



Economic Commission for Europe**Conference of European Statisticians****Sixty-seventh plenary session**

Paris, 26–28 June 2019

Item 4 (b) of the provisional agenda

Measuring older populations in institutions**Recommendations for Measuring Older Populations in Institutions****Note by the Task Force on measuring older populations in institutions***Summary*

The document presents a short version of the *Recommendations for Measuring Older Populations in Institutions*. The Recommendations were prepared by a Task Force composed of the United Kingdom (Chair), Armenia, Austria, Canada, Colombia, Hungary, Israel, Italy, Latvia, Lithuania, Mexico, Philippines, Russian Federation, Turkey, Eurostat, United Nations Economic Commission for Europe, GESIS – Leibniz Institute for the Social Sciences (Germany) and the University of Oslo (Norway).

The current short version of the Recommendations is prepared for translation purposes. From all substantive chapters, it includes the sections of introduction, recommendations and further work.

The full text of the Recommendations has been sent to all members of the Conference of European Statisticians (CES) for electronic consultation. It is available at <http://www.unece.org/index.php?id=48575>. Subject to a positive outcome of the consultation, the CES plenary session will be invited to endorse the Recommendations.



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I. Introduction

1. This document is a product of a Task Force established by the Bureau of the Conference of European Statisticians (CES) 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.

A. Importance and policy relevance

2. As populations across the region of United Nations Economic Commission for Europe (UNECE) 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.

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 disadvantage and especially those which otherwise remain hidden. For all these reasons, a study of the needs and possibilities for producing statistics on older populations in institutions is timely.

B. Background and work of the Task Force

6. In view of the evident need for guidance on the subject, in February 2017 the CES Bureau 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. 12 countries¹ 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, 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.

C. 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 II: 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 forthcoming international Census Recommendations.

Chapter III: 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 IV: 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 V: 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

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

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 VI: 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 VII: Conclusions²

15. This chapter gives an overview of the main recommendations and suggestions for future work made throughout the chapters and offers some overarching conclusions from the Task Force.

II. Definitions of older populations in institutions

A. 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 considered 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

² In this shortened version, chapter 7 only includes the conclusions; the recommendations and suggestions for future work are presented under the respective substantive chapters.

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 work, however, uses the terms “institution” and “communal establishment” interchangeably.

seniors' residences which grant more autonomy to residents than nursing homes, for example. 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 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 national statistical offices (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.

B. Existing standards and guidance

[text available in the full version]

C. Current approaches

[text available in the full version]

D. Recommendations

21. Classify institutions by the characteristics of the social and health care services provided, rather than by name of the institution. For example, the kinds of services and residents of "nursing homes" may vary greatly across countries, despite the institutions being similarly named.

E. Further work required in this area

22. Future work could aim to develop a 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 System of Health Accounts and

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.

Organization for Economic Cooperation and Development and would enhance the harmonization of internationally collected data on institutions.

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

A. Introduction

23. A central premise of the work of the present 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.

24. 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.

25. 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). We can expect distinctiveness 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.

26. General conclusions about the extent of bias are difficult to make, since both factors, relative size and statistical distinctiveness, are necessary conditions for bias. Figure 1 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.

Figure 1

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

| <i>Proportion of institutional residents (in target population)</i> | <i>Statistical distinctiveness of institutional residents (in a specific variable)</i> | | |
|---|--|---------------|-------------|
| | <i>Low</i> | <i>Medium</i> | <i>High</i> |
| Small | | | |
| Medium | | | |
| Large | | | |

