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**Promotion and protection of all human rights, civil,  
political, economic, social and cultural rights,  
including the right to development****Human rights of older persons: the data gap****Report of the Independent Expert on the enjoyment of all human rights  
by older persons***Summary*

The present report is submitted to the Human Rights Council pursuant to resolution 42/12 on the human rights of older persons.

In the report, the Independent Expert examines the significance of data for the realization of the human rights of older persons, as a prerequisite for evidence-based and informed decision-making and normative action. In particular, the Independent Expert analyses the current data gap on older persons, its causes, and its impacts on the enjoyment of all human rights by older persons, as well as the prospects and risks associated with the data revolution in this context. The report also contains an overview of the activities of the Independent Expert and her predecessor during the reporting period.



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## I. Introduction

1. The present report is submitted to the Human Rights Council pursuant to resolution 42/12 on the human rights of older persons. In the report, the Independent Expert on the enjoyment of all human rights by older persons examines the significance of data for the realization of the human rights of older persons, as a prerequisite for evidence-based and informed decision-making and normative action. In particular, the Independent Expert analyses the current data gap on older persons, its causes, and its impact on the enjoyment of all human rights by older persons, as well as the prospects and risks associated with the data revolution in this context.<sup>1</sup> The report also contains an overview of the activities of the Independent Expert and her predecessor during the reporting period.

2. The Independent Expert, Claudia Mahler, assumed her mandate on 1 May 2020. She expresses her deep gratitude to her predecessor, Rosa Kornfeld-Matte, for the path-breaking work that she undertook and for her contribution and substantive analysis towards the present report.

## II. Activities of the Independent Experts

3. During the reporting period, the former Independent Expert, Rosa Kornfeld-Matte, visited China from 25 November to 3 December 2019 (see A/HRC/45/14/Add.1) and New Zealand from 2 to 12 March 2020 (see A/HRC/45/14/Add.2). Ms. Kornfeld-Matte expressed her appreciation to the Governments of those countries for their cooperation before, during and after her visits, and for the fruitful and constructive dialogue.

4. On the margins of the forty-second session of the Human Rights Council, on 13 September 2019, the Independent Expert convened a participatory panel discussion with representatives from States, international organizations, United Nations agencies and civil society, entitled “Context gaps and the human rights imperative for older persons in and beyond humanitarian emergencies”. The event was organized together with representatives of Argentina, Chile, the United Nations High Commissioner for Refugees, and HelpAge, and with the support of the Group of Friends on the Human Rights of Older Persons.<sup>2</sup> It enabled an in-depth dialogue on the findings of the Independent Expert’s report on the human rights of older persons in emergency situations (A/HRC/42/43), during which the Independent Expert stressed the imperative need for a human rights-based approach to ageing. She noted that this entailed active measures against ageism, and reconceptualizing the way in which societies viewed older persons. It was essential to portray older persons as active contributors to society rather than as passive receivers of care and assistance or an impending burden on welfare systems. Participants also exchanged views on the achievements made since the mandate was established in 2013, as well as on common challenges. In this context, the Independent Expert reaffirmed the importance of preserving the cross-regional commitment towards overcoming remaining divergences of view on how to strengthen the protection of the human rights of older persons.

5. On 24 September 2019, the Independent Expert, together with the Office of the United Nations High Commissioner for Refugees and HelpAge, held a panel discussion on

<sup>1</sup> See [www.undatarevolution.org/data-revolution/#nav-mobile](http://www.undatarevolution.org/data-revolution/#nav-mobile). The need for a “data revolution” was first expressed by the High-level Panel of Eminent Persons on the Post-2015 Development Agenda, appointed by the then Secretary-General of the United Nations, Ban Ki-moon, to advise on the global development agenda after the Millennium Development Goals. The report of the high-level panel was quite brief, leaving quite a lot of room for interpretation: “Better data and statistics will help governments track progress and make sure their decisions are evidence-based; they can also strengthen accountability. This is not just about governments. International agencies, civil society organizations and the private sector should be involved.” Moreover, “a true data revolution would draw on existing and new sources of data to fully integrate statistics into decision-making, promote open access to, and use of, data, and ensure increased support for statistical systems.” *A New Global Partnership: Eradicate Poverty and Transform Economies through Sustainable Development: The Report of the High-level Panel of Eminent Persons on the Post-2015 Development Agenda*, p. 23 ff.

<sup>2</sup> Widely known informally as GoF-HROP.

older persons in situations of forced displacement. The Independent Expert's annual report on older persons in emergency situations (A/HRC/42/43), which highlighted specific obstacles to the enjoyment of human rights by older persons in these contexts, served as a basis for the discussions. The panellists agreed that in situations of forced displacement, whether conflict- or climate-induced, older persons faced a heightened risk of violence, exploitation and abuse, exacerbated by additional barriers in gaining access to humanitarian assistance and basic services. The discussants stressed that older refugees and displaced persons, in spite of being disproportionately affected, had a substantial capacity to contribute to responses and solution pathways, especially when their right to participation was being upheld.

6. Pursuant to General Assembly resolution 72/144, on 1 October 2019 the Independent Expert addressed and engaged in an interactive dialogue with the Assembly under the prescribed agenda item of "social development". She welcomed on this occasion the particular opportunity to address the Third Committee on the International Day of Older Persons, since older persons continued to remain invisible, both figuratively and in policymaking. Her presentation focused on older persons in emergency situations, an issue that she considers to be of crucial importance if existing protection gaps are to be addressed effectively. She shared her main findings and made recommendations on the issue aimed at assisting States and other stakeholders in designing and implementing appropriate and effective frameworks to ensure the promotion and protection of the rights of older persons.

7. In her statement marking the thirtieth International Day of Older Persons, on 1 October 2019, the Independent Expert called on everyone to stand up for older persons' rights. She stressed that older persons – unlike women, children, persons with disabilities and migrants or refugees – were not protected by a specific universal human rights instrument, and noted that the absence of a dedicated legal instrument for older persons may also explain the lack of attention to the specific challenges that older men and women faced in the global policy framework, including in the Sustainable Development Goals, which guided the actions of the United Nations on the ground. She emphasized that it was essential for the implementation of the Sustainable Development Goals to be grounded in the international human rights framework in order to ensure the inclusiveness and sustainability of the gains over time.

8. On 30 September and 1 October 2019, the Ministry of Labour and Social Affairs of Czechia convened an international conference on the human rights of older persons, and invited the mandate to participate in the panel discussion on violence, abuse, maltreatment and neglect. The conference brought together some 150 participants around two interactive panel discussions on implementation and regulatory shortcomings. The debate was informed by a compilation of previous reports and recommendations by the mandate.

