

# Global AgeWatch Insights

The right to health for older people,  
the right to be counted

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Executive summary



Published by HelpAge International

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ISBN 978-1-910743-44-7

## Acknowledgements

The report was supported by a grant from AARP (aarp.org).

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## The universal right to health

At the heart of the Universal Declaration of Human Rights (UDHR) and the foundation of the World Health Organization (WHO) was the global commitment to establish the right to health of all people everywhere. Now, 70 years on, is a good time to assess how far in practice this vision has been inclusive of older people.

The right to health was recognised in the International Covenant on Economic, Social and Cultural Rights (ICESCR), and goes beyond access to health services to embrace “a wide range of socioeconomic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health”.<sup>1</sup> The United Nations Committee on Economic, Social and Cultural Rights (CESCR) set out four core components to the right to health: availability, accessibility, acceptability and quality.<sup>2</sup> These aspects have become foundational for universal health coverage (UHC) and the people-centred approach to health, both of which will be key to the realignment of health systems needed to ensure older people’s right to health is met.

## Older people’s right to health

The right to health, like all human rights, is universal and inalienable and must be enjoyed without discrimination on the basis of age, ethnicity or any other status. Specific reference to older people’s right to health has been made by the CESCR, which stated that it is “clear that older persons are entitled to enjoy the full range of rights” recognised in the ICESCR.<sup>3</sup> The committee asserts the importance of an integrated approach, combining preventive, curative and rehabilitative health treatment,<sup>4</sup> stating that such an approach should maintain the functional ability and autonomy of older persons.<sup>5</sup> Other provisions also specifically include older people, including the recommendation by the Committee on the Elimination of Discrimination against Women (CEDAW) to ensure older women’s access to affordable care and to specially trained health workers.<sup>6</sup>



## 70 years since the Universal Declaration of Human Rights

This enshrined everyone’s right to health without discrimination based on age, gender, ethnicity or any other status. However, the right to health has not been specifically applied to the context of older age in international human rights law.

Despite these protections, progress in health for older people remains deeply unequal and often limited. Older people’s right to health is not therefore being realised. In low- and middle-income countries (LMICs) in particular, older people continue to suffer exclusion and to face multiple challenges in accessing services.

A rights-based approach to health requires that health systems and services address inequity by making those who are furthest behind the first priority. This principle is echoed in the United Nations (UN) *2030 Agenda for sustainable development* and its Sustainable Development Goals (SDGs), and in efforts towards UHC.<sup>7</sup>

This report outlines the extent to which older people are being left behind through an analysis of the available data on older people’s health and by highlighting the gaps – where older people are simply not being counted.

## Barriers to older people’s right to health

Older people experience a number of barriers to their inclusion in health systems and services.

Discrimination in the form of ageism is common, including among health workers, who may fail to consult older people on their care and restrict or deny access to interventions on the basis of age. Other barriers include poor physical accessibility of services, lack of outreach to communities, poverty and prohibitive costs, lower health literacy and less access to health information. In many LMICs, health workers are inadequately prepared to respond to health challenges common in older age, and there is a lack of medical and gerontological training in the care of older people.

Many health systems are structured to manage acute, episodic illness and are less able to respond to longer-term, chronic health conditions. This means they are often unable to provide the people-centred, integrated care that is important in older age, and fail to respond to the specific needs of older populations.

In addition to such barriers, health systems have failed to keep pace with two major, interlinked global transitions: a demographic transition and an epidemiological transition.<sup>8</sup>

### Demographic transition

Progress in global health and development has led to declines in the rates of both fertility and mortality, and rapid ageing of the global population. By 2020, the number of people in the world aged 60 and over is projected to pass the 1 billion mark, and to reach 2 billion by 2050.<sup>9</sup> The pace of this demographic change is fastest in LMICs, where 70 per cent of people aged 60 and over live.<sup>10</sup>

### Epidemiological transition

The global pattern of disease has been shifting over recent years away from communicable diseases towards non-communicable diseases (NCDs). NCDs have a disproportionate impact on people in older age. It was estimated that, in 2011, people aged 60 and over accounted for 75 per cent of deaths from NCDs in LMICs.<sup>11</sup> In addition to high rates

## The three transitions



### The demographic transition

- The world is ageing rapidly – by 2020, there will be more than 1 billion people aged 60 and over.
- Low- and middle-income countries are home to 70% of the world's older people.
- Women outlive men around the world by an average of 4.7 years.



