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### **Agenda item 11**

HIV and ageing

### **BACKGROUND NOTE**

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## Introduction

1. The 37th UNAIDS Programme Coordinating Board (PCB) meeting agreed that the theme for the Thematic Segment of the 39th meeting to be held in December 2016 would be HIV and Ageing.
2. In September 2015, the 2030 Agenda for Sustainable Development was adopted, with a plan of action to leave no one behind. Following this, in May 2016, the World Health Assembly adopted the *First Global strategy and plan of action on ageing and health 2016-2020: towards a world in which everyone can live a long and healthy life*, which spans the 15-year period of the Sustainable Development Goals (SDGs) and calls for a global campaign to combat ageism [1,2].
3. Out of an estimated 36.7<sup>1</sup> million people living with HIV in 2015 globally, 5.8<sup>2</sup> million people (2.5<sup>3</sup> million women and 3.3<sup>4</sup> million men) are aged 50 and older and this figure continues to grow [3]. A concerted effort is clearly required to firmly place HIV and ageing on the international agenda. It is extremely important and timely that this topic be addressed from a people-centred and public health perspective.
4. Older people living with HIV, similar to other age groups, are characterized by great diversity – there is no typical older person [4]. Women and men aged 50 and over living with HIV are heterosexual, transgender, lesbian, gay men and other men who have sex with men, sex workers, people who use drugs, people in prisons, among other, and as such, have different needs and different challenges. These ageing adults face significant social, psychological and physical challenges associated with the ageing process [5].
5. For people living with HIV aged 50 and older, the HIV-related and ageing-related health and social needs converge. HIV and ageing is also an important issue for people who are at risk and/or acquiring HIV at 50 years and above. HIV and ageing is an important issue for all people living with HIV, as to achieve the goal of universal access to antiretroviral therapy (ART) by 2030, ending the AIDS epidemic requires a healthy population of people living with HIV throughout the lifecycle.
6. Ageing and HIV is also important for children and young people living with HIV who will be managing an HIV infection for almost their entire lives. This includes people born with HIV who are living with HIV since birth. Although the ageing-related needs of this younger population group of people living with HIV are extremely important, this paper focuses more on the people living with HIV aged 50 and above.
7. The paper explores the state of the epidemic among people living with HIV and at risk of acquiring HIV aged 50 and above, the impact of ageing with HIV, including for key populations and women living with HIV, identifies areas of health and social sector responses and ends with recommendations for future actions.

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<sup>1</sup> Uncertainty bounds [34.0 million-39.8 million]

<sup>2</sup> Uncertainty bounds [5.4 million – 6.3 million]

<sup>3</sup> Uncertainty bounds [2.3 million – 2.8 million]

<sup>4</sup> Uncertainty bounds [3.0 million – 3.5 million]

## THE STATUS OF THE EPIDEMIC AMONG PEOPLE OLDER THAN 50 YEARS

8. An increasingly significant trend in the global HIV epidemic is the growing number of people living with HIV aged 50 and over [6]. This is partly due to the success of ART in prolonging the lives of people living with HIV. Where ART is available and accessible, HIV has become a treatable chronic infection and many people living with HIV who acquired the virus in youth are now living into their 50s, 60s and beyond [7]. In addition, more middle-aged and older adults are contracting HIV [8]. This fits into the broader context of the global demographic shift where, in many settings, an increasing percentage of the population is over 50 due to increased life expectancy and falling fertility rates [4]. Though data on HIV prevalence and particularly incidence in this older population are limited, especially in low- and middle-income countries (LMIC), some studies suggest that both prevalence and incidence in the over-50-year-olds may be higher than expected; and yet the risk factors appear almost totally unexplored [9].
  
9. Globally, 17% of the adult population (15 and over) living with HIV is aged 50 and over and there are some notable differences between high and low-and-middle-income countries (see *Figure 1 below*). In 2015, more than 3 million people living with HIV<sup>5</sup> aged 50 and over (2 million<sup>6</sup> women and 1.6 million<sup>7</sup> men) live in sub-Saharan Africa, constituting 80% of females and 50% of males living with HIV aged 50 and older globally [3]. This has increased from 1.4 million for women, and 1.2 million for men in 2010. In 2015, there were 580,000<sup>8</sup> people aged 50 and over living with HIV in the Asia-Pacific region, 300,000<sup>9</sup> in Eastern and Central Asia and 370,000<sup>10</sup> in Latin America and the Caribbean and 860,000<sup>11</sup> people living with HIV aged 50 and over in Western and Central Europe [3]. (see *Figure 2 below*). People aged 50 and over living with HIV in low-and middle-income countries represent 15% of adults (15 and over) living with HIV. In high-income countries, people aged 50 and over represent 31% of the adult population living with HIV in 2015, having increased from 13% in 2000 [3]. Modeling estimates in 2015 indicate an ongoing shift in the age composition of the HIV epidemic towards older ages [3].

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<sup>5</sup> uncertainty bounds [3.2 million – 4.0 million]

<sup>6</sup> uncertainty bounds [1.8 million – 2,2 million]

<sup>7</sup> uncertainty bounds [1.4 million-1.8 million]