9. From 5 to 7 November 2019, the mandate holder participated in a workshop entitled "Legal, ethical and social implications of ageing: towards an international legal framework to advance the human rights and health of older persons", the conceptualization of which the mandate had supported substantially. The workshop was organized by the Brocher Foundation in Geneva<sup>3</sup> and brought together an interdisciplinary group of scholars, as well as senior representatives from international organizations, including the World Health Organization (WHO), the Office of the United Nations High Commissioner for Human Rights (OHCHR) and the United Nations Research Institute for Social Development, as well as Geneva-based institutions such as the International Federation of the Red Cross and the NGO Committee on Ageing, to consider comprehensively the question of how to advance questions pertaining to health and human rights and harness synergies in a potential legal instrument on older persons. The Independent Expert's comprehensive report of 2016 (A/HRC/33/44) provided the foundation for a constructive and creative discussion on how to contribute to the implementation of these recommendations. The debate dwelled on regional developments and in-depth case studies on global health law, such as the genesis of the WHO Framework Convention on Tobacco Control and its

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<sup>3</sup> Particular appreciation in this context is owed to Stefania Negri, Allyn Taylor, Patricia C. Kuszler, Angus E.M. Wallace and Jamie Behrendt.

implementation and monitoring mechanism, with a view to distilling lessons for the ongoing efforts towards the adoption of global standards. It explored alternative treaty body monitoring mechanisms, seeking to forge consensus as a concrete input into the negotiations at the level of the Open-ended Working Group on Ageing. This also served to prepare a hackathon road map on the human rights of older persons<sup>4</sup> to identify innovative solutions that could be adopted in this regard.

10. On 18 November 2019, the mandate briefed the Intergovernmental Working Group on Ageing of the Economic Commission for Europe on the findings and recommendations with regard to older persons in humanitarian emergency situations. The briefing was part of the Working Group's own discussions on the same topic, and had been convened to inform the Commission's Policy Brief No. 25 on Older Persons in Emergency Situations.<sup>5</sup>

11. On 17 and 18 December 2019, the mandate participated in the first-ever Global Refugee Forum, which was held in Geneva. The engagement provided an opportunity to further disseminate the findings and recommendations in the Independent Expert's report on older persons in emergency situations (A/HRC/42/43) to the expert constituency of the Forum, and also served as a basis for concrete pledges to promote and protect the human rights of forcibly displaced older persons, as part of building more inclusive societies.

12. On 21 January 2020, the mandate holder participated in a webinar meeting with the International Telecommunication Union and the inter-agency group on ageing, which focused on information and communications technologies and older persons. This was an opportunity to further disseminate the mandate's accumulated findings from various analyses and to share specific recommendations on the potential and risks associated with the advancement of digitalization, from a human rights angle.

13. In the context of the coronavirus disease (COVID-19) outbreak, the Independent Expert issued a call to exercise solidarity and better protect older persons. She expressed her deep concerns that decisions around the allocation of scarce medical resources may be made solely on the basis of age, and urged that triage protocols be developed and followed to ensure that such decisions were based on medical needs and the best scientific evidence available. The Independent Expert deplored the deep-rooted ageism that the pandemic had brought to the fore. On 28 April 2020, she issued a joint statement with the Special Envoy of the Secretary-General on Disability and Accessibility, María Soledad Cisternas Reyes, highlighting the disproportionately negative impact of the COVID-19 pandemic on women and girls with disabilities and on older women.

14. In this connection, on 1 May 2020 the Secretary-General of the United Nations launched his Policy Brief on the Impact of COVID-19 on Older Persons, highlighting the untold fear and suffering for older persons across the world caused by the COVID-19 pandemic. He also stated that the crisis had revealed important gaps in the availability of age-specific data, noting the need for the review of disaggregation protocols for data. Furthermore, he called for the building of stronger legal frameworks at both the national and the international levels to protect the human rights of older persons.

15. The impact of COVID-19 has also marked the initial activities of the new Independent Expert, Claudia Mahler, who took up her duties on 1 May 2020. Against that background, she engaged in a virtual conversation with the United Nations High Commissioner for Human Rights on 12 May 2020 on ways to promote the rights of older persons during these challenging times and on how to move from debate to action. The webinar was organized by the NGO Committee on Ageing. The Permanent Representatives of Chile and of Slovenia, in their respective capacities as chairpersons of the Groups of Friends of the Rights of Older Persons, in New York and in Geneva, addressed the event at the opening and closing.

<sup>4</sup> This themed creative problem-solving event, which was planned to be held in April 2020 on the margins of the eleventh session of the Open-ended Working Group on Ageing, has been postponed due to the outbreak of coronavirus disease (COVID-19).

<sup>5</sup> See ECE/WG.1/2019/RD2.

16. On 21 May 2020, the Independent Expert participated as a panellist in a webinar on palliative care and COVID-19. She stressed the need for urgent and sustainable responses to improve palliative care for older persons and emphasized the obligation of States to prevent pain and suffering – that could amount to cruel, inhuman or degrading treatment. She was also a panellist in a webinar entitled “Protecting the rights of older persons during the COVID-19 pandemic”, organized by the United Nations Population Fund (UNFPA) and held on 27 May 2020, where she outlined the priority issues that she intended to address during the COVID-19 pandemic and stressed the necessity of moving the rights of older persons to the centre of the political and policy arenas.

17. Considering the regional dimension, on 5 June 2020 the Independent Expert took part as a panellist in a web talk convened by the Stakeholder Group on Ageing, an African regional coalition of civil society organizations, on the impact of COVID-19 on the human rights of older persons. Her intervention focused on the importance of the Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Older Persons in Africa as a normative framework that provides guidance to help address the key challenges of this health pandemic.

18. In her statement to the press on World Elder Abuse Awareness Day on 15 June 2020, the Independent Expert urged Governments and the international community to exercise global solidarity and step up action to effectively prevent, and protect older persons from, physical and psychological abuse, including neglect. She referred to distressing verbal and derogatory online abuse in the context of the COVID-19 outbreak, noting that derogatory comments in the media constituted a direct attack against the dignity of older persons. She urged States to implement and monitor measures to avoid ageist approaches and stressed that older persons needed to have access to accountability mechanisms that provided for remedies and redress when their human rights were violated.

### III. Representative and meaningful data on older persons<sup>6</sup>

#### A. Why data matters

19. To date, there is a serious gap in the data available to capture the lived realities of older persons and the enjoyment of their human rights. This lack of significant data and information on older persons is, in itself, an alarming sign of exclusion and renders meaningful policymaking and normative action practically impossible. Overcoming these impediments to the realization of the rights of older persons requires a fundamental conceptual shift in method and process that takes into account the entanglement of digital and analogue realities, or the so-called digitality.<sup>7</sup>

20. Comprehensive, meaningful and reliable data plays a key role in enhancing the understanding of global ageing and the impact of age-structural change. It fosters essential knowledge about the needs of older persons and creates the conditions for assessing the effectiveness of existing measures. It also provides the evidence base required to identify concrete gaps, to improve the formulation of targeted measures, to monitor their implementation and to report on progress. Data is necessary to reflect how the accessibility of the built environment, income adequacy or social protection enable or restrict older persons’ autonomy. The inclusion of older persons in public data, disaggregated by age, sex

<sup>6</sup> “Data” is used as a generic term, which includes but is not limited to statistics. It is seen as encompassing a wide range of quantitative or qualitative standardized information compiled by national statistical offices as well as other governmental or non-governmental entities, whether at the local, national, regional or global level.