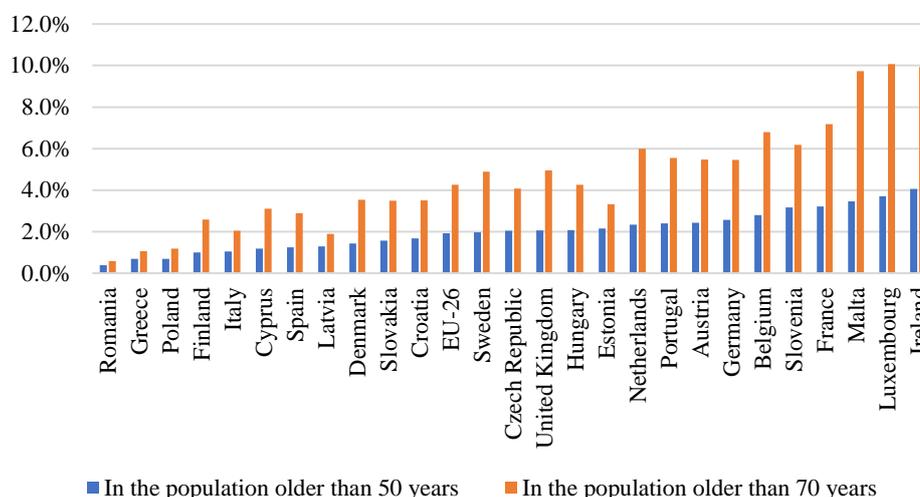
Lighter shading indicates low bias; darker shading indicates high bias.

27. 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 European Union population older than 50 years lived in institutions in the 2011 round of European census (see figure 2). 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 European Union population aged older than 70 years lived in institutions, with a greater variance across

countries (figure 2).⁵ 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 2

Proportion of the population living in collective living quarters according to the 2011 census (Eurostat 2018)



28. 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 house 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; Luppá et al. 2010; McCann, Grundy, and O'Reilly 2012; Noël-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 came to the opposite conclusion (Einio et al. 2012; Gaugler et al. 2007; Luppá et al. 2010; Martikainen et al. 2009).⁶ Also, the results 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.

29. 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; Luppá et al. 2010; Noël-Miller 2010; Rodríguez-Sánchez et al. 2017; Toot et al. 2017), as well as limitations in activities of daily living, disability or a stronger physical dependency (Cambois et al. 2016; Castora-Binkley, Meng, and Hyer 2014; Gaugler et al. 2007; Laferrère, Heede, and Bosch 2012; Noël-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

⁵ Among those Europeans older than 85 years 12.6 per cent were institutionalized in 2011 (Eurostat 2015).

⁶ Einio and colleagues found different sex effects for Belgium and Finland (2012).

institutionalization (Castora-Binkley, Meng, and Hyer 2014; Einio et al. 2012; Luck et al. 2008; McCann, Grundy, and O'Reilly 2012; Nöel-Miller 2010).

B. Current approaches

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C. Assessment of potential effects of bias

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D. Recommendations

30. 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.⁷

31. 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.

32. 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.

E. Further work required in this area

33. 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.

⁷ Most European Union (EU) 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, USA and Israel that included institutional residents (Schanze 2017).

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

A. Introduction

34. 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.

35. 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 include cognitive or health limitations, especially dementia; the need or acceptability of gathering data via proxy respondents; and the potential irrelevance of some typical household survey questions to a non-private-household setting.

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

37. 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.

B. Existing standards and guidance

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C. Current approaches

[text available in the full version]

D. Recommendations

38. 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.

39. 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.

40. 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).

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

42. 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.

E. Further work required in this area

43. 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.

44. Relatedly, it is important that research and experience about 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 it risks missing out on potentially important sharing of knowledge.

V. Methods for measuring older populations in institutions using administrative data

A. Introduction

45. Measuring older populations in institutions can be difficult using conventional survey methods. Traditional household-based surveys do not usually capture communal establishments, for a variety of reasons. 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).

46. 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 chapters 5 and 6, respectively), although it may also pose new challenges in both respects.

47. 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.

48. 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.

B. Existing standards and guidance

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C. Current approaches

[text available in the full version]

D. Recommendations

49. 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.

E. Further work required in this area

50. 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.

VI. Ethical considerations for collecting information on older populations in institutions

A. Introduction

51. 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.

52. 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.”