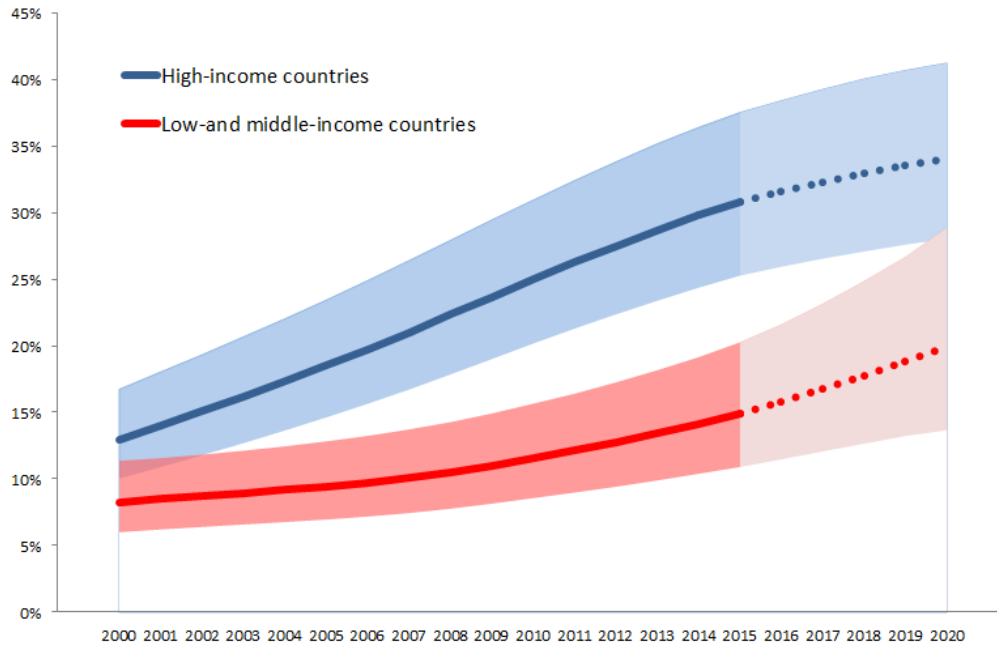
<sup>8</sup> uncertainty bounds [500,000-680, 000]

<sup>9</sup> uncertainty bounds [280,000-320,000]

<sup>10</sup> uncertainty bounds [320,000-430,000]

<sup>11</sup> uncertainty bounds [790,000-950,000]

Figure 1: Among adults (15+) living with HIV, the percent who are aged 50 and over, high-income countries and low-and middle-income countries, 2000–2020

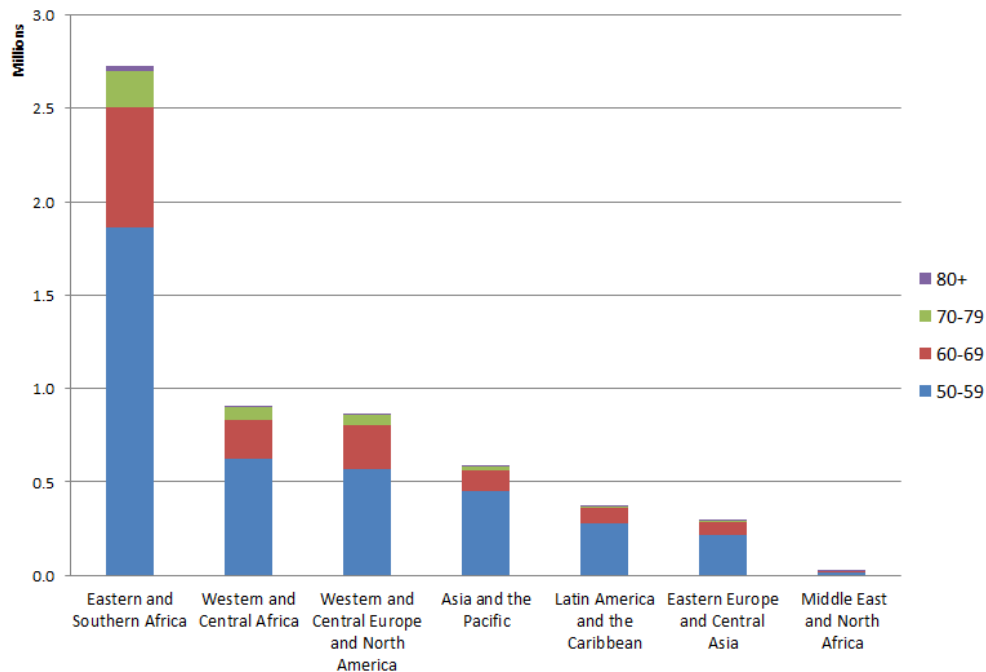


Source: UNAIDS 2016

Estimates. Projections 2016-2020 are based on an assumed scale-up of ART to reach 81% coverage by 2020.

Note: Based on 2015 high-income and low-and-middle-income countries definitions.

Figure 2: Number of people living with HIV aged 50 and over, by regions, 2015



Source: UNAIDS 2016 estimates.

10. There is very little directly measured data on HIV prevalence and incidence among those aged 50 and over. In a 2012 national HIV survey in South Africa, HIV prevalence was 13% among people aged 50–54 years, and 12% among women and 6.9% among men aged 55–59 years (compared to 18% among men and women aged 15–49 years) [10]. In Kenya, HIV prevalence was 5% among people aged 50–64 years (compared with 7.4% in people aged 15–49 years). In Swaziland, a 2006–2007 national population-based survey, found 13% of men and 7% of women aged 60–64 years were living with HIV (compared to 27% among men and women aged 15–49 years). In the cases of South Africa and Kenya where surveys have been repeated, prevalence among older individuals had increased compared to data from previous surveys [6]. Evidence from a study in the US suggested that the number of HIV cases in older women is expected to continue to increase as women live longer and where they engage in unsafe sex [11,12]. Systematic and relevant age- and sex-disaggregated data is needed in order to strengthen evidence-based policy and planning.

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#### Ageing with HIV, Poland

During those 30 years I had pneumonia twice, bronchitis many times, I came close to tuberculosis, got infected with HCV type 3A, but got rid of it after 48 weeks of treatment with interferon, and have had cataracts in both eyes. In 2000, I was diagnosed with chronic obstructive pulmonary disease (COPD) and recently bronchiectasis. In addition, I have degeneration of the spine. Despite these small problems, all the time I am on ARV therapy but for various reasons I changed combinations of drugs and for the last 18 months I am on treatment one-tablet Stribild. My CD4 increased to 1009 copies and my viral load has been undetectable for years. The most important thing for me is my family, my three children, their spouses, and my four grandchildren and two on the way.