<sup>7</sup> “Digitality” refers to the entanglement of digital and analogue realities, whereby analogue not only encompasses anything that is offline, but is also used as a synonym for “obsolete”, which is understood as being replaced by the digital as the new. In the context of the report, it therefore also refers to the need for a new conceptual framework underpinning older persons’ data. See Manuel Castells, *The Rise of the Network Society*, second edition (Wiley-Blackwell, 2009).

and relevant socioeconomic characteristics, is essential to effective public policymaking that is inclusive of older persons.<sup>8</sup>

21. The framing of the ageing category, as circumscribed for statistical purposes, reproduces societal assumptions about later life and older persons, including ageist attitudes. Engaging older persons and their representative organisations in data-collection efforts will improve the breadth and depth of information on this population group, avoiding stereotypical and simplified portrayals of old age and older persons, which may perpetuate their exclusion and discrimination. It will ensure that data not only depicts the challenges that older persons face, but also the opportunities of ageing both at the societal and the individual level.

22. Another key function of data collection is its contribution to awareness-raising and empowerment. Shedding light on structural and systematic ways in which older persons are left behind, as well as on the roles in which they contribute to society, can help to gradually change perceptions of later life, especially for it to be more than an inevitable stage of deficit and decline.

23. To prevent old age inequalities, interventions are needed in early life. Data that can effectively inform action therefore needs to take a life course approach and identify the early- and mid-life factors that have the most impact on later lives. Furthermore, factors such as socioeconomic conditions, gender, disability, or being from an ethnic minority, and other characteristics and conditions that may lead to inequalities, tend to be amplified in old age.

24. Moreover, the prevalence of multiple, intersecting and aggravated forms of discrimination faced by older persons, and the high incidence of poverty and isolation, especially among older women, persons with disabilities, persons of African descent, individuals belonging to indigenous peoples, persons belonging to national or ethnic, religious and linguistic minorities, rural persons, persons living on the streets, migrants and refugees, among other groups (see A/HRC/RES/33/5), need to be ascertained and supported by significant data to allow for informed policymaking to tackle the colossal task of addressing old age exclusion and inequality.

## **B. The data gap conundrum**

### **1. Availability**

25. The availability of data is a prerequisite in determining the human rights protection gaps of older persons and addressing them effectively in law, policy and practice. The exclusion of older persons from surveys and national censuses affects the ability to understand the extent to which they are able to participate in society and enjoy their human rights on an equal basis with others. Due to the lack of significant data and statistics, inequalities faced by older persons often remain invisible.<sup>9</sup>

26. There is not yet a critical mass of dedicated studies on ageing or on older persons worldwide that would enable an analysis of the extent to which older persons enjoy their human rights. Where such studies are carried out, they are not necessarily comprehensive in scope and leave out important human rights aspects.

27. As for general surveys, they are not specifically designed to capture the situation of older persons in an all-encompassing manner. They either exclude older persons *de facto* or do not cover the whole range of their human rights challenges. Out of 133 countries included in a survey by WHO, for example, only 17 per cent gathered data on abuse of and violence against older persons.<sup>10</sup> A human rights-based approach to data requires that older persons, particularly the most disadvantaged or marginalized, be included in national and large-scale data-collection efforts.

<sup>8</sup> Secretary-General of the United Nations, Policy Brief on the Impact of COVID-19 on Older Persons.

<sup>9</sup> *Ibid.*

<sup>10</sup> Available from [www.who.int/violence\\_injury\\_prevention/violence/status\\_report/2014/en/](http://www.who.int/violence_injury_prevention/violence/status_report/2014/en/).

28. Countries vary in the relative and absolute numbers of older persons, and as regards whether older persons are more likely to be living in rural, urban or peri-urban areas, including informal settlements and areas with high numbers of refugees or displaced persons, and also as regards whether older persons are more likely to live within a family, alone, or in a retirement home. It speaks volumes that whereas the older population is growing everywhere, classic population censuses are not standard throughout the world and some countries simply do not gather any data on older persons. Moreover, where population censuses are conducted, older persons rarely constitute the focus of a separate thematic census report.<sup>11</sup>

29. The inclusion of older persons at the planning and design stage of data-collection programmes is indispensable. Where standard sample design fails to yield sufficient representation of older persons, alternate sampling and data-collection approaches have to be considered.

## **2. Accessibility**

30. Another precondition for significant data-gathering is ensuring that older persons participate in public policy discussions about them. This, in turn, requires information on data-collection efforts and on whether and how such data can be accessed. To facilitate the accessibility of data on older persons, and analysis and interpretation of it, metadata (i.e. data describing the data) and paradata (i.e. data about the process by which the data was collected) need to be available and standardized, as relevant, across data collectors and data-collection instruments.<sup>12</sup> This is essential in order to understand data limitations and identify potential biases before determining the informative value and representativeness of data sets.

31. Metadata and paradata may reveal the use of cut-off ages, sample sizes and coverage. They make it possible to determine, for instance, whether older persons in institutional care settings were part of the sample, whether unemployment figures included those who are retired, or whether care provisions covered both formal and informal care. Openly accessible information on the research design and the data-collection methodology, which includes the sources, methods and procedures used to produce official statistics, is therefore critical in order to evaluate the suitability and appropriateness of the data and, thus, to ensure accurate analysis and reading.

## **3. Meaningful and representative data**

32. A central element for a human rights-based approach to data is its disaggregation. This allows then for an initial comparison and appraisal of older persons with other population groups and forms part of the human rights obligations of States.<sup>13</sup> Disaggregated data is, for instance, crucial in order to provide information about the extent of possible inequality and discrimination, and constitutes a prerequisite for the design and formulation of targeted public policies. At the same time, the technical specifications used in designing how the data is to be collected, and the breakdown of the data, will assist in monitoring and measuring the impact of policies and normative action.

33. Typically, older persons are represented in statistics as a single age cohort of 55 plus, 60 plus or 65 plus. Such a large, indefinite age group does not provide statistical lucidity as regards variations in life-course experiences at different stages of old age. Also, it does not make it possible to expose patterns of inequality and discrimination, or underlying factors that lead to poverty, isolation and long-term unemployment. As a consequence, absence of age-disaggregated data impedes targeted policy planning and

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<sup>11</sup> HelpAge International, “Data mapping on ageing in Asia and the Pacific: analytical report” (2015).

<sup>12</sup> Office of the United Nations High Commissioner for Human Rights (OHCHR), “A human rights-based approach to data: leaving no one behind in the 2030 Agenda for Sustainable Development” (2018), p. 7.

<sup>13</sup> Ibid.



responses, including in precarious situations, such as emergency situations, where the needs and rights of older persons are more likely to be overlooked.<sup>14</sup>

34. Data needs not only to be disaggregated by age, but also by other critical dimensions, including sex, disability, marital status, household or family composition, and type of living quarters, in order to achieve a more granular and meaningful data analysis to inform policies affecting older persons. There is a need to review existing disaggregation protocols for data on social welfare, violence, public participation and other essential indicators to ensure full older-age disaggregation of crucial data, and to promote the generation and tabulation of available data on older persons by 5-year age groups.<sup>15</sup>

35. In this context, the use of small sample sizes renders disaggregation of data on older persons difficult. General surveys that collect information on older persons often use sample sizes in older age groups that are too small to allow disaggregation by the most basic sociodemographic variables and to expose life-course specificities, such as differences between the third and fourth age. Similarly, longitudinal surveys often fail to include older age groups, leading to significant data gaps on the specific challenges at the intersection of older age with other dimensions such as gender or socioeconomic status.

