

Including older women and men in HIV data



This paper explores how data on HIV is collected, analysed and reported, and the challenges arising for older women and men as a result. It highlights the risks and implications of HIV for the older age group and recommends how to ensure that data includes people aged 50 and over.

A key challenge in addressing the needs of older women and men living with and affected by HIV has long been the exclusion of people aged 50 and over in HIV monitoring and reporting. HIV is a global issue with an advanced and successful monitoring system that provides a detailed picture of the status of the epidemic around the world. In 2012, 186 out of 193 UN Member States submitted country progress reports to the UN on their response to HIV, providing evidence against core global indicators set by UNAIDS.¹ Yet, despite the sophistication of the monitoring systems in place, gaps remain where data is not collected. Therefore, the epidemic cannot be fully understood.

One such gap is the absence of data on older women and men. With little data collected on people aged 50 and over – from basic prevalence to information on their attitudes, knowledge and behaviour – the nature and scale of the epidemic among women and men aged 50 and over² and the rate of the demographic shift occurring in the population living with HIV, has remained largely unknown. This neglect has led to a lack of understanding on how to address their needs and provide appropriate information and support.

Historically, data on HIV, and specifically estimates on prevalence and numbers of people living with the virus, were collected from women attending antenatal clinics. It was later recognised that by using this type of data, a whole picture of the epidemic was lacking and there was subsequently a shift towards using other sources. Increasingly, national household surveys, including Demographic and Health Surveys (DHS) and AIDS Indicator Surveys (AIS) have been used, alongside health facility and other survey data. But this shift has not overcome the challenge of the exclusion of older women and men. As DHS originally focused on reproductive health and family planning and targeted women and men between the ages of 15 and 49, their use has continued the trend of only collecting HIV data for younger adults.

In 2006, UNAIDS recognised that “the burden of disease extends beyond the age of 49” and stated that a “substantial proportion of people living with HIV and AIDS were aged 50 years and older”.³ As a result, UNAIDS and WHO estimates for the number of people living with HIV, new infections and AIDS-related deaths were extended beyond the 15-49 year age bracket to include all adults aged 15 and over. However, HIV prevalence data remained restricted to the 15-49 age group, as did a number of the core global UN General Assembly Special Session (UNGASS) indicators used to monitor the HIV epidemic, whose data source was DHS.

When the UNGASS indicators were reviewed in 2010-11, the challenge of including indicators restricted to the

15-49 year age group was recognised. Three out of four consultation groups recommended the expansion of the indicators to include women and men aged 50 and over.⁴ Although this recommendation was not taken forward and the Global AIDS Response Progress Reporting (GARPR) indicators (which replaced the UNGASS indicators) continue to include some restricted to the 15-49 year age group,⁵ the UNAIDS Monitoring and Evaluation Reference Group (MERG) recognised the issue and the need for more information to inform an ongoing discussion.

Why a change in data collection is critical now

The ageing of the HIV epidemic

Over recent years, significant progress has been made in gathering data and generating estimates that provide a better insight into the nature and scale of the HIV epidemic among older women and men. This data clearly demonstrates an ageing of the epidemic with increasing numbers of women and men in their 50s, 60s and beyond living with HIV.

In 2013, UNAIDS published *HIV and Aging: A special supplement to the UNAIDS report on the global AIDS epidemic 2013*. The report estimates that 10 per cent of adults living with HIV worldwide are aged 50 or over, and is a clear indication of UNAIDS’ recognition of the ageing of the epidemic and the need for more attention to be given to the older age group.

Table 1: Older women and men living with HIV in sub-Saharan Africa

Country	Number of people living with HIV aged 50+	50+ as percentage of total people (15+) living with HIV	HIV prevalence in people aged 50+ (15-49 prevalence)
Botswana	49,700	17.8	24.4 (23.9)
Ethiopia	157,700	17.7	2.1 (2.1)
Ghana	33,900	13.6	1.4 (1.9)
Kenya	169,100	10.6	5.6 (7.8)
Lesotho	61,900	23.8	27.8 (23.2)
Mozambique	228,500	16.3	11.2 (12.5)
Nigeria	300,300	12.5	2.1 (3.1)
South Africa	679,700	12.6	10.2 (18.1)
Swaziland	31,400	18.5	29.2 (26.1)
Uganda	150,100	18.5	6.8 (5.4)
Zimbabwe	206,600	17.2	15.2 (15.3)

Source: Negin J and Cumming R, 2010

At the end of 2012, 9.7 million people living with HIV in low- and middle-income countries were receiving anti-retroviral therapy (ART). This represented a more than 30-fold increase since 2003, and close to a 20 per cent increase in just one year.⁶ It is largely this rapidly scaled-up access to ART that is changing the face of the epidemic and leading to the increased numbers of older women and men living with HIV. A major success of treatment efforts is the fact that people are able to live with HIV for longer, including into older age. But long-term survival is not the only factor: older women and men also remain sexually active and are becoming newly infected and diagnosed.