### The epidemiological transition

- The global pattern of disease is shifting towards non-communicable diseases (NCDs).
- NCDs have a disproportionate impact on older people – in 2011, 75% of deaths from NCDs in low- and middle-income countries were of people aged 60 and over.



### The health systems transition

- Health systems need to adapt to the world's ageing population and the growth in NCDs to ensure older people's right to health is met.
- The Sustainable Development Goals and the global push towards universal health coverage provide opportunities to guide this transition.

of NCDs in older age, there are also high rates of multimorbidity. As people age, they are more likely to experience more than one chronic condition at the same time.

The health-related challenges represented by the high rates of NCDs and multimorbidity in older people are often accompanied by the need for more support with tasks of daily living in order to sustain independence and autonomy, resulting in health and social care becoming increasingly complex and interdependent. Health systems, and care and support systems, have so far failed to address this

complexity. The demographic and epidemiological transitions require health systems to adapt to a new reality, moving away from the vertical structures that address specific diseases towards more integrated and coordinated services that respond holistically.

There is a clearly gendered dimension to the demographic transition, and by extension to the epidemiological transition. The clearest difference between men and women is in life expectancy. Women continue to outlive men in most countries of the world, living for an average of 4.7 years longer.<sup>12</sup> The prevalence of different conditions varies by sex for older people. Older women and men face different consequences of discrimination based on their sex and other factors, including socioeconomic status. Gender- and age-sensitive health systems and services are needed that are able to respond to the gendered drivers of health differences.

## Universal health coverage

The 2030 Agenda as agreed by world leaders establishes 17 goals to “realise the human rights of all”.<sup>13</sup> Its central pledge is to leave no one behind and to reach the furthest behind first. Significant opportunities are thus opened up by the 2030 Agenda to advance the realisation of human rights for people of all ages, including older people. The right to health across the life course has gained increased attention with the adoption of the SDGs. To ensure healthy lives and promote wellbeing for all at all ages, SDG3 provides a critical opportunity to realise older people’s right to health.

Significantly, target 3.4 on NCDs recognises the shifting burden of disease and promises increased focus in this area of particular concern for older people. Meanwhile, to achieve UHC, SDG target 3.8 provides a potential pathway for the transitions needed to meet the demands of the demographic and epidemiological transitions. Older people currently face a number of challenges in realising the right to health however, including those related to access, quality and affordability – the three core components of UHC. Given the high rates of income

insecurity in older age, the financial risk-protection element of UHC will be key. In order to address the barriers, the implications for access, quality and financial protection for older people should be explicitly identified in each step of the process of developing systems to deliver UHC. The complexity of health in older age, including the prevalence of multimorbidity, means adaptations to systems to achieve UHC should ensure that care is person-centred and integrated.

The 2030 Agenda commits to the SDG indicators being disaggregated by income, sex, age, race, ethnicity, disability, geographical location and migratory status, including the indicators to measure progress towards UHC. Despite this commitment, older people are still excluded from the data currently collected against many indicators.

## Care centred on older people

### Beyond universal health coverage

Advocates for UHC have tended to focus on responses such as the removal of financial barriers, abolishing user fees in particular.<sup>14</sup> But the global health community also needs to address other barriers impeding access to health services, such as geographical distance, cultural differences, gender norms, citizenship and the social determinants of health. The goal of UHC, reaffirmed by SDG3, is to reach vulnerable populations so that no one is left behind, and therefore, “innovative methods are needed so that health services reach beyond and around these barriers”.<sup>15</sup>

### People- and person-centred care

While a single definition of people-centred care has not been agreed, key features include putting people and communities rather than diseases at the centre of health systems, and empowering people in relation to their health rather than making them passive recipients. Provision should thus be integrated rather than fragmented. The people-centred approach is at the level of populations and health systems, while for individual health



Older person from Buenaventura, Colombia

providers and patients, the relationship is person-centred. To achieve the best outcomes for older people, the principle of organising care around the concerns and priorities of the people themselves is a central goal in both people- and person-centred care.