36. There are other challenges to accurate data collection on older persons that must be considered. Definitions of old age, for example, determine the way in which data is collected, needs are assessed and responses are shaped. For the purposes of law, policy and data collection, old age and older persons are typically determined in merely chronological terms. Bearing in mind that age is a social construct, definitions based only on chronological age fall short of local life-course realities and perceptions. In some contexts, older persons are likely to consist of those with grown-up children or grandchildren or who are leading figures in societies and other domains. Certain subpopulations, due to adverse life conditions, may face biological signs of ageing earlier than others – such as refugees or prisoners. Persons who have endured conditions of war, conflict and natural disaster cannot be regarded with the healthy ageing metrics of affluent societies.<sup>16</sup>

37. Data on older persons, where it is collected, often portrays a homogenous group, whereas it is the most diverse of all age groups, in terms of chronological age, health status, life stages, living arrangements, and needs. Statistical systems need, therefore, to embody a more nuanced understanding of old age and the different forms of participation and potential for contributions by older persons.

38. There are also methodological limitations that constrain the availability and validity of data on older persons. Most surveys, even those dedicated to older persons, fail to take account of older persons in institutional care facilities, older prisoners, or older homeless persons. Among the reasons for this are difficulties in enlisting older persons to participate, due to incomplete official registers of information, or a lack thereof, the use of traditional household surveys, and the use of so-called gatekeepers who have to give their consent. In addition, some populations, such as older migrants, older persons who receive care at home, older persons with dementia, and those living in rural or remote areas, may be excluded due to language barriers, lack of administrative records, physical or cognitive impairments, and remoteness. The use of proxies to overcome these limitations may not yield accurate results.

39. Applying a participatory approach can help to improve response rates among certain groups of older persons. This may be particularly relevant for older persons who experience multiple forms of discrimination, as well as those who are excluded from traditional household surveys, which tend to perpetuate the invisibility of older persons, or those who

<sup>14</sup> A/HRC/42/43, para. 46.

<sup>15</sup> Principles and Recommendations for Population and Housing Censuses (2017), revision 3, available at [https://unstats.un.org/unsd/demographic-social/Standards-and-Methods/files/Principles\\_and\\_Recommendations/Population-and-Housing-Censuses/Series\\_M67rev3-E.pdf](https://unstats.un.org/unsd/demographic-social/Standards-and-Methods/files/Principles_and_Recommendations/Population-and-Housing-Censuses/Series_M67rev3-E.pdf).

<sup>16</sup> Médecins sans frontières, “Older people in crises: A review of MSF’s approach to vulnerability and needs”, available at [www.msf.org.uk/sites/uk/files/older\\_people\\_in\\_crisis\\_final\\_oct\\_2012.pdf](http://www.msf.org.uk/sites/uk/files/older_people_in_crisis_final_oct_2012.pdf), p. 4.

are excluded from administrative records, such as undocumented older migrants, refugees and displaced persons.

40. The lack of a uniform approach and a uniform understanding of old age, and of standardized concepts and questions, variables and age groups, means that existing data is neither consistent nor comparable within and among countries.<sup>17</sup>

### C. Data revolution

41. New technologies are leading to an exponential increase of the data available in terms of volume, level of detail, and speed. This data revolution creates unprecedented possibilities for addressing the data gap on older persons, through the integration and the broadening of the scope of data, by incorporating non-traditional sources that have so far not been utilized in official statistics.<sup>18</sup>

42. Much of the new data is collected passively, from the digital footprints people leave behind, or from sensor-enabled objects, or is inferred via algorithms. The risk of overlooking digitally invisible older persons constitutes an important challenge. The adoption rate among older persons of “smart” digital technology and of online social networks is significantly lower than the average in the population, and digital footprints may therefore not be representative of older persons and in particular of the oldest old. Barriers to the digital inclusion of older persons include low digital literacy, and connectivity differentials, as well as uneven power relations within households that may deny older persons access to digital devices, but also hearing, visual and cognitive impairments, and mental conditions, such as dementia. Any decision-making based on such data is likely to overlook the more vulnerable members of the age groups. There is a risk, furthermore, of algorithms reproducing the underlying lack of understanding of ageing and human bias vis-à-vis older persons.<sup>19</sup>

43. Data gathered through the use by older persons of assistive and smart ageing technology is particularly sensitive. It links personal and physiological or health data with data on behavioural patterns and with environmental data, such as air humidity and temperature, to enable an all-round analysis and continuous monitoring, in order to design tailored services, including more precise predictability of health conditions and care needs of older persons. While the objective is to enable older persons to lead autonomous and independent lives for longer, there are significant concerns about data protection and privacy. Data that relates sensitive personal information, including health status, should be handled only with the express consent of the older person concerned.<sup>20</sup> As devices become more autonomous, data collection will further expand, since these systems function on the basis of data collection and analysis, and such concerns will be magnified.

44. Data generated passively and comprehensively, including, in particular, behavioural data, allows a categorization of older persons into those who are autonomous, those who are semi-autonomous and those who are dependent, and makes it possible to make individualized predictions of their needs, and prescriptions to address them. Respect for

<sup>17</sup> Economic Commission for Europe, *Recommendations on Ageing-related Statistics*, prepared by the Task Force on Ageing-related Statistics (United Nations publication, 2016).

<sup>18</sup> See the report of the High-level Panel of Eminent Persons on the Post-2015 Development Agenda, available at [www.post2020hlp.org/wp-content/uploads/docs/UN-Report.pdf](http://www.post2020hlp.org/wp-content/uploads/docs/UN-Report.pdf).

<sup>19</sup> Mario Callegaro and Yongwei Yang, “The role of surveys in the era of ‘big data’”, *The Palgrave Handbook of Survey Research* (2017), pp. 175–192; Robin Allen and Dee Masters, “Artificial intelligence: the right to protection from discrimination caused by algorithms, machine learning and automated decision-making”, published online on 2 October 2019, pp. 1–14; and Anthony Flores et al., “False positives, false negatives, and false analyses: a rejoinder to ‘Machine bias: there’s software used across the country to predict future criminals. and it’s biased against blacks’”, *Federal Probation Journal*, vol. 80, No. 2 (2016), pp. 38–46.

<sup>20</sup> OHCHR, “A human rights-based approach to data: leaving no one behind in the 2030 Agenda for Sustainable Development” (2018), p. 17.

individual autonomy also means that older persons need to be allowed to deviate from what is expected of them.

45. The growing gap between the data that older persons actively offer and the massive amounts of passive data being generated and mediated by third parties magnifies challenges relating to data protection, individual data sovereignty and informational self-determination that need to be addressed. There is a need to assess existing frameworks comprehensively and to update them to address challenges emerging from data collection via new technologies.<sup>21</sup>

#### **D. Overview of the legal and policy framework and recent initiatives**

46. The existing international human rights framework does not currently include a specific obligation for data on older persons to be gathered in order to effectively monitor and measure the implementation of their rights.

