarters

IR . . . . Institutional Residents

ISCED . . . . International Standard Classification of Education

ISTAT . . . . Italian National Institute of Statistics (Italy)

JSTAR . . . . Japanese Study of Aging and Retirement (Japan)

KLoSA . . . . Korean Longitudinal Study of Aging (Republic of Korea)

LASI . . . . Longitudinal Aging Study in India (India)

LEILA 75+ . . . . Leipzig Longitudinal Study of the Aged

LFS . . . . Labour Force Survey

MEA . . . . Mannheim Research Institute for the Economics of Ageing

MHAS . . . . Mexican Health and Aging Study (Mexico)

NDS . . . . National Disability Survey (Ireland)

NSI . . . . National Statistics Institute

NSO . . . . National Statistical Office

NUTS . . . . Nomenclature of Territorial Units for Statistics

OECD . . . . Organization for Economic Co-operation and Development

ONS . . . . Office for National Statistics (United Kingdom)

PHR . . . . Private Household Residents

SERISS . . . . Synergies for Europe's Research Infrastructures in the Social Sciences

SHA . . . . System of Health Accounts

SHARE . . . . Survey of Health, Ageing and Retirement in Europe

TCGA . . . . Titchfield City Group on Ageing and Age-disaggregated Data

UNECE . . . . United Nations Economic Commission for Europe

Chapter 1

Introduction

1.   This document is the product of a Task Force established by the CES Bureau in February 2017 and chaired by the United Kingdom's Office for National Statistics. The overarching objective of this Task Force was to provide guidelines to inform and support statistical offices on whether, when and how to include populations of older people in institutions in the production of statistics on ageing-related topics. The Conference of European Statisticians endorsed the present Recommendations at its 67th plenary session in June 2019.

1.1   Importance and policy relevance

2.   As populations across the UNECE region and throughout the world grow older, it becomes increasingly important both to produce statistics on topics of specific relevance to ageing and older people, and to ensure adequate, representative coverage of older people in the production of statistics on all topic areas. With this in mind, a UNECE Task Force produced the *Recommendations on Ageing-related Statistics*, published in 2016. Among the priority areas identified for future work in those Recommendations was the issue of how to approach the inclusion in statistics of older people who are not part of a private household, but who instead live in an institution. The relative size of such institutional populations of older people varies widely across countries—in some it is growing, while in others, social policies promoting 'ageing in place' mean that it is shrinking. Irrespective of size and trends, however, the population of older people living in institutions is distinctive and likely to vary systematically in many respects from the general population or even from the general older population.

3.   Statistics on social and demographic topics are, in many countries, typically produced from surveys of private households. For many statistics this is suitable, especially when balanced against the additional costs that the coverage of institutional populations would entail. The exclusion of institutional populations is usually justified by practical concerns and higher costs (Pickering et al. 2008).

4.   In ageing populations, however, it becomes necessary to consider how bias might be introduced into statistics as a result of excluding the older populations living in institutions; by virtue of the absolute size of such populations, their size relative to the total population, and the degree to which their characteristics vary systematically from those of the population of older people in private households. While such bias is recognized, views on what to do about it vary widely, as evidenced by strongly-expressed and polarized comments received during consultation on the *Recommendations on Ageing-related Statistics*.

5.   The importance of taking into account the characteristics of the institutionalized older population, no matter how small these populations might be and therefore how minor might be their influence on overall statistics of the general population, has been brought to the fore by the 2030 Agenda for Sustainable Development. This framework calls for efforts to ensure that 'no-one is left behind' in the design and application of policies to improve lives. For this to happen, statistics must endeavour to take into consideration small groups, in particular those whose characteristics might make them especially vulnerable or disadvantaged and especially those who otherwise remain hidden. For all these reasons, a study of the needs and possibilities for producing statistics on older populations in institutions is timely.

1.2   Background and work of the Task Force

6.   In view of the evident need for guidance on the subject, in February 2017 the Bureau of the Conference of European Statisticians (CES) established a Task Force on Measuring Older Populations in Institutions. The overarching objective was to provide guidelines to inform and support statistical offices on whether, when and how to include populations of older people in institutions in the production of statistics on ageing-related topics. The Task Force was asked to review definitions and classifications of institutions; to enumerate current approaches and identify good practices; to provide estimates of the extent to which exclusion of institutional populations biases ageing-related statistics; and to formulate recommendations for the treatment of institutional populations of older persons in social surveys and other data sources for the production of ageing-related statistics.

7.   The Task Force comprised members from 19 countries and organizations, whose first task was to provide information from their own countries about current practices, definitions, challenges and needs. Twelve countries[1] provided information which formed the backdrop from which the work plan of the Task Force was developed.

8.   Based on the information gathered from Task Force members, it became apparent that information should be gathered from other countries, to provide a more comprehensive picture of the diversity of situations and practices across the region. The Task Force therefore prepared an online survey which was sent to member countries of the CES,[2] resulting in responses from 36 countries. Much of the material that follows in this document is based on the responses obtained through these two information-gathering exercises.

---

1   Austria, Canada, Germany, Hungary, Israel, Italy, Latvia, Lithuania, Mexico, Russian Federation, Turkey, United Kingdom.

2   See Appendix II for the full text of the survey.

1.3   Overview of the Recommendations

9.   The information-gathering exercises of the Task Force identified five distinct strands of work to be conducted. Each of these was undertaken by a sub-team of the Task Force and resulted in a chapter of this document.

Chapter 2:   Definitions of older populations in institutions

10.   The starting point of this work is an overview of current variation across countries in how they define and classify institutions, how they separate 'older population' from general population for statistical purposes, and how the definitions and classifications are applied in practice. This chapter gives information about country practices and attempts to identify commonalities among those practices. It makes some recommendations for countries, as well as suggesting some considerations for future international Census Recommendations.

Chapter 3:   Assessing bias arising from omission of older populations in institutions from surveys

11.   One of the underlying rationales for establishing this Task Force was the assumption that excluding institutional populations of older people from social surveys will result in biased statistics, especially in the case of ageing-related statistics which specifically aim to measure characteristics of the older population. There are good reasons to consider the population of older people in institutions as distinctive: both because they are older than the general population, and because their reasons for being in an institution may be related to poor health, disability, etc. This chapter presents a proposed methodology to assess the extent of statistical bias, demonstrating that the degree of bias of course depends both on the relative size of the institutional population and on its distinctiveness. It recommends that attention be focused on those variables most vulnerable to bias (i.e., those with the greatest distinctiveness between the institutional and non-institutional population), including health, age, marital status, education and others.

Chapter 4:   Design of instruments and survey methods to collect information on older populations in institutions

12.   Drawing on information provided by Task Force members and by countries that answered the survey, as well as on existing research and guidance, this chapter considers the principal challenges associated with identifying, accessing and gathering data from older respondents in institutions. The difficulties arise both from the fact of them being older people, and from the fact that they reside in institutions. The combination of these two factors makes the challenges especially great. The chapter highlights some important considerations for sampling, survey design and use of proxies.

Chapter 5: Methods for measuring older populations in institutions using administrative data

13.   Noting the general move towards favouring administrative sources in the name of increased efficiency and reduced respondent burden, this chapter looks at some of the specific considerations when using administrative sources for producing statistics on older people in institutions. It notes that administrative sources can be useful both as a means of identifying the institutions and sampling units, and also, for some topics, as the source of data for producing the statistics themselves. The pros and cons of these uses are discussed in the framework of a more general consideration of the pros and cons of using administrative and secondary sources. Some of the challenges in accessing individuals and administering surveys can be overcome using administrative sources, but there are limitations in the thematic areas of social statistics that are covered by such sources.

Chapter 6: Ethical considerations for collecting information on older populations in institutions

14.   There are ethical issues surrounding all social survey-based research, and especially for surveys gathering responses from older people who may have cognitive limitations. Additional ethical challenges arise when conducting surveys in an institutional setting. Even when administrative sources are used instead of traditional surveys, particular ethical considerations arise. This chapter outlines the issues to be taken into account and makes some recommendations.

Chapter 7: Recommendations and future work

15.   This chapter gives an overview of the main recommendations and suggestions for future work made throughout the chapters, gives some proposals for prioritizing among these, and offers some overarching conclusions from the Task Force. The chapter highlights the fit between this work and the remit of the Titchfield City Group on Ageing and Age-disaggregated Data (TCGA). This may provide a useful forum for taking forward any future work arising from the recommendations of this Task Force.

Chapter 2

Definitions of older populations in institutions

2.1   Introduction

16.   A basic premise of the work of the Task Force is that populations of older persons living in institutions are usually excluded from statistics gathered via household surveys[3]. This premise rests on several fundamental assumptions: namely, that the terms 'older persons', 'living', and 'institutions' are well-defined and that they are used uniformly across countries and across surveys within a given country. When these assumptions are examined more closely, however, it becomes apparent that these terms are not, in fact, so clearly defined and applied. In particular the concept of an institution is often defined through omission (i.e. by considering what is *not* taken to be a private household and covered in household surveys), rather than a positive definition based on a clear set of criteria.

17.   As is very often the case when applying definitions and classifications to real-life situations for the sake of producing statistics, the concepts in question are found to be fuzzy and difficult to fit into a neat framework of categories. This has long been acknowledged in the case of 'older people', where it has now become widely understood that there is no fixed threshold age at which a person suddenly transitions from being 'not old' to being an 'older person', and furthermore that the social context including retirement age, population health and life expectancy, cultural expectations and many other factors mediate the transition into older age.

18.   The work of this Task Force reveals that a similar 'fuzziness' surrounds the other important concepts relevant for this work. While in the past it might perhaps have been relatively simple to distinguish private households from institutions, and to say who was living in each, there is now a proliferation of living arrangements in many countries evolving to meet the needs of their ageing populations. This includes assisted living facilities and seniors' residences which grant more autonomy to residents than nursing homes, for example. In some countries it could also include informal settings that appear to meet the criteria to be considered an institution, but which have no formal basis. This growing and changing variety makes it increasingly challenging to define the distinction between private households and institutions.

19.   There is no simple dichotomy between people who live permanently in a private home, either alone or with their family, versus those who have moved permanently to a nursing home or older people's residence. People may come and go between different arrangements according to changes in their health or socioeconomic status. Furthermore, the institutions with which they are connected may include a variety of features, some of which are typically thought of as defining characteristics of institutions and others which are used as criteria to define private residence. The buildings, sleeping arrangements, cooking and washing facilities and provision

---

3   Some countries, as well as some international guidelines, use the term 'communal establishment' as a synonym for institution. The former term is preferred by some who consider 'institution' to have negative connotations, and/or to refer to intangible practices or customs rather than only physical entities – e.g. 'the institution of marriage'. This publication, however, uses the terms 'institution' and 'communal establishment' interchangeably.

of services may not be uniform for all residents of a given institution. Indeed, a single institution for older people may provide different services to different individuals, such that some clients or residents would be better defined as living in an institution and some as living in a private household. Relatedly, the services provided to a given individual may evolve over time according to need, such that what may start out as private living may gradually become institutional living, without that person having physically changed location.

20. The first planned activity of the Task Force, and one which was expressly called for in the *Recommendations on Ageing-related Statistics*, was to conduct a review of definitions of institutions relevant to older people as currently employed by countries, and to examine the extent to which and reasons why these vary from the definitions given in the CES Census Recommendations. To this end, the Task Force developed an online survey which was sent to NSOs participating in the CES, resulting in 36 responses (in addition to information gathered from the countries represented by Task Force members). This chapter presents an overview of the main findings of these information-gathering exercises with respect to definitions. As well as reviewing definitions of institutions, countries were asked about how 'older populations' are defined[4], as well as about the application of the concept of usual residence to determine where a person is living for the purposes of statistical data collection.

2.2   Existing standards and guidance

21. The CES Census Recommendations[5] are the main source of international guidance on how institutions should be defined for statistical purposes. These Recommendations are, of course, designed to guide countries in conducting a population and housing census, but they can also be applied more broadly. Following the Recommendations permits comparison between countries. They state that:

> "an institutional household comprises persons whose need for shelter and subsistence are being provided by an institution. An institution is understood to be a legal body for the purpose of long-term inhabitation and provision of services to a group of persons. Institutions usually have common facilities shared by the occupants (bath, lounges, eating facilities, dormitory and so forth). The great majority of institutional households fall under the following categories:
>
> Residences for students
>
> (1.0)   Hospitals, convalescent homes, establishments for the disabled, psychiatric institutions, old people's homes and nursing homes
> (2.0)   Assisted living facilities and welfare institutions including those for the homeless
> (3.0)   Military barracks
> (4.0)   Correctional and penal institutions

---

4   It should be noted that in the remainder of this chapter, responses from countries are reported as given, with only minor editing for the sake of clarity. Therefore while the preferred terms of this Task Force are 'older person' and 'older population', terms such as 'elderly' are reproduced if used by the responding country.

5   Appendix I contains the full text of all relevant definitions from the CES Census Recommmedations.

(5.0)   Religious institutions

(6.0)   Worker dormitories" (p.163)

22.   The categories of institutions most relevant for the topic of ageing-related statistics are categories 2.0, 3.0, 5.0 and 6.0 of the list above.

23.   In the Census Recommendations it is also added that:

"an 'institution' is a separate and independent set of premises comprising all or part of a permanent building or set of buildings which by the way it has been built, rebuilt or converted is designed for habitation by a large group of persons who are subject to a common authority or regime or bound by a common objective or personal interest, and which is used as the usual residence of at least one person at the census reference time. Such collective living quarters usually have certain shared common facilities such as cooking and toilet facilities, baths, lounge rooms or dormitories. This category includes premises such as nurses' hostels, student residences, hospitals, sanatoria and convalescent homes, welfare institutions, monasteries, convents, military and police barracks, prisons and reformatories." (p.189)

24.   The Recommendations state that the institution should be taken as the place of usual residence if the person has spent or is likely to spend, at time of the interview, twelve months or more as inmates. (p.80)

25.   The System of Health Accounts (SHA)[6] also provides a definition of only a selection of institutions, namely residential long-term care facilities. This category comprises:

"establishments that are primarily engaged in providing residential long-term care that combines nursing, supervisory or other types of care as required by the residents. In these establishments, a significant part of the production process and the care provided is a mix of health and social services, with the health services being largely at the level of nursing care, in combination with personal care services. The medical components of care are, however, much less intensive than those provided in hospitals."

2.3   Current approaches

26.   Countries were asked how their census distinguishes between households and institutions. They were then asked whether and to what extent the census in their country uses the definitions given in the CES Census Recommendations. Respondents were asked to give further detail in cases where there are differences, and to explain whether and why concepts, definitions and classifications differ across different surveys and administrative sources beyond the census.[7]

27.   The results of the survey of CES countries revealed some variation in the definitions used, as summarized in Table 1.

---

6   2017 revision available at https://ec.europa.eu/eurostat/web/products-manuals-and-guidelines/-/KS-05-19-103

7   For the complete text of the survey sent to countries, see Appendix II.

Table 1. Use of definitions of institutions as given in Census Recommendations, in responding countries

Does the Census in your country use the definitions given in the CES Census Recommendations?				
Answer category	Definition of institution		Classification of types of institutions	
Different	2	6%	3	8%
Exactly the same	24	67%	18	50%
Similar	10	28%	14	39%
Not given	0	0%	1	3%
Total	36	100%	36	100%

28.   In addition to the information gathered in the survey, it is important to bear in mind the particular approach to institutional care of older people that is followed in any given country, and the impact this may have on their statistics. De-institutionalization is a general trend for Scandinavian long-term care over recent decades, for example. Denmark and Sweden have taken this trend a step further than Norway and Finland. Denmark suspended institutional care altogether in 1987 and Sweden in 1992. Since then, residential care has been provided to individuals in these countries in special housing of various forms. This housing is in principle 'independent housing' or 'assisted living', where residents are tenants and are provided services according to needs rather than according to location. Housing of this type is not considered as an institution.[8] In the Netherlands, too, for several decades there has been a trend towards older people living independently for as long as possible, resulting in fewer of them living in institutions. Since the reform of long-term care in the Netherlands in 2015, many residential care homes have closed or have been transformed into nursing homes. In Iceland there is very little activity when it comes to statistics on institutions for old-age persons. Statistics Iceland has published a table 'Occupants of retirement homes and nursing homes and wards by sex and age 1993-2010'.[9] There are no plans to update this table with more recent data.

29.   For these countries, therefore, the distinction between household and institution becomes more blurred and indeed less necessary, as time goes on.

2.3.1 Definitions and classifications of institutions

30.   It is important to consider not only the criteria used by countries to determine what is included and what is excluded from the overall definition of institutions, but also what categories of institution exist and how these are defined. While a great many possible types of institutions exist, the present work is concerned only with those which pertain to older people and to ageing-related statistics. Hence, for example, student residences, military barracks, children's orphanages and juvenile detention centres are not considered here. On the other hand, the Task Force considered it important to keep in mind that the institutions of concern to older populations are not limited only

---

8   See Daatland et al. (2015) for more information.

9   Available at http://px.hagstofa.is/pxen/pxweb/en/Samfelag/Samfelag__felagsmal__aldradir/HEI03000.px

to nursing and care homes, hospices and older persons' residences or retirement homes: other types of institution, such as prisons, shelters and religious institutions are potentially important as well.

Austria

31.   An institution is understood to be a legal body for the purpose of long-term inhabitation and provision of services to a group of persons. Institutions usually have common facilities shared by the occupants (baths, lounges, eating facilities, dormitories and so forth). Members of an institutional household are those that have their place of usual residence at the institution.

32.   The classification of institutions used is:
   a)   Health care institutions or institutions for retired or elderly people
   b)   Institutions for disabled
   c)   Religious institutions
   d)   Correctional and penal institutions
   e)   Institutions for refugees
   f)   Welfare institutions including institutions for the homeless
   g)   Other institutions.

Canada

33.   A collective dwelling is a dwelling identified as being of a communal, institutional or commercial nature. The definition used is the following: Facilities for elderly residents that provide accommodations with health care services or personal support/assisted living care. Health care services include professional health monitoring and skilled nursing care and supervision 24 hours a day, seven day a week, for people who are not independent in most activities of daily living. Included are nursing homes, residences for senior citizens, and facilities that are a mix of both a nursing home and a residence for senior citizens. Excluded are facilities licensed as hospitals and facilities that do not provide any services. The same definitions and classifications are used across collections.

34.   For the census, all collectives for senior citizens are in the same classification (nursing home and/or residence for senior citizens). Previously we classified collectives for independent living, assisted living and nursing care separately. However, it was decided to combine them into a single classification due to the great difficulty in accurately maintaining separate groupings.

Finland

35.   Statistics on institutional care and housing services on social care in Finland, including institutions for elderly persons, are collected and published by the National Institute for Health and Welfare.[10]

---

10   Information on these statistics is available at https://www.thl.fi/en/web/thlfi-en/statistics/statistics-by-topic/social-services-older-people/institutional-care-and-housing-services-in-social-care

36.   The Care Register for Social Welfare (henceforth the care register) contains data on institutional care and housing services with 24-hour/part-time assistance for older people, people with physical or intellectual disabilities and people with mental health problems. The data on institutional care and housing services are based on discharges.

37.   The statistical population consists of all people receiving institutional care or sheltered housing provided as social care. It does not include people living in child welfare institutions, family homes for children and young people, assignment-based family care or housing service units operated as part of services for substance abusers.

38.   When a new person is included in the care register, there is no check against the population register. Thus undercounts and double counts may occur.

39.   Institutions can be classified as: municipal and private-sector residential homes for older people, sheltered housing units with 24-hour assistance for older people, institutional care and housing services with 24-hour assistance for people with intellectual disabilities, sheltered housing units with 24-hour assistance for people with severe disabilities and psychiatric patients, detoxification and rehabilitation centres operated as part of services for substance abusers.

Germany

40.   In the census, institutions are defined as permanent facilities that serve residents with special needs with accommodation and services. To determine the approach to data collection, institutions are classified as sensitive and non-sensitive. Residents of sensitive institutions (e.g., institutions for disabled people, hospitals, prisons, etc.) could suffer from stigmatization if their place of residence was known. Institutions for the elderly should mostly belong to the category of non-sensitive institutions (except for hospitals, hospices or psychiatric institutions).

41.   In contrast to the German census, the microcensus does not distinguish between sensitive and non-sensitive institutions.

Hungary

42.   The definition for institutions used in the Census: an institution is any premises or group of premises providing collective accommodation and certain boarding for five or more persons (e.g. infants' and children's home, students' hostel, old people's home, hospital, hotel). The definition for institutions used in the data collections and in the social register are based on the Act III of 1993 on Social Governance and Social Benefits. If an institution is licensed by the Central Administration of the National Pension Insurance as the competent authority, it is also recorded as an institution in the social register and is a respondent of the data collections. Types of social service provided by the institutions relevant to the topic (used in the data collections and in the social register) are:
    a)   Long-term residential social institutions (home for elderly persons)
    b)   Short-term residential social institutions (temporary home for elderly persons)

    (Note, however, that older people may also live in other types of institutions, such as homes for psychiatric patients, disabled persons, addicts and homeless persons).

Israel

43.   An institution is "an administrative unit that provides accommodation and food services to at least five residents for a period of three months or more."

44.   Classification of institutions: nursing home; assisted living; hospital for long-term care (including nursing and mentally frail patients); nursing ward in a nursing home (or in a kibbutz); hostel for the elderly.

Italy

45.   In Italy an institution is a public or private structure providing residential care and social and health services (hospitality with overnight accommodation) to people in need. The structure is uniquely determined by the combination of name and address. The census considers as a collective residential building a place where groups of people with common interests and objectives are accommodated. The main type of institutions are: hospitals, children's or elderly persons' care homes, hostels, special schools, prisons, monasteries etc.

46.   In agreement with all regions, institutions are classified using a national classification. This classification uses four variables to identify each institution: type of institution (familial, community); social protection function; level of health services provided (absent, low, middle, high), main type of recipients of services.