Measuring progress in establishing integrated people-centred health services is challenging, however. Measures of integration or people-centredness are not included, for example, in WHO's global health observatory, in the monitoring and evaluation frameworks for UHC and the SDGs, or in the WHO global reference list of 100 core health indicators.<sup>16</sup>

Person-centred care is especially challenging – and necessary – with the most physically and mentally frail older people. Given that a high proportion of those needing care and support in older age are living with dementia, building an evidence base around the key features of person-centred care is of great importance here. Person-centred care is not confined to treatment in an institutional setting – person-centred approaches can also inform prevention and management in the community. Singapore, for example, has paid increasing attention in recent years to a range of interventions addressing the needs of people living with dementia as part of the wider older population, including appropriate public housing and transport, employment and support services.<sup>17</sup>

### **Long-term care and support**

While the focus of this report is older people's health, social support plays a key role. For people who experience a significant loss of intrinsic capacity, long-term care and support may be needed. Long-term care is defined as the activities undertaken by others to ensure that people with, or at risk of, a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity.<sup>18</sup> This definition moves the purpose of such care and support beyond that of meeting basic needs, recognising the agency of older people,

including their right to make decisions about their own lives and living arrangements.

In almost all LMICs, the most significant provision of care is that provided by close relatives without financial or other support. “This results in millions of vulnerable older people not having their basic needs met, or in some instances experiencing flagrant abuses of their fundamental rights. It also places an unnecessary burden on caregivers, who are overwhelmingly female.”<sup>19</sup>

One of the limiting factors in constructing policy around long-term care and support is the marked absence of comprehensive data. There is no consistent data collection on long-term care and support at the global and regional levels, and there are often gaps at the national level. The studies that do exist reveal that a significant proportion of older people are care-dependent, a prevalence that increases with age. This prevalence is also significantly higher in LMICs, where care infrastructures are weaker than in high-income countries.<sup>20</sup>

### **Data systems hinder older people's right to health**

The ability to assess whether the universal and inalienable right to health is enjoyed by all older people, without discrimination and on equal terms with others, depends on the existence of, and access to, good-quality, timely data. So too does the ability to identify gaps in relation to the availability, accessibility, acceptability and quality of health services for older people. The international data system has failed to keep step, however, with the shifts both in understanding of health as people age and in the reality of the population dynamics and trends in patterns of disease.

A number of issues persist across the collection, analysis, reporting and use of data on ageing and older people. These exist within data systems in general and in the production of health statistics specifically.





Older women and men are frequently excluded from data collection mechanisms. Much of the data relied on in LMICs, including on health, comes from household surveys. Some have age caps and therefore do not routinely include older people. Another limitation is that they often provide data and analysis at the household rather than individual level, telling us little about older people's health situation or access.

When data is collected, it is not always disaggregated and analysed by age. Data collected during humanitarian and emergency situations, for example, is often disaggregated by age in only two cohorts, aged up to five and over five.

Under-reported data includes that for adults in institutional care, individuals residing in informal settings or who are homeless, and people whose sexual orientation or gender identity is lesbian, gay, bisexual, transgender or queer or questioning.

To compile the research informing this report, the researchers set out to gather and analyse national data on older people's health from 12 countries. This exercise in itself revealed the following significant issues in the accessibility of data on health in older age.

- Data across several indicators was difficult to locate or did not exist in some countries.
- Data was not readily accessible, and locating sources relied heavily on personal professional relationships and networks, and was very time consuming.
- Where the researchers were able to access data, in some cases it could not be included in the analysis due to factors such as missing or incomplete labelling and the lack of guidance to understand how the data was organised.
- For some data sets, metadata needed to assess the quality of the data was missing, while other data was not stratified by key variables.