53. The focus of this chapter is on the ethical issues around collecting the data itself, but the above paragraph is a reminder that there are ethical considerations in the exclusion of groups from data collection, meaning that measurement for issues such as equality may be affected if groups are excluded. Furthermore, there are also several societal trends which may affect how older people are perceived in society which may also result in a reduction in their decisional capability, due to their opinions not being respected. This raises multiple ethical issues.

54. There are ethical considerations in any data collection and the purpose of this document is not to cover all ethical issues, rather it is to point out the particular issues with collecting data from older people in institutions. The following is also quite generic, legal standards and considerations in individual countries may help guide or 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.

55. However, there is some overlap between these areas. An overarching consideration is to consider older people in institutions as vulnerable adults. Household data collections may already have procedures to handle issues around vulnerable adults⁸. The chapter then considers new technologies and safeguarding.

1. Access to respondents

56. Older people receiving care also live in private households. Access to them for the purposes of data collection is likely to either be direct, if they live on their own, or via a family member or carer. While there are ethical considerations in the household domain to accessing respondents, the 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 you need to collect the information. The Adult Social Care Survey in England,⁹ for example, is clear about the level of mental incapacity that would preclude someone from taking part in the survey and ensures this is communicated to managers.

57. 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 will not always be the case.

2. Ability to complete/proxy completion

58. 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 elderly people in institutions are physically and/or mentally impaired it is not so easy to interview them (measurement errors will occur). People with a decrease in 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).

59. Specialized training should also be provided to interviewers enable direct interviews in different kinds of impairments. Ethical considerations may mean it is better to interview them 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 child, spouse/partner, caregiver, manager of the care-institution) should

⁸ Two examples are provided here – one from government around a survey of safeguarding around 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>.

⁹ 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.

be restricted. Where it is used it should be noted that there is evidence of differences in answers between direct and proxy question.

60. 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). It should also be considered as to whether an impairment might be temporary, for example, related to variations in health (for example loss of speech after a stroke may be temporary). Even the time of day might affect impairment. For example, there is evidence that dementia is worse as the sun goes down (“Sundowning”: see Alzheimer’s Society 2018).

3. Privacy

61. 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.¹⁰

62. 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.

63. If a respondent is interviewed in an institution, it may be more difficult to find a private area, or it may be that a care-taker 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 exceptionally 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.

64. 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.

4. Informed consent

65. A key aspect of modern data use is informed consent.¹¹ There are particular ethical issues around obtaining consent where, through 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 as to the future as well as the immediate use of the data. There should also be consideration around consent to link any data collected to other data, for example, administrative records or records from technology.

5. Use of new technologies

66. Through information and communication technologies (ICTs) and ambient assisted technologies (AAT) we might obtain a lot of additional information about people living in institutions: for example, as by-product when using ICTs to collect data from multiple sensors for monitoring the safety of the residents in institutions, or via ambulatory assessment. In

¹⁰ 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”.

¹¹ An example document on obtaining informed consent can be found at <https://www.gov.uk/service-manual/user-research/getting-users-consent-for-research>.

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.

67. 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. As far as the working group is aware, there are no internationally accepted standards or guidance documents on ethics in research, only at national or organisational level (e.g. national statistical law).

6. Safeguarding

68. 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 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 at a risk of harm, there is an imperative that such neglect or harm is reported appropriately.

B. Concluding remarks and recommendations

69. The practical aspects of conducting research on institutional population can present a unique set of challenges. Researchers need to be aware of the legal constraints regulating issues around mental capacity and equality of people in institutions.

70. 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 criticise health care professionals or feeling coerced to participate in research as a captive audience. In general, however, it has been shown that older people regard their participation in research as a valuable contribution to the future lives of others and that such participation can have substantial therapeutic benefits.

71. An assessment of ethical considerations in nursing home studies (Karlawish 2015) 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.

72. 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.

VII. Conclusions

73. The work of this Task Force and the present document 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. The recommendation is that definitions and classifications used should be based on the ways in which institutions are organized and the services they provide, and not only on the names of the institutions or the length of stay.

74. 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.

75. This work has relied on 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 highlighted some particular considerations in each of these areas when the older people in institutions are the population of interest. The 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.

76. 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, 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.

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