Latvia

47.   Collective (institutional) households cover persons residing in various organizations or institutions (hospitals, elderly care facilities, monasteries, barracks, prisons, etc.) where they are provided with necessary accommodations and provisions, as well as persons residing in dormitories of higher education institutions.

Lithuania

48.   In the population census an institution is a collective residential building or group of buildings to accommodate groups of people with common interests and objectives or who obey the established procedure or regime. In the labour force and employment surveys an institution is a place that satisfies shelter and basic living needs. This includes long-term care hospitals, children's or elderly care homes, hostels, special schools, places of imprisonment, monasteries, etc. The personal social service survey deals with only a selection of institutions. They are defined as legal entities, other organizations or their units providing personal social services, established in the Republic of Lithuania or in another European Union Member State or EEA state.

49.   In the consumer opinion survey, institutions are defined as children's and elderly persons' care homes, nursing and health long-term care institutions, religious institutions (monasteries),

correctional and criminal authorities. In this study, when describing institutions, it is emphasized that persons living in the institutions are not responsible for providing themselves with the necessary means of living.

50. The resident health survey excludes clients in health care institutions from the study. When it comes to administrative statistics on health care, sources of the administrative data available in the country allow us to see, for example, how many people were treated in hospitals in a specific municipality (location of the institution), and how many residents of a particular municipality were treated in a hospital (person's residence regardless of the hospital's address). An institution is understood to be a legal body for the purpose of long-term inhabitation and provision of services to a group of persons, usually with common facilities shared by the occupants (baths, lounges, eating facilities etc.).

51. According to the Social Services Catalogue (2006) institutions are classified as follows: "Social service institutions for adults are grouped by type: 1. care institution for the elderly; 2. care institution for adults with disabilities; 3. other (special) care institution; 4. independent living home for the elderly and adults with disabilities; 5. group living home for the elderly and adults with disabilities." In addition to this, personal social service institutions are also grouped according to ownership (state, municipality, community organization, religious community, private person).

52. Looking more broadly, institutions for the elderly include: foster care institutions (foster care homes, hostels, etc.); medical institutions (hospitals and sanatoriums); religious institutions (monasteries, seminaries); military institutions (barracks); other institutions (correctional institutions, places of custody).

53. The majority of institutional households fall under the following categories: hospitals, convalescent homes, establishments for the disabled, psychiatric institutions, old people's homes and nursing homes, institutions including those for the homeless, asylum seekers or refugees; military barracks; student residences (dormitories); correctional and penal institutions, retention premises; religious institutions; worker dormitories. Persons doing compulsory military service (conscripts) are always excluded from the private household population.

Mexico

54. There is no precise definition for 'institution', but similar concepts are used in the various statistical projects of the office.

55. In the population and housing census, the concept used is that of the collective housing unit: a housing unit that provides accommodation to people who share or are subject to norms of coexistence and behaviour for reasons of health, education, discipline, religion, work and social assistance, among others, and that at the time of the collection has habitual residents.

56. Collective housing units are classified according to their main function and the characteristics of the population housed therein, whether for reasons of health, education, discipline, religion, work and social assistance, etc.

57.   In the Social Assistance Accommodations Census (CAAS), the concept used is that of the establishment for social assistance, defined as an economic unit that, settled permanently and delimited by buildings and fixed facilities, combines actions and resources under the control of a single owner or controlling entity, for the provision of social assistance services. The CAAS focuses only on establishments that provide shelter to vulnerable populations. For example, due to the characteristics of this population, the criteria for establishing residence captures a minimum of one overnight stay, to avoid losing information.

58.   In the population and housing census the institutions were classified as follow:

   a)   Hotel, motel, inn. Collective housing unit that provides temporary accommodation to people, in exchange for a payment.

   b)   Pension, guest house, house of assistance. Collective housing unit that provides accommodation services to people indefinitely, in exchange for a payment.

   c)   Hospital, sanatorium, clinic, medical treatment centre. Collective housing unit that provides accommodation to internal people who receive medical care and treatment. Includes rehabilitation centres for people with addictions.

   d)   Orphanage. Collective housing unit that provides accommodation, food, clothing and education, among other services, to minor orphans.

   e)   Retirement home, nursing home. Collective housing unit providing accommodation, food and medical care, among other services, for the elderly.

   f)   Shelter for victims of domestic violence. Collective housing unit that provides shelter, medical, psychological and legal support, among other services, to individuals who require it for any violent situation in their housing unit.

   g)   Shelter, public dormitory. Collective housing unit that provides temporary housing for needy people.

   h)   Boarding school, student residence. Collective housing unit that provides accommodation to resident students attending some level of education. It includes indigenous school shelters.

   i)   Convent, monastery, religious congregation, seminary. Collective housing unit that provides accommodation to people of a religious community or to those who are preparing for the priesthood or a religious order.

   j)   Prison, jail, penitentiary, penal colony. Collective housing unit belonging to the state and in which people aged 18 and over who have committed any crime or infraction of the law are imprisoned, depriving them of their freedom and other civil rights.

   k)   Rehabilitation centre for juvenile offenders, correctional. Collective housing belonging to the state, in which people under 18 years who have committed any crime or infraction of the laws are deprived of their freedom with the purpose of correcting criminal behaviour.

   l)   Work camp, workers' tent, medical residence. Collective housing provided by an institution, company or employer, generally to temporarily accommodate people who work for them in exchange for a payment or providing their social service. Includes oil rigs and merchant ships.

m) Barracks, camp, military, naval or police detachment. Collective housing unit that provides accommodation to members of the army, navy or police, whose mission is to safeguard the national territory, the security of the population and to maintain public order. Includes navy ships.

n) Disaster relief camp. Improvised collective housing providing temporary community housing for people affected by catastrophes.

o) Migrant shelter. Collective housing unit that provides temporary accommodation for people in transit who do not have another place of habitual residence in the locality of reference.

p) Other type of collective housing. Collective housing unit that provides accommodation and was not included in previous types. Includes brothels and communes, among others.

Norway

59.   An institution[11] is defined as a building where parts of the floorage are shared between residents, the household is common and care personnel are present 24 hours a day. This definition embraces several kinds of institutions as follows: nursing homes, old people's homes, combined nursing and old people's homes and in addition various municipal dwellings with full-time services. Institutions of this kind are regulated by law. Statistics Norway keeps a list of such institutions, based on a more general register of establishments (the business register).

60.   The category of 'dwellings for the aged and disabled' includes other kinds of municipal dwellings reserved for persons in need of help because of old age or because of disabilities. These dwellings are not included in the institution category, as they do not have a full-time service offer. The residents own or pay rent for the dwelling. Some of them have care and nursing services during parts of the day. The other dwellings do not have this offer, and the residents are instead users of the home-based services in the same way as other ordinary users. Many of these flats are equipped for residents with functional disability and some of them have some degree of common floorage and household.

The Netherlands

61.   Statistics Netherlands defines an institutional household as follows: "a household consisting of one or more persons living in one accommodation whose housing and daily needs are provided professionally. It includes persons living in nursing homes, homes for the elderly, children's homes, rehabilitation centres and penitentiary for people who will remain there for at least one year." From 2014, the people are presented in institutional households in three groups, namely: homes for the elderly and nursing homes, other health care institution and other type of institution. Homes for the elderly are defined as "homes for permanent residence of old persons, including care such as meals, cleaning, monitoring alarm systems and personal support."[12]

---

11   Information about institutional care is available from Statistics Norway; see https://www.ssb.no/en/helse/statistikker/pleie

12   See https://opendata.cbs.nl/statline/#/CBS/en/dataset/82905ENG/table?ts=1517494966129

62.   Statistics Netherlands keeps a list of addresses that are defined as institutions (Verbeek-Oudijk and Van Campen 2017). These addresses are marked as such in the population register.

The Philippines

63.   For the Philippine population census, a household is defined as a social unit consisting of a person living alone or a group of persons who sleep in the same housing unit and have a common arrangement in the preparation and consumption of food. Institutional population comprises persons who are found living in institutional living quarters (ILQs). They may have their own families or households elsewhere but at the time of the census, they are committed or confined in institutions, or they live in ILQs and are usually subject to a common authority or management, or are bound by either a common public objective or a common personal interest. An ILQ is a structurally separate and independent place of abode intended for habitation by large groups of individuals. Such quarters usually have certain common facilities such as kitchen and dining rooms, toilet and bath, and lounge areas which are shared by the occupants.

64.   In the Philippines, persons are to be considered as members of the institutional population if they are:
- a)   Permanent lodgers in boarding houses
- b)   Dormitory residents who do not usually go home to their respective households at least once a week
- c)   Hotel residents who have stayed in the hotel for more than six months at the time of the census
- d)   Boarders in residential houses provided that they number 10 or more. If the number of boarders in a house is less than 10, they will be considered as members of regular households, not of institutions.
- e)   Patients in hospitals who are confined for more than six months
- f)   Patients confined in mental hospitals, leprosaria or leper colonies, and drug rehabilitation centres, regardless of the length of their confinement
- g)   Wards in orphanages, homes for the aged, and other welfare institutions
- h)   Prisoners of corrective and penal institutions
- i)   Seminarians, nuns in convents, monks, and postulants
- j)   Soldiers residing in military camps
- k)   Workers in mining and similar camps.

65.   Common ILQs are the following:
- a)   Hotels, motels, inns, dormitories, pension houses, and other lodging houses which provide lodging on a fee basis
- b)   Hospitals, sanitaria and rehabilitation centres
- c)   Orphanages and homes for the aged
- d)   Seminaries, convents, nunneries, boarding schools, and other religious training centres
- e)   Corrective and penal institutions
- f)   Military camps and barracks

g)   Logging, mining, and construction/public work camps

h)   Oceangoing and interisland/coastal vessels at port

i)   Refugee camps.

Russian Federation

66.   An institution is defined as in-patient organization providing social services for the elderly and persons with disability. These include boarding houses for the elderly and persons with disability, special homes for single elderly people, psycho-neurological boarding schools and houses, gerontological centres, geronto-psychiatric centres and houses of mercy.

Turkey

67.   An institutional household is defined as persons whose daily living necessities are partially or wholly met by private or public institutions/organizations established by a legal arrangement. Also, members of these households are partially or totally dependent on the rules of the competent authority in their individual decisions and behaviours.

68.   Collective living quarters or institutions include:

a)   Nursing homes:
i.   state nursing homes
ii.   private/association/foundation nursing homes

b)   Hospital rehabilitation and health centres:
i.   state rehabilitation and health centres
ii.   private/association/foundation rehabilitation and health centres

c)   Social protection institutions

d)   Child care homes

e)   Women's shelters

f)   Boarding schools and dormitories:
i.   state dormitories
ii.   private/association/foundation dormitories

g)   Police boarding schools

h)   Military schools

i)   Religious places

j)   Penal institutions:
i.   closed prisons
ii.   semi-open prisons
iii.   open prisons
iv.   juvenile prisons

k)   Military barracks/garrisons

l)   Other institutions not elsewhere classified.

United Kingdom

69.   In the 2011 UK censuses, 'communal establishments' were broadly defined as being establishments 'providing managed accommodation'. 'Managed' in this context means full-time or part-time supervision of the accommodation. Within this, inclusions of specific relevance to older people include sheltered accommodation units where fewer than 50 per cent of the units in the establishment have their own cooking facilities, or similar accommodation where elderly people have their own rooms, but the main meal is provided. Where fewer than 50 per cent have their own cooking facilities, residences in the spaces with cooking facilities were counted as communal residents (e.g. a care home).

70.   The 2011 UK censuses collected information on the nature of the collective establishment, the age group it catered for (except in Scotland where this was not asked) the groups it catered for and management type. Classifications were created using this information. For establishment type, the 'medical and care' subcategory included 'care home' (with and without nursing), 'sheltered housing only' and 'other medical and care establishment'. For age (England and Wales/ Northern Ireland only), a category 'aged 65 and above' was included and the question on who the establishment caters for included a number of categories of relevance for older people. The response options on management facilitate understanding of who is providing the type of accommodation (i.e. health service, local/national government, private sector).

2.3.2 Main observations

71.   The definitions listed in the preceding section have some common features. In all the definitions, institutions were identified as collective dwellings with common facilities shared by occupants, and with services provided partially or totally by private (for-profit or non-profit) or public organizations.

72.   There are, however, some differences worth highlighting: including for example the fact that some include as institutional residents in their respective surveys or registers only persons with a specific length of the stay in the institution. Some countries use the CES recommendation for this (namely, the definition of usual residence[13]), while others use a different length of stay such as six months. There are differences as to whether *actual* or *expected* length of stay is taken as the criterion.

73.   In some countries the criteria to determine what constitutes an institution include the length of time per day during which services are provided: this may be 12 or 24 hours per day, depending on the country.

74.   Some surveys or registers consider only institutions that provide health services, while in other countries both social and health services were considered. This is a key issue from the point of view of ageing-related statistics, since the population living in institutions that provide health services could be very different from the population living in social institutions. This is especially true for older people.

---

13 "For persons who, at the census reference time, have spent, or are likely to spend, twelve months or more as inmates in a communal establishment or institution, the institution should be taken as the place of usual residence." (CES 2015, p.80)

75.   Definitions of institutions for older people are similar in Finland, the Netherlands, and Norway, with local variations. In practice, they reflect the intentions of the CES recommended definition. Statistical authorities in all three countries keep lists of institutions, which are updated annually. One issue is the place of residence of a person who lives in an institution. In the Netherlands, this is coordinated with the population register. In Finland and in Norway, this is not the case. Undercounts and double counts may occur.

76.   It is noteworthy that many of the definitions given above – including that used in the CES Census Recommendations – use phrases such as 'understood to be', 'usually', 'typically', as well as words that are subject to interpretation in the absence of further definition, such as 'large group', 'long-term', 'managed'. That is, the definitions of institutions are often formulated as a *description* of what is commonly thought of as an institution, rather than as a concrete set of *objective criteria* that could be applied to a candidate establishment to determine whether it should be considered as an institution.

77.   It is very difficult to find commonalities among the classifications of type of institutions used by each country. Even where on the surface the terms used might be similar, there may be differences underlying these in terms of the concepts covered by the names. On the one hand, institutions identified with the same name (e.g. 'nursing home') may in fact provide different services, while on the other hand, institutions identified with different names in different countries might in fact provide the same or similar services. These differences are compounded by differences in laws surrounding care provision and cultural contexts, such as the social expectation for older people to remain in independent households or to enter residential care facilities. In societies where the older population is larger and/or where institutional care is more common, there may also be a wider variation in the types of such care and therefore a greater need to distinguish these different forms in any classification.

78.   The preceding section illustrates that countries use different and often overlapping criteria as the basis for classifying institutions. These include services provided (both type of service, e.g. medical, social, and timing of services, both in terms of hours per day and in terms of length of stay), types of inmates/clientele, type of provider.

79.   One solution to navigate this diversity would be to develop a classification of institutions based on these characteristics. This would take into account the types of services and facilities provided, the organization or provider of the institutional care, the kind or level of health care services, clients' or inmates' needs, physical environment, etc. Using a 'checklist' of such criteria rather than using everyday terminology that might mask underlying differences would be a step towards greater harmonization across countries. This would also assist where institutions that provide integrated services are not easy to differentiate, allowing analytical users to select the institutions that best fit their research needs.

80.   It is important to note, however, that just as for definitions of institutions, classifications of institutions used by countries are applied to a reality that is more fluid and less clear-cut than the categories used might imply. Hence some countries have an 'other' category for institutions not elsewhere classified.

81.   The Task Force noted the importance of 'future-proofing' classifications, given the constant and rapid evolution in the types of residential care and assisted living provided to older people in ageing populations. It also noted that detailed classifications lose their value if they cannot be easily and uniformly applied, for example if countries consider that they do not cater for the observed variety or that they do not adequately distinguish differences that are considered important in that country. **The Task Force therefore decided that recommending any particular classification would not currently be appropriate**. Instead the Task Force emphasizes the necessity of gathering information on the services provided by institutions and the characteristics of the groups to whom they cater, as well as the importance of disaggregating statistics on institutional populations to the greatest extent possible.

2.3.3 Definition of older persons or older populations

82.   It is apparent from the preceding section that many types of institution are of limited or no relevance to older populations and therefore their inclusion or exclusion from data collections would have little impact for ageing-related statistics. When limiting consideration only to those kinds of institutions that do cater primarily to older people, however, international comparison will still be difficult if the threshold used to define 'older people' is different across countries. Differences can arise due to the nature of the institutions themselves—for example, in the ages cutoffs used to determine eligibility to be a resident—and due to the practices of statistical offices in collection and publication of age-disaggregated statistics. In Mexico, for example, census data on the population living in collective housing are published by sex only, not by age, while the CAAS presents data by five-year groups, up to 89 years, with a final group of 90 years old and over. The United Kingdom publishes data for the communal establishment population using the age categories 0-15 years, 16-19 years, then in five-year age groups until 90 years old and over.

83.   The table below shows the age cutoffs used by countries responding to the expert survey.

"If such information is available, indicate another cutoff used in your country to define 'older people'"

Table 2.   Cutoffs to define 'older' in responding countries

Country	Age cut off if different from 65
Armenia	71+
Czechia	66
France	75
Philippines	60 years and over
Republic of Azerbaijan	70 years and over
Switzerland	85
Ukraine	60 and more

84.   This demonstrates the diversity across countries in what is collected and published. There is of course no suggestion that a single harmonized definition of 'older' be applied, as per the UNECE *Recommendations on Ageing-related Statistics* which state that, "life expectancies and other characteristics of people at age 65 differ substantially across countries and over time", (UNECE 2016, p. 9). A key recommendation from that work was that statistics pertaining to older people should be disaggregated to the maximum feasible extent, with age groups 55-59, … , 80-84 and 85 and older wherever possible. Whatever thresholds or categories are used, it is essential to keep in mind the possible impacts of cross-country variation when, for example, comparing populations of 'older people living in nursing homes' in different countries.

2.4   Recommendations

85.   Classify institutions for older people by the characteristics of the social and health care services provided, rather than just by name or type of institution. For example, the kinds of services and residents of 'nursing homes' may vary greatly across countries, despite the institutions being similarly named.

2.5   Further work required in this area

86.   Future work could aim to develop a statistical classification of institutions based on certain characteristics, such as services and facilities provided, clients' needs, type of organization, and physical environment. Such work should rely on the characteristics collected for SHA and OECD, and would enhance the harmonization of internationally-collected data on institutions. A classification would need to be 'future-proof' since types of residential care and assisted living offered to older populations are constantly evolving. A detailed classification would lose its value if its categories were in the future to become obsolete, redundant or unable to distinguish pertinent differences. Therefore, it would be necessary to gather information on the services provided by institutions and characteristics of the groups to whom they cater, as well as to disaggregate statistics on institutional populations to the greatest extent possible. Developing a checklist of internationally-defined criteria would be a key step towards greater harmonization across countries.

Chapter 3

Assessing bias arising from omission of older populations in institutions from surveys

3.1   Introduction

87.   A central premise of the work of the Task Force is that by excluding populations of older persons living in institutions, the resulting statistics on social and demographic topics, and especially on ageing-related topics, will be biased. This rests on the assumption that there are significant differences in the distribution of characteristics of interest between the institutional population of older people and the population (of older people) living in private households.

88.   This chapter tests such assumptions by conducting some analyses with survey data and administrative census data to assess the extent of any bias on a range of ageing-related topics.

89.   Bias is a product of two factors: the relative size of the excluded part of a population (in this case the population of older people living in institutions) and its statistical distinctiveness compared to the general population (in this case the population living in private households) (Groves et al. 2009). Distinctiveness can be expected for two reasons: first, because the population in question is older than the general population, on average (and therefore, like the older cohorts of non-institutionalized population, they may have higher prevalence of disability, poorer health, etc. than younger groups); and second, because the very existence of a disability or poor health may be the reason or one of the reasons why a person enters an institution.

90.   General conclusions about the extent of bias are difficult to make, since both factors, relative size and statistical distinctiveness, are necessary conditions for bias. Table 3 illustrates the relationship between relative size and statistical distinctiveness and their influence on bias. The extent of bias always depends on the target population and the specific variables of interest.

91.   Although not covered directly in this chapter, it should be recognized that location and geographical clustering of institutions may influence the extent of bias and that these variables could also therefore be considered in assessing bias.

Table 3.   Expected impact of bias depending on the size and statistical distinctiveness of the excluded population

Proportion of institutional residents (in target population)	Statistical distinctiveness of institutional residents (in a specific variable)		
	Low	**Medium**	**High**
Small	Bias in case 1a	Bias in case 1b	Bias in case 1c
Medium	Bias in case 2a	Bias in case 2b	Bias in case 2c
Large	Bias in case 3a	Bias in case 3b	Bias in case 3c

92.   Regarding the relative size, in many societies worldwide the number of older people overall and the number of older people in need of institutional long-term care is likely to increase in the next few decades (Colombo et al. 2011). On average, 1.9 per cent of the EU population older than 50 years lived in institutions in the 2011 round of European censuses (see Figure I). The aggregate data hides differences between specific groups and between different European regions. The proportion of older institutional residents clearly increases in older age cohorts. On average, 4.3 per cent of the EU population aged older than 70 years lived in institutions, with a greater variance across countries (Figure I).[14] The variance also exists within countries at the regional level. In some regions in France, the Netherlands and Malta, every third resident aged 85 years or older lived in a retirement or nursing home in 2011 (Eurostat 2015, p. 148).