We need good-quality, timely data disaggregated by sex, age, disability and other relevant characteristics to measure, understand and respond to the diverse and specific needs of older men and women, and to monitor progress on the right to health for all.

- The comparability of variables across data sets was particularly challenging as the wording of questions and possible responses varied considerably.
- Other issues included the age of the data and the regularity with which it had been updated, sample sizes, and challenges compiling qualitative and quantitative data.

Predictions based on global estimates to understand trends across countries, population groups and time have limitations in the general quality of underlying data sources, model assumptions and in time lags between conduct of national surveys.

There is a pressing need for data to be collected across the life course and then disaggregated by age, but also by social group, gender, disability, ethnicity and location, to draw attention to the differentials in health and life expectancy within ageing populations, and to enable effective planning to meet their needs.

This includes the need to improve the coverage and quality of civil registration and vital statistics (CRVS) across LMICs to provide continuous demographic and health data on births and causes of death.

In addition, large-scale longitudinal studies conducted in multiple settings have an important role to play in improving the data

environment. These have the potential to capture data on the distribution of health and disability among older populations as well as on morbidity trajectories.

New sources of data (such as mobile phones, internet usage and social media, credit and debit cards, satellite imagery) generate real-time data faster, in a greater amount and on a wider range of topics than ever before. It is not clear, however, to what extent new sources of data can close the evidence gaps.

There have been positive responses, though, to the data gaps on ageing and older people, such as the establishment of the Titchfield City Group on ageing-related statistics and age-disaggregated data<sup>21</sup>, and the emerging development of conceptual and analytical frameworks for ageing-related statistics collected over the life course.

## What the data tells us about the health of older people

### Life expectancy

Data from the 12 profile countries included in this report shows that life expectancy for both men and women has been rising. Rates of increase differ across the countries, showing different stages of demographic transition, and therefore likely epidemiological transition, as well as significant inequities in health and wellbeing between countries.

The ratio of healthy life expectancy (HALE) to life expectancy indicates the proportion of life expected to be in good health. Globally, HALE is increasing, but may not be doing so at the same rate as life expectancy. For the proportion of life in good health to increase, gains in HALE will need to outpace those in broader life expectancy. In Kenya, Moldova and Serbia, the gap between HALE and life expectancy is increasing for men, meaning a greater proportion of life in poorer health. In Pakistan, Vietnam and Zimbabwe, by contrast, HALE is rising faster than life expectancy. Globally, women's HALE both at birth and age 60 is higher

than men's, but women can expect to live a greater proportion of their lives in poorer health than men.

### The shifting burden of disease

The majority of the burden that diminishes healthy life expectancy is now created by NCDs. While communicable diseases remain a concern for people of all ages in many LMICs, NCDs and injuries are the major contributors to poor health and death in most.

The prevalence of NCDs typically rises with age. The leading contributors to disease burden in the older population globally are cardiovascular disease (CVD, accounting for 30.3 per cent of the total disease burden), cancers (15.1 per cent), chronic respiratory diseases (9.5 per cent), musculoskeletal diseases (7.5 per cent), and neurological and mental disorders (6.6 per cent).<sup>22</sup> While CVD is declining as a cause of death among older people in many of the profile countries, the data suggests cancer is increasing in 11 out of 12. There is also a general trend towards an increased contribution from diabetes as a cause of death among older people. In the African countries, HIV remains a significant cause of death in the group aged 15 to 49, but also contributes, albeit to a lesser extent, to deaths at older ages.

### Cardiovascular disease

Data for the 12 profile countries shows that the prevalence of heart attacks increases with age.<sup>23</sup> In many, the prevalence of heart attacks tends to be lower in women than men in younger old age, but rates rise more quickly as women get older.

### Diabetes

Across the countries, prevalence of diabetes is generally increasing with age, peaking around age 70 before starting to decline. Increasing prevalence with age could be related to a host of both individual and

systemic issues, including insulin factors in older age, higher levels of abdominal obesity and other conditions that increase the risk of diabetes, and inadequate screening and poor access to treatment and support for older people. For both older women and men, the impacts of diabetes are high and increase with age, as shown by data on the disease's complications, such as visual impairment.