47. The Committee on Economic, Social and Cultural Rights recognizes the role of data in giving effect to the International Covenant on Economic, Social and Cultural Rights. In its general comment No. 20 (2009) on non-discrimination in economic, social and cultural rights, the Committee calls for national strategies, policies and plans to use appropriate indicators and benchmarks, disaggregated on the basis of the prohibited grounds of discrimination. By noting that age is a prohibited ground, but, however, in *several contexts* only, the Committee failed to attribute to age discrimination equal standards of protection as to other grounds. The Committee only focused on discrimination in the fields of work and pensions. Read together, the general obligation for data collection, analysis and dissemination and the lack of a generalized prohibition of age discrimination do not create an adequate framework for monitoring older persons' rights and collecting data as evidence of age discrimination. Neither did the Committee's earlier general comment No. 6 (1995) on the economic, social and cultural rights of older persons include a reference to data collection and disaggregation. General recommendation No. 27 (2010) of the Committee on the Elimination of Discrimination against Women, though referring to the need for data disaggregated by age and sex, and highlighting vulnerable groups and situations,<sup>22</sup> applies to older women only.

48. There is some guidance at the regional level deriving from the Inter-American Convention on Protecting the Human Rights of Older Persons and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa. For example, article 30 of the Inter-American Convention calls on member States to ensure equal access to financial services. This obligation could inform the implementation of target 8.10 of the Sustainable Development Goals on expanding access to banking, insurance and financial services for all.<sup>23</sup> Article 21 of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Older Persons in Africa considers the coordination and collection of data, and stipulates that States parties are to ensure the systematic collection and analysis of national data on older persons. Article 21 also calls for the development of a national mechanism on ageing with the responsibility to assess, monitor, evaluate and coordinate the integration and implementation of older persons' rights in national policies, strategies and legislation.

49. The Madrid International Plan of Action on Ageing, as the main international policy framework on older persons, makes very few references to the need for improved data collection and analysis. To facilitate the national reviews and appraisals of the Plan of

<sup>21</sup> Data Strategy of the Secretary-General for Action by Everyone, Everywhere, with Insight, Impact and Integrity, 2020–2022, p. 27.

<sup>22</sup> General recommendation No. 27 (2010) on older women and the protection of their human rights, para. 19.

<sup>23</sup> Economic Commission for Latin America and the Caribbean, Sandra Huenchuan and Emiliana Rivera (eds.), *Experiencias y Prioridades Para Incluir a las Personas Mayores en la Implementación y Seguimiento de la Agenda 2030 para el Desarrollo Sostenible* (United Nations publication, LC/MEX/SEM.245/1).

Action, the Department of Economic and Social Affairs has developed indicators.<sup>24</sup> In the context of the implementation of the Plan of Action, several countries also conducted studies on older persons that enhanced the understanding of their situation and needs.<sup>25</sup> In addition, regional efforts have contributed to progress in the availability, accessibility and comparability of data in support of the implementation of the Plan of Action,<sup>26</sup> although this cannot substitute for the lack of a comprehensive global approach to the monitoring of the Plan of Action.<sup>27</sup> While progress has been made, it remains limited and uneven and data gaps persist.

50. The Sustainable Development Goals constitute an invaluable opportunity to increase the visibility of older persons and to highlight inequalities in old age. Specific references to older persons are, however, rare. The references to “all” or to people of “all ages” reflect the intention in the Goals to meet the needs of all social groups, which naturally includes older persons. It is noteworthy that for most indicators, implementation must be disaggregated by age. Target 17.18, for instance, is to increase significantly the availability of high-quality, timely and reliable data disaggregated by age. There are significant gaps, however. The indicator of premature death, used to measure Sustainable Development Goal 3, excludes persons who die from non-communicable diseases after the age of 70.<sup>28</sup> Such indicators support ageist attitudes and practices while remaining largely unnoticed and unaddressed. Whereas the Sustainable Development Goals have been a catalyst for improving general data collection around the world, many countries still lag behind in producing data on older persons and lack systematic disaggregated analysis that is necessary for monitoring the implementation of the Goals.

51. There have been repeated calls and initiatives in multilateral institutions, such as the United Nations and international human rights mechanisms, to increase the collection and dissemination of data on older persons<sup>29</sup> and also at the regional levels. The Bureau of the Conference of European Statisticians, for instance, established the Task Force on Ageing-related Statistics, in 2013, which developed guidelines aimed at improving the availability, accessibility and comparability of data in this field.<sup>30</sup>

52. An initiative at the global level is the so-called Titchfield Group on Ageing-related Statistics and Age-disaggregated Data. This informal consultation group of experts, primarily from national statistical agencies, was created in 2018 with the endorsement of the Statistical Commission to improve the availability, accessibility and comparability of statistical data in support of ageing-related policymaking.

53. The overall objective of the Titchfield Group is to develop standardized tools and methods for producing data on the major dimensions of ageing, and age-disaggregated data across the life cycle, and to encourage countries to do so. The identification of the critical domains relating to ageing is derived from the recommendations of the Madrid International Plan of Action on Ageing, taking into account more recent strategies, such as

<sup>24</sup> Department of Economic and Social Affairs, *Guidelines for Review and Appraisal of the Madrid International Plan of Action on Ageing: Bottom-up Participatory Approach*, available at [www.monitoringris.org/documents/imp\\_glob/Guidelines\\_draft\\_final\\_June.pdf](http://www.monitoringris.org/documents/imp_glob/Guidelines_draft_final_June.pdf).

<sup>25</sup> See A/HRC/33/44.

<sup>26</sup> See [www.unece.org/statistics/networks-of-experts/task-force-on-ageing-related-statistics.html](http://www.unece.org/statistics/networks-of-experts/task-force-on-ageing-related-statistics.html); Asghar Zaidi, Jane Parry and Jinpil Um, “Developing a toolkit to monitor implementation of the Madrid International Plan of Action on Ageing in the context of the Asia-Pacific region”, Social Development Working Paper No. 2018/02; and Michael Murphy, “Ageing in sub-Saharan Africa in the context of global development: the Multiple Indicator Survey project”, 2018.

<sup>27</sup> Asghar Zaidi, *Implementing the Madrid Plan of Action on Ageing: What have we learned? And, where do we go from here?* (2018), available at <http://hdr.undp.org/en/content/implementing-madrid-plan-action-ageing-what-have-we-learned-and-where-do-we-go-here>.

<sup>28</sup> See <https://ageing-equal.org/trying-to-make-sense-of-ageism-in-health/>; Peter Lloyd-Sherlock et al., “Population ageing and health”, *The Lancet*, vol. 379, issue No. 9823, pp. 1295–1296; and [www.bmj.com/content/354/bmj.i4514](http://www.bmj.com/content/354/bmj.i4514).

<sup>29</sup> See, for instance, A/61/167; General Assembly resolution 68/134; General Assembly resolution 69/146; A/HRC/41/32; General Assembly resolution 69/2, para. 10; and World Health Organization (WHO), *World Report on Ageing and Health*, paras. 17–18.