Figure I   Proportion of the population living in collective living quarters according to the 2011 census (Eurostat 2016)
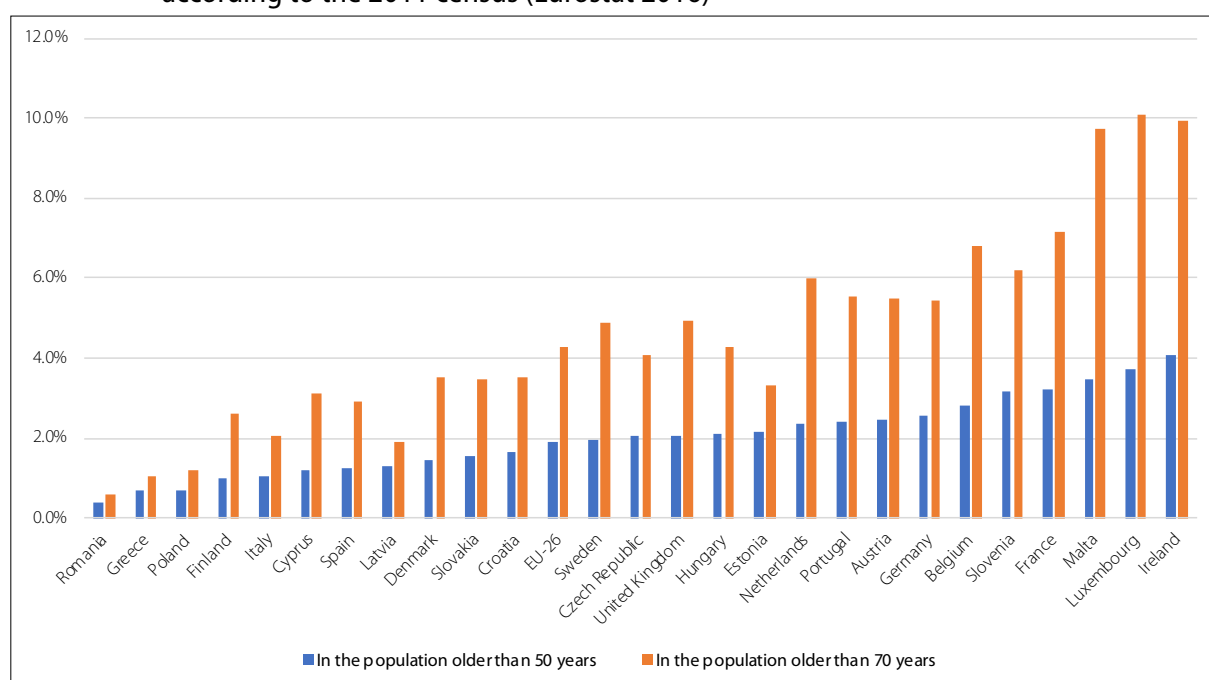
93.   Which variables are likely to be biased when the older population in institutions is not included? Previous findings in scientific literature on the factors that lead to institutionalization give an indication of the statistical distinctiveness. A higher **age**, **not being married** or being **widowed**, **living alone** without a partner or children, not being a home owner, and having a **smaller social network** lead to a higher likelihood of institutionalization (Asakawa et al. 2009; Castora-Binkley, Meng, and Hyer 2014; Einio et al. 2012; Gaugler et al. 2007; Laferrère, Heede, and Bosch 2012; Luppa et al. 2010; McCann, Grundy, and O'Reilly 2012; Nöel-Miller 2010). For **sex**, some studies find a higher likelihood of institutionalization for women (Einio et al. 2012; McCann, Grundy, and O'Reilly 2012), while other studies come to the opposite conclusion (Einio et al. 2012; Gaugler et al. 2007; Luppa et al. 2010; Martikainen et al. 2009).[15] Also, the results

---

14   Among those Europeans older than 85 years 12.6 per cent were institutionalized in 2011 (Eurostat 2015).

15   Einio and colleagues found different sex effects for Belgium and Finland (2012).

for socio-economic variables such as **income** and **education** are mixed. Some studies found a higher likelihood of institutionalization for a low income (Gaugler et al. 2007; Laferrère, Heede, and Bosch 2012; Martikainen et al. 2009) and a low level of education (Asakawa et al. 2009; Einio et al. 2012), whereas other authors identified a higher income (Rodríguez-Sánchez et al. 2017) and a higher level of education (Castora-Binkley, Meng, and Hyer 2014) as being associated with a higher likelihood of institutionalization. National contextual factors such as the health care and welfare system may help to explain some of these contradictory results.

94.   All of the studies mentioned above identified health and decreased mobility as strong explanatory factors for institutionalization among elderly persons in addition to demographic and socio-economic factors. **Cognitive impairments**, **dementia**, and **medical conditions** (Castora-Binkley, Meng, and Hyer 2014; Einio et al. 2012; Gaugler et al. 2007; Laferrère, Heede, and Bosch 2012; Luppa et al. 2010; Nöel-Miller 2010; Rodríguez-Sánchez et al. 2017; Toot et al. 2017), as well as **limitations in activities of daily living**, **disability** or a greater degree of **physical dependency** (Cambois et al. 2016; Castora-Binkley, Meng, and Hyer 2014; Gaugler et al. 2007; Laferrère, Heede, and Bosch 2012; Nöel-Miller 2010; Toot et al. 2017) increase the need for institutional care among elderly persons. Apart from objective measures of health, a worse **self-rated level of health** is also an indicator for an increased risk of institutionalization (Castora-Binkley, Meng, and Hyer 2014; Einio et al. 2012; Luck et al. 2008; McCann, Grundy, and O'Reilly 2012; Nöel-Miller 2010).

3.2   Current approaches

95.   The size and statistical distinctiveness of the institutional population might call for a better inclusion of institutionalized older people in statistics. However, in many National Statistical Offices the amount of information and the knowledge about this part of the population appears to be somewhat limited. This is evidenced by results of the survey conducted by the Task Force. When asked to assess five statements on the statistical characteristics of the old-age institutional population, a significant proportion of respondents from the 36 participating NSOs could not reply to a couple of the statements. 36 per cent of all respondents did not know whether the "old age population in institutions is, on average, older than the old-age population in private households". More than half of all respondents did not know whether the old-age population in institutions is less healthy, and 81 per cent of all respondents did not know whether the old-age institutional population is less economically well off.

96.   Those respondents who were able to give substantive replies to these questions showed awareness of the issues surrounding older people in institutions and their statistical distinctiveness. Nearly half of all respondents confirmed that the proportion of older people living in institutions is growing in their countries. A majority of respondents agreed with the statements that the institutional population was older, less healthy and had a different sex distribution on average than the older population in general.

3.3   Assessment of bias

97.   This chapter briefly introduces the two different types of data used by the Task Force to examine the potential bias in case of non-coverage of the institutionalized older population. The Task Force relied on European census data and relevant survey data which covered the institutional population. This permitted illustration of the bias in relevant variables if institutional respondents are left out of the sample. Both data sources are suitable for assessing the bias in samples of private households, but they are also associated with specific drawbacks, as discussed below.

3.3.1 Data

98.   In the decennial European censuses, the countries of the European Union are required to collect information about the population living in collective living quarters or institutions. For the 2011 census round, Eurostat aggregated the data and made them publicly available on their homepage (Eurostat 2016). Users can construct and download hypercubes (cross-tabulations of multiple variables) for all European Union countries at the national level or even at a lower regional level in some countries (down to the NUTS 3 level). Apart from general issues related to census data, such as a lack of timeliness and availability of a rather small number of variables, Eurostat does not provide any information about the types of institutions (Schanze 2017). As a consequence, institutional residents in the census data comprise persons living in retirement homes, nursing homes, religious institutions, prisons or any other types of institutions, treated as a whole without the possibility of disaggregation.

99.   Surveys that include institutional residents can provide rich information on health status and many other variables. International ageing surveys, namely the HRS (USA), MHAS (Mexico), CRELES (Costa Rica), SHARE (Europe), ELSA (England), KLoSA (Korea), JSTAR (Japan), CHARLS (China), and LASI (India), could be very useful as comparable sources of information on institutional residents in multiple continents.[16] However, out of these surveys only HRS, SHARE, and ELSA included institutional respondents. In the following analysis, SHARE data were used.[17]

100.   The *Survey of Health, Ageing and Retirement in Europe*[18] is a cross-national survey programme which covers up to 27 European countries plus Israel in six panel waves (Börsch-Supan et al. 2013). In the first wave in 2004, the SHARE target population was defined as all households with at least one member older than 50 years "and not living abroad or in an institution such as a prison during the duration of field work" (Börsch-Supan et al. 2005, p.30). In addition, residents of institutions for the elderly also belong to the SHARE target population and were sampled and interviewed

---

16   An overview of waves and variables in these surveys is available online at https://g2aging.org/?section=surveyOverview.

17   The decision to use SHARE for this analysis was based on the number of countries and panel waves available and on the availability of relevant variables. However, the points illustrated by this analysis and the conclusions reached could apply equally to other social survey data. Indeed, the aim of this chapter is to argue that the bias exhibited is a widespread phenomenon and not something specific to SHARE data.

18   See http://www.share-project.org for further information on the survey.

(Klevmarken, Swensson, and Hesselius 2005; De Luca, Rossetto, and Malter 2015).[19] The institutional population can be classified as a hard-to-survey population. As a consequence, surveys like SHARE are likely to suffer from greater coverage and nonresponse issues for those respondents living in institutions for the elderly than the census data (see De Luca, Rossetto, and Malter 2015). In the following analysis, data from the fifth wave of SHARE are used (Börsch-Supan 2017).

3.3.2 Course of analysis

101.   As mentioned above, bias is the result of the size of the excluded population multiplied by its statistical distinctiveness in comparison to the covered population (Groves et al. 2009). To allow interested readers to draw some general conclusions about the potential impact of bias even if their country of interest is not located in Europe, the analysis that follows systematically highlights different cases of bias on the basis of relative size and statistical distinctiveness (see Table 3).

102.   With respect to the relative size, the countries from both data sources were grouped according to the relative size of the institutional population. In the analysis of SHARE, all the countries in wave 5 were grouped with respect to the proportion of institutional respondents in the data. This strategy made it possible to identify three different groups of countries.[20] The first group consists of Italy, Spain, and Slovenia. In these countries, only a small proportion of institutional respondents (0.7 per cent in wave 5) were interviewed as part of SHARE. Austria, Germany and Czechia included a medium proportion of institutional respondents and these countries constitute a second group in the analysis (1.43 per cent). The highest portion of institutional respondents can be found in Denmark, Belgium and the Netherlands, which form a third group of countries (3 per cent). It can be argued that these groups are also meaningful in terms of geographical proximity and cultural as well as systemic factors that influence the number of institutional residents.

103.   For the census data, countries were categorized into the three groups based on the proportion of institutional residents in the population aged 50 and over (see Figure I). The first group contains countries with a small proportion of institutional populations (less than 1.3 per cent).[21] The second group contains countries with a medium proportion of institutional populations (between 1.4 and 2.3 per cent).[22] The third group contains countries with a large proportion of institutional populations (more than 2.3 per cent).[23] In the results presented in the following section, the countries were included with equal weights by calculating the average of their percentages within the three groups. Population sizes were not taken into account as this would have caused the results to be heavily influenced by large countries such as France, Germany, Italy, Spain and the United Kingdom.[24]

---

19   Note that persons included in the census data were *not* covered by the target population in SHARE. This is also the reason why the two types of data were taken as distinct bodies of information and census data were not used to correct the SHARE data for institutionalized elderly.

20   Multiple variables were used to identify the institutional respondents in the dataset: interviewer observations on the type of building and replies of respondents about whether they had stayed permanently in a nursing home during the last year.

21   Bulgaria, Poland, Greece, Lithuania, Italy, Cyprus, Spain and Latvia.

22   Denmark, Norway, Slovakia, Croatia, Estonia, Germany, Sweden, Czech Republic, United Kingdom and Hungary.

23   Portugal, Austria, Slovenia, Netherlands, Belgium, France, Malta and Iceland.

24   This method also reflects the use of survey data without population weights.

104.   The European censuses and SHARE allow us to analyze the extent of bias in a selection of variables. On the basis of previous literature presented above, variables chosen included demographic variables (e.g., age, sex and marital status), socio-economic variables (income and education) and health-related variables (self-perceived health, limitations with activities of daily living, and dementia).[25] As shown in Table 3, an increasing bias can be expected with the increasing proportion of institutional residents and the statistical distinctiveness of the institutional population in a given variable.

105.   For the census data it was possible to distinguish between different age cohorts, because the relative size of institutional residents typically increases with age (see Figure I) and therefore the expected bias should also increase with age.[26] For the SHARE data, age was not used as an additional variable to split the sample due to the rather small number of institutional respondents within the three groups.

3.3.3 Results

106.   Results from the analyses with European census data and SHARE data are presented in the following section. Further variables were examined but are beyond the scope of this chapter. Some of these additional results can be found in Appendix III.

3.3.3.1 Demographic and socio-economic variables

107.   Table 4 shows the proportions of five different age cohorts of older people in the fifth wave of SHARE. For each of the three groups of countries the table gives the total value, which contains the group of private household respondents *and* the group of institutional respondents. The second row denotes the respective proportion only for those respondents who have been identified as living in private households. The differences between those two proportions, as shown in the third row, are an indication of the bias in a sample of private household respondents compared to the 'true' value in the total population, in this case the entire sample of SHARE. A positive difference indicates an overestimation of the respective proportion, while a negative value indicates an underestimation of the respective proportion.[27]

108.   As expected, the numbers of younger respondents aged between 50 and 69 years are overestimated in all three groups of countries when only private household respondents are considered. The extent of bias increases with the relative proportion of institutional respondents across the three groups of countries (see also Figure II).

---

25   Health-related variables were only available in the SHARE data.

26   Age was not used as a main variable to split the sample in three groups because the age cohorts as such differ to a large extent in various respects. In this light a comparison of statistical distinctiveness could be confounded with multiple other variables.

27   The equivalent numbers for the institutional respondents can be found in Appendix III.

Table 4. Distribution of age cohorts in SHARE (wave 5) within different country groups of countries

		50 to 59 years	60 to 69 years	70 to 79 years	80 to 89 years	More than 90 years
Small proportion of IR (ES; IT; SI)	Total	25.53	32.53	25.9	14.04	2.00
	Private hh.	25.68	32.72	25.9	13.84	1.86
	Difference	0.15	0.19	0.00	-0.20	-0.14
Medium proportion of IR (AT; CZ; DE)	Total	26.97	36.26	26.12	9.55	1.11
	Private hh.	27.28	36.63	26.10	9.06	0.92
	Difference	0.31	0.37	-0.02	-0.49	-0.19
Large proportion of IR (BE; DK; NL)	Total	31.22	35.19	21.27	10.62	1.70
	Private hh.	32.09	36.00	21.31	9.47	1.13
	Difference	0.87	0.81	0.04	-1.15	-0.57

IR=institutional residents; hh=households

Figure II Age deviation of community-dwelling population compared to total population (= 100%) in SHARE wave 5 (2013)
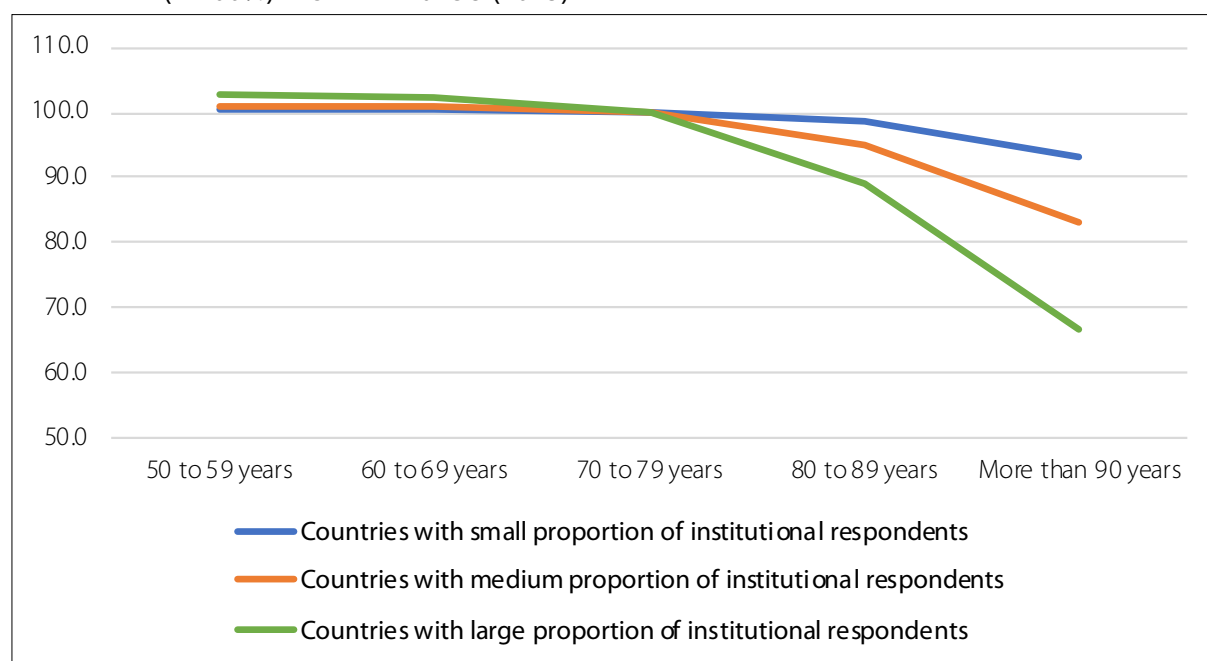
109. Figure II shows the deviation in per cent. The numbers are calculated by dividing the proportion of a given category among private household residents by the proportion of all SHARE respondents. A value of 100 per cent, as is nearly reached for all groups of countries in the age cohort of respondents aged 70 to 79 years, indicates a perfect representation even when institutional respondents are not covered by the sample. Figure II accounts for the number of respondents within the respective age groups. For instance, in countries with a large proportion

of institutional respondents the deviation in the youngest age cohort is larger than in the oldest age cohort in absolute terms. However, the relative weight of the deviation is larger in the oldest age cohort where there are fewer respondents.

Figure III   Proportions married in different age cohorts in countries with a small proportion of institutional residents (Eurostat 2016) (per cent)
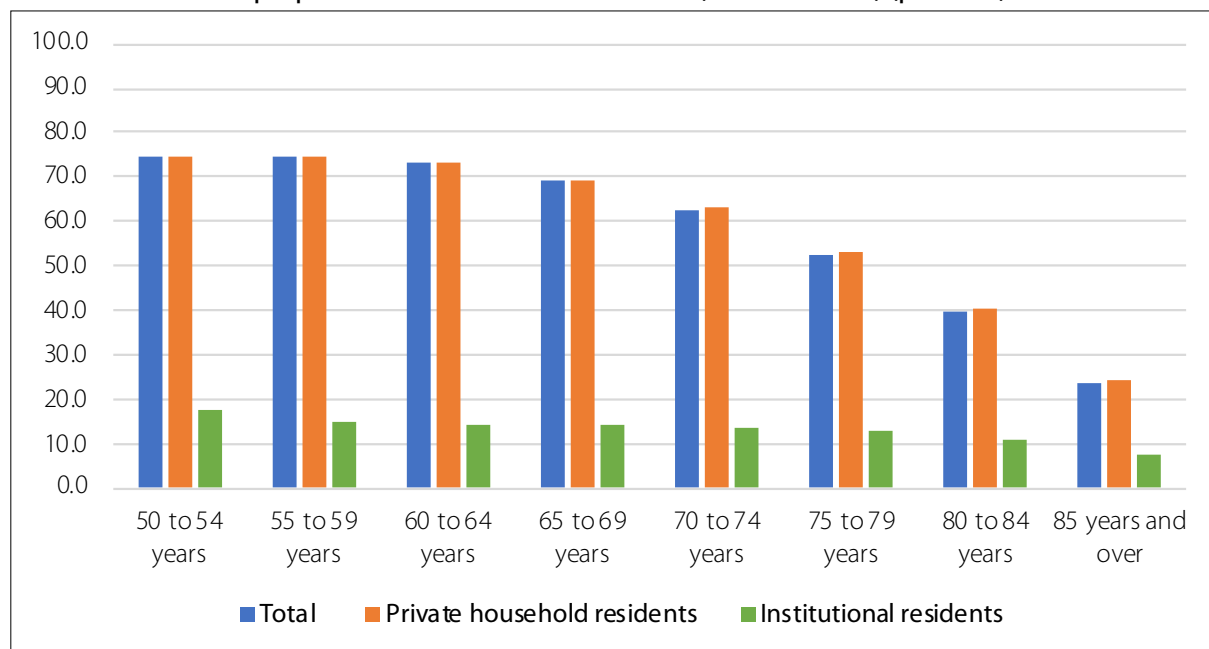
Figure IV   Proportions married in different age cohorts in countries with a large proportion of institutional residents (Eurostat 2016) (per cent)
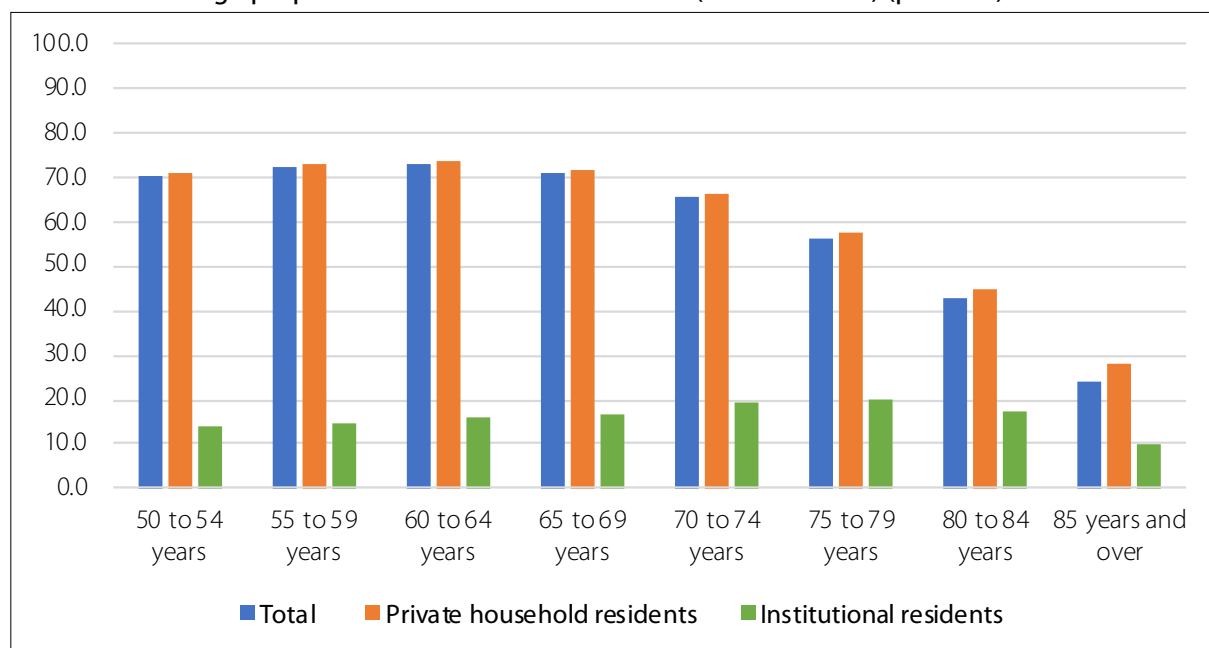
110. Figure III and Figure IV are based on results from the 2011 censuses conducted in European countries. Marital status was identified as a strong explanatory factor for institutionalization in the literature. Indeed, it can be confirmed that very few institutional residents were currently married in the three groups of countries. The difference between the green bars (institutional residents) and the orange bars (private household residents) shows the statistical distinctiveness of the institutional population in the respective age cohorts and is very pronounced. Bias is shown by the difference between the private household residents (orange bars) and the total population (blue bars).