I think I still have a lot to do here on earth

**Wojciech J. Tomczyński, Chairman of Polish Network of PLWHA "Sieć Plus", Warsaw, Poland, 70 years old and living 30 years with HIV**

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11. While it is important to consider the population of people living with HIV ageing into this older age bracket, it is also important to consider the prevention and care needs of the people who acquire HIV at 50 years and older. In 2015, 120,000<sup>12</sup> people (50,000 women<sup>13</sup> and 71,000 men<sup>14</sup> aged 50 years and older acquired HIV [3]. A better understanding of the epidemiology of incident infection in older populations – specifically where these infections are occurring, the demographics of those newly infected, and the risk factors for incident HIV infection – is key in order to implement appropriate prevention and care interventions.
12. Older people represent a significant proportion of those attending treatment facilities for ART. In one multicenter cohort across nine countries in sub-Saharan Africa over 11% of people on ART were over 50 [13]. In a study in Uganda 11% of the ART patients were over 50 and a South Africa study reported 15% of patients living with HIV over 45 ([14–16], cited in [17]). This group of people aged 50 and over on ART would include those who have been

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<sup>12</sup> uncertainty bounds [110,000–140,000]

<sup>13</sup> uncertainty bounds [44,000–58,000]

<sup>14</sup> uncertainty bounds [62,000–81,000]

on treatment for many years and those newly diagnosed, with some different considerations for support and medical management.

13. People living with HIV aged 50 and over who are not on treatment appear to progress more rapidly to AIDS than younger people who are not on treatment [18]. Several studies have shown that after starting ART, CD4 reconstitution is significantly slower among older persons ([13,19], cited in [17]). Though WHO recommends prompt initiation of ART for all people living with HIV, the reported slower rate of immune reconstitution in older adults underlines the importance of particularly rapid and early ART initiation for this age group [17].
14. Evidence also shows that older people are less likely to be routinely screened for HIV or take a test and, as a result, they are more likely to be diagnosed late in the course of HIV infection [20]. Confounding factors contributing to delayed diagnosis among people living with HIV aged 50 and older include long asymptomatic periods before the onset of advanced immunodeficiency, lack of patient awareness about or disclosure of risk factors for HIV infection, diagnostic confusion in patients of this age group [18] and providers who are either not aware of HIV in older populations or perceive that individuals in this age group are not at risk.

## **AGEING WITH HIV: THE INTERCONNECTION OF GETTING OLDER AND GETTING OLDER WITH HIV**

15. The effects of ageing with HIV are still being studied. This is due in part to the fact that it is only recently that there has been a substantial cohort of people living with HIV for 20-30 years, many of whom are now aged 50 and above, and in part due to the fact that people living with HIV have often been seen as a homogeneous group with no variance in needs based on age groups.

### **Health challenges**

16. People living with HIV aged 50 and above face particular health challenges. The interconnection of HIV and non-communicable diseases is influenced by increasing survival due to effective ART, lifestyle factors, long-term complications of ARVs and other disease conditions associated with ageing [21].
17. People living with HIV face an increased risk of developing a number of age-associated non-communicable diseases (NCDs) [22], which may worsen HIV disease progression [18]. HIV-associated NCDs include cardiovascular disease, various cancers, neurological complications, liver and renal problems, bone abnormalities and 'frailty', diabetes, hypertension, chronic obstructive pulmonary disease and liver and kidney disease [8,23].
18. People living with HIV have long been known to be at increased risk of certain AIDS-defining cancers such as Kaposi's sarcoma, cervical cancer, and anal and non-Hodgkin's lymphoma [24]. People living with HIV tend to develop such cancers younger and have advanced stage cancers more frequently. As a result, it is now understood that HIV leads to 'early' or 'accelerated' ageing [17]. Chronic inflammation and immune activation, usually seen in



elderly people, can therefore be present in people living with HIV who experience a type of premature ageing that affects quality of life [25].

19. People living with HIV are at increased risk of cardiovascular disease compared to HIV-negative people in the same age ranges, and cardiovascular disease accounts for an increasing proportion of mortality among people living with HIV [21]. Studies have confirmed that the risk of both myocardial infarction and cerebrovascular disease is 40–70% higher among people with HIV than among HIV-negative people of similar age and sex. Similar findings have also been reported in children and adolescents with HIV [21].
20. A large study in the US and Europe found that 60% of people living with HIV smoked. People living with HIV on ART may lose more life years due to smoking than through HIV, and mortality associated with smoking increases significantly with age [26].
21. In people living with HIV, ageing may result in an increased susceptibility to secondary infections and a delayed immune response [27]. Good nutrition is an important consideration in the clinical care of people living with HIV, one which is particularly important in the context of associated NCDs such as diabetes, hypertension, cardiovascular and renal disease.
22. Studies from developed and developing countries have found that accelerated ageing could be a factor in cataract disease among people living with HIV [28,29]. Cataract disease is the leading cause of blindness worldwide. Ageing people living with HIV are also more susceptible to frailty, a condition that is associated with increased comorbidity and loss of autonomy [30]. In a study in France, 2 out of 3 people living with HIV were frail or pre-frail and 1 out of 2 were precarious.
23. HIV co-infections, in particular co-infection with TB and Hepatitis C (HCV), pose increasing challenges for people living with HIV. TB is one of the leading causes of death in people living with HIV. With increasing life expectancy and growing exposure to TB, it is possible that TB in the elderly may become an increasing problem globally [31]. Worldwide there are 2 300 000 HIV-HCV co-infections of which 1 363 000 are in people who use drugs [32,33]. Response to HCV treatment is weaker among people living with HIV. Several studies have shown that HIV-HCV co-infection is associated with more rapid progression to cirrhosis, end-stage liver disease, and liver cancer [32,34,35]. Drug use, HCV, and ageing together serve to worsen the neurocognitive profile of HIV [36] and increase the burden of disease for people who are co-infected with HIV and HCV.
24. While more work is needed to understand the impact of ageing for people living with HIV, responding to the health needs of people living with HIV over 50 needs to be placed within the broader context of the health systems response to the health needs of older adults. As people age, they are more likely to experience comorbidity – the presence of more than one co-existing chronic condition at the same time. Comorbidity has a significant effect on functioning and quality of life and increases the risk of mortality. In high-income countries, more than half of all older people are affected by comorbidity, with prevalence increasing sharply in very old age [4]. In low- and middle-income countries comorbidity is likely to be more prevalent given the double burden of communicable and non-communicable diseases. In clinical practice comorbidity is under-recognized, under-diagnosed, underestimated and undertreated. [37].