<sup>30</sup> See [www.unece.org/statistics/networks-of-experts/task-force-on-ageing-related-statistics.html](http://www.unece.org/statistics/networks-of-experts/task-force-on-ageing-related-statistics.html)

the Economic Commission for Europe *Recommendations on Ageing-related Statistics* and the WHO global strategy and action plan on ageing and health for 2016–2020, as well as the requirements of the 2030 Agenda for Sustainable Development. For the Titchfield Group to contribute towards meaningful data on the enjoyment by older persons of their human rights, it will also need to embrace the human rights framework and the related obligations towards improving statistical measurement, and to influence policymaking, in order to ensure a human rights-based approach.<sup>31</sup>

54. The Active Ageing Index is another initiative that is aimed at capturing the potential of older persons and has been used to inform the implementation of the priorities at the national level in the context of the Madrid International Plan of Action on Ageing. This has resulted in greater comparability of data across Europe. Another concrete attempt to provide data for evidence-based policies on older persons is the Global AgeWatch Index, which measures the quality of life of older persons around the world. While both indices are valuable tools that use existing data to assess progress and provide insights into how countries can improve their performance on selected indicators, a comprehensive human rights-based index that is based on the structure-process-outcome framework developed by OHCHR and that covers the whole range of human rights remains essential to measure effectively the implementation of the human rights of older persons.<sup>32</sup>

55. The COVID-19 pandemic has further revealed the invisibility of older persons in public data analysis, as recognized by the Secretary-General of the United Nations in his Policy Brief on the Impact of COVID-19 on Older Persons, issued in May 2020. In the context of the pandemic, the Statistics Division is stepping up its support on standardized data-collection advice. UNFPA, the Economic Commission for Africa and the Global Partnership for Sustainable Development Data decided to provide data support to African countries in regard to COVID-19.<sup>33</sup>

## **E. Data gap impact**

### **1. Ageism and age discrimination**

56. Ageism is a key societal concern at the global level. The term was coined in 1969 by Robert Neil Butler, who also identified the concept, to describe stereotyping and/or discrimination against individuals or groups on the basis of their age. Tackling ageism requires targeted evidence-based measures: ageism, or old age stereotypes, negative attitudes and prejudices against older persons, are not currently considered in data sets.

57. A distinct characteristic of ageism is its pervasive nature and social acceptance. Although there is increasing consciousness about how ageism drives human rights violations in old age, it ranks low among the priorities in terms of data collection. It is essential to develop the tools required to collect information on perceptions and attitudes towards older persons and ageing.<sup>34</sup> Data on awareness of rights and the possibilities for redress is also needed.

58. Moreover, capturing age discrimination involves an element of subjectivity and an aspect of comparison. When it comes to older persons, the reference point is unclear. In addition to subjective evaluations of experiences of discrimination, data needs to be gathered around existing age limitations that restrict access to certain services and benefits. Surveys, for example to detect barriers in accessing care, need to uncover whether the differential treatment of older persons as compared to other groups with the same needs results in different outcomes. There are important discrepancies, for instance between

<sup>31</sup> See E/CN.3/2018/19.

<sup>32</sup> OHCHR, “A human rights-based approach to data: leaving no one behind in the 2030 Agenda for Sustainable Development”.

<sup>33</sup> United Nations Population Fund, “Implications of COVID-19 for older persons: responding to the pandemic”, technical brief, April 2020, p. 14.

<sup>34</sup> See E/CN.5/2013/6; and Michael Murphy, “Ageing in sub-Saharan Africa in the context of global development: the Multiple Indicator Survey project”, 2018.

systems targeted at older persons with disabilities and those targeted at younger persons with disabilities and/or those targeted at older persons who have acquired disability earlier in life.<sup>35</sup> Data sets should include an indicator about the existence of national legislation or policy stipulating equal access to care and support regardless of age. Data-collection efforts also need to be expanded to measure the risk of multiple discrimination, as well as the intersection of old age with other characteristics.

59. The old-age dependency ratio,<sup>36</sup> which is widely used, assumes that any person above a certain age is economically dependent. It does not consider that older persons are living healthier lives, continue being engaged in economic and informal activities and contribute actively in many different roles to society. Data that portrays older persons as passive recipients of benefits nurtures and perpetuates stereotypes. Collating data that corroborates the contributions of older persons is necessary in order to redress the image and position of older persons in society. Data should be geared towards breaking down stereotypes and tackling all forms of discrimination against older persons.

## 2. Violence, abuse, maltreatment and neglect

60. Data on experiences of violence, abuse, maltreatment and neglect in later life is largely missing.<sup>37</sup> Demographic and health surveys, despite their potential for filling informational gaps, typically exclude from their remit women aged 50 and over, and men aged 55 or 60 and over, for instance.<sup>38</sup> Abuse of older persons therefore remains largely invisible. This has wide repercussions, as these data sets form the basis for reporting on progress in the context of the implementation of Sustainable Development Goal 5 in regard to violence against women.

61. Moreover, experience shows that, even without age cut-offs, older persons are rarely part of surveys on violence, and that indicators used may not be suitable for detecting all manifestations of violence against and abuse of older persons. Abuse of older persons cannot be equated with gender-based violence in terms of causes, manifestations, perpetrators and consequences. Existing surveys – even if they were to be extended to the older population – are not apt for uncovering violence against and neglect of older persons, in particular the structural causes, including institutionalized ageism and lack of resources, which are prevalent in care settings.

62. The WHO Study on Global Ageing and Adult Health,<sup>39</sup> for example, though it focuses on older persons, does not include a module on violence, maltreatment, abuse or neglect. Questions around safety, health status and injuries can partially disclose whether injuries were intentionally inflicted by others, but cannot detect all forms of physical violence, for example when it did not result in injury – such as kicking or pushing.<sup>40</sup> Likewise, there is no measurement of verbal, emotional, sexual and financial abuse or neglect, nor reporting about the relationship between the perpetrator and the victim, that is, whether it is a relative or an informal or formal caregiver.

63. The lack of detailed information and analysis limits the possibility of revealing abuse patterns and determining the gaps in existing interventions, as well as of identifying concrete action that is needed to further protect older persons. To understand violence against and abuse of older persons, it is necessary to identify particularly vulnerable groups and risk factors – for example, the lack of legislation to prevent and address abuse, as research shows that older women are often excluded from legislation on domestic

<sup>35</sup> See A/74/186.

<sup>36</sup> See [www.oecd-ilibrary.org/docserver/pension\\_glance-2017-22-en.pdf?expires=1583244426&id=id&accname=guest&checksum=5357EA66F290291524E95D537636731F](http://www.oecd-ilibrary.org/docserver/pension_glance-2017-22-en.pdf?expires=1583244426&id=id&accname=guest&checksum=5357EA66F290291524E95D537636731F).

<sup>37</sup> Economic Commission for Europe, Policy Brief on Ageing No. 14: Abuse of Older Persons; and HelpAge International, “How data systems leave older people behind”, 2017.

<sup>38</sup> HelpAge International, “Global AgeWatch Insights: The right to health for older people, the right to be counted”, 2018.

<sup>39</sup> See [www.who.int/healthinfo/sage/en/](http://www.who.int/healthinfo/sage/en/).

<sup>40</sup> HelpAge International, “How data systems leave older people behind”.

violence.<sup>41</sup> Information is required about the avenues to report abuse, existing support for victims and access to remedy. Special attention must also be paid to issues that are considered taboos, such as sexual violence and rape in later life.<sup>42</sup>

64. Furthermore, dedicated surveys would be instrumental in overcoming existing underreporting challenges, provided that they were conducted by trained personnel, in compliance with high ethical standards. This could help address the estimated 80 per cent underreporting rate,<sup>43</sup> which is attributed to the fear of exposing a family member, losing services or being placed in a nursing home against the older person's will, and lack of support and information,<sup>44</sup> as well as the internalization of ageism, which leads older persons to play down abuse.<sup>45</sup>

### 3. Adequate standard of living

65. Another gap within existing data sets concerns old-age poverty. Pension inadequacy is often used as the main explanatory criterion for which an older person's standard of living falls below an adequate level.<sup>46</sup> This indicator alone does not capture the reality of older persons' standard of living, which will also depend on the availability of other sources of income, such as income from work or family support, and on unavoidable expenses, such as out-of-pocket payments to access health care, care, and other essential services. Measuring poverty through pension levels does not take into account whether older persons provide support to family members. Such knowledge gaps encourage portrayals of older persons as a burden and could induce intergenerational divides.