111. Comparison of the group of countries with a small proportion of institutional residents (Figure III) with the countries that have a large proportion of institutional residents (Figure IV) confirms the impact of the relative size in two ways: first, the differences between private household residents and the total population are more pronounced in the countries with a higher proportion of institutional residents.[28] Second, bias becomes stronger in older age cohorts with an increasing proportion of institutional residents, even though the statistical distinctiveness of institutional residents compared to private household residents is less pronounced.

112. Table 5 and Figure V present the analysis of SHARE data with respect to the household income of respondents. To make the numbers more comparable across countries, it was decided to divide the sample in each country into deciles of household income. Two of those deciles were grouped for the following table and figure.

Table 5.   Distribution of country-specific income deciles in SHARE wave 5 (2013) within different groups of countries

		Lower 20%	20 to 40%	40 to 60%	60 to 80%	Upper 20%
Small proportion	Total	20.13	19.91	19.96	20.04	19.95
	Private hh.	20.01	19.81	20.01	20.12	20.05
	Difference	-0.12	-0.10	0.05	0.08	0.10
Medium proportion	Total	20.02	20.00	20.10	19.91	19.99
	Private hh.	19.50	19.85	20.30	20.10	20.24
	Difference	-0.52	-0.15	0.20	0.19	0.25
Large proportion	Total	20.01	20.01	20.00	20.05	19.93
	Private hh.	18.87	19.89	20.32	20.48	20.45
	Difference	-1.14	-0.12	0.32	0.43	0.52

113. The numbers and the diagram show again how the size of the institutional population acts as mediator for the bias in samples of private household respondents. For this variable, the extent of deviation shown in Figure V is not influenced by the number of respondents in the 5 different categories, since the deciles have roughly the same size. All three groups of countries tend to underestimate the proportion of poor respondents if institutional respondents are left

---

28   For an equivalent diagram of the second group of countries with a medium share of institutional residents, see Appendix III.

out of the sample, whereas the proportion of comparatively richer respondents is somewhat overestimated. The proportion with incomes in the middle of the scale (20 to 40 per cent and 40 to 60 per cent) suffers rather less from bias than the extreme sides of the income scale. The expected ranking of the three groups of countries according to their proportion of institutional respondents can be observed again.

Figure V   Income deciles - Deviation of community-dwelling population compared to total population (= 100%) in SHARE wave 5 (2013)
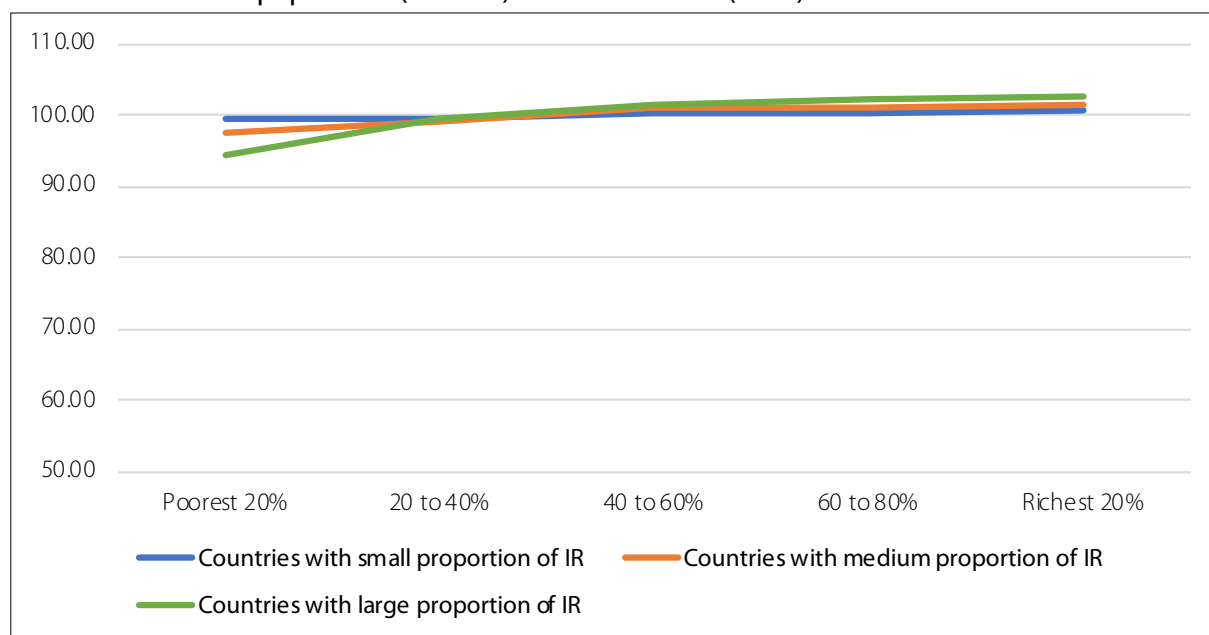
114.   Eurostat aggregated information on the level of education of residents from the 2011 European censuses. Figure VI shows the average percentage of residents with lower education levels in the grouped countries with a medium proportion of institutional residents, while Figure VII shows the equivalent diagram for the countries with a large proportion of institutional residents. In contrast to the previous examples, the bias in the second group of countries is larger than in the third group of countries. This is due to a greater resemblance of the levels of education between institutional and private household residents in the countries with a larger proportion of institutional residents. In Table 3 earlier in this chapter, this example would fall into cell 3a, with a large proportion of institutional residents and a low degree of statistical distinctiveness. The situation in group 2 corresponds to cell 2b in the table, with a medium proportion of institutional residents and a medium degree of statistical distinctiveness. The example of education underlines the interaction between relative size and statistical distinctiveness as two necessary conditions for bias.

Figure VI Proportion of persons with a lower educational level (ISCED ≤ 1) in different age cohorts in countries with a medium proportion of institutional residents (Eurostat 2016)
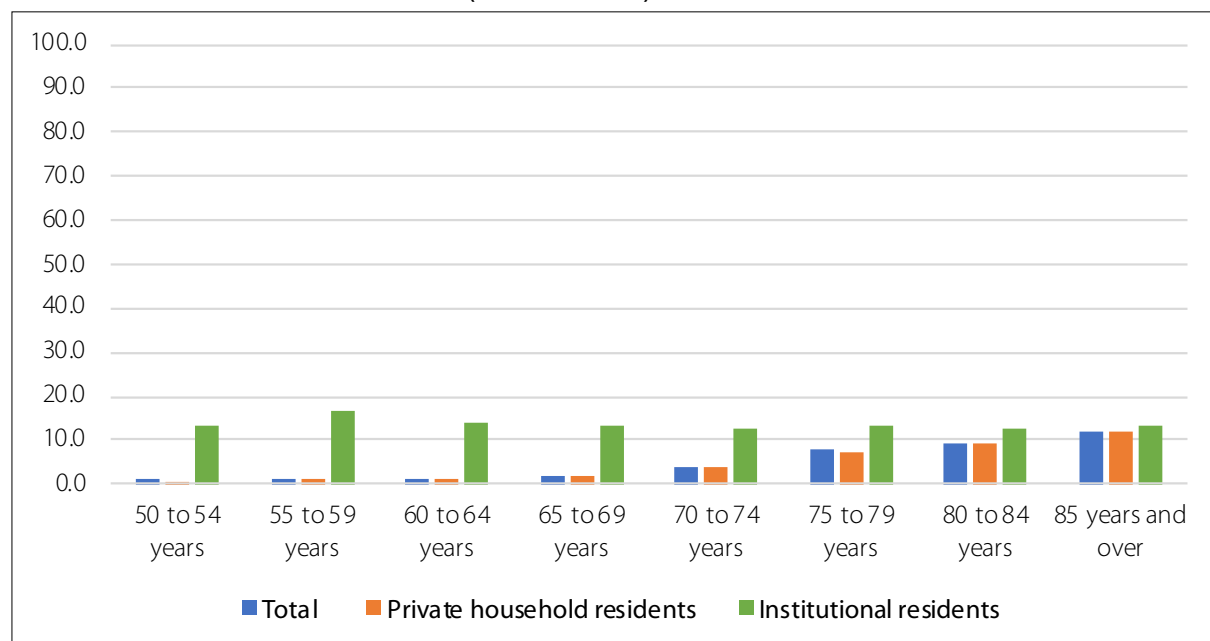
Figure VII Proportion of persons with a lower educational level (ISCED ≤ 1) in different age cohorts in countries with a large proportion of institutional residents (Eurostat 2016)
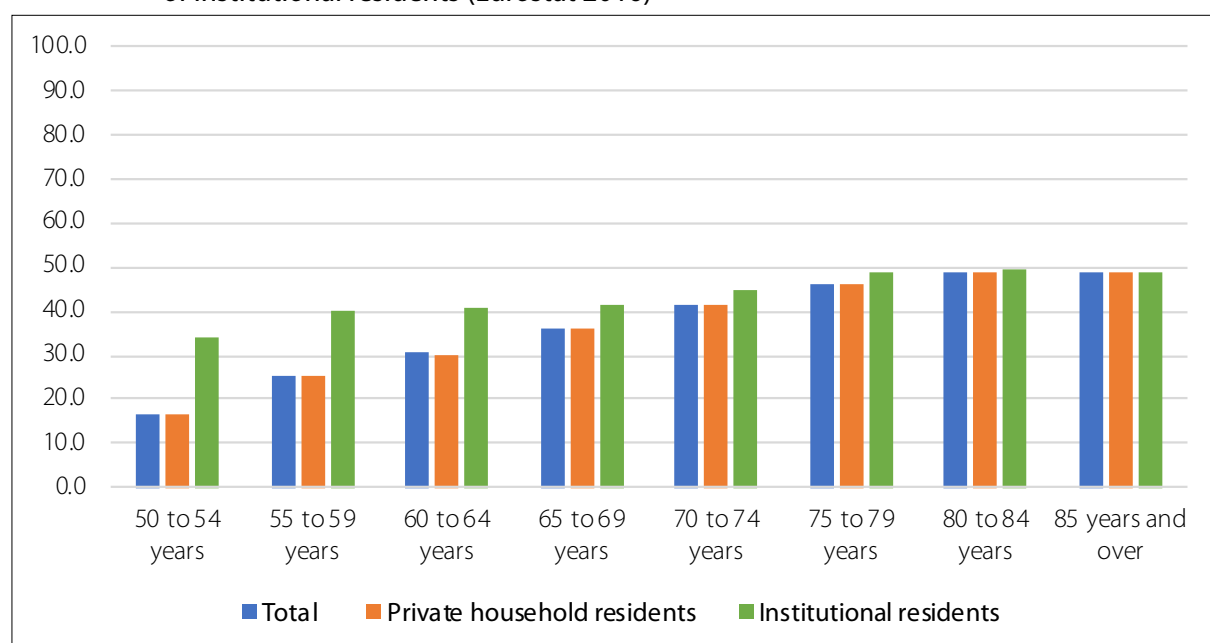
3.3.3.2 Health-related variables

115.   Health-related variables strongly influence the institutionalization of older persons, as the brief summary of scientific literature in this chapter has shown. Even though some NSOs might have information on health that would enable them to assess the bias, Eurostat did not aggregate statistics on health because they were not part of the obligatory information the countries were required to collect in the census. Survey data typically contain more information on health, which is why SHARE data were used for the analyses in the following subsection.

Table 6.   Distribution of dementia in SHARE wave 5 (2013) within different groups of countries

		No dementia	Dementia
Small proportion countries	Total	97.08	2.92
	Private households	97.32	2.68
	Institutional hh.	61.46	38.54
	Diff. (total −private)	0.24	-0.24
Medium proportion countries	Total	98.47	1.53
	Private households	98.66	1.34
	Institutional hh.	85.65	14.35
	Diff.	0.19	-0.19
Large proportion countries	Total	98.63	1.37
	Private households	99.13	0.87
	Institutional hh.	82.34	17.66
	Diff.	0.50	-0.50

hh=household. Diff= difference

116.   Table 6 shows the proportion of respondents with a diagnosis of Alzheimer's disease or dementia. The analysis of dementia reveals a slightly stronger deviation within the group of countries with a small proportion of institutional respondents (N=96) compared to the group of countries with a medium proportion of institutional respondents (N=223). This is a consequence of a greater degree of statistical distinctiveness of respondents in the first group of countries. In addition to potential contextual factors leading to this result, this can be also explained by a stronger selection mechanism in countries with fewer institutional residents (see Cambois et al. 2016). Where there is a relatively small institutional population, either because of supply constraints or less demand, the population that the institutions accommodate is likely to be highly selected and different from the private household population, particularly in their health status. Where there is a large institutional population, institutions will accommodate a larger and more varied population, which may differ less from the rest of population.

117. Figure VIII and Figure IX confirm the impact of health-related factors and mobility on institutionalization of older people.[29] Both variables show bias, especially in the group of countries with a large proportion of institutional respondents. As for age, the relative impact of the deviation in the number of limitations in activities of daily living (ADL) is stronger in those categories with fewer respondents. Among residents of private households, between 88 and 89 per cent of the respondents do not have any limitation, whereas this only holds true for half of all institutional respondents (see Appendix III). In those countries with a small proportion of institutional respondents, the pattern of an even stronger deviation can be confirmed. Only one out of four respondents did not have any limitations with ADL in this group of countries.

**Figure VIII** Number of limitations in ADL - Deviation of community-dwelling population compared to total population (= 100%) in SHARE wave 5 (2013)
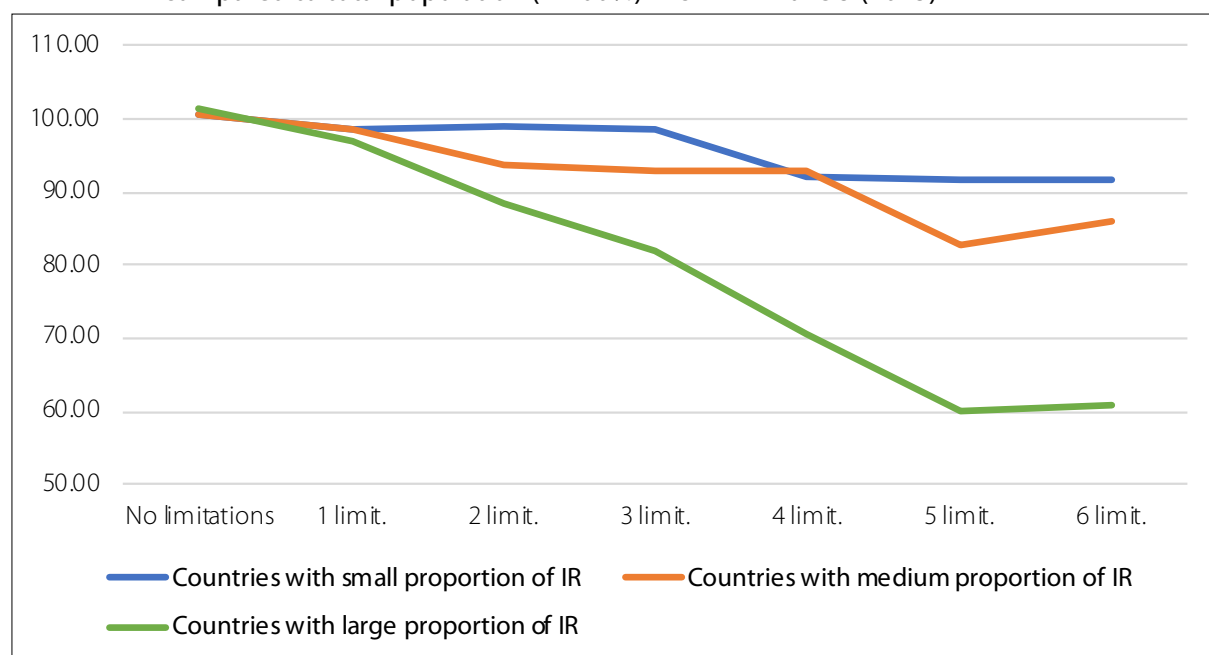
118. For self-rated health the expected pattern is observed. In all three groups of countries, samples of institutional respondents underestimate the proportion of people with poor or fair health, whereas the proportion of people with very good or excellent health is overestimated. While the extreme categories on both sides of the scale suffer from a stronger bias, the middle category with those respondents claiming to be in good health is closer to the value in the total SHARE sample, with a maximum deviation of 0.8 per cent in the group of countries with a large proportion of institutional respondents. This is due to the slightly larger number of respondents in this category, but can be also explained by a less distinct deviation of institutional respondents compared to private household respondents, as was already observed for the middle categories of the income deciles.

---

29   The underlying numbers for both figures can be found in Appendix III.

Figure IX   Self-rated health - Deviation of community-dwelling population compared to total population (= 100%) in SHARE wave 5 (2013)
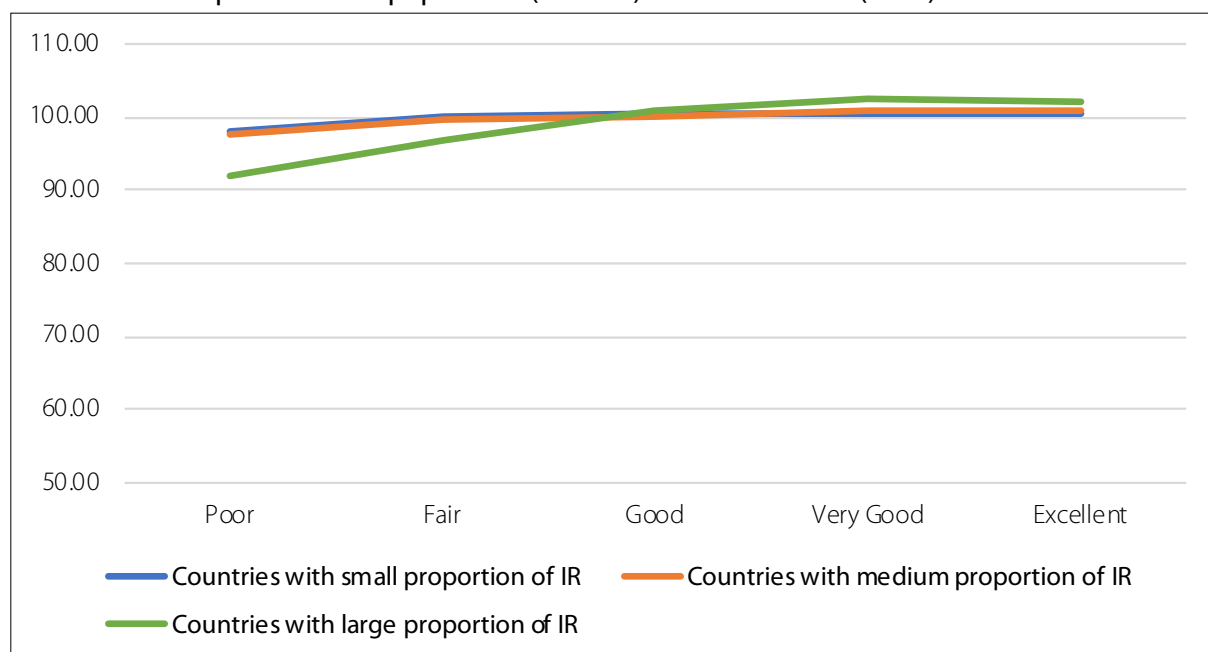
119.   Summing up the results of this descriptive analysis of two different data sources, it has been shown that bias affects variables and even single categories of variables to different extents. The size of the excluded population and its statistical distinctiveness are the determining factors of the extent of bias. In the analysis, countries in the 2011 European censuses and the fifth wave of SHARE were categorized according to their proportion of institutional residents and institutional respondents, respectively. For those three groups of countries, bias in several demographic, socio-economic and health-related variables was examined.

120.   In line with the expectations advanced in Table 3, the extent of bias increased with the size of the institutional population. However, even in countries with a small proportion of institutional residents, bias could be a peril for ageing-related statistics. This analysis has confirmed previous results of Cambois and colleagues, who observed a stronger statistical deviation of institutional respondents in those countries. Continuing the reference to Table 3, cells 1b or 1c are more likely to be observed than cell 1a with a smaller statistical distinctiveness. Moreover, the analyses with census data revealed a larger degree of bias in the older age cohorts. In addition, the bias influences single categories of variables in different way and to a different extent. Extreme values of variables, in particular, can be biased, with a higher likelihood due to the inherent characteristics of institutional residents and due to smaller numbers of residents to whom these categories apply.

121.   The implication of this analysis is that it cannot simply be stated that 'countries bias their ageing-related statistics by excluding older populations living in institutions'. The degree to which this is true varies by the relative size of the excluded population and its distinctiveness, which in turn varies according to the topic in question. Hence, there can be no 'across the board' recommendation regarding including or excluding such populations. Rather, the recommendations to which this analysis gives rise must be more nuanced, recognizing the different aims of different statistical endeavours.