### **Cognitive and mental health – dementia, depression and suicide**

The contribution of dementia to mortality and years lived with disability is increasing. Around 50 million people live with dementia worldwide, the majority in LMICs, a figure projected to increase to 82 million by 2030.<sup>24</sup> The understanding of dementia remains limited, care inadequate and diagnostic coverage low.

The prevalence of dementia increases with age in all the 12 profile countries, rising steadily until mid-older age at around age 70 before rising more rapidly and then levelling off in the oldest (aged over 90). The prevalence of dementia is higher in women than in men aged 70 and over in all 12 countries.

Data on depression for the 12 profile countries shows a somewhat less consistent trend than was seen with the other physical and mental health conditions. A gender analysis presents more consistency: in all countries, prevalence of depression is higher in older women than men (with the exception of Myanmar, where the difference is very small, but the prevalence is higher for men).

In seven of the 12 countries, mortality rates due to self-harm are highest in the group aged 70 and over, followed by the group aged 50 to 69, and lowest among 15- to 49-year-olds. Self-harm or suicide mortality rates are higher in men than women across the 12 countries. The trends point to the importance of targeted interventions on depression and self-harm that are sensitive to the specific needs of population groups and individuals.

### **The complexity of health in older age: what do we measure?**

For health systems to be adapted to respond to the changing contexts of the demographic and epidemiological transitions, far more specific and nuanced data is required. This should highlight the complexities of health in older age, and how health challenges may be accompanied by a declining functional ability requiring health and social care. Data on activities of daily living (ADLs) and instrumental activities of daily living (IADLs) could provide more useful information, yet large-scale, comparable data is not available.

One example of how ADL and IADL data can be collected is shown by the 2012 Myanmar ageing survey.<sup>25</sup> This included an analysis of older people's mobility, a key element in assessing ADLs. The results show that challenges with mobility increase with age across the range of questions asked. For example, 16 per cent of men and 22 per cent of women between the ages of 60 and 69 reported some degree of difficulty with walking 200-300m, increasing to 38 per cent for men and 53 per cent for women aged 70 and over.

The Myanmar ageing survey also included other ADLs focused on older people's ability to take care of themselves without daily assistance from others – and the challenges increased with age for both women and men. IADLs were also included, with older people asked about their ability to do household chores, manage money, use transport, make phone calls and remember to take medication. Difficulties with IADLs increased with age but were typically more pronounced in older women than in men.

### **Universal health coverage**

To adequately monitor whether older people's right to health is being met, the core components of the right to health and of UHC need to be measured. The sourcing of data for this report has highlighted an almost complete absence of relevant data, however, and data that is collected within a broader population group is rarely disaggregated



Older person from an intergenerational self-help group in Vietnam

by age. Data has not been found that specifically covers the issues faced by older people in relation to the right-to-health components of availability, accessibility, acceptability and quality. On older people's access to health services and support more broadly, large-scale, representative, comparable data is again not available. Instead, there is a reliance on smaller-scale data sets or individual pieces of research. Where these have been found, they have shown that older people's right to health is not being met, and challenges with inequity, including by age and gender, persist in many countries.

Looking at the social determinants of health and linking with the SDG indicators, this project attempted to explore data on violence, water and sanitation, and poverty. The only issue for which data was found specifically for older people was violence. Some data on the prevalence of physical, sexual and psychological violence was available across all 12 countries for people aged 50 and over, with further age disaggregation.

There was no data for older people on access to water and sanitation, nor on SDG poverty indicators as reported by the UN Statistics Division. Sourcing data on the components of UHC was equally challenging. The SDG indicator on the coverage of essential health services is measured using an index reliant on WHO-managed non-communicable disease data that mostly excludes older people, and age disaggregation is not possible. The SDG indicator that monitors the financial risk-protection element of UHC is measured at the household rather than the individual level, thus providing no evidence for older people. Broader measures of the financial element of UHC, such as out-of-pocket expenditure, have similar limitations.