By 2015, over 50 per cent of people living with HIV in the United States will be aged 50 or over,⁷ with San Francisco the first city to reach this milestone in 2013.⁸ In 2010, it was estimated that approximately 3 million women and men aged 50 and over were living with HIV in sub-Saharan Africa, accounting for approximately 14 per cent of all people living with HIV in the region.⁹ Table 1 shows the number of older women and men living with HIV in selected countries in sub-Saharan Africa. In many countries, women and men aged 50 and over constitute over 15 per cent of all people living with HIV. Projections show the number of older women and men living with HIV in the region tripling to around 9 million by 2040, accounting for over 25 per cent of people living with HIV.¹⁰

In addition to those surviving into their older age with HIV, some data has emerged on new infections in older age. The Government of Kenya estimated that in 2011, between 5.5 and 16.5 per cent of new infections were among those aged 50 and above.¹¹ In Brazil, incidence has increased in both the 50-59 and 60 and over age groups. Incidence in men aged 50-59 increased from 22.2 per 100,000 in 1998 to 28.6 in 2010. In women in the same age group, the increase was from 9.5 to 16.3 per 100,000.¹²

Global population ageing

The ageing of the HIV epidemic is occurring in the context of broader population ageing – one of the most significant trends of the 21st century. One in nine people in the world is currently aged 60 years or over, with this figure projected to increase to one in five by 2050.¹³ Table 2 shows the projected number of people aged 60 and over and the likely increase between 2011 and 2050. These figures demonstrate the increasing number of women and men who will continue to be excluded from HIV data, and neglected in the response to the epidemic if current monitoring practices and data sources are maintained.

Risks and implications of HIV for older women and men

With increasing numbers of older women and men living with HIV but limited data and understanding of how best to provide information and support, there is a significant risk that older women and men will remain neglected in the HIV response. This will lead to inadequate information and support and increased risk behaviour. The growing numbers of older women and men living with HIV represent one of the major markers of success of treatment efforts, yet a lack of understanding on how best to meet their health needs and support their ongoing ART adherence could place this success in jeopardy.

The GARPR indicators restricted to people aged 15-49 are largely focused on behaviour, both in relation to sexual activity and health-seeking behaviour. As a result of the age restriction of these indicators and the exclusion of older women and men from DHS and AIS which ask these questions, little is known about their behaviour and potential risks. Despite the exclusion of people aged 50 and over from indicators and surveys, some countries have begun to collect data for older men, usually up to the age of 59, that gives an insight into their attitudes, knowledge and behaviour. However, data is very rarely collected for older women.

Table 2: Population growth of people aged 60 and over (millions)

Country	2011	2050
Africa	58	215
Asia	430	1,253
Europe	164	242
Latin America and the Caribbean	61	188
North America	66	121
Oceania	6	13
Total	785	2,032

Source: United Nations, *World Population Prospects: The 2010 Revision*

Data on sexual behaviour among older women and men shows that people often remain sexually active into their older age but are much less likely to practise safer sex than younger people.

Evidence from Lesotho shows 12.6 per cent of men aged 50-59 had two or more sexual partners in the previous 12 months, compared to 21.9 per cent of men aged 15-49.¹⁴ In Swaziland, the figures are 10.1 per cent for men in the 50 and over age group and 22.9 per cent of men aged 15-49. Data is also available for Swazi women, with 1.2 per cent of aged 50 and over reporting sex with two or more partners in comparison with 2.3 per cent of younger women aged 15-49.¹⁵ In Nigeria, higher rates of sex with multiple partners are seen in older men, with 12.9 per cent of men aged 50-59 in comparison with 9.9 per cent of men aged 15-49.¹⁶

Figure 1 shows rates of condom use at last sex among men who have had higher-risk sex in the last 12 months. Rates are consistently much lower in men aged 50-59 than in those aged between 15 and 49.¹⁷⁻³⁰

Data on HIV testing among older women and men also gives a clear indication of the risks of excluding older women and men from the HIV response. A major challenge for older people living with HIV is late diagnosis. Research undertaken in France has shown that older women and men are more likely to have HIV diagnosed late. This is likely a result of their low

perceived self-risk, and health professionals being less inclined to recommend an HIV test for older women and men with symptoms suggestive of HIV.³¹ Similar findings have also been seen in the UK.³²

In Swaziland and Botswana, data on HIV testing shows a need to increase access among older women and men. Table 3 shows the lower coverage of testing seen among women aged 50 and over in Swaziland compared to women aged 15-49.