3.4   Recommendations

122.   It is clear from the foregoing that NSOs should be concerned about the potential for bias if institutional residents are not covered or are inadequately covered. Such bias has been shown as significant in many scientific studies as well as in the analysis presented here. The growth of the oldest population, which is the group most likely to live in institutions, may increase this measurement bias even further. It is recommended to tackle the bias as follows:

   a)   as a first step, obtain good estimates of the number of institutional residents by age and sex, and if possible also by region.

   b)   as a second step, focus on the variables where the potential bias is highest, such as marital status, education, income, health and mobility[30].

123.   In most countries, the proportion of institutional population is below five per cent, and the censuses and large sample surveys that allow analysis of this group are typically carried out by NSOs. A few NSOs already provide and publish some relevant information. In expanding their offer of statistics on institutional populations, the type of institution and health status of residents are the variables of crucial importance and should be given special attention.

124.   Countries should systematically take into consideration the general rule of thumb illustrated by this chapter—that bias is greater when the excluded population is larger and/or when it is more distinctive—when deciding whether the amount of bias 'matters' in any given instance.

3.5   Further work required in this area

125.   The choice of data sources for the above analysis was based on availability and broad cross-country comparability. This does not preclude similar analyses being conducted on other data sets. Future work should examine other international survey data, as well as national data for individual countries, to produce a more complete picture of the extent of bias arising from omission of institutional residents. This could bolster the evidence base to drive countries to begin including this population group more systematically in data collection, especially in cases where the bias is found to be significant. Comparison of the different extent of bias among different data sources from a single country could also be valuable and may help analysts to make a more informed choice as to which data sources to use for their analyses, as well as helping data producers to target improvements.

---

30   Most European Union countries already have surveys that include institutional residents, which would permit an assessment of the extent of bias. The EU-funded SERISS project compiled an inventory of 150 national and cross-national surveys in European countries, Australia, Canada, the USA and Israel that included institutional residents (Schanze 2017).

Chapter 4

Design of instruments and survey methods to collect information on older populations in institutions

4.1 Introduction

126. In spite of the increases in numbers and proportions of older people in many countries across the UNECE region, the absolute numbers living in institutions remain small. Because of this small size, and due to the characteristics of the institutions themselves (for example, communications being channelled through a central authority; reluctance of such authorities to grant survey-takers access to residents), there are numerous challenges in reaching and interviewing individual residents to administer censuses and surveys. At the same time, as argued in the preceding chapter, the importance of doing so is clear, especially when we are concerned with ageing-related topics and issues that particularly affect the oldest-old, since the proportion of these age groups living in institutions can reach high levels.

127. Furthermore, even after successfully identifying and accessing an individual to administer a survey, the particular characteristics of those who live in institutions create additional challenges for data collection. These may include cognitive or health limitations, especially dementia; the need for and acceptability of gathering data via proxy respondents; and the potential irrelevance of some typical household survey questions to a non-private-household setting.

128. Put simply, older populations living in institutions are both *hard to sample* and *hard to interview*.

129. In the case of the first issue – the challenges of sampling rare and/or hard to reach groups – much general research and guidance exists, a great deal of which can be applied to the case of older people living in institutions. Nevertheless, there are some specificities, which are the focus of this chapter. The second issue, namely the challenges of administering surveys to older people in institutions, has received less attention. This chapter reviews some of the issues identified by countries and the possible solutions, leading to some recommendations for good practice.

4.2 Existing standards and guidance

130. Methodological guidance exists for a) reaching hard-to-sample populations, b) use of proxies and c) adapting instruments to older people including those with cognitive impairments. The UNECE *Recommendations on Ageing-related Statistics* and the report of the European Health Interview Survey Task Force on Institutionalized people (Beukenhorst 2011) offer recommendations in these areas. The latter recommends, among other things, that proxy interviews be used only when there is a severe cognitive (as opposed to sensory) impairment; and that interviews conducted via a proxy must be identifiable in finished datasets, along with information about the relationship of the proxy respondent to the target respondent.

131.   The UNECE *Policy Brief on Dignity and non-discrimination for persons with dementia* (UNECE 2015b) discusses the particular case of people with severe cognitive impairments, and the importance of maintaining dignity in institutional care settings. This is relevant to the topic at hand since one aspect of dignity is ensuring that such things as participating in research are done with informed consent to the greatest extent possible, and ensuring that choices are protected. Hence proxy responses to interviews should not be given in cases where it could reasonably be expected that the individual would have chosen not to participate, had they been able to express that choice.

132.   Countries will also need to be aware of their own legal requirements and restrictions affecting data collection in the national context.

4.3   Current approaches

133.   The survey of current practices of NSOs conducted by this Task Force shows that the proportion of people living in institutions is growing in many countries. However, a majority of responding countries reported that older people in institutions are not included in any of their existing surveys (other than the census) nor are they surveyed separately.

134.   In total 26 per cent of the responding NSOs (nine countries) do include people in institutions in one or more surveys (other than the census), in some way. Some of these are surveys of disability and ageing, some conduct surveys specifically targeting institutions, such as surveys of Institutions and Establishments for Long-Term Care or Surveys of Social Welfare Institutions, and in some cases data collection is based on reports from responsible organizations.

135.   The potential reasons for only including the residents of private households are:

   a)   non-household residents cannot be identified, located and approached in the same way as residents of private households

   b)   even once successfully included in a sample, residents of institutions may have impaired ability to take part in survey research, and this likelihood of impairment may rise with age.

136.   The ability of older people to take part in a survey may be limited by the respondents' health or functioning capacities; factors related to their motivation or willingness to participate; and/ or 'gatekeeper' challenges, such as the efforts of staff or family to protect institutional residents by keeping survey-takers at a distance. Limitations in vision, hearing, speech and recall may all impact the quality of data (Feskens 2009). Feskens also notes that the likelihood of missing data ("don't know" answers) might increase with the age of respondents, but on the other hand there can be a general tendency towards greater introspection among older people that could lead to a greater interest in survey research and willingness to answer questions. Hence it should not be assumed that older respondents will necessarily generate lower quality data.

137.   It is important to bear in mind that the importance or necessity of including older people living in institutions in samples, and of gathering detailed data from them, will vary widely according to the nature of the data collection exercise in question. For instance, in a population census it is vital that all individuals should be covered. Therefore a great deal of importance can

be placed on identifying institutions and the individuals who reside within them, and on gaining access to them for enumeration. In a survey designed specifically to measure ageing-related variables, similarly, investment of significant effort may be considered worthwhile. For example, if a survey is intended to gather data about health issues faced by older people, it is clearly worth ensuring that the questions can be completed by those dealing with health limitations, otherwise the results would be biased. This is especially true if the investigation in question is aiming to gather data specifically about conditions for older people living in institutions, as opposed to older people in general. Bearing in mind the discussions in chapter 3, however, offices designing surveys to gather data about the general population may reach a different conclusion in their cost-benefit analysis when considering whether and how to adapt sampling procedures, instrument design and interview techniques to older people in institutions, as such adaptations could be expensive and time-consuming.

138.   In cases where a decision is reached to include older people in institutions in a survey, special considerations need to be given to sampling, identifying and accessing respondents, and obtaining responses. Each of these aspects is discussed below.

4.3.1 Sampling

139.   The specific aims of any given data collection activity will determine whether the sample should include only institutional residents, or both institutional and community-dwelling (private household) individuals. It the latter is needed, then a sampling frame must be used that includes both groups, or else a dual-frame approach, based on two distinct sampling frames, must be used.

140.   The various possible aims of data collection activities give rise to two fundamentally different possibilities for approaching sampling in institutions: either the *institutions themselves* can be targeted, or the targets can be *individuals* who happen to be residents of institutions (see chapter 5 for further discussion of techniques for identifying institutions or their residents).

141.   As in all data-gathering activities, limitations of time and resources generate trade-offs. Sampling approaches that might be considered 'gold standard' techniques in terms of the quality of data collected may not always be feasible, and the chosen point in any cost-benefit analysis for selecting techniques will, to a great extent, be influenced by what the specific data-gathering exercise is trying to achieve.

142.   Depending on the aims of the data collection and on the resources available, countries responding to the Task Force's survey reported that they form their samples based on population registers, business registers, existing address lists or lists of institutions, and/or administrative sources.

143.   The use of census or population register data as a sampling frame to draw a sample of institutional residents can be considered the most desirable method, where circumstances make this feasible. In some countries it is even possible to identify institutions in the sampling frame (see Poulain & Herm 2013, p.203ff.). This allows surveys to use oversampling of institutionalized residents. In other cases they could use disproportionate sampling and sample the older population with a higher sampling fraction than younger age cohorts. Schanze (2017) gives

information about the different types of registers (registers of individuals, of households, etc.) and the implications of each for sampling the institutional population.

144. An alternative approach is to use a comprehensive list of institutions, and to draw a sample of institutions from this. Individual respondents are then selected from the sampled institutions.

145. Some surveys use either census data or other surveys to follow up on parts of the respondents that are of special interest for the survey. This can be a very good means of identifying rare populations and compiling a decent sampling frame at lower cost. Censuses or other administrative data collections, with their large coverage, are especially well-suited for this kind of 'piggy-back sampling'. For instance, the Irish National Disability Survey (NDS) drew a sample from the 370,000 inhabitants who reported a disability in the 2006 Irish census. The NDS interviewed 14,500 disabled persons, 650 of whom were living in institutions. Depending on the definition of the target population of the survey used as a screener, this approach can also impose restrictions. For instance, the English Longitudinal Study of Ageing (ELSA) used the sample of the Health Survey for England (HSE) to start their panel. This created problems because the HSE excludes institutional residents. As a consequence, the ELSA sample suffered from undercoverage in this part of the population and could only interview those panel respondents who moved to institutions between two waves.

146. Where the data collection exercise is intended to produce information specifically about older people in institutions, it may be necessary to use specialized methods in the formation of the sample. Techniques employed for sampling rare or hard-to-reach populations, and small area estimation techniques, can be useful for sampling older people living in institutions. In general, the smaller the domain relative to the total population, the more specialized the sampling techniques required.

147. Kalton (2009) provides a valuable overview of methods for oversampling rare domains (screening, disproportionate stratification, two-phase sampling, use of multiple frames, location sampling), as well as the criteria determining when each of these is appropriate.

4.3.2 Accessing respondents

148. Once a sample has been drawn, the individuals must be contacted and their participation as respondents secured. In the case of institutional residents this brings particular challenges. Feskens (2009) notes that it is not usually possible to contact individual respondents living in older people's homes and nursing homes directly, but instead they often must be contacted via the authorities responsible for the institution. This could potentially lead to 'gatekeeper' issues, whereby the institution imposes its own criteria on whom it considers able or eligible to participate in a survey, or otherwise erects barriers between survey-takers and potential respondents. Gaining trust and cooperation with institutions is therefore crucial to ensuring adequate response rates.

149. There may be an assumption among institution staff that residents should be 'protected' against unwanted approaches by survey-takers. However, this may not reflect the view of residents, who may be eager to participate, and it would therefore not be appropriate that their opportunity to respond is hampered.

150.   'Gatekeepers' are not limited only to staff of institutions but also family members or friends who may deliberately or inadvertently present obstacles that inhibit survey-takers' access to respondents.

4.3.3 Obtaining responses

151.   Even having identified and accessed a respondent and obtained their informed consent to participate in a survey, the particular features of the older population call for special attention to be paid to survey design. This includes both instrument design and survey mode.

152.   First, there are considerations that apply to older people in general: questions must be posed in a way that makes sense to respondents in these age groups, while also taking care not to introduce stereotyped assumptions through omission: that is, not necessarily leaving out of a survey entirely the questions on topics which we might *assume* are irrelevant to older people, but which in fact may be relevant to them—such as questions on sexual and reproductive health and behaviours, physical activity, civic engagement, use of new technology, or many other domains that are often subject to age-related stereotypes.

153.   Second, there are considerations specific to the fact that they are resident in institutions. Hence some of the questions typically asked in a labour force survey, a household expenditure survey, or even a health survey, may be irrelevant or inapplicable as a result of the respondent not living in a private household, or may need to be adapted to maintain their relevance.

154.   Consideration must be given to the mode of data collection. For example, telephone interviews may help address the 'gatekeeper' issues mentioned above, but they also pose additional challenges for older people who may be hard of hearing or may not have access to a private telephone line.

155.   Many countries reported that they simplify questions or shorten their questionnaires for institutional residents in order to obtain better data. Some countries collect specific extra information – for example on the degree of dependency, or anthropometric measures.

4.3.3.1 Use of proxy respondents

156.   Consideration must be given to the question of whether or not to allow responses to be given by proxy, and under what circumstances. It is possible to include a block of questions at the start of the main survey to assess the respondent's capability to continue; or the decision can be made in advance through discussion with the institution.

157.   In a pilot study in the Netherlands (Feskens 2009) which was designed to assess the feasibility of administering social surveys to older people in nursing homes and older people's residences, the interviewers and institution staff decided collectively on the capability of each respondent to respond directly, and where a sampled unit was considered unable to participate, a questionnaire was sent to a proxy (by the institution, to maintain privacy). Not surprisingly, the study found that the proportion of sampled individuals considered capable of giving a direct response, not through a proxy, was lower in nursing homes than in residences for older people (principally due to the prevalence of dementia in nursing homes). Nevertheless, the researchers also found that

by allowing proxy responses they were able to obtain respectable response rates from both types of institution. This pilot study informed the procedures used by Statistics Netherlands in their Study of Elderly in Institutions in 2015-6 and 2019 (see Schols & Cremers 2015).

158.   The Task Force's survey reveals that some countries do allow proxies under some circumstances. For some the information comes from administrative data, although the original source of that information is not identified. For example, in Switzerland and Germany proxy interviews are allowed, in Croatia proxies are not used and in Kazakhstan reports are provided by legal entities.

159.   In Australia the survey of Disability, Ageing and Carers is conducted by asking staff of the establishment to complete the form for the selected respondent, referring to records where appropriate. Australia's experience in the 1980s showed that over 50 per cent of the population in hospitals, nursing homes etc. were unable to answer questions for themselves, and in cases where guardians had been appointed, permission had to be obtained to conduct interviews. The methodology was revised to streamline the enumeration process.

160.   The recommendation contained in the *UNECE Recommendations on Ageing-related Statistics* (drawing in turn from the EHIS Task Force) bears repeating:

> "In addition to the potential problems associated with contacting institutions in order to interview some of their residents, a major difficulty arises when sensory or cognitive impairments of the interviewee hamper the normal interview procedure. In cases where the impairment is only sensory, the EHIS Task Force proposes proceeding with the direct interview using alternative means. However, in the case of cognitive impairment an interview by proxy is often inevitable. In this case, clear instructions are needed to guide the interviewer. In particular, the instructions should specify who is eligible to act as a proxy. The fact that the interview is answered by proxy and the nature of the proxy (e.g. family member, nurse, other institution staff) should be recorded in the questionnaire. In addition, it should be borne in mind that certain topic areas are not appropriate for proxy interviewing—for example, questions on subjective well-being or on sensitive personal matters." (p.61)

4.4   Recommendations

161.   Due to their large coverage, censuses and other administrative data collections can serve as screeners for surveys interested in rare populations, such as institutional residents. NSOs should examine whether their samples and/or their census data could be used as sampling frames for 'piggy-back' surveys, e.g. by permitting identification of older people living in institutions.

162.   Where a full compilation (register or census) of all institutions is gathered, e.g. for the purposes of the population census, the type of institution and the number of residents in each institution should be recorded so that it is possible to give equal sampling likelihood to each individual rather than to each institution.

163.   Administrative data may be used as a 'data enhancer'. That is, many of the kinds of things that NSOs want to measure in social surveys (subjective well-being, community engagement,

etc.) cannot be gleaned from administrative sources, but such sources can and should be used to the greatest extent possible to permit the maximum possible reduction of actual survey content (this is discussed in more detail in chapter 5).

164.   Relatedly, surveys administered to older respondents (whether in an institution or not) should be parsimonious—kept to the minimum necessary and relevant.

165.   Where it is decided that proxy responses should be permitted, this should always be recorded and the type of proxy (e.g. relationship to target respondent) should be given.

4.5   Further work required in this area

166.   NSOs should foster synergies between their offices and survey researchers from academia and beyond. This would permit the sharing of further learning about the topics covered in this chapter, since survey researchers also grapple extensively with gatekeeper issues, mode effects, and sampling of hard-to-reach groups.

167.   Relatedly, it is important that research and experience about privacy, proxy responses, non-response, gatekeepers, and other issues that has been conducted in the context of surveying *private households* should be 'cross-fertilized' with the specific learning and experiences related to *older people*, and to *institutions*. That is, these three should not be viewed as isolated topics as this risks missing out on potentially important sharing of knowledge.

168.   Responding to consultation on a draft of these Recommendations, some countries indicated that a question bank of tested and standardized questions would be helpful. Such a question bank could aid the design of survey instruments and help to ensure comparability across surveys and across countries.

Chapter 5

Methods for measuring older populations in institutions using administrative data

5.1 Introduction

169. Measuring older populations in institutions using conventional survey methods can be difficult. For a variety of reasons traditional household-based surveys do not usually capture communal establishments. The chosen sampling approach may deliberately exclude institutions for practical and logistical reasons, i.e. because it would be difficult and expensive to identify and select institutions and/or individual respondents living in them (as detailed in chapter 4); or the content and design of the survey may be deemed not relevant to individuals who do not live in private households (for example, household expenditure surveys or labour force surveys).

170. Yet there are plenty of situations where, setting aside practical limitations, it would be desirable for the institutional population of older people to be included in statistics about the general population. It is here that administrative records are increasingly emerging as an important complement to traditional censuses and surveys. Administrative records allow a greater efficiency in all stages of the statistical production process, and the size of datasets can permit a heightened level of detail and thematic coverage. Using administrative sources can overcome both practical and ethical challenges (discussed in this chapter and in chapter 6, respectively), although it may also pose new challenges in both respects.

171. This chapter outlines the factors that must be taken into consideration when drawing on administrative sources to produce ageing-related statistics: evaluation of coverage, review of the variables included, quality and frequency of the information gathered and the ways in which administrative data can be transformed into meaningful statistics on ageing-related topics. Administrative data may come from central, regional or local government or directly from institutions themselves.

172. Conceptually there are three ways in which administrative data can be used for the topic in question:

   a)   using administrative sources to construct a statistical register of institutions. This list can be used as a sampling frame for targeting statistical exercises that then gather information on the size, structure and characteristics of the populations (see chapter 4 for more about 'piggy-back' sampling)

   b)   more direct use of administrative sources to supplement information on the population gathered directly from the institutions. Sources may be able to provide information about characteristics, demographics, health information, education and living conditions

   c)   as part of a full register-based collection system, in those countries which have a fully register-based census.

5.2   Existing standards and guidance

173.   A body of international guidance exists already on the use of administrative sources for producing statistics either in general, or on specific thematic areas. For example, the UNECE handbook *Using Administrative and Secondary Sources for Official Statistics* (UNECE 2011) provides definitions, discusses the potential costs and benefits, outlines frameworks (legal and statistical) under which administrative sources can be used, and, of particular relevance to institutional populations, discusses matching administrative data with survey sources. The UNECE *Guidelines on the use of registers and administrative data for population and housing censuses* (UNECE 2018) also provides guidance specifically directed at census-taking. Poulain and Herm (2013) give an overview of studies that have made use of registers to analyze institutionalization.

174.   Some definitions are given by Laitila et al (2011), which are helpful for clarifying the concepts under discussion:

a)   **"Register:** Corresponds to a list of objects that seeks to contain the total elements of a specific population and individualized data on its main characteristics. Additionally, they allow unequivocal identification of each object in such a way that the record can be updated and expanded with new variables for each object.

b)   **Administrative register:** The record used for administrative purposes in an administrative information system. It will contain the objects to be managed, including the identification and variables used for administrative purposes. A simple typology of data sources is used to consider how administrative sources should be defined. Firstly, all data sources are divided into primary sources (data collected for statistical purposes) and secondary sources (all other data).

c)   **Population base register:** Refers to the register that establishes the foundations for basic demographic statistics, which are intended to describe the structure of the population and its changes over time. The important variables in a population base register are those that identify a person and can be used to link that person with other base registers.

d)   **Statistical base population register:** This is created from the transformation of one or several administrative registers, in such a way that the objects and the variables are adjusted to satisfy the statistical needs. It is also possible to create a statistical record from the processing of administrative records together with other statistical records."

5.2.1 Potential costs and benefits of using administrative sources

175.   Sections 5.2.1 to 5.2.5 consist largely of material taken verbatim from the UNECE handbook on administrative sources (UNECE 2011). The material is reproduced here without quote marks for ease of reading, and is combined with some commentary on the specific issues at hand for the present Task Force.

176.   Statistical surveys are an expensive way of collecting data. Questionnaires have to be developed, samples have to be designed, respondents have to be contacted and possibly re-contacted to encourage them to reply, responses have to be processed and verified, and

results have to be calculated. In contrast, access to administrative sources is often free of charge, particularly if the data originate from the public sector. Even if there is a charge, it is often still cheaper to use administrative data than to collect the same information via a survey. Such considerations are not unique to the collection of data on ageing-related topics from older populations in institutions. However, they take on particular importance because of the increased challenges (and therefore expense) involved in identifying and accessing individuals living in institutions compared to those in private households.

177.   The statistical registers used to produce sampling frames are often so large and complex that it is very difficult and expensive to satisfactorily populate and maintain them using survey or census data. Therefore, even if administrative data do not replace statistical surveys, they can still be used to populate and maintain statistical registers, and thus help to reduce overall costs.

178.   Using data from administrative sources helps to reduce the response burden on data suppliers, since administrative sources allow statistics to be produced more frequently, with no extra response burden, and little extra cost. Again, this is especially pertinent to the case of older people in institutions where the response burden can be particularly high.