66. Documenting and addressing old-age inequalities requires that data on income and poverty take into account the multiple sources of income of older persons, and, therefore, a comprehensive approach involving a number of indicators. It also needs to factor in whether older persons can dispose of their resources freely and autonomously, and how their income is spent, as well as intrafamily transfers.

67. The common use of household surveys cannot provide conclusive evidence about the income and living conditions of older persons. Where older persons live with younger generations, household surveys do not provide for the required differentiation of the situation of older persons as opposed to other members of their household. Older persons may not benefit from an equal share of the household income, even though they may have increased needs as compared to other household members, for instance to cover their health or care costs.<sup>47</sup>

68. Most national and regional statistics do not contain data on the situation of older persons aged 75 and over. Data needs to be collected about the socioeconomic realities of different age cohorts among the older population, particularly of the oldest old, which is the fastest-growing segment of the population. The older old, for instance, have a higher risk of poverty than older persons who have retired recently when pensions are not indexed and as a result of higher health and long-term care costs. Statistics that were more granular would make it possible to reflect more accurately these increased challenges to the right to an adequate standard of living for the older old.

<sup>41</sup> See [www.un.org/esa/socdev/documents/ageing/ReportofEGMNeglectAbuseandViolenceofOlderWomen.pdf](http://www.un.org/esa/socdev/documents/ageing/ReportofEGMNeglectAbuseandViolenceofOlderWomen.pdf).

<sup>42</sup> A/HRC/42/43/Add.2, para. 86; and A/HRC/42/43, para. 95.

<sup>43</sup> WHO, *A Global Response to Elder Abuse and Neglect: Building Primary Health Care Capacity to Deal with the Problem Worldwide* (2008).

<sup>44</sup> Economic Commission for Europe, Policy Brief on Ageing No. 14: Abuse of Older Persons; and WHO, *European Report on Preventing Elder Maltreatment* (2011).

<sup>45</sup> John Williams, "When I'm sixty-four: lawyers, law and old age", *Cambrian Law Review*, vol. 34 (2003), p. 103.

<sup>46</sup> Economic Commission for Europe, *Recommendations on Ageing-related Statistics*, prepared by the Task Force on Ageing-related Statistics.

<sup>47</sup> A/HRC/42/43, para. 47.

#### 4. Social protection and the right to work

69. The lack of age-disaggregated data to measure the social and economic well-being of older persons has long been considered a main reason for the lack of attention to and knowledge of the life circumstances of older persons within national development strategies and programmes.

70. Many national statistics relevant to the right of social protection and the right to work disaggregate data only until the age of 65.<sup>48</sup> For Labour Force Surveys, for instance, the disaggregation of indicators in a number of countries is cut off at the age of 65,<sup>49</sup> and persons beyond this age are often included in the inactive rather than the unemployed population, from the moment they reach the statutory retirement age.<sup>50</sup> Older persons who continue to work formally and informally beyond the legal retirement age and those who are not retired but unemployed are therefore not taken into account. This does not provide an accurate picture of the roles and contributions of older persons, and impedes the development of measures to address certain areas such as unemployment of older workers, which is growing due to the extension of working lives.

71. More information about discrimination in the labour market, incentives for working longer and statutory retirement ages is needed.<sup>51</sup> Moreover, the reasons for which older persons leave the labour market have to be further exposed. Data on age-friendly practices and environments that enable older persons to extend their working lives are required in order to determine the changes needed at the level of regulatory, fiscal, education and other policies.<sup>52</sup>

#### 5. Care

72. Indicators on long-term care are largely underdeveloped.<sup>53</sup> Whereas several countries collect information about access to care, there is a lack of knowledge about the quality of care. There is no data, for example, on the use of physical or chemical restraints, or on whether care recipients receive adequate support to participate in society and engage in social activities. Information about the level of training received by caregivers is also largely lacking.<sup>54</sup>

73. More information is required about the practices of care institutions and professional caregivers in the community that may impede the enjoyment by older persons of their human rights.<sup>55</sup> Data on the right to maintain personal and family life is rarely included in surveys.<sup>56</sup>

74. Similarly, existing surveys do not adequately capture the degree of choice afforded by long-term care systems.<sup>57</sup> There is some evidence that persons are admitted to institutions without their consent.<sup>58</sup> To understand whether there is meaningful freedom of

<sup>48</sup> Economic Commission for Europe, *Recommendations on Ageing-related Statistics*, prepared by the Task Force on Ageing-related Statistics.

<sup>49</sup> See E/CN.3/2018/19.

<sup>50</sup> Economic Commission for Europe, *Recommendations on Ageing-related Statistics*, prepared by the Task Force on Ageing-related Statistics.

<sup>51</sup> Ibid.

<sup>52</sup> A/HRC/33/44, para. 61.

<sup>53</sup> HelpAge International, “How data systems leave older people behind”.

<sup>54</sup> Economic Commission for Europe, *Recommendations on Ageing-related Statistics*, prepared by the Task Force on Ageing-related Statistics.

<sup>55</sup> European Network of National Human Rights Institutions, *We Have the Same Rights: The Human Rights of Older Persons in Long-term Care in Europe*, available at [http://ennhri.org/IMG/pdf/ennhri\\_hr\\_op\\_web.pdf](http://ennhri.org/IMG/pdf/ennhri_hr_op_web.pdf); and see [www.ncbi.nlm.nih.gov/pubmed/29584865](http://www.ncbi.nlm.nih.gov/pubmed/29584865).

<sup>56</sup> Magdi Birtha et al., *From Disability Rights towards a Rights-Based Approach to Long-term Care in Europe: Building an Index of Rights-Based Policies for Older People* (Vienna, European Centre for Social Welfare Policy and Research, 2019).

<sup>57</sup> Ibid.

<sup>58</sup> European Network of National Human Rights Institutions, *We Have the Same Rights: The Human Rights of Older Persons in Long-term Care in Europe*; and see [www.ncbi.nlm.nih.gov/pubmed/29584865](http://www.ncbi.nlm.nih.gov/pubmed/29584865) and <https://ageing-equal.org/human-rights-watch-guest-post/>.



choice, information is needed about whether legal entitlements to long-term care exist, and if so, what they actually cover. If public funding support, for instance, is only available for long-term care in institutional settings, this may affect the right to receive care at home. Further restrictions may simply result from the unavailability of services, such as the lack of care providers in rural areas, which de facto prevents older persons from exercising their freedom of choice when it comes to the type of care services.

75. The significant role of informal caregivers is not reflected effectively in existing surveys. Also, indicators do not measure the level of support, if any, available to informal caregivers, such as financial compensation, respite care, or accumulation of social protection rights. These aspects need to be further developed.

76. As regards aspects of health, surveys using age cut-offs in data collection lead to incomplete information and analysis on the situation of older persons, regarding health risks and other barriers to their right to health. This could also lead to discriminatory health spending. A separate module of demographic and health surveys for older persons would be required in this regard.