25. Research from high income countries shows that people living with HIV may have up to five times the risk of chronic disease, geriatric syndromes and comorbidity, even for those whose HIV infection is well treated and managed [38,39]. People managing multiple chronic conditions may be taking a number of medications at the same time (polypharmacy) alongside antiretroviral (ARV), medication increasing the chance of medication interaction. New technologies aimed at reducing cardiac and cancer comorbidities among people aged 50 and older living with HIV could be both effective and cost-effective. For example, evidence suggests that a polypill (a medication that combines multiple active pharmaceutical ingredients) could have a role in reducing both cardiovascular and also cancer deaths [17].
26. Demographic projections for Africa and current data from rapidly developing countries, such as India and China, show that chronic diseases associated with ageing pose a high burden ([40] cited in [17]). For people living with HIV aged 50 and older in Africa, this indicates a triple threat in that HIV risk is likely underestimated, chronic diseases receive little attention and people living with HIV experience an increase in age-associated comorbidities such as cardiovascular disease and neurocognitive decline [17].
27. According to modeling, an increasing number of older adults living with HIV with frailty, geriatric syndromes and disability depict a “geriatric HIV” scenario and multimorbidity will be the norm. The proportion of people living with HIV 50 years and above will increase from 42% in 2015 to 95% in 2030; 30% of people living with HIV will have geriatric syndrome and 34% will be disabled [41]. This highlights the urgency to Fast Track the response for people living with HIV 50 years and above.

### **Impact of long-term antiretroviral therapy**

28. People living with HIV aged 50 and over are more susceptible to the adverse effects of ARVs, lower rates of immune reconstitution, and experience higher rates of mortality even though virological responses to treatment are greater than those of younger individuals [42,43]. While adherence to HIV treatment among older people appears better than among younger people [44], the presence of other chronic illnesses may also often negatively impact on adherence rates [8].
29. People living with HIV aged 50 and over will increasingly have to manage the long-term side-effects of ARVs. Those with co-morbid conditions may be at higher risk for adverse effects, and are more likely to be taking multiple medications, increasing the risk of ART non-adherence and complications with medication interactions, threatening the efficacy of ART and the person’s overall health. The actual side effects of long-term antiretroviral therapy affect men and women differently.

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#### **Ageing with HIV, South Africa**

“Physically I am heavily restricted and while I tend to put on a brave ‘no problem’ face, I am uncomfortable most of the time [in any position, except when on my couch at a 45 degree angle or lying down on my bed]...anything else is very uncomfortable like sitting in a chair or plane seat/car seat] and in the past weeks, the pain in my hips and knees has escalated and is getting worse...I am destined to end up in wheelchair, it’s just a matter of time. Not a reality I am looking forward to, but a reality none the less. My issues are not fixable and are degenerative. Fact.

I tell people that none of this is HIV related and while there is an element of truth in this, it’s not 100% honest...long term use of ARV’s have contributed to what I am dealing with - almost 13 years on

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Chemo [ARVS] have taken their toll on my body. The neuropathy, osteoporosis and osteoarthritis are as a direct result of long-term exposure to ARV's. So I am out there advocating people getting on treatment but not telling them the long term effects of both the ARV's as well as the ageing process...the longer you are on ARV'S and the older you get, the more complications you have as you have to add ageing conditions/illnesses to the equations, so it gets complicated"

**David Ross Patient, South Africa, 55 years old, Inspirational Speaker, Trainer, Author and long-term survivor of HIV**

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30. Resistance to ARVs poses a real challenge for all people living with HIV, including those aged 50 and over as well as to the health systems that support them. Acquired resistance (development of resistance within an individual on treatment) and transmitted resistance (spread of drug-resistant strains) may reduce the effectiveness of treatment programmes at an individual and population level, and may result in a less profound effect of the ART scale-up ([45] cited in [46]). In people living with HIV who develop drug resistance, suppression of viral replication may not occur, potentially resulting in disease progression, shorter survival times and higher risk of HIV transmission. For those in more developed countries, resistance can be managed by changing to second and third-line ART regimens. However, for those living in less developed countries, most treatment programmes are not well equipped to deal with drug resistance since monitoring for resistance as well as provision of second and third-line treatment are expensive and require specialized health provider knowledge [46]. If the prevalence of resistance increases, the effectiveness of treatment coverage will decline, potentially posing a serious challenge to the goal of epidemic control.

31. Investment in new medicines formulations is much needed and both women and men over 50 living with HIV can and should be included in clinical trials.

#### **Vihaan Care and Support Programme for People Living with HIV and AIDS, India**

The Vihaan Care and Support Programme was set up by the HIV/AIDS Alliance and established 359 Care & Support Care & Support Centres (CSCs). The CSCs were linked to the government's ART centres across the country, serving as a comprehensive unit for treatment support for retention, adherence, positive living, referral and linkages to services. The CSCs also helped create an enabling environment for people living with HIV by working closely with service providers to ensure stigma-free and holistic services, especially those from high risk groups, and women and children living with and affected by HIV. Vihaan has been implemented in 32 states and 3 union territories across India, and has thus far enrolled 988,359 people living with HIV in active HIV care. Of these, 114,260 (12%) are in the 50+ age group including 71,635 male, 42,461 female, and 164 transgender individuals. Vihaan's greatest success has been in identifying the unique issues faced by people living with HIV in the 50+ age group. For example, Vihaan's data indicated that patients over 50 are more prone to discontinuing ART, therefore an active outreach team was set up to help with adherence and to track patient outcomes. A major challenge identified by Vihaan Care is the implementation of age-supportive policies – for example, among social protection schemes, priority is given to orphans and widows, yet many people living with HIV aged over 50 may be equally vulnerable due to increasing health issues associated with ageing.