If efforts towards the achievement of UHC are to be monitored effectively, significant work will be needed to ensure appropriate disaggregation is possible.

## Conclusions

Across different societies, many long-established norms, practices and systems regarding ageing and older people are no longer fit for purpose, and older people are not enjoying their right to health. The data reviewed for this report shows that older people in LMICs are living longer but often with unnecessary ill health, disability and loss of wellbeing. Across the majority of the 12 profile countries surveyed, the data indicates that the gap between healthy life expectancy and life expectancy is growing.

Clear variations are evident in national patterns of life expectancy, healthy life expectancy, trajectories of disease and causes of death. Women can expect to live a greater proportion of their lives in poorer health than men, for example. These variations highlight the inequities in people's experience of health and wellbeing in older age.

If the challenges facing health systems in LMICs are immense, so too are the possibilities in settings where health and care systems have not become as institutionalised and entrenched as they are in high-income countries. There is an opportunity to shape holistic and integrated responses to the health needs of older populations, and to develop people-centred care models. UHC offers an opportunity for countries to strengthen their health systems and to adapt to demographic and epidemiological transitions.

The international data system has failed to keep step with the shifts in our understanding of health as we age, in the reality of population dynamics, and in trends and patterns of disease. Far more precise and nuanced data is required that highlights the complexities of health in older age and the challenges associated with declining functional ability that require integrated health and social care responses. Data on activities of daily living (ADLs) and instrumental activities of daily living (IADLs) could inform the development of more targeted services and support for older people.

In relation to availability, accessibility, acceptability and quality – the components of the right to health – almost no data specific to the issues faced by older people has been found. Both the focus of health data collection on younger age groups and the way data is collected results in this exclusion.

The findings of our mapping of data systems provide further concrete evidence of the gaps at national levels in the data available for planning for ageing and the health and wellbeing of older people. The gaps are such that it is simply not yet possible to systematically measure those SDG indicators that are relevant to older people. Notwithstanding the data gaps, the review of data for this report has clearly shown that, as populations grow older, the transition from acute infectious disease to NCDs presents a huge challenge.

### **Actions needed**

As we celebrate the 70th anniversaries of the UDHR and the foundation of the World Health Organization, now is a key time to make the changes needed to realise older people's right to health. The following actions are needed.

#### **Stakeholders must work in partnership with older people:**

- older people's voices, knowledge and perspectives should inform and guide collaborative action to design and implement integrated health systems that are shaped around the priorities and concerns of older people themselves.

#### **In response to the current demographic and epidemiological transitions, governments must:**

- include ageing and older people in national health policy, planning and implementation

- establish the right to health in legislation at the national level
- close the gap in the recognition of dementia, depression and other mental and cognitive health conditions in older age
- implement gendered and inclusive-health responses, taking account of the needs of specific groups of older people
- recognise and respond to the violence, abuse and neglect experienced by older people
- develop models of UHC that are holistic, person-centred and integrated across health and care and support systems
- define services for inclusion in UHC that are age-specific and responsive to the needs of older people
- support the development of geriatric and gerontological competence among all sectors of the health workforce.

#### **Multilateral agencies, governments and national statistical offices must ensure that:**

- older people are counted and included in statistical systems, and at all stages of data collection, analysis and use
- age caps are removed from international surveys
- statistics frameworks incorporate a life-course approach, providing more nuanced and useful data on ageing, health and functional ability
- data is disaggregated by age, gender, disability and location, and that age-specific results are published

- use of the ageist concept of “premature mortality” is discontinued
- LMICs are adequately supported in the development of CRVS and that capacity is built in their national statistical offices
- measurements of UHC are extended to include indicators on older people
- data is collected for a better understanding of the relationship between poverty and health across the life course and, specifically, in later life
- the deliberations and outputs of the Titchfield City Group on ageing-related statistics and age-disaggregated data are proactively supported, disseminated and used.

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