77. Another topic that has received limited attention is palliative care. There is no global standard definition of palliative care, and it is unclear whether relevant statistics in this area are being collected systematically.<sup>59</sup> The adverse effect of mental health conditions, such as depression, in the growing suicide rates among persons aged 75 and over also needs to be further substantiated.<sup>60</sup>

78. Another area of concern is the lack of data on the effect of medicines on older persons, as they are often excluded from clinical research and studies,<sup>61</sup> potentially leading to inappropriate medication and drug prescription, which is a major risk factor for geriatric patients.<sup>62</sup> Systematic collection of data is essential given that older persons have different patterns of disease presentation than younger adults, respond to treatments and therapies in different ways, and frequently have complex social needs that are related to their chronic medical conditions.

#### IV. Conclusions and recommendations

79. **Currently, there is a serious gap in the data available to capture the lived realities of older persons, including in terms of enjoyment of human rights. This lack of significant data and information on older persons is, in itself, an alarming sign of exclusion and renders meaningful policymaking and normative action practically impossible. Overcoming these impediments to the realization of the rights of older persons requires a fundamental conceptual shift in method and process that takes into account the entanglement of digital and analogue realities, or the so-called digitality.**

80. **Data is significant for the realization of human rights. It is necessary in order to provide evidence of the extent of the challenges faced by older persons and of the policy and legislative needs. Data collection is crucial to create visibility and build an evidence base about human rights impediments for older persons and potential responses, to dispel stereotypes that feed ageism, stigma and discrimination, and to aid policymakers and advocates in the formulation of measures regarding anti-discrimination action, socioeconomic inclusion, and access to health and care.**

81. **There is a need to set standards and reporting requirements for data gathering, in order to improve the existing data ecosystem and as an important impetus for statistical offices to gather more data on older persons.**

<sup>59</sup> Economic Commission for Europe, *Recommendations on Ageing-related Statistics*, prepared by the Task Force on Ageing-related Statistics.

<sup>60</sup> A/67/188, para. 33.

<sup>61</sup> See [www.age-platform.eu/sites/default/files/AGE\\_letter\\_to\\_world\\_data\\_forum\\_Jan2016.pdf](http://www.age-platform.eu/sites/default/files/AGE_letter_to_world_data_forum_Jan2016.pdf).

<sup>62</sup> A/HRC/30/43/Add.2, para. 78.

82. Understanding the nature of barriers is essential in order to define the measures that are required to address them. It is of fundamental importance to conduct baseline studies at the national level on the impediments to the enjoyment of all human rights by older persons – such as all forms of discrimination on the basis of age, individually and cumulatively; exclusion; poverty; and all forms of violence, abuse, maltreatment and neglect. Data sets need to be adapted and expanded, with common sets of definitions, concepts and standards, following a human rights-based approach, to allow for comparability and monitoring.

83. Data used in assessments needs to be disaggregated by age and other critical sociodemographic variables and to expose life-course specificities. Age cohorts need to reflect the heterogeneous nature of the older population to allow for a differentiation of older and very old persons, who have different needs and capacities. They have to be granular enough to make it possible to take into account the *relativity of the notion of age*, depending on the context, given that age is a social construct, and that persons who have endured conditions of war, conflict and natural disaster cannot be regarded with the healthy ageing metrics of affluent societies.

84. There is a need for conceptual frameworks incorporating a life-course approach that are able to provide more comprehensive, comparable and nuanced data on older persons. This would also enable the tracking of systemic and institutionalized discrimination. The development of a global rights-based monitoring framework or index on the rights of older persons, using structure, process and outcome indicators, would be essential in this regard.

85. As a key human rights requirement, the involvement of older persons at all stages of data collection, analysis, use and reporting, including in the development of surveys, is crucial. There is increasing evidence of how citizen-generated data can help reveal the situation of marginalized groups, fill in data gaps and drive policy change. This would also contribute to changing societal assumptions and attitudes on old age and older persons, which is imperative given their significance for the framing of the ageing category as circumscribed for statistical purposes.

86. An important contribution would be the establishment of focal points at the national level, that allows for coordinated efforts to improve data collection, analysis and reporting on ageing and older persons, including by making better use of existing data.

87. To achieve statistical representativeness and permit disaggregation, existing surveys need to oversample older persons in the higher age groups or resort to alternate sampling and data-collection methods, such as targeted sampling or respondent-driven sampling, and possibly develop quotas for the inclusion of older persons in surveys. Metadata and paradata needs to be available, standardized and accessible, as relevant, across data collectors and data-collection instruments.<sup>63</sup>

88. Guidance is required on data linkage, including of official and unofficial data, and on the integration of traditional and non-traditional data-collection methods. This particularly applies to data from new technologies and their use in artificial intelligence and automated decision-making, in view of potential risks.<sup>64</sup>

89. Statistical offices, national human rights institutions and non-governmental organizations need to work together more closely. Collaboration can range from consultation on the development of surveys and on agenda-setting, to reviewing existing data to identify gaps, to participating in the training of statisticians so that

<sup>63</sup> OHCHR, “A human rights-based approach to data: leaving no one behind in the 2030 Agenda for Sustainable Development”.

<sup>64</sup> Secretary-General of the United Nations, Policy Brief on the Impact of COVID-19 on Older Persons; Data Strategy of the Secretary-General for Action by Everyone, Everywhere, with Insight, Impact and Integrity, 2020–2022; OHCHR, “A human rights-based approach to data: leaving no one behind in the 2030 Agenda for Sustainable Development”; OHCHR, *Human Rights Indicators: A Guide to Measurement and Implementation* (HR/PUB/12/5); and General Assembly resolution 45/95, “Guidelines for the regulation of computerized personal data files”.

they are more aware of the lived experiences of older persons. It is also important to develop targeted training for civil society, and older advocates, on various aspects of data collection and handling, thereby increasing data literacy.

90. There is a need to develop statistical guidance to improve data collection, analysis and use. In this context, specific guidance is required on methodology, such as the identification of older survey participants and the conducting of qualitative and quantitative interviews, particularly with older persons living in institutional settings, care recipients and the oldest old. Training programmes on age-sensitive interviewing, including the basics of gerontology and geriatrics, are essential for ensuring a biopsychosocial cultural approach to ageing.<sup>65</sup>

91. It is imperative that older persons receive clear and adequate information about the purposes of studies, in order to ensure the actual exercise of meaningful, free and informed consent as regards the collection and use of their data. They need to have the possibility of changing their mind or opting out at any stage of the data-collection process. Collected data must exclusively be used for the purpose that older persons have consented to, with full respect for the principle of data minimization and for human rights standards. There is a need for robust data protection in view of the challenges related to privacy, individual data sovereignty and informational self-determination, including those arising from the increasing passive collection of data.

92. With reference to the Data Strategy of the Secretary-General for Action by Everyone, Everywhere, with Insight, Impact and Integrity, the ongoing data revolution offers a unique opportunity to overcome current data gaps on older persons and to unleash the full strength of data, provided that it is underpinned by a human rights-based approach. It has the potential to induce a data-driven transformation towards a more inclusive, equitable and age-friendly society, anchored in human rights.<sup>66</sup>

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<sup>65</sup> A/HRC/39/50/Add.1, para. 119.

<sup>66</sup> Strategy for 2020–2022.