The evidence of continued sexual activity, low levels of condom use during higher-risk sex and low rates of testing among older women and men provide a clear indication of the risks of their continued exclusion from surveys and in data collection. The limited data available, mainly for older men, points to some of the challenges for the HIV response and the need for much improved information and support for older women and men.

Including older women and men in surveys

Including older women and men in DHS and AIS would not be without implications. Adding people aged 50 and over mean increasing the sample size and, therefore, the number of interviewers and time needed for data analysis. These issues would lead to some increase in the cost of conducting surveys. However, with older women and men often present in the households where surveys are already being conducted, interviewers would not often have to visit an increased number of households. Rather, they

Figure 1: Rates of condom use among men aged 50-59 and 15-49

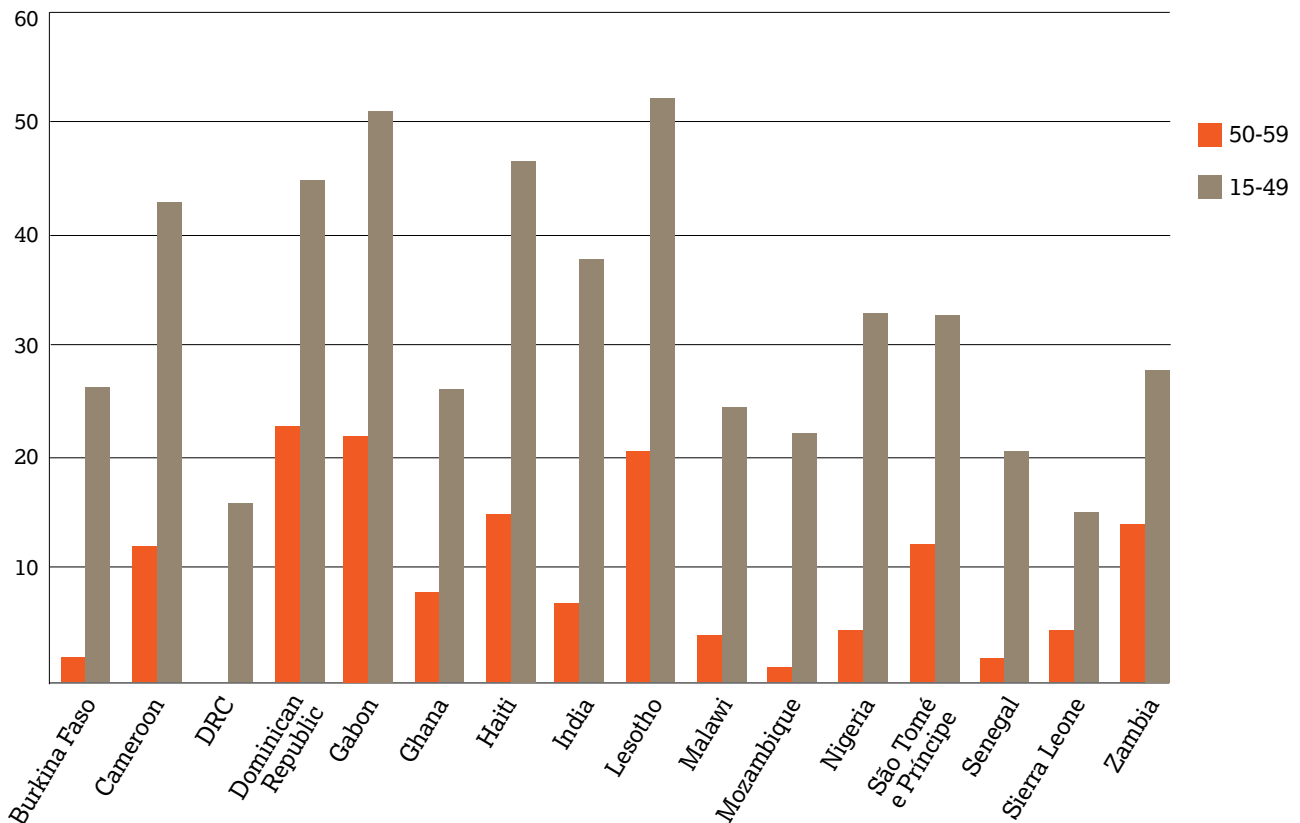


Table 3: Coverage of testing among women in Swaziland

	Women 50+	Women 15-49
Received results from last HIV test taken in last 12 months	10.2%	21.9%
Know where to get an HIV test	71.1%	91.8%
Ever tested and received results	15.6%	35.8%
Ever tested	18%	40.7%
Never tested	82%	59.3%

would interview more people within the same households, ensuring they also capture information from older women and men. The time taken for data collection would, therefore, increase but not as much as if new households had to be sought and visited.

As DHS is historically a survey focused on reproductive and child health, there will be elements of the survey that are not relevant to older women and men. However, as the survey template has changed over time to include additional issues, the benefits of expanding the survey to include older women and men have become more apparent. The survey already includes options to skip questions that are not relevant to the respondent and similar filters could be added for older people.