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### Quality of life, mental and social effects

32. The effects of ageing and HIV are complex, impacting on overall quality of life including mental, physical and social effects.
33. Studies have shown a higher prevalence of depressive symptoms, alcohol and other drug abuse or dependence among people living with HIV across continents and within HIV key population groups [47,48]. Common mental health comorbidities among people living with HIV include depression, anxiety, dementia and other cognitive disorders [4]. Depression is the most common comorbid condition for people living with HIV, with prevalence rates up to three times higher than the general population [49]. In a large study of people 50 and over living with HIV, 39% showed symptoms of major depression [5]. Depression was significantly related to increased HIV-associated stigma, increased loneliness, reduced levels of energy and decreased cognitive functioning. As depression does not decline in populations living with HIV, it becomes increasingly relevant for older populations [50]. People living with HIV who have depression are less likely to adhere optimally to ART [21]. There is also evidence that depression and stress are adversely associated with HIV disease progression including increases in viral load, decreased CD4 count and greater risk for clinical decline and mortality [51]. People aged 50 and above living with HIV who report more psychological symptoms, also report more HIV-related stress, less support from friends and, importantly, reduced access to health care and social services due to AIDS-related stigma [52]. Key elements in the treatment of depression occurring in association with HIV and ageing include medication, psychotherapy (individually or in groups), and community support services including psychosocial support [53]. Of note, primary health-care providers, including HIV counsellors, can be trained to recognize and treat common mental and substance-use disorders and refer patients to specialized services when warranted.

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#### Planning for the Long Term: A Psychoeducational Workshop Series for People Ageing with HIV, Canada

HIV prevalence data in Ontario shows that increasing numbers of people living with HIV in the region are aged 50+. Ageing service users at the AIDS Committee of Toronto requested a group-based intervention to help address social isolation among people ageing with HIV, including long-term survivors, and provide knowledge about topics related to HIV and ageing across physical, emotional, and financial health categories. In response, Planning for the Long Term (PLT) was developed, and is funded via federal and municipal government grants. PLT takes the form of a workshop conducted twice per year, covering two dimensions: the April-June sessions focus on health, and the October-December sessions focuses on emotional wellness. The workshop comprises ten weekly 3-hour sessions, with facilitators who also coordinate participant recruitment. The workshops guest speakers are drawn from across disciplines and expertise, and include people living with HIV, doctors, researchers, and other allied health professionals. Topics addressed include aspects of physical health such as HIV treatment, nutrition, smoking cessation, and substance use and harm reduction, as well as aspects of emotional wellness such as mental health, communication with doctors and service providers, healthy relationships and social networks, and resilience. Over 100 people have participated in the workshops, and all have reported positive changes in physical, sexual, mental, and cognitive health, as well as social engagement. Many of the workshop participants have gone on to access referred services such as cognitive screening, exercise programmes, employment services, and other supports. Furthermore, many have also formed informal support networks, maintaining their connection even after the completion of PLT.

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34. For people living with HIV aged 50 and older, the consequences of stigma, including self-stigma and discrimination are potentially devastating. Alongside complex health challenges caused by comorbidities, HIV has significant social, emotional and economic impact on people aged 50 and older. Studies have shown that HIV-related stigma negatively affects adherence to ARVs [54] and acts as a significant barrier to seeking care and support. Alongside experiences of stigma and discrimination that may include being shunned by family, peers and the wider community, poor quality and delayed health services significantly reduce the potential for positive outcomes from HIV treatment [55].
35. HIV-associated stigma is positively and significantly associated with depression in older people [5]. Self-stigma or internal stigma negatively impacts self-worth, self-esteem and psychological well-being; 48% of older adults felt ashamed of their illness at least some of the time [56].
36. Older people living with HIV are more likely to live alone, be without a primary partner and may have fewer friends and social support networks than younger people living with HIV [56]. In studies of older women living with HIV, profound experiences of self-stigma were reported where women believed no one would enter into an intimate relationship with them and they described themselves as feeling dirty [57]. People living with HIV aged 50 and over tend to disclose their HIV status to fewer people. This may in turn have implications on their willingness to seek appropriate services and support [56].

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#### Seta Equal Ageing Project, Finland

Seta, a national NGO which advocates for LGBTI rights in Finland, created a training programme focused on good practice to overcome discrimination, and encourage participation, education, and lifelong learning. Fear of discrimination can be a significant barrier to accessing services for Finnish LGBTI, with one third of participants in a 2013 study stating that they chose not to use social or healthcare services because of this fear. Furthermore, a 2012 study on LGBTI and ageing had shown that three quarters of elderly care staff had not been given training in issues concerning LGBTI seniors. To address these needs, Equal Ageing was created to raise awareness of these issues among social and health care professionals, students, teachers, and elderly care service providers, and other service users. The programme includes the "I Wish I Could Tell" training documentary, produced in 2014, which makes LGBTI people's views on ageing and elderly care visible, and incorporates the story of nine Finnish LGBTI seniors who share experiences about their childhood, youth and ageing. Complementing this is the Rainbow Senior training session, which takes the form of a one-hour training workshop including discussion of ways to create an inclusive, non-discriminating, and safe care environment for LGBTI seniors. The Equal Ageing project has a wide network that includes elderly care service providers, universities, vocational education institutions, NGOs working in the elderly care sector, researchers of LGBTI and ageing issues, and Finnish and European LGBTI organizations. This cooperation has been instrumental for the success of the project, helping raise awareness about elderly LGBTI persons. Equal Ageing practice develops the whole elderly care sector to be more inclusive instead of creating segregated services for LGBTI seniors, and supports service providers and professionals to see the diversity of the older community. It has also helped overcome social exclusion by offering elders a platform for interaction with other LGBTI seniors.