179.   The coverage of administrative sources often gives complete, or almost complete, coverage of their target population, whereas sample surveys can often cover only a relatively small proportion directly. The use of administrative sources therefore eliminates survey errors, removes (or significantly reduces) non-response, and provides more accurate and detailed estimates for various sub-populations.

180.   The use of administrative sources may increase the timeliness of statistical outputs by allowing access to more up-to-date information concerning certain variables.

181.   A drawback of using administrative sources is their thematic coverage. While many health-related, economic and demographic variables might realistically be covered by administrative sources, it is very challenging to envisage a way in which such sources could be used to provide information about subjective topics (such as self-perceived health and well-being), civic engagement, and many other topics that are important to provide a full spectrum of ageing-related statistics.

182.   A further potential challenge arises when comparing data arising from more than one source. Combining sources can increase the richness of available information, can help to reveal issues with any given source, and the strengths of one source may compensate for gaps in another—but combining sources can be difficult due to the existence of different definitions, different reference periods, and different coverage.

5.2.2 Frameworks (legal and statistical) under which administrative sources can be used

183.   Legal frameworks are normally constructed at the national level, and are specific to national sources and circumstances. In some cases, however, there may also be relevant legislation at the sub-national level.

184.   Most NSOs have legal texts defining their roles and responsibilities, typically in the form of a statistics act.

185.   As well as providing for access to data from administrative sources, legal frameworks also set out the limits to such access, and to the uses of administrative data. Often there are restrictions stating that data can only be used for specific statistical purposes, and that the confidentiality of individual records should be maintained.

5.2.3 Particular considerations for institutional populations of older people

186. **Units:** it is important to consider the potential for a lack of correspondence between administrative units and statistical units (in this case the institution/household differences). One major problem often encountered when using administrative sources is that the units used in those sources do not correspond directly to the definition of the required statistical units. The process of converting from administrative units to statistical units can be quite difficult conceptually, and often involves some form of modelling.

187.   In addition, it is necessary to standardize the variables; this process involves adapting the definitions of the variables of each register.

188. **Timelines:** matching the administrative data with survey source reference periods. There are three separate issues relating to timeliness that affect the usefulness of administrative data for statistical purposes:

    a)   Administrative data may not be available in time to meet statistical needs

    b)   Administrative data may relate to a period that does not coincide with the statistical reference period

    c)   Administrative data may be measured over a period, whilst the statistical requirement is for a specific point in time (or vice-versa).

189.   There will generally be some sort of lag between an event happening in the real world, and it being recorded by an administrative source. This is then followed by a further lag before the data are made available to the national statistical office. By analyzing lags in this way, it is possible to produce summary statistics to estimate their impact. With the measure of the lags, the statistician understands the nature and impact of the lags in the sources used to compile statistics. It also gives information that can be used to inform adjustments to improve the quality of the statistical outputs.

5.2.4 Transformation of administrative registers into population base statistical registers

190.   It must be recognized that at any point during the information generation process, mistakes can be made that could distort the results generated. This makes it necessary to apply consistency review criteria and information debugging techniques. It is necessary to apply a set of rules to review the coherence of the information in the registry received and establish the most appropriate correction measures, in accordance with the objectives and goals of the statistical generation project.

191. The validation criteria are:
    a)   Abide by the conceptual framework defined by each information provider
    b)   Respect as much as possible the information correctly recorded in each variable
    c)   Universally apply the criteria to all records
    d)   Use rules of logical congruence
    e)   Assign values only if there is information supported by other associated variables
    f)   Do not eliminate cases that could be considered erroneous.

192.   Because different information providers can periodically send files with different variable names and with different structure, it is necessary to determine the reference between the names of variables that are used in the population base statistics register and the variable names of files from each information provider.

5.2.4.1 Standardization

193.   Standardization of variables involves adapting the definitions of the variables of each administrative record to the standardized definitions of the population base statistical register. The homologation takes into account the change of name for the variables and encoding categories of variables of each administrative register to the names and categories established for the variables in the statistical base population register.

5.2.4.2 Review and validation of information

194.   At this stage of the process, validation rules should be created to detect inconsistencies in the data; this allows identification of problems in the information such as discrepancies with respect to a reference value, outliers, lack of response in the variables and coding errors.

5.2.5 Using administrative data to supplement statistical surveys

195.   This section presents an overview of different models for using administrative data to supplement data collected in statistical surveys. It shows how a mixed-source approach can be used to produce statistics at lower cost, better quality, or both. This section focuses on the different models for using data from a mixture of administrative and statistical sources to produce statistical outputs.

5.2.5.1 Mixed-source Models

The Split Population Approach

196.   In this model the statistical population is split into two or more parts for data collection purposes. Data from administrative sources are used for units where these data are of sufficient quality, and statistical sources are used for the remainder of the units.

The Split Data Approach

197. In this approach, a population of statistical units and a data requirement are identified. Instead of providing all of the variables for part of the population, administrative sources are used to provide some of the variables for all of the population.

Pre-filled Questionnaires

198. This approach is really a special case of the split data model in that statistical questionnaires are still used to collect data about statistical units, but those questionnaires are pre-filled using administrative data as far as possible, with respondents being asked merely to check and correct these data where necessary.

Using Administrative Data for Non-responders

199. This approach can be seen as a variant of both the split source and the split data models. In this case, the statistical survey remains the primary means of data collection. However, statistical surveys tend to suffer from varying degrees of nonresponse, which affects the efficiency of the sampling process, and the quality of the resulting statistics.

Using Administrative Data for Estimation

200. When a sample survey is used to collect statistical data, it is often necessary to use estimation techniques, particularly if population totals (rather than proportions) are required. Some basis to estimate the values for the non-sampled part of the population is therefore needed. Sometimes this process can use variables from the survey frame used to draw the sample, but in some cases it may be possible to improve accuracy by using data from administrative sources as auxiliary variables in the estimation process.

5.2.6 Definitions

201. The CES Census Recommendations state that "…(a)n institutional household comprises persons whose need for shelter and subsistence are being provided by an institution… members of an institutional household are those that have their place of usual residence… at the institution. People who would otherwise be members of private households but who are living in an institution at the census reference time are considered to (be) members of the institutional household if their actual or expected length of residence there exceeds one year." (UNECE 2015a). This latter recommendation is intended to avoid situations in which persons are linked to both a private and an institutional household. Undercounts and double counts may occur when a new person is included in the care register, without checking against the population register.

5.3 Current approaches

202. The work of the Task Force revealed some specific examples of how different countries use administrative data on older populations in institutions.

203. *Using administrative sources directly.* In Finland, statistics on institutional care and housing services on social care, including institutions for elderly persons, are collected and published by the National Institute for Health and Welfare.[31] The Care Register for Social Welfare contains data on institutional care and housing services with 24-hour/part-time assistance for older people, people with physical or intellectual disabilities and people with mental health problems. The data on institutional care and housing services are based on discharge notifications collected from municipal and private-sector residential homes for older people and sheltered housing units with 24-hour assistance for older people, among others. When a new person is included in the care register, there is no check against the population register. Thus, undercounts and double counts may occur.

204. *Using administrative sources to build a register of institutions.* Statistics Norway keeps a list of institutions, based on a more general register of establishments (the business register). The category of "dwellings for the aged and disabled" includes other kinds of municipal dwellings reserved for persons in need of help because of old age or because of handicap. These dwellings are not included in the institution category, since they do not have a full-time service offer. Some of them have care and nursing services during parts of the day. The other dwellings do not have this offer, and the residents are instead users of the home-based services in the same way as other ordinary users. Many of these apartments are equipped for functionally disabled residents and some of them have to some extent common floorage and household.

205. Similarly to the case of Finland, there is no check against the population register in Norway. Therefore, double counts and undercounts may occur.

206. Statistics Norway publishes data on the household structure of the population. In addition to several types of private households, there is one remainder category, labelled as 'other households'. This includes persons who are homeless and persons whose addresses should not be disclosed, in addition to persons who live in an institution. Addresses of persons who belong to the category 'other households' are updated regularly using information from various sources, such as the population register and the general register of establishments.

207. Australia also make use of administrative data for older people in institutions. The statistical office draws together information from data sets across government into a linked research dataset called GEN. The data set has been set up by the Australian Government Institute for Health and Welfare. GEN is described as "a comprehensive 'one–stop shop' for data and information about aged care services in Australia. It reports on capacity and activity in the aged care system focusing on the people, their care assessments and the services they use."[32]

---

31 Information on these statistics is available at https://www.thl.fi/en/web/thlfi-en/statistics/statistics-by-topic/social-services-older-people/institutional-care-and-housing-services-in-social-care

32 See https://www.gen-agedcaredata.gov.au/about

208.   Statistics Netherlands keeps a list of addresses that are defined as institutions (Verbeek-Oudijk and Van Campen 2017). These addresses are marked as such in the population register. Hence undercounts or double counts do not occur, at least not in principle.

209.   Recently, Colombia carried out the national census of population and housing and used a strategy for special places of housing such as jails, barracks, orphanages, nursing homes, etc. The collection strategy consisted of extracting the institutions that reported being special places of housing from the register of establishments, contacting them and proceeding to fill out the census of the people who lived in the institution through a web application. This information was automatically converted into a statistical register and was constructed from the administrative records provided by the institutions consulted. This is a relatively inexpensive way to obtain information.

5.4   Recommendations

210.   Existing general guidance on the use of administrative sources, including international guidance such as the UNECE handbook on using administrative sources, is directly relevant to this issue and should be considered when using administrative sources for measuring older populations in institutions.

211.   National Statistical Offices should consider whether and how they can influence the collection of administrative data such that their usefulness for statistical purposes is maximized. This could involve fostering relationships with institutions themselves and securing their collaboration to improve the statistical value of the administrative data they produce.

212.   This chapter has not considered 'big data' specifically. Many of the sources commonly thought of as big data, such as mobile telephone records or social media data, are unlikely to provide much added value for the production of statistics on older populations in institutions, since the coverage of such populations is likely to be low in these sources. It is conceivable that in the future, technologies used in institutions for older people, such as tools to assist with daily living, may become sources of big data. There would, however, be ethical considerations to take into account in using such data.

5.5   Further work required in this area

213.   The discussions in this chapter have taken as an assumption that if an administrative source exists for older people's institutions, it will cover all such institutions. In reality this may not be the case. Some may be excluded, either because they are informal or because they are very small. In some countries there may be a large group of such small institutions. Specific guidance is absent for gathering administrative data from these. Development of such guidance would be valuable.

214.   While a variety of international guidance on the integration of multiple sources exists or is currently being developed, it may be useful to develop guidance that gives particular attention to administrative data sources from institutions.

Chapter 6

Ethical considerations for collecting information on older populations in institutions

6.1   Introduction

215.   Collecting data from older people living in institutions poses several ethical challenges. Some of these challenges arise from the nature of the respondents (older people, possibly with functional and/or cognitive limitations), but are not necessarily unique to older populations in institutions. That is, the same issues can arise when collecting data from older people in private households. Other ethical questions arise as a result of the institutional setting, and apply to any institutional population (for example, surrounding privacy during interviews, confidentiality and freedom to opt out). In both cases, there is already considerable research and guidance available, including guidance developed in the academic arena whose principles could be transferred to the context of official statistics to assist NSOs in their data gathering. The particular ethical challenges for this topic, for which there is, as yet, less guidance at hand, come from the *combination* of these two factors – older respondents and institutional settings – which necessitates extra care in designing and conducting surveys.

216.   The 2017 European Handbook on Equality Data (Makkonen 2016) helpfully sets out some key ethical domains that need to be considered. It notes that "Statisticians have obligations to the data subjects, customers, funders and society at large. These stakeholders often have diverging or even conflicting interests. …Ethical guidelines complement legal standards, clarify their meaning in practice and help statisticians and researchers to maintain high standards of scientific integrity and quality."

217.   The focus of this chapter is on the ethical issues around collecting data, but the above paragraph is a reminder that there are ethical considerations also in the exclusion of groups from data collection; measurement of issues such as equality may be affected if groups are excluded. There are legislative, ethical and political imperatives to ensure accurate data collection from all groups in society so that the realities and needs of all groups are known and can be addressed (including international frameworks such as the Fundamental Principles of Official Statistics and the 2030 Agenda for Sustainable Development)—but these imperatives must be carefully balanced against the ethical challenges entailed in obtaining such data. Furthermore, there are also several societal trends which may affect how older people are perceived in society which may in turn result in a reduction in their decision-making capability, due to their opinions not being respected. This raises multiple ethical issues.

218.   There are ethical considerations in any data collection and the purpose of this chapter is not to cover all ethical issues, but rather to point out the particular issues with collecting data from older people in institutions. Legal standards and considerations in individual countries may help to guide or may provide additional barriers to the collection of such data. This chapter highlights four areas:

a)   Access to respondents

b)   Ability to complete/proxy completion

c)   Privacy

d)   Informed consent.

219.   However, there is some overlap between these areas. An overarching consideration is that older people in institutions may be vulnerable adults. Household data collections may already have procedures to handle issues around vulnerable adults[33]. The chapter then considers new technologies and safeguarding.

6.1.1 Access to respondents

220.   Older people receiving care can also live in private households. Access to them for the purposes of data collection is likely to be either direct, if they live on their own, or via a family member or carer. While there are ethical considerations in the household domain related to accessing respondents, access to older people in institutions is much more likely to be through an administrator/manager of the institution. This is likely to be true even if the person is still able to understand and make their own decisions. There needs, therefore, to be clarity about the purpose of the survey and its ethical basis. There also needs to be a clarity around from whom the survey-takers need to collect the information. The Adult Social Care Survey in England[34], for example, is clear about the level of mental incapacity that would preclude someone from taking part in the survey and ensures that this is communicated to managers.

221.   Some professional and institutional codes of conduct appear to contradict best interviewing ethics practice. For example, an interviewer may wish to treat the residents of care homes as autonomous and fully responsible adults, but the manager of the ward or home will normally expect the interviewer to seek permission before speaking to (or observing) any resident. Managers and administrators of institutions should be aware of the sensitivity around data as part of their professional training – but this is not always the case in practice.

33   Two examples are provided here: one from the UK Government regarding a survey of safeguarding for vulnerable adults https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/social-care-user-surveys/guidance/adult-social-care-survey-2016-17-guidance-for-local-authorities (this survey includes communal establishments), and one from a market research company, https://www.mrs.org.uk/pdf/MRS%20Researching%20Vulnerable%20Participants%20best%20practice%20note.pdf.

34   Personal Social Services: Adult Social Care Survey England: Information and guidance for the 2018-19 survey year https://digital.nhs.uk/binaries/content/assets/website-assets/data-and-information/data-collections/social-care-user-surveys/ascs_guidance_2018-19.pdf.

6.1.2 Ability to complete/proxy completion

222. It could be assumed that a smaller proportion of the older population in institutions are able to complete surveys, relative to the general population. Since many older people in institutions have physical and/or mental impairments it is not so easy to interview them (measurement errors will occur). People with impaired short-term memory may have difficulties in answering certain questions. There is therefore an ethical imperative to design questions (including collection mode) that can be understood and answered as simply as possible (see chapter 4 on instrument design and survey methods).

223. Specialized training should also be provided to interviewers facilitate the conduction of direct interviews for individuals with various kinds of impairments. Ethical considerations may mean it is better to interview these individuals but face-to-face, rather than using telephone or postal surveys. It may be that somebody else is present during the interview, or even helping to give answers. Proxy interview/proxy reporting (e.g. by a son or daughter, spouse/partner, caregiver, manager of the care-institution) should be restricted. Where it is used it should be noted that there is evidence of differences in answers between direct and proxy questioning.

224. For example, people with dementia have been found to have higher hopes for their quality of life than their caregivers do for them (Thorgrimsen et al 2003). Consideration should also be given as to whether an impairment might be temporary—for example, related to variations in health (loss of speech after a stroke may be temporary). Even the time of day might affect the extent of impairment. For example, there is evidence that dementia is worse as the sun goes down ("Sundowning": see Alzheimer's Society 2018).

6.1.3 Privacy

225. A key aspect of institutional living is that it is communal. The right to privacy is protected, for example under Article 8 of the European Convention on Human Rights.[35] The right to respect for private life encompasses the right to respect for information relating to private life. Therefore, the processing of personal data, including sensitive data, falls within the ambit of Article 8. It is possible that privacy considerations may also vary by the different kinds of information/data collected: socio-demographic; socio-economic; and, health-related.

226. If a respondent is interviewed in an institution it may be more difficult to find a private area, or it may be that a carer is required to be present. This provides an extra challenge alongside the usual ethical issues around privacy. The populations in institutions may well contain some unique individuals, for example those with exceptional old age, or members of a minority. In general men are in the minority in the oldest old population. This may mean that additional consideration needs to be given to disclosure control of results to ensure privacy.

---

35 Article 8 – Right to respect for private and family life: "1: Everyone has the right to respect for his private and family life, his home and his correspondence. 2: There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic wellbeing of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others."

227.   However, there is a balance here as the vulnerabilities of some sick and frail older people are real but they are not, in all cases, manifest or known. For example, asking apparently innocuous questions about 'where you came from' or 'what you used to do' (let alone about health, spouses or children) can prompt painful thoughts or memories, and deep distress. Known or possible vulnerabilities will need to be taken into account in some research designs. In some cases, ensuring that support or medical cover is on hand is essential.

6.1.4 Informed consent

228.   A key aspect of modern data use is informed consent.[36] There are particular ethical issues around obtaining consent where for reasons of ill health respondents are unable to provide their consent. In this case it may be that consent needs to be sought from institution managers, relatives, or medical staff as appropriate. Informed consent is about the use of the data collected so consideration should be given to the future use as well as the immediate use of the data. There should also be consideration given to consent for linking any data collected to other data such as administrative records or records from technology. Of course, being clear and concise about the objectives of the survey and the benefits to those completing it is especially important for people with impaired mental faculties. There should also be a clear recording of consent from the respondent or from the person responding on their behalf.

6.1.5 Use of new technologies

229.   Through Information and Communication Technologies (ICTs) and Ambient Assisted Technologies (AAT) it might be possible to obtain a lot of additional information about people living in institutions: for example, as by-products of using ICTs to collect data from multiple sensors for monitoring the safety of the residents in institutions, or via ambulatory assessment. In addition, new technologies open opportunities for new uses of existing data, e.g. record-linkage options or other possibilities for big data analysis including genetic data use.

230.   For such technologies there is a general need to address the issue of data protection and privacy in a more systematic way. Clearer rules and ethical codes are required in this context, both at legislative and organizational levels. To the knowledge of the Task Torce, there are no internationally-accepted standards or guidance documents on ethics in statistical research, only at national or organizational level (e.g. national statistical laws).

6.1.6 Safeguarding

231.   As previously stated, older people in institutions may all (with the exception perhaps of those in religious institutions or prisons) be considered vulnerable adults. As part of any exercise to collect information there needs to be an awareness of potential safeguarding issues that may

---

36   An example document on obtaining informed consent can be found at https://www.gov.uk/service-manual/user-research/getting-users-consent-for-research

become apparent, either observed or through answers to questions. If interviewers or analysts realise that an older adult is or has been neglected, abused, exploited or is at risk of harm there is an imperative that such neglect or harm is reported appropriately.

6.2   Concluding remarks and recommendations

232.   The practical aspects of conducting research on institutional populations can present a unique set of ethical challenges. Researchers need to be aware of the legal constraints regulating issues around mental capacity and equality of people in institutions. Interviewers should be trained thoroughly.

233.   It has been shown that older people may readily agree to participate in research studies, for example to increase their human contact, or simply for enjoyment (Hall et al 2009). There have also been concerns over institutionalized participants feeling a reluctance to criticize health care professionals or feeling coerced to participate in research as a captive audience. In general, however, it has been shown that older people more often regard their participation in research as a valuable contribution to the future lives of others and that such participation can have substantial therapeutic benefits.

234.   An assessment of ethical considerations in nursing home studies (Karlawish 1999) found that "in publications of research that involves nursing home residents, basic standards of research ethics are not typically reported." However, on average, nursing home studies were providing more information on research ethics than other studies.

235.   Ethical issues must obviously be considered in any data collection and they are more complex in the case of institutional population. It is therefore very important that the specific ethical issues related to institutional population are carefully considered in designing the surveys that cover them.

Chapter 7

Recommendations and further work

7.1 Summary of the recommendations

236. Countries should classify institutions by the characteristics of the social and health care services provided, rather than by name or type of institution ('nursing home' etc.).

237. NSOs should be concerned about the potential for bias if institutional residents are not covered or are inadequately covered. It is recommended to tackle the bias as follows.
   a) As a first step, obtain good estimates of the number of institutional residents by age and sex, and if possible also by region.
   b) As a second step, focus on the variables where the potential bias is highest, such as marital status, education, income, health and mobility.

238. NSOs should give special attention to types of institutions and health-related variables when expanding their statistics on institutional populations.

239. Countries should systematically take into consideration the general rule of thumb—that bias is greater when the excluded population is larger and/or when it is more distinctive—when deciding whether the amount of bias 'matters' in any given instance.

240. NSOs should examine whether their samples and/or their census data could be used as sampling frames for 'piggy-back' surveys, e.g. by permitting identification of older people living in institutions.

241. Where a full compilation (register or census) of all institutions is gathered, e.g. for the purposes of the population census, the type of institution and the number of residents in each institution should be recorded.

242. Administrative data may be used as a 'data enhancer'. That is, many of the kinds of things that NSOs want to measure in social surveys (subjective well-being, community engagement etc.) cannot be gleaned from administrative sources, but such sources can and should be used to the greatest extent possible to permit the maximum possible reduction of actual survey content.

243. Surveys administered to older respondents (whether in an institution or not) should be parsimonious—kept to the minimum necessary and relevant.

244. Where it is decided that proxy responses should be permitted, this should always be recorded and the type of proxy (e.g. relationship to target respondent) should be given.