There has also been a concern about how expanding the sample of surveys to include different age groups could affect comparability of findings with previous surveys conducted with the 15-49 year age group only. This issue has already been addressed in surveys that have included men aged 50-59 by including data for the 15-49, 50-59 and 15-59 year age groups.

As the increased cost of including older women and men is most commonly cited as the major barrier to their inclusion, this issue needs to be considered. Cost should, however, by no means be the driving factor as to whether older women and men are included in surveys in the future. The data in this paper shows both the rapidly increasing numbers of older women and men living with HIV and their risk behaviour as a result of low-perceived risk and poor access to information and services. This points to the need for better targeting of older women and men in the HIV response, and better data to inform the nature of that response. The fact that some surveys conducted in recent years have included older men, and in a few instances older women, demonstrates that the collection of data is both feasible and useful.

A review of the DHS template in early 2014 provides a window of opportunity for a discussion of the implications of including older women and men in the surveys. Through joint effort, solutions to the challenges of expanding surveys can be reached, allowing for the inclusion of older women and men in future DHS and AIS. The ageing of HIV is a key challenge in this fourth decade of the epidemic. The collection of data on older women and men is, therefore, the first step in the provision of a comprehensive and appropriate HIV response.

Recommendations

- The expansion of the DHS and AIS templates to include women and men aged 50 and over to ensure improved data collection and a more comprehensive understanding of the nature and scale of the epidemic among older people.
- Increased commitment from governments to ensure their DHS and AIS include older women and men and that data is fully analysed, reported and used to inform the HIV response.
- Increased commitment from donors to provide funding for the inclusion of older women and men in DHS and AIS.
- The expansion of GARPR indicators currently restricted to the 15-49 year age group with data disaggregated by age and sex.