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37. Adults ageing with HIV often experience added complexities related to the social determinants of health and the double stigma of ageism and living with HIV [58]. Many older

people face stigma and discrimination not just because of their HIV status but also because of their age, which in turn can lead to further isolation and negative impacts on emotional well-being [59]. In addition, life events such as retirements, illness, relocation and death of family and loved ones can result in shrinking social networks [60]. For key populations such as gay men and other men who have sex with men, ageing can be viewed as a triple threat - the homophobia related to their sexuality, the stigma of HIV, and then ageism as they live longer [61]. Collectively, these combined health-related consequences and increased longevity of people living with HIV result in an increase in the disability experienced by older adults living with HIV [62].

38. Age discrimination and ageism is seen across the world. While the rights of older people are embedded in international human rights conventions on economic, social, civil and political rights, they are rarely made specific. Although rights do not change as people age, older men and women are considered to be inherently less valuable to society. Older people become more dependent on others, can lose some or all of their personal autonomy and participation becomes harder. They can be more susceptible to neglect, abuse and violation of their rights at family, community and institutional levels. This is further exacerbated for people living with HIV as a result of HIV-related stigma and discrimination. Specific threats in relation to age discrimination, which are similar for HIV discrimination include access to health care, employment, property and inheritance rights, access to information and education [63]. Indirect age discrimination includes for example, not collecting data on HIV infection in women and men over 49 as the failure to collect data results in the exclusion of older people from HIV and AIDS prevention programmes, and, therefore, discriminates against them [63].

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#### Improving the Quality of Life for Older Persons and the People Under their Care in Uganda

Uganda has around 150 100 people aged 50+ living with HIV, and the prevalence among this age group is estimated at 6.8%. Of these, only 10% know their HIV status, partly due to the fact that HIV counselling and testing centres are not age friendly. Help Age International and Uganda Reach the Aged Association (URAA) identified the need to establish the HIV Prevention, Care, and Treatment Advocacy Group in 2008, in order to mitigate the impact of HIV among older people in the country. URAA supports the advocacy group through Help Age International, coordinated by the Uganda Network of AIDS Service Organisations (UNASO). The advocacy group is implementing a 5-year project with participation of members from various civil society organizations, older persons' associations, and government departments. The group's objective is to advocate for increased access to HIV prevention, care, and treatment for older persons in Uganda, and influence policy development and implementation using an evidence-informed approach. The advocacy group has reached over 200 older people. Moreover, it has contributed to the inclusion of older people in data collection by the Ministry of Health, raising the age cut off limit from 45 to 65. Older people have also now been included into national HIV and AIDS policies, strategies, and plans. The programme has also seen an increase in the number of older people accessing HIV counselling and testing services in the country's Iganga district since January 2015. The inclusion of individuals from key stakeholder institutions was a factor contributing to the project's success, including those living with HIV, who are passionate about championing the issues faced by their peers.

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39. Studies have shown that ageing with HIV is accompanied by wisdom, patience, contentment, moderation, and a greater respect for health and life – traits that enable older adults to cope well with their illness [64]. In a 2011 study, resilience was identified among older people living with HIV as a positive concept of ageing and was related to self-acceptance, optimism, and self-management strategies [65]. Positive stories of ageing with HIV accompanied by a sharing of practical coping strategies should be widely promoted.



Involving older people living with HIV in research and advocacy as well as the development of programmes will ensure innovative and sustainable approaches. Better understanding successful and positive ageing can support in the identification of effective interventions that reduce disability and enhance the overall health of older adults with HIV [62].

## AGEING AND HIV: A DIVERSE AND HETEROGENEOUS POPULATION

### HIV prevention among people aged 50 and over

40. A key factor that is often overlooked in considering people 50 and over, is that this group is sexually active, and have varying levels of knowledge on sexual and reproductive health. An estimated 98,000<sup>15</sup> people in low- and middle-income countries aged 50 years or over (45,000<sup>16</sup> women and 53,000<sup>17</sup> men) acquired HIV in 2015 and of these 83% live in sub-Saharan Africa [3]. There has been very little research into the sexual behavior and HIV incidence among this age group [46]. In addition, few prevention and comprehensive sexuality education programmes are age-appropriate for people over 50 years of age.
41. In a 2012 nationally representative household survey in South Africa, 6% of men aged 50 years and older reported having had multiple partners in the 12 months prior to the survey. Only 15% of those men reported using a condom at last sex [10]. In another study, older adults were one-sixth as likely to use condoms and one-fifth as likely to seek testing in comparison to people in their twenties [66].
42. Studies have shown that older people have lower levels of knowledge about HIV compared to younger people (even among young people knowledge remains low). This is of particular concern as people over 50 remain sexually active and at risk of HIV. In addition, with the roll out of ARVs, more people living with HIV are living longer. Older people are often regarded as influential community members and leaders and play an important role as caregivers and educators. Many older people act as gatekeepers of information for the young adults and children they care for, reinforcing attitudes and normative behavior in societies [67].
43. Data shows that condom usage declines with age despite evidence that older adults living with HIV engage in unprotected insertive sex. The challenges that older men face to sustain an erection contribute to lack of condom use. Older women living with HIV report that because they are post-menopausal, their male partners do not perceive the need to use a condom [68].
44. People aged 50 and older are less likely to have been tested for HIV and are less likely to have spoken to their partners about HIV. Despite the apparent sexual activity of people aged 50 and over, healthcare providers infrequently discuss HIV infection or offer HIV testing to this age cohort.
45. Women aged 50 and older may not perceive themselves at risk of HIV despite having moderate to high levels of lifetime risk and exposure [69] and HIV testing is not routinely

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<sup>15</sup> uncertainty bounds [75,000-130,000]

<sup>16</sup> uncertainty bounds [35,000-59,000]

<sup>17</sup> uncertainty bounds [41,000-69,000]

offered. In a survey carried out in nine sites in West, East and Southern Africa, general HIV awareness was found to be very low among women 50 years and older [67]. Even where they may have general knowledge about HIV and HIV transmission, they have much less knowledge about their own personal risks [70]. Midlife women are more likely than younger women to have had changes in relationship status, for example divorce, separation, or death of a partner, and as such may acquire new partners after a long period of not having a partner [71]. Older women who have new relationships (6 months or shorter) were more likely to report having multiple partners [72]. These women may be less likely to discuss protection against HIV, and in general find sexual communication challenging [73].