245. Existing general guidance on the use of administrative sources, including international guidance such as the UNECE handbook on using administrative sources, is directly relevant to this issue and should be considered when using administrative sources for measuring older population in institutions

246.   Ethical issues must obviously be considered in any data collection and they are more complex in the case of institutional population. It is therefore very important that the specific ethical issues related to institutional population are carefully considered in designing the surveys that cover them.

7.2   Further work

247.   Future work could aim to develop **a statistical classification of institutions** based on certain characteristics, such as facilities provided, type of organization, and physical environment. Such work should rely on the characteristics collected for SHA and OECD, and would enhance the harmonization of internationally-collected data on institutions.

248.   Future work should conduct **analyses to assess bias**, similar to those in chapter 3, on other international survey data, as well as national data for individual countries. This would produce a more complete picture of the extent of bias arising from omission of institutional residents. This could bolster the evidence base to drive countries to begin including this population group more systematically in data collection, especially in cases where the bias is found to be significant.

249.   NSOs should foster **synergies between their offices and survey researchers** from academia and beyond. This would permit the sharing of further learning about the topics covered in the current work, especially the issues covered in chapter 4, since survey researchers also grapple extensively with gatekeeper issues, mode effects, and sampling of hard-to-reach groups.

250.   Relatedly, it is important that research and experience about privacy, proxy response, non-response, gatekeepers, and other issues that has been conducted in the context of surveying *private households* should be 'cross-fertilized' with **the specific learning and experiences related to older people, and to institutions**. That is, these three should not be viewed as isolated topics as this risks missing out on potentially important sharing of knowledge.

251.   Specific guidance is absent for gathering administrative data from the numerous **small institutions** that exist in some countries. Development of such guidance would be valuable.

252.   Responding to consultation on a draft of these Recommendations, some countries indicated that a **question bank of tested and standardized questions** would be helpful. Such a question bank could aid the design of survey instruments and help to ensure comparability across surveys and across countries.

253.   While a variety of international guidance on the integration of multiple sources exists or is currently being developed, it may be useful to develop **guidance that gives particular attention to administrative data sources from institutions**.

254.   The focus of this work has been cross-sectional analysis, but the potential value of **longitudinal analyses** should also be recognized. By examining the antecedent life experiences in terms of family, households, health and socio-economic variables there would be greater understanding of the circumstances leading to living in an institution, which may offer insight both about potential future needs for institutions and about actions that may prevent the need for residing in an institution. Future work could therefore consider **the data needs for applying a longitudinal perspective to the study of older populations in institutions**.

60

255. It should be noted that this work has been undertaken by a Task Force convened by the Conference of European Statisticians, whose members come primarily from countries of the UNECE region and other highly-developed nations. Further work on this topic could be expanded to consider the different situations—with respect both to the institutions available for older persons and to the data environment—in **other regions of the world** including in developing countries.

256. The Titchfield City Group on Ageing and Age-disaggregated Data (TCGA) could provide a suitable forum for some of these areas of future work to be taken forward.

7.3   Conclusions

257. The work of this Task Force and the present publication demonstrate some key findings. The first, as expected from the outset, is that definitions pose a challenge. The Task Force found that no single definition could be fit for the diversity of purposes nor for the ever-changing landscape of institutions. Instead the recommendation is that definitions and classifications used should be based on the ways in which institutions are organized and the services they provide, rather than on the names of the institutions or the length of stay.

258. A second key finding is that the bias introduced into statistics by omitting older populations in institutions – something that has long been suspected but rarely quantified – is real and important. The key contribution of this work is in clarifying that such 'importance' is not a simple binary variable but varies according to the relative size of the population living in institutions and its distinctiveness along the dimensions in question. Clearly, then, the bias is more of an issue for ageing-related statistics and in ageing societies than elsewhere. NSOs will need to take note of this and adapt their approach as they expand their offer of ageing-related statistics.

259. This work has relied on demonstrated strong overlaps with existing areas of work and research – data collection techniques, the use of administrative sources, tackling small and hard-to-reach populations, and ethical issues – and at the same time has highlighted some particular considerations in each of these areas when older people in institutions are the population of interest. These findings highlight at one and the same time the need to engage closely with each of these sub-domains of statistical work, and the need to ensure that older populations receive due consideration in such work.

260. It is clear that further work remains to be done. Continued population ageing and the evolution and proliferation of care-giving arrangements and institutional formats will mean that the statistical challenges will only increase. A better statistical basis for policymaking will become ever more important. The underlying principle of the 2030 Agenda for Sustainable Development, that no-one should be left behind, increases the imperative to ensure that some of those who are the hardest to include in statistics, such as the oldest-old, people with cognitive impairments, and people with limited social connections, are included in the statistics so that their experiences, too, are taken into account in the formulation of policies that affect their lives.

References

Alzheimer's Society (2018). Sundowning. https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms/sundowning.

Asakawa, K., Feeny, D., Ambikaipakan, S., Johnson, J., & Rolfson, D. (2009). Do the Determinants of Health Differ between People Living in the Community and in Institutions? Social Science and Medicine, 69(3), 345–353.

Beukenhorst, D., Calleja, N., Koponen, P., Maggiori, C., Milan, G., Vike, L., & Gourdol, A. (2011). *European Health Interview Survey Task Force IV - report on institutionalised people*. Eurostat: Luxembourg.

Blangiardo, G. C., Migliorati, S., & Terzera, L. (2004). Center sampling: from applicative issues to methodological aspects. *Atti della XLII Riunione Scientifica della SIS, volume Sessioni plenarie e Sessioni specializzate*, 377-388.

Börsch-Supan, A. (2017). Survey of Health, Ageing and Retirement in Europe (SHARE) Wave 5. SHARE-ERIC.

Börsch-Supan, A., Brandt, M., Hunkler, C., Kneip, T., Korbmacher, J., Malter, F., Zuber, S. (2013). Data Resource Profile: The Survey of Health, Ageing and Retirement in Europe (SHARE). *International Journal of Epidemiology, 42*(4), 992–1001.

Börsch-Supan, A., Brugiavini, A., Jürges, H., Mackenbach, J., Siegrist, J., & Weber, G. (2005). Health, Ageing and Retirement in Europe: First Results from the Survey of Health, Ageing and Retirement in Europe. Mannheim Research Institute for the Economics of Aging.

Bridges, S., Hussey, D., & Blake, M. (2015). *The dynamics of ageing: the 2012 English Longitudinal Study of Ageing (Wave 6): Technical Report*.

Bristle, J., Butt, S., Emery, T., Luijx, R., Maineri, A. M., Pflüger, S.-M., Zins, S. (2016). Report on auxiliary data in available country registers. In *Work Package: 2-Representing the population*: SERISS (Synergies for Europe's Research Infrastructures in the Social Sciences).

Brooks, J., Gridley, K. & Parker, G. (2019) Doing research in care homes: the experiences of researchers and participants *Social Research Practice, 8* (Autumn), 19-27.

Cambois, E., Jagger, C., Nussleder, W., Van Oyen, H., & Robine, J.-M. (2016). International Comparisons of Disability Prevalence Estimates: Impact of Accounting or Not Accounting for the Institutionalized Population. *International Measurement of Disability*, 207–229.

Castora-Binkley, M., Meng, H., & Hyer, K. (2014). Predictors of Long-Term Nursing Home Placement under Competing Risk: Evidence from the Health and Retirement Study. *Journal of the American Geriatrics Society*, 62(5), 913–918.

Chávez Villegas, C., & Samman, E. (2015). *Exclusion in household surveys: Causes, impacts and ways forward* (ISSN: 2052-7209).

Colombo, F., Llena-Nozal, A., Mercier, J., & Tjadens, F. (2011). *Help Wanted? Providing and Paying for Long-Term Care*.

Daatland, S. O., Høyland, K., & Otnes, B. (2015). Scandinavian Contrasts and Norwegian Variations in Special Housing for Older People. *Journal of Housing For the Elderly, 29*(1-2), 180-196.

de Luca, G., Rossetti, C., & Malter, F. (2015). *SHARE Wave 5: Innovations & Methodology*.

Directorate for Health Information and Research, Malta Department of Health. (2012). *Needs Assessment of the Elderly in Malta: National needs assessment amongst the Maltese population aged 75 years and over* (Final Report 31012014). Malta.

Einio, E., Guilbault, C., Martikainen, P., & Poulain, M. (2012). Gender Differences in Care Home Use Among Older Finns and Belgians. *Population, 67*(1), 75–101.

ESS Sampling Expert Panel. (2016). Sampling Guidelines: Principles and Implementation for the European Social Survey. In. London: ESS ERIC Headquarters.

Eurostat. (2011a). European Health and Social Integration Survey (EHSIS). In *Questionnaire and Interviewer Instructions*: Eurostat.

Eurostat. (2011b). Technical Group on Health and Health Interview Survey Statistics: Task Force on institutionalised people: presentation slides from a meeting on 28-29 March 2011. In (Item 4.2 ed.): Eurostat: Luxembourg.

Eurostat. (2013). European Health Interview Survey (EHIS wave 2) - Methodological manual. In *Methodologies and Working Papers* (2013 edition ed.). Luxembourg: Publications Office of the European Union.

Eurostat. (2015). *People in the EU: who are we and how do we live?* (2015 edition ed.). Luxembourg: Publications Office of the European Union.

Eurostat. (2018). European Statistical System – Census Hub. https://ec.europa.eu/CensusHub2

Federal Interagency Forum on Aging-Related Statistics. (2016). *Older Americans: Key Indicators of Well-being*.

Feskens, R. C. W. (2009). *Difficult Groups in Survey Research and the Development of Tailor-made Approach Strategies*. Centraal Bureau voor de Statistiek (Statistics Netherlands) and Utrecht University, Utrecht.

Gaugler, J., Duval, S., Anderson, K., & Kane, R. (2007). Predicting Nursing Home Admission in the U.S: A Meta-Analysis. *BMC Geriatrics, 7*(13), 1–14.

Groom, G., Morris, L., & Tortoriello, M. (2009). *Communal Establishments Survey, Findings of the Pilot Stage: Summary Report*.

Groves, R., Fowler, F., Couper, M., Lepkowski, J., Singer, E., & Tourangeau, R. (2009). Survey Methodology. In (Second edition ed.). New York: John Wiley & Sons, Inc. (Reprinted from: Second edition).

Haan, M., Ongena, Y. P., & Aarts, K. (2014). Reaching Hard-to-Survey Populations: Mode Choice and Mode Preference. *Journal of Official Statistics, 30*(2), 355-379.

Hall, S., Longhurst, S., & Higginson, I. J. (2009). Challenges to conducting research with older people living in nursing homes. *BMC geriatrics, 9*, 38-38.

INEGI. *Glossary of terms for vulnerable populations*. (Excel file). Personal communication.

Kalton, G. (2009). Methods for Oversampling Rare Subpopulations in Social Surveys. *Survey Methodology, 35*(2), 125-141.

Karlawish, J. H. T., Hougham, G. W., Stocking, C. B., & Sachs, G. A. (1999). What is the Quality of the Reporting of Research Ethics in Publications of Nursing Home Research? *Journal of the American Geriatrics Society, 47*(1), 76-81.

Klevmarken, A., Swensson, B., & Hesselius, P. (2005). The SHARE Sampling Procedures and Calibrated Design Weights. *The Survey of Health, Ageing and Retirement in Europe – Methodology*, 28–37.

Knops, J., Houben-van Herten, M., Maas, B., Roels, J., de Heij, V., & Gouweleeuw, J. (2016). *Ouderen in Instellingen en Tehuizen 2015/2016: Onderzoeksdocumentatie en Kwaliteitsanalyse* (Projectnummer 300542).

Krabina, B., Prorok, T., & Tamm, H. (2005, 2005). *RISER: Trans-European eService in Civil Registration*. Paper presented at the Electronic Government. Workshop and Poster Proceedings of the Fourth International EGOV Conference 2005, August 22-26, Copenhagen, Denmark.

Laferrère, A., Van Den Heede, A., & Van Den Bosch, K. (2012). Entry into Institutional Care: Predictors and Alternatives. In A. Börsch-Supan, M. Brandt, H. Litwin, & G. Weber (Eds.), *Active Ageing and Solidarity between Generations in Europe* (pp. 253–264).

Laitila, T., Wallgren, A., & Wallgren, B. (2011). *Quality Assessment of Administrative Data*. Örebro.

Luca, G. D., Rossetto, C., & Malter, F. (2015). Sample Design and Weighting Strategies in SHARE Wave 5. *SHARE Wave 5: Innovations & Methodology*, 75–84.

Luck, T., Luppa, M., Weber, S., Matschinger, H., Glaesmer, H., König, H. H., . . . Riedel-Heller, S. G. (2008). Time until Institutionalization in Incident Dementia Cases - Results of the Leipzig Longitudinal Study of the Aged (LEILA 75+). *Neuroepidemiology, 31*(2), 100–108.

Luppa, M., Luck, T., Weyerer, S., König, H. H., Brähler, E., & Riedel-Heller, S. (2010). Prediction of Institutionalization in the Elderly. A Systematic Review. *Age and Ageing, 39*(1), 31–38.

Makkonen, T. (2016). *New European Handbook on Equality Data*. Brussels.

Martikainen, P., Moustgaard, H., Murphy, M., Einiö, E., Koskinen, S., Martelin, T., & Noro, A. (2009). Gender, Living Arrangements, and Social Circumstances as Determinants of Entry into and Exit from Long-Term Institutional Care at Older Ages: A 6-Year Follow-Up Study of Older Finns. *Gerontologist, 49*(1), 34–45.

McCann, M., Grundy, E., & O'Reilly, D. (2012). Why Is Housing Tenure Associated with a Lower Risk of Admission to a Nursing or Residential Home? Wealth, Health and the Incentive to Keep 'My Home'. *Journal of Epidemiology & Community Health, 66*(2), 166–169.

Meltzer, H. (2004). Groups often omitted from national, household surveys: implications for disability statistics. Presentation delivered at the Fourth Meeting of the Washington Group on Disability Statistics, 29 September-1 October 2004, Bangkok, Thailand.

Nöel-Miller, C. (2010). Spousal Loss, Children, and the Risk of Nursing Home Admission. *Journals of Gerontology, Series B, 65*(3), 370–380.

OECD. (2017). OECD Health Statistics 2017: Definitions, Sources and Methods. OECD.

Office for National Statistics. (2002). Estimates of Household Population (Experimental). Office for National Statistics.

Office for National Statistics. (2015). *2011 Census Analysis: What Does the 2011 Census Tell Us About People Living in Communal Establishments?*

Peeters, H., Debels, A., & Verpoorten, R. (2013). Excluding Institutionalized Elderly from Surveys: Consequences for Income and Poverty Statistics. *Social Indicators Research*, 110(2), 751-769.

Pickering, K., Smith, P., Bryson, C., & Farmer, C. (2008). *British Crime Survey: options for extending the coverage to children and people living in communal establishments*.

Poulain, M., & Herm, A. (2013). Central population registers as a source of demographic statistics in Europe. *Population, 68*(2), 183-212.

Rodríguez-Sánchez, B., Angelini, V., Feenstra, T., & Alessie, R. (2017). Diabetes-Associated Factors as Predictors of Nursing Home Admission and Costs in the Elderly Across Europe. *Journal of the American Medical Directors' Association, 18*(1), 74–82.

Schanze, J.-L. (2016a). Extending the coverage to non-private citizens: exclusion of the institutional population and the comparability of administrative data in Europe. Presentation delivered at the Conference of European Statistics Stakeholders, Budapest, 21 October 2016.

Schanze, J.-L. (2016b). *The undercoverage of the institutional population: Why it can bias survey results and how European surveys could include non-private respondents*. Paper presented at the Reaching out to hard-to-survey groups among the poor (Summer school), Leuven, Belgium.

Schanze, J.-L. (2017). Report on Sampling Practices for the Institutionalized Population in Social Surveys. In *Work Package: 2-Representing the population*: SERISS (Synergies for Europe's Research Infrastructures in the Social Sciences).

Schanze, J.-L., Levinson, M. a., Alcock, T., & von der Heyde, L. (2017). *Report on sampling practices for the institutionalized population in social surveys* (Deliverable Number: 2.16).

Scherpenzeel, A., Maineri, A. M., Bristle, J., Pflüger, S.-M., Mindarova, I., Butt, S., Luijkx, R. (2017). Report on the use of sampling frames in European studies. In *Work Package: 2-Representing the population*: SERISS (Synergies for Europe's Research Infrastructures in the Social Sciences).

Schols, M., & Cremers, M. (2015). *Ouderen in Instellingen 2015*. Heerlen: CBS Netherlands.

She, P., & Stapleton, D. C. (2006). A Review of Disability Data for the Institutional Population. Cornell University Institute for Policy Research.

Thorgrimsen, L., Selwood, A., Spector, A., Royan, L., de Madariaga Lopez, M., Woods, R. T., & Orrell, M. (2003). Whose Quality of Life Is It Anyway?: The Validity and Reliability of the Quality of Life-Alzheimer's Disease (QoL-AD) Scale. *Alzheimer Disease & Associated Disorders*, 17(4), 201-208.

Toot, S., Swinson, T., Devine, M., Challis, D., & Orrell, M. (2017). Causes of Nursing Home Placement for Older People with Dementia: A Systematic Review and Meta-Analysis. *International Psychogeriatrics, 29*(2), 195–208.

Tourangeau, R., Edwards, B., Johnson, T. P., Wolter, K. M., & Bates, N. (Eds.). (2014). *Hard-to-Survey Populations*. Cambridge: Cambridge University Press.

UNECE. (2011). *Using Administrative and Secondary Sources for Official Statistics: a Handbook of Principles and Practices*. New York and Geneva.

UNECE. (2015a). *Conference of European Statisticians' Recommendations for the 2020 Censuses of Population and housing*. New York and Geneva.

UNECE. (2015b). *Dignity and non-discrimination for persons with dementia*. New York and Geneva.

UNECE. (2016). *Recommendations on Ageing-related Statistics*. New York and Geneva.

UNECE. (2018). *Guidelines on the use of registers and administrative data for population and housing censuses*. New York and Geneva.

Verbeek-Oudijk, D., & van Campen, C. (2017). *Summary: Older persons in nursing and care homes*. The Hague, Netherlands.

Willis, G. B., Smith, T. W., Shariff-Marco, S., & English, N. (2014). Overview of the Special Issue on Surveying the Hard-to-Reach. *Journal of Official Statistics, 30*(2), 171-176.

Appendix I:
Definitions according to the CES Census Recommendations

The CES 2020 Census Recommendations suggest that place of usual residence is determined and that this is then used to determine whether a person is part of a private household or living in an institution. A number of detailed definitions are reproduced below for the sake of easy reference. All page numbers refer to UNECE (2015).

a) **Usual residence** is defined in paragraphs 392-393 (p. 78).

"The '*place of usual residence*' is the geographic place where the enumerated person usually spends their daily rest, assessed over a defined period of time including the census reference time.

The population base to be used for international comparisons purposes is the 'usually resident population'. The '*usually resident population*' of a country is composed of those persons who have their place of usual residence in the country at the census reference time and have lived, or intend to live, there for a continuous period of time of at least 12 months.

A 'continuous period of time' means that absences (from the country of usual residence) whose durations are shorter than 12 months do not affect the country of usual residence.

The same criteria apply for any relevant territorial division (being the place of usual residence) within the country."

b) **Usual residence as it concerns people in institutions** is defined in paragraph 404 (p. 80)

"For persons who, at the census reference time, have spent, or are likely to spend, twelve months or more as inmates in a communal establishment or institution, the institution should be taken as the place of usual residence. Examples of inmates of institutions include patients in hospitals or hospices, old persons in nursing homes or convalescent homes, prisoners and those in juvenile detention centres."

c) **Private household**, **housekeeping concept** and **household-dwelling concept** are defined in paragraphs 768-770 (pp. 162-163).

"A *private household* is either:

(a) *A one-person household* that is a person who lives alone in a separate housing unit or who occupies, as a lodger, a separate room (or rooms) of a housing unit but does not join with any of the other occupants of the housing unit to form part of a multi-person household as defined below; or

(b) *A multi-person household* that is a group of two or more persons who combine to occupy the whole or part of a housing unit and to provide themselves with food and possibly other essentials for living. Members of the group may pool their incomes to a greater or lesser extent.

This concept of a private household is known as the *housekeeping concept* and does not assume that the number of private households is necessarily equal to the number of housing units. Within this concept, it is useful to distinguish between 'boarders' and 'lodgers' where relevant. *Boarders* take meals with the household and generally are allowed to use the household facilities. They are thus to be considered as members of the household as defined above. Lodgers on the other hand rent part of the housing unit for their exclusive use. They will belong to a different household even though they may share the same housing unit.

Some countries may be unable to collect data on households based on this housekeeping concept, for example where their census is register-based. Many such countries use a different concept – *the household-dwelling concept* – which considers all persons living in the same housing unit to be members of the same household, such that there is one household per occupied housing unit and the number of occupied housing units and the number of households occupying them are equal."

d)   **Institutional household** is defined and described in paragraphs 772-778 (pp. 163-164).

"An *institutional household* comprises persons whose need for shelter and subsistence are being provided by an institution. An institution is understood to be a legal body for the purpose of long-term inhabitation and provision of services to a group of persons. Institutions usually have common facilities shared by the occupants (baths, lounges, eating facilities, dormitories and so forth)…

Members of an institutional household are those that have their place of usual residence… at the institution. People who would otherwise be members of private households but who are living in an institution at the census reference time are considered to members of the institutional household if their actual or expected length of residence there exceeds one year.

Countries should endeavour to distinguish between the institutional population and persons who are part of private households located within the collective living quarters of the institution … For example, employees of the institution who live alone or with their family at the institution (or in housing units located outside the collective living quarters of the institution) should be treated as members of private households.

Prior to the census enumeration, countries should consider carrying out a living quarters validation exercise. A brief survey questionnaire can identify, among other things, the nature and functions of collective living quarters, the potential presence of private households, and whether services are offered to persons considered homeless … Also, one main advantage of using such a survey is that it allows for the identification of multipurpose institutional households. Thus, parts of an institutional household may need to be classified differently.