Notes

- 1 See www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries
- 2 With the HIV response and data focused on the 15-49 age group, the term 'older women and men' is used in this paper and in the wider HIV community to refer to people aged 50 and over. This is in contrast to the UN definition of 'older people' as people aged 60 and over.
- 3 UNAIDS, *Report on the global AIDS epidemic: A UNAIDS 10th anniversary special edition*, Geneva, UNAIDS, 2006
- 4 Consultation groups on prevention, care and support and the health sector
- 5 Indicators: 1.3 Percentage of adults aged 15–49 who had sexual intercourse with more than one partner in the past 12 months; 1.4 Percentage of adults aged 15–49 who had more than one sexual partner in the past 12 months who report the use of a condom during their last intercourse; 1.5 Percentage of women and men aged 15-49 who received an HIV test in the past 12 months and know their results; 7.1 Proportion of ever-married or partnered women aged 15-49 who experienced physical or sexual violence from a male intimate partner in the past 12 months.
- 6 World Health Organization, UNICEF and UNAIDS, *Global update on HIV treatment 2013: Results, impact and opportunities*, Geneva, World Health Organization, 2013
- 7 Centers for Disease Control and Prevention, Surveillance data, Gordon Smith, Senate Committee on Aging, 2005
- 8 See www.aidsmap.com/Over-half-of-people-living-with-AIDS-in-San-Francisco-are-aged-50-or-older/page/2679010
- 9 Negin J and Cumming R, "HIV infection in older adults in sub-Saharan Africa: extrapolating prevalence from existing data", *Bulletin of the World Health Organization*, 88:11, November 2010, pp.847-853
- 10 Hontelez JAC et al, "The impact of antiretroviral treatment on the age composition of the HIV epidemic in sub-Saharan Africa", *AIDS*, 26, 2012, pp. S19-S30
- 11 Government of Kenya, *The Kenya AIDS epidemic update 2011*, Nairobi, Office of the President, National AIDS Control Council, 2012
- 12 Brazilian Ministry of Health, Progress report on the Brazilian response to HIV/AIDS (2010-2011), 2012
- 13 UNFPA and HelpAge International, *Ageing in the twenty-first century: A celebration and a challenge*, New York and London, 2012
- 14 Government of Lesotho, *Demographic and Health Survey 2009*, Maseru, Ministry of Health and Social Welfare, 2010
- 15 Government of Swaziland, *Demographic and Health Survey 2006-07*, Mbabane, Central Statistics Office, 2008
- 16 Federal Republic of Nigeria, *Demographic and Health Survey 2008*, Abuja, National Population Commission, 2009
- 17 Institut National de la Statistique et de la Démographie (INSD), *Enquête Démographique et de Santé et à Indicateurs Multiples (EDSBF-MICS IV) 2010*, Ministère de l'Économie et des Finances, 2012
- 18 Institut National de la Statistique, *Enquête Démographique et de Santé et à Indicateurs Multiples 2011*, Ministère de l'Économie de la Planification et de l'Aménagement du Territoire Ministère de la Santé Publique, 2012
- 19 Ministère du Plan avec la collaboration du Ministère de la Santé, *Enquête Démographique et de Santé République Démocratique du Congo 2007, 2008*
- 20 Centro de Estudios Sociales y Demográficos (CESDEM), *Encuesta Demográfica Y De Salud Republica Dominicana 2007, 2008*
- 21 Direction Générale de la Statistique, *Enquête Démographique et de Santé 2013*, 2013
- 22 Ghana Statistical Service, *Demographic and Health Survey 2008*, Accra, Ghana Health Service, 2009
- 23 République D'Haiti, *Enquête Mortalité, Morbidité et Utilisation des Services 2012*, Ministère de la Santé Publique et de la Population (MSPP), 2013
- 24 Government of India, *National Family Health Survey 2005-06*, Ministry of Health and Family Welfare, 2007
- 25 National Statistical Office, *Demographic and Health Survey 2010*
- 26 Ministério da Saúde Instituto Nacional de Saúde, Inquérito Nacional de Prevalência, Riscos Comportamentais e Informação sobre o HIV e SIDA em Moçambique 2009, 2010
- 27 Instituto Nacional de Estatística Ministério da Saúde, *Inquérito Demográfico e Sanitário (IDS STP 2008-2009)*, 2010
- 28 Agence Nationale de la Statistique et de la Démographie (ANSD), *Enquête Démographique et de Santé à Indicateurs Multiples Sénégal (EDS-MICS) 2010-2011*, 2012
- 29 Statistics Sierra Leone, *Demographic and Health Survey 2008*, Ministry of Health and Sanitation, 2009
- 30 Central Statistics Office, *Demographic and Health Survey 2007*, Ministry of Health Zambia, 2009
- 31 Cuzin L et al, "Immunological and clinical responses to highly active antiretroviral therapy in patients with HIV infection aged > 50 years", *Clinical Infectious Diseases*, 45, 2007, pp. 654-657
- 32 Smith R et al, "HIV transmission and high rates of late diagnosis among adults aged 50 and over", *AIDS*, 24:13, August 2010

HelpAge International helps older people claim their rights, challenge discrimination and overcome poverty, so that they can lead dignified, secure, active and healthy lives.

HelpAge International
PO Box 70156
London WC1A 9GB, UK
Tel +44 (0)20 7278 7778
Fax +44 (0)20 7387 6992
info@helpage.org
www.helpage.org

Written by Rachel Albone, HIV Policy Adviser, HelpAge International

Edited by Portia Reyes

Copyright © 2013 HelpAge International
Registered charity no. 288180

Front page photo © Kate Holt / HelpAge International

Any parts of this publication may be reproduced for non-profit purposes unless indicated otherwise. Please clearly credit HelpAge International and send us a copy of the reprinted article or a web link.

Supported by