### **Women living with HIV aged 50 and over**

46. Women living with HIV aged 50 and over face specific health and social challenges that require careful consideration. The increasing burden of cervical cancer among women living with HIV, associated with human papillomavirus infection, requires specific attention, particularly given the availability of effective human papillomavirus vaccine, and the availability of feasible and cost-effective approaches to screening and treatment for precancerous lesions.
47. Peri-menopausal and menopausal women have particular biological and social vulnerabilities. For instance, biological changes can put sexually active older women at higher risk of acquiring HIV. The wall of the vagina thins after menopause, which increases the chances of lesions and tears, thereby increasing the risk of HIV transmission during sex [74].
48. Women living with HIV appear to lose ovarian function earlier in life than HIV-negative women and are also at increased risk of developing chronic age-related conditions such as cardiovascular disease [75] and impaired cognitive function [76]. Women living with HIV demonstrate reduced bone density, which may be caused by a combination of altered nutritional status, hormonal function and body composition [77].
49. Menopause aggravates the ageing process in women, and post-menopausal women are at a greater risk than men for complications since the loss of sex hormones contributes to immune dysregulation and senescence (the condition or process of deterioration with age) [76].
50. For the most vulnerable women, such as those living in poverty and women who use drugs, the issues are further heightened. For example, drug use and poverty are related to more severe menopausal symptoms and chronic stress is related to worse psychological and cardiovascular risk [75]. It is therefore imperative that more attention is given to how menopause interacts with HIV infection and then communicated to clinicians so they can appropriately diagnose and treat women living with HIV during the menopausal transition [75].
51. Achieving full sexual health involves more than merely addressing vulnerabilities and risks and treating clinical conditions. The sexual needs, desires and behaviours of older women need to be acknowledged and respected, regardless of their marital status or sexual orientation [78].



52. There are differences in the sexual risk taking between older men and women living with HIV. For instance, 72% of older heterosexual men were sexually active, compared to 36% of older gay men and other men who have sex with men/ bisexual men, and 21% of older heterosexual women, but the heterosexual men reported slightly lower rates of irregular condom use than the other two groups [79]. Older women had more difficulty having a sexual relationship after their HIV diagnosis [80]. Older women, particularly those who are widowed or single, may find it embarrassing or difficult to procure condoms or to seek advice on safe sexual practices [78].
53. Intimate partner violence in older women living with HIV can lead to physical injuries from which recovery can be complicated and also psychological distress for which they may be less likely to seek help [81]. Among older women, intimate partner violence is associated with greater risk for HIV. This includes a history of STIs, multiple partners and sexual risk behaviours in partners. Women of all ages experience multiple forms of discrimination based on their sex, as a result of unequal power relations between men and women and this discrimination can be exacerbated as women age. It is a major obstacle for women in accessing HIV prevention, treatment and care and support. Behavioural interventions for older women living with or at risk of HIV need to take into consideration the dynamics of power and oppression that are often present, particularly in heterosexual relationships [69], as well as at the institutional levels.
54. Unequal distribution of caregiving responsibilities present a unique challenge for older women living with HIV. As a result of weak health systems, countries rely on home-based care where millions of older women are caring for adult and young children, including elderly parents or relatives. For the most part this work is unpaid and unrecognized [82]. Caregiving can contribute to fatigue, financial burden and also increase the overall mental, psychological, emotional and physical stress on older women living with HIV [83] The stigma surrounding HIV can reduce the social support available to caregivers, increasing their risk of burnout and isolation [23].

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Action to Promote the Legal Empowerment of Women in the Context of HIV in Cameroon, Ghana, Kenya, Malawi, Nigeria, Rwanda, Tanzania, Uganda, and Zimbabwe

In many parts of sub-Saharan Africa, discriminatory laws, customs, and traditions may negatively impact on women's rights, opportunities, and access to resources or services. These inequalities increase women's risk of HIV infection, as well as diminishing their ability to access care, support, and treatment. Older women living with HIV, and women living with HIV in general, are vulnerable to property and inheritance rights violations due to widespread stigma, and in some cases they may be stripped of their assets, and forcibly evicted from their land and homes. This may be worsened among widows and older women living with HIV, who are often blamed for the AIDS-related deaths of their husbands. UN Women has implemented the "Action to Promote the Legal Empowerment of Women in the Context of HIV and AIDS" programme with support from the Department of Foreign Affairs, Trade, and Development of the Government of Canada. To date, it has awarded \$2.2 million in small grants to 20 legal services organisations, community-based organizations, grassroots networks, and organisations of women living with HIV in Cameroon, Ghana, Kenya, Malawi, Nigeria, Rwanda, Tanzania, Uganda, and Zimbabwe. The programme's aims were to: 1) increase the number of legal frameworks and processes that effectively promote and protect women's property and inheritance rights in the context of HIV; 2) strengthen the enabling environment for promoting and protecting women's property and inheritance rights at the community level; and 3) work with local groups and NGOs to help women living with HIV, including older women, to better claim and advocate for their property and inheritance rights. 130,774 people

living with or affected by HIV in the target countries now have increased access to information about women's legal, property, and inheritance rights, 85% of whom are women. Eight of the programme's grantee organisations made progress towards changing national-level legal frameworks and legal procedures regarding women's property and inheritance rights in their countries, whilst five grantee projects directly challenged customary laws, or tried in their activities to enforce legislation protecting women.  
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55. There is a need for specific research for women ageing with HIV that includes examining menopause, hormone replacement therapy, the impact of ART and other age related shifts such as cognitive changes. Research into older women's sexuality should include data about sexual choice, behaviour and condom use. Research on gender-related barriers in accessing HIV knowledge, testing, treatment, care and support is also needed, as well as a better understanding of the interactions, risks and benefits of using ARVs together with hormone replacement therapy [69].
56. The International Community of Women Living with HIV (ICW) recently called for action to fight ageism and ensure that women living with HIV have the opportunity to age gracefully, healthy and well [84]. They urged leaders to: address sexist ageism and gender inequality within the HIV response; consult directly with older women living with HIV to understand their needs concerns, values and perspectives; prioritise research on older women with HIV and provide data dis-aggregated by age and gender; strengthen health systems to ensure quality HIV and other health systems throughout the life span; ensure the sustainable development goals do not leave older women living with HIV behind and prioritise and invest in a rights-based approach to sustainable universal health care for older women living with HIV.