There may be differences between countries in the ways in which the boundary between the population living in private households and the population living in institutional or other households is drawn. The definitions used should therefore be explained clearly in the census reports and metadata, and attention should be drawn to any differences between national practice and these recommendations.

There is an increasing amount of accommodation which is being specifically provided for the elderly, the disabled, and other special groups where the distinction between an institutional and a private household is not clear, in that meals can be taken communally or by each household with its own cooking facilities. It is suggested that if at least half the population living in such accommodation possess their own cooking facilities, then all persons should be treated as living in private households and, if possible, identified separately in the output."

e)   A **classification of institutional households** is given in paragraph 773 (p. 163).

The great majority of institutional households fall under the following categories:
(1.0)   Residences for students
(2.0)   Hospitals, convalescent homes, establishments for the disabled, psychiatric institutions, old people's homes and nursing homes
(3.0)   Assisted living facilities and welfare institutions including those for the homeless
(4.0)   Military barracks
(5.0)   Correctional and penal institutions
(6.0)   Religious institutions
(7.0)   Worker dormitories.

f)   **Institution** is defined in paragraph 887b (p. 189).

"An '*institution*' is a separate and independent set of premises comprising all or part of a permanent building or set of buildings which by the way it has been built, rebuilt or converted is designed for habitation by a large group of persons who are subject to a common authority or regime or bound by a common objective or personal interest, and which is used as the usual residence of at least one person at the census reference time. Such collective living quarters usually have certain shared common facilities such as cooking and toilet facilities, baths, lounge rooms or dormitories. This category includes premises such as nurses' hostels, student residences, hospitals, sanatoria and convalescent homes, welfare institutions, monasteries, convents, military and police barracks, prisons and reformatories."

Appendix II:
Survey sent to CES countries in April 2018

Introduction and contact details

This questionnaire is designed to gather inputs for the CES Task Force on Measuring Older Populations in Institutions. As a starting point for the Task Force, we wish to learn about the current practices in CES countries for collecting data on institutional populations of older people; the challenges faced; and methods for tackling these challenges.

The questionnaire contains 21 questions and may take about 15 minutes to complete. It should be completed by someone with good knowledge of population characteristics and data sources on older age groups. Completion of the questionnaire may necessitate consultation among several colleagues. You may save your responses and return to them later.

None of the questions are mandatory except for your contact details. If you have any questions or encounter any problems, email [secretariat email address].

For more information about the work of the Task Force, see our terms of reference.

* 1.   Please enter the contact information of the person completing this questionnaire
    •   Country:
    •   Name of organization and department (or division, unit etc.):
    •   Name of contact person:
    •   Email address:

1.   Definitions

These questions explore the definitions and classifications of institutions and private households used in your country.

The CES 2020 Census Recommendations suggest that place of usual residence is determined and that this is then used to determine whether a person in part of a private household or living in an institution.

You may wish to refer to the following definitions in preparing your responses to these questions.

Usual residence is defined in paragraphs 392-393 (p. 78).

Usual residence as it concerns people in institutions is defined in paragraph 404 (p. 80) Private household, housekeeping concept and household-dwelling concept are defined in paragraphs 768-770 (pp. 162-163).

Institutional household is defined and described in paragraphs 772-778 (pp. 163-164). A classification of institutional households is given in paragraph 773 (p. 163). Institution is defined in paragraph 887b (p. 189).

2. How does the Census in your country distinguish between households and institutions?
   - using the housekeeping concept as described in the Census Recommendations?
   - using another definition of the housekeeping concept (please describe)?
   - using some other method (please describe)?

3. Does the Census in your country use the definitions given in the CES Census Recommendations?

   Exactly the same   Similar   Different
   - Definition of private household
   - Definition of usual residence as it concerns people in institutions (cf. Census Recs. para. 404)
   - Definition of institution
   - Classification of types of institutions.

Please give information about definitions that are not the same as the Census Recommendations. How do they differ?

4. Are the same concepts, definitions and classifications used across surveys and administrative data collections of your NSI, other than the Census? If they differ, how and why?

2.   Demographic backdrop and policy context

These questions look at the relevance and importance of institutional populations in statistics, especially ageing-related statistics, and ask whether/why we need information on this specific group.

In the rest of this survey, we are interested in the population of older persons whose usual place of residence is in an institution for retired or elderly persons (e.g. retirement homes, nursing homes).

5. If such information is available, what proportion of people over 65 (or another cutoff used in your country to define 'older people') live in older people's institutions?
   - Proportion
   - Age cutoff if different from 65
   - Types of older people's institutions included in this estimate
   - Source of this estimate

6. According to currently available evidence, which of the following statements are true in your country?

   **Definitely true   Probably true   Probably false   Definitely false
   Don't know/Not enough evidence to say**
   - The proportion of older people living in institutions is **growing** [Comments]

- The old-age population in institutions is, on average, **older** than the old- age population in private households [Comments]

- The old-age population in institutions is, on average, **less healthy** than the old-age population in private households [Comments]

- The old-age population in institutions has a **different sex distribution** to the old-age population in private households [Comments]

- The old-age population in institutions is, on average, **less economically well off** than the old-age population in private households [Comments]

3.   Data collection

These questions aim to find out whether and how your country collects data on older persons living in institutions.

7.   Are older people in institutions included within any of the existing surveys (other than the Census) conducted by your national statistical office, and/or are they surveyed separately?
   - Included in one or more survey(s)
   - Separate survey(s)
   - Neither
   - Other (please specify)

8.   Please name the surveys which include the population of older people in institutions
   - Survey(s) in which older people in institutions are sampled as part of a broader population of interest:
   - Survey(s) in which older people in institutions are the population of interest:

For questions 9-12, please consider only the largest or most important of the surveys you mentioned in question 7, if any.

9.   Which survey is the largest or most important of those you named in question 7? I(f you do not have sufficient knowledge to answer about the largest/most important, please choose one for which you are able to give answers)

10.   How are the institutional populations identified and sampled?

11.   Under what circumstances, if any, do you allow the use of proxies (answers provided by one person about another person) ? Why?

12.   Are survey questionnaires and methods adapted to the specific needs of institutional residents? If so, how?

13. Does your country use administrative sources to provide information about older people living in institutions (including register-based Census data)? If so, please tell us what sources are used and what kinds of information are produced.

14. If administrative sources are used, do they give rise to any coverage issues specific to older people in institutions? Please explain (for example, health service administrative files may miss those who receive medical care directly within an institution).

4. Other information

These questions allow you to share with the Task Force other information or materials that may be useful in their work, and to make any other suggestions or observations you wish.

15. What challenges has your country faced in the collection of data from older persons living in institutions?

16. Has your office, or any other institution that you are aware of, conducted any surveys, experiments or research, to assess the differences between statistics produced with and without the inclusion of older persons living in institutions? If so, please describe and give links to any online reports.

17. Specifically with regard to ageing-related statistics, do you think that your own national statistical office should attempt to (better) incorporate older people living in institutions?
    - Yes
    - No
    - Don't know

18. If yes, what would be the ideal way of doing this, in your opinion?

19. Would you consider any of your country's practices in this area to be examples of good practice that other countries can learn from? If so, why?

Thank you for contributing to the work of this Task Force

20. If you have any further information, comments or suggestions which may help the Task Force in its work, please give details in the box. You can also email the Secretariat at [secretariat email address].

* 21. Would you be willing for the Task Force contact you to request more information about your answers to this survey?
    - Yes
    - No.

Appendix III:
Additional analyses for Chapter 3

Additional analyses with 2011 European census data

Figure X   Percentage married among persons aged 50 and over in medium-share countries
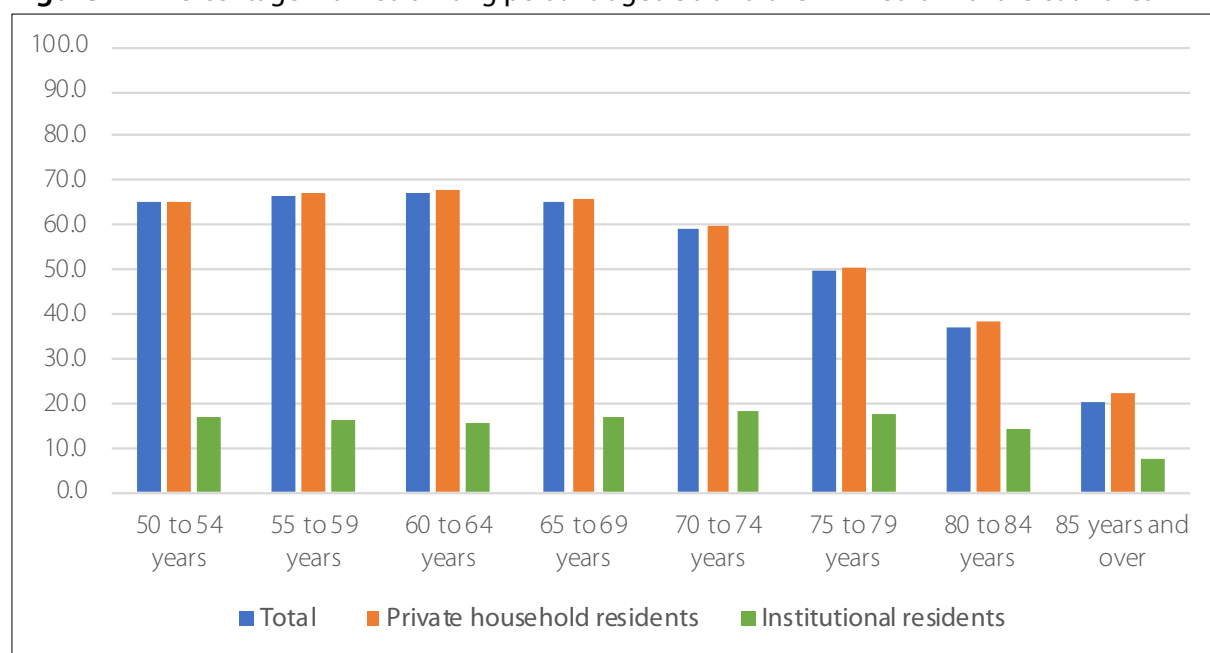
Figure XI   Percentage with lower education levels among persons aged 50 and over in small-share countries
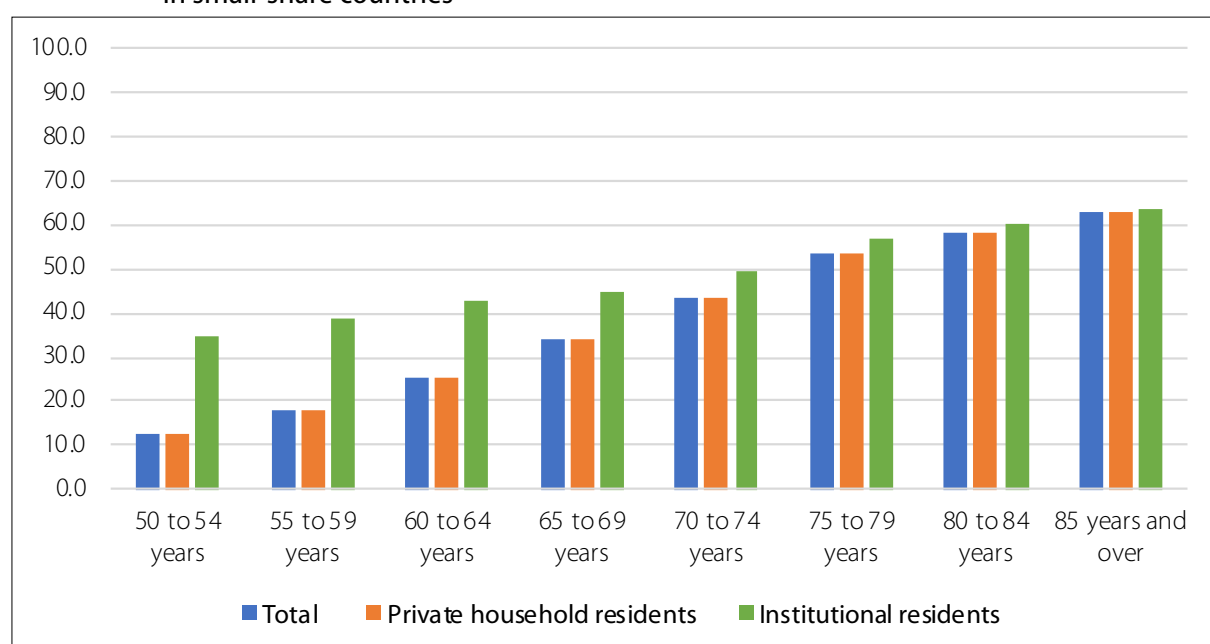
Table 7. Proportions married in three groups of countries with different shares of institutional residents (Eurostat 2016)

	Age cohort	Proportion married (per cent)		
		Total	Private hh	Institutional residents
Group 1	50 to 54 years	74.7	74.9	17.7
	55 to 59 years	74.4	74.6	15.0
	60 to 64 years	72.9	73.2	14.3
	65 to 69 years	69.2	69.5	14.2
	70 to 74 years	62.6	62.9	13.6
	75 to 79 years	52.7	53.2	12.8
	80 to 84 years	39.9	40.5	11.0
	85 years and over	23.6	24.5	7.8
Group 2	50 to 54 years	65.2	65.5	17.1
	55 to 59 years	66.9	67.2	16.5
	60 to 64 years	67.5	67.9	15.7
	65 to 69 years	65.2	65.6	17.3
	70 to 74 years	59.3	59.8	18.4
	75 to 79 years	49.8	50.6	18.0
	80 to 84 years	37.2	38.4	14.4
	85 years and over	20.4	22.2	7.5
Group 3	50 to 54 years	70.4	70.8	14.0
	55 to 59 years	72.5	72.9	14.7
	60 to 64 years	73.3	73.8	15.8
	65 to 69 years	71.3	71.9	17.0
	70 to 74 years	65.8	66.7	19.2
	75 to 79 years	56.0	57.4	19.9
	80 to 84 years	42.8	45.2	17.6
	85 years and over	23.9	28.1	9.7

See paragraph 103 in Chapter 3 for details of country groupings.

Additional tables from the fifth wave of SHARE

	Proportion of persons who reached low and tertiary education levels (in per cent)								
	Age cohort (years)	Small proportion (Group 1)			Medium proportion (Group 2)			Large proportion (Group 3)		
		Total	PHR	IR	Total	PHR	IR	Total	PHR	IR
Lower education	50 to 54	12.6	12.5	35.0	0.9	0.8	13.6	16.9	16.8	34.1
	55 to 59	17.9	17.8	38.7	1.0	0.9	16.6	25.7	25.6	40.3
	60 to 64	25.3	25.3	42.7	1.2	1.1	14.2	30.4	30.3	40.8
	65 to 69	33.8	33.8	45.1	2.0	1.9	13.1	35.9	35.9	41.4
	70 to 74	43.4	43.4	49.8	3.8	3.7	12.5	41.6	41.6	44.6
	75 to 79	53.6	53.5	56.9	7.6	7.5	13.5	46.4	46.3	48.7
	80 to 84	58.3	58.3	60.4	9.6	9.5	12.4	49.0	48.9	49.3
	85+	62.8	62.7	63.3	12.0	11.8	13.7	48.7	48.8	48.7
Tertiary education	50 to 54	28.0	28.0	12.0	25.9	26.0	10.0	20.6	20.6	12.6
	55 to 59	25.1	25.2	11.3	23.8	23.8	11.0	18.7	18.7	11.4
	60 to 64	20.4	20.5	10.7	21.8	21.9	10.7	17.0	17.0	11.9
	65 to 69	16.3	16.4	11.1	20.6	20.7	10.5	13.9	13.9	14.8
	70 to 74	13.5	13.5	9.6	16.9	17.0	9.4	10.7	10.6	12.4
	75 to 79	10.2	10.2	7.2	13.8	13.9	8.8	8.2	8.2	9.7
	80 to 84	8.8	8.8	6.3	12.1	12.3	8.3	7.5	7.4	8.6
	85+	7.0	7.1	5.8	9.6	9.8	7.4	6.8	6.8	7.5

Additional tables from the fifth wave of SHARE (continued)

	Small proportion (ES; IT; SI)			Medium proportion (AT; CZ; DE)			Large proportion (BE; DK; NL)		
	Total	Private hh	Institutions	Total	Private hh	Institutions	Total	Private hh	Institutions
Age									
50-59	25.53	25.68	3.09	26.97	27.28	5.38	31.22	32.09	3.77
60-69	32.53	32.72	5.15	36.26	36.63	11.21	35.19	36.00	9.91
70-79	25.90	25.90	25.77	26.12	26.10	26.91	21.27	21.31	20.05
80-89	14.04	13.84	43.30	9.55	9.06	43.05	10.62	9.47	46.70
90+	2.0	1.86	22.68	1.11	0.92	13.45	1.70	1.13	19.58
N	14,188	14,091	97	15,470	15,247	223	13,738	13,314	424
Married									
No	22.61	22.29	71.13	32.55	31.89	78.67	28.62	27.39	67.92
Yes	77.39	77.71	28.87	67.45	68.11	21.33	71.38	72.61	32.08
N	14,416	14,319	97	15,777	15,552	225	13,954	13,530	424
Widowed									
No	86.38	86.58	55.67	84.96	85.41	53.78	87.84	88.97	51.89
Yes	13.62	13.42	44.33	15.04	14.59	46.22	12.16	11.03	48.11
N	14,416	14,319	97	15,777	15,552	225	13,954	13,530	424
Born abroad									
No	94.71	94.68	98.92	90.98	91.00	89.73	92.82	92.75	95.00
Yes	5.29	5.32	1.08	9.02	9.00	10.27	7.18	7.25	5.00
N	14,213	14,120	93	15,639	15,415	224	13,808	13,388	420
Income deciles									
1	10.01	9.96	17.53	10.02	9.77	27.56	10	9.18	36.32
2	10.12	10.05	20.62	10	9.73	28.44	10.01	9.69	20.28
3	10.39	10.32	20.62	9.99	9.86	18.67	9.99	9.89	13.21
4	9.52	9.49	14.43	10.01	9.99	11.11	10.02	10	10.61
5	9.95	9.96	9.28	10.03	10.13	3.11	9.99	10.16	4.72
6	10.01	10.05	4.12	10.07	10.17	2.67	10.01	10.16	5.42
7	10.02	10.06	3.09	9.91	9.99	4.00	10.02	10.24	3.07
8	10.02	10.06	5.15	10	10.11	2.22	10.03	10.24	3.07
9	9.96	9.99	5.15	10	10.14	0.00	9.95	10.24	0.71
10	9.99	10.06	0.00	9.99	10.1	2.22	9.98	10.21	2.59
N	14,416	14,319	97	15,777	15,552	225	13,954	13 530	424

Additional tables from the fifth wave of SHARE (continued)

	Small proportion (ES; IT; SI)			Medium proportion (AT; CZ; DE)			Large proportion (BE; DK; NL)		
	Total	Private hh	Institutions	Total	Private hh	Institutions	Total	Private hh	Institutions
Long-term illness									
No	54.70	54.95	17.71	46.32	46.67	21.97	50.91	51.64	27.62
Yes	45.30	45.05	82.29	53.68	53.33	78.03	49.09	48.36	72.38
N	14,390	14,294	96	15,727	15,504	223	13,926	13,506	419
No. ADL limitations									
0	87.93	88.34	24.47	88.65	89.24	47.98	88.93	90.17	48.69
1	4.91	4.85	13.83	5.53	5.45	11.66	6.05	5.86	12.17
2	2.02	2.00	5.32	2.40	2.25	12.56	2.23	1.97	10.74
3	1.25	1.23	4.26	1.30	1.21	7.62	1.12	0.92	7.64
4	0.99	0.91	13.83	0.83	0.77	4.93	0.58	0.41	5.97
5	0.95	0.87	11.70	0.58	0.48	7.17	0.5	0.3	6.92
6	1.95	1.79	26.60	0.71	0.61	8.07	0.59	0.36	7.88
N	14,388	14,294	94	15,580	15,723	223	13,924	13,505	419
Self-perceived health									
Poor	13.70	13.44	53.13	10.91	10.66	28.25	5.44	5.00	19.52
Fair	27.97	28.04	17.71	28.51	28.44	33.18	21.00	20.32	42.86
Good	38.78	38.90	20.83	37.83	37.92	31.84	37.68	38.00	27.62
Very Good	14.32	14.37	7.29	16.95	17.13	4.48	22.39	22.92	5.48
Excellent	5.23	5.25	1.04	5.80	5.85	2.24	13.49	13.77	4.52
N	14,390	14,294	96	15,726	15,503	223	13,924	13,504	420

Recommendations for Measuring Older Populations in Institutions

Statistics on social and demographic topics are usually produced from surveys of private households. People living in institutions are often excluded because it can be complicated and expensive to identify and sample the institutions and their residents.

But populations across the UNECE region and throughout the world are growing older, and for many countries this means that the population of older people living in institutions is increasing. Even in those countries where this group is not growing, the small population of older people in institutions may be very distinctive, with characteristics such as health status and economic circumstances that vary systematically from those of the population of older people living in private households.

In ageing populations, therefore, it is increasingly necessary to consider the bias introduced into statistics—especially those specifically aiming to shed light on the situation of older people—by excluding people living in institutions. While such bias is recognized, views on what to do about it vary widely.

This is not only a matter of biasing general statistics, but also a question of shining the spotlight on a small and underserved group. With the 2030 Agenda for Sustainable Development calling on decision-makers to reach the furthest behind first, statistics on this often-overlooked population, many of whom are among the most vulnerable members of our societies, are necessary in their own right, to help governments and service-providers better understand the complex needs of these people.

This publication guides national statistical offices in deciding whether, when and how to include institutional populations of older people on the production of ageing-related statistics. It examines definitions and classifications; proposes a methodology for quantifying bias; and considers the particular challenges for survey design and data collection posed by institutional populations of older people, including challenges in using administrative data sources and ethical considerations particular to this group.