### **Key populations**

57. Among ageing key populations of sex workers, people who use drugs, gay men and other men who have sex with men, transgender and people in prisons, the data is even more scarce but nonetheless alarming. Key populations of all ages are at much higher risk of HIV, often due to a combination of socio-legal factors including stigma, discrimination, prohibitive laws and policies and lack of services. People who inject drugs aged 18-49 are 24 times more likely to acquire HIV than adults in the general population, gay men and other men who have sex with men aged 15-49 are 24 times more likely to acquire HIV, sex workers aged 18-49 are 10 times more likely to acquire HIV, transgender people are 49 times more likely to be living with HIV, and prisoners are five times more likely to be living with HIV than adults in the general population [85]. It is projected that this increased risk also exists for older people of key populations. The impact of ageing with HIV among migrants and displaced populations should also be considered. There is overwhelming evidence to suggest that the mental and physical health of lesbian, gay men and other men who have sex with men, bisexual and transgender people is poorer than that of their heterosexual counterparts, with associated consequences for the lifespan that include higher risk of life-limiting and life-threatening diseases such as cardiovascular disease and obesity. Key populations such as people who use drugs and sex workers continue to face punitive legal environments, often experience human rights abuses and have poor access to services. They are almost universally criminalized. In many low- and middle-income countries, the majority of people who use drugs living with HIV lag far behind other people living with HIV in accessing life-saving HIV treatment due to factors such as high levels of self and societal-stigma, discrimination and criminalization. Key populations experience higher rates of

mental distress and are more vulnerable to higher rates of smoking and alcohol consumption [86].

58. Globally, gay men and other men who have sex with men continue to be at significantly increased risk for HIV infection, across the age spectrum. Studies have shown that many gay men and other men who have sex with men do not disclose their sexual orientation or risk behaviors to health care providers and one study found that those who disclosed were twice as likely to have been tested for HIV [87]. Many older HIV-positive gay men and other men who have sex with men continue to be sexually active, and a number report high risk behaviors, including high rates of unprotected sex and drug use [88]. As noted, depression is common in older adults living with HIV [5] and in HIV-positive gay men and other men who have sex with men moderate levels of depression have been associated with ongoing sexual risk behavior [89]. Recent WHO guidance outlines recommendations for key populations, including men who have sex with men [90].
59. Transgender people experience exclusion, discrimination, violence and lack of access to appropriate care [55]. A large proportion of transgender women engage in selling sex, which has been significantly associated with homelessness, low levels of education, drug use and a perceived lack of social support. As they age, transgender people therefore report higher rates of disability, general poor health, depression, anxiety, loneliness and suicidal ideation. Many transgender elders enter their later years with severe health concerns yet without the social and community supports necessary to address them [91]. Many health workers not only lack the knowledge to deal with the clinical issues associated with ageing but also the awareness of the needs of key populations, such as transgender people. For transgender women, little research has been done on the interaction between PrEP, ARVs and feminizing hormones remains a significant concern for transgender women who prioritise hormone use over antiretroviral therapy [92].
60. A French study found that the prevalence of HIV was almost five times higher among older people who use drugs than younger people who use drugs and for people with HCV twice as high [93]. Treatment for infectious diseases is also more problematic for older people who use drugs. In addition, they are disproportionately affected by failure of treatment for hepatitis C. This is because treatment of this disease is less effective when it is started at an older age, due to the deterioration of the immune response associated with ageing. This highlights the need for wider access to hepatitis C testing and treatment, so that treatment can start at a younger, asymptomatic age when there is a better immune response [94].
61. A recent study in Europe looking at national data on opioid substitution treatment found that in some countries more than half of the clients are aged 40 or more. In the most recent data, this age group accounted for 26.5 % of all reported drug-induced deaths. Drug-induced deaths can be direct, including overdoses, and indirect, including those due to other causes, such as AIDS, traffic accidents, violence, suicide and chronic health problems caused by repeated use of drugs (e.g. cardiovascular problems). [94]. Where harm reduction services do exist, they are often offered by younger people who may not understand the specific needs and concerns of older people using drugs who may also be living with HIV.
62. Older female sex workers may be at higher risk of HIV than their younger peers. A recent study of female sex workers in Guangxi, China suggested a significantly higher rate of HIV among this group compared to their younger peers [95]. However, very little research has been conducted into the behavioural risk factors. Older female sex workers may be

disadvantaged compared to younger sex workers. They may be more likely to work in less protected environments where HIV risk is much higher [96]. In addition, with families to support, increased financial pressure may make older female sex workers more willing to have unprotected sex for more money or to accept clients who are at high risk of HIV [97].

63. For people in prisons, issues of ageing with HIV are particularly challenging. For example, a 50-year old prisoner is likely to have the health problems of a 60-year old person living in a community. Older prisoners suffer chronic and multiple health problems including physical and mental conditions. Older prisoners living with HIV are likely to face even greater health challenges without adequate access to appropriate medical services [98]. Key population offenders, in particular lesbian, bisexual, gay men and other men who have sex with men and transgender (LGBT) people are more likely to suffer from STIs, including HIV, drug use related problems and other health conditions. Rape in prisons also significantly raises the risk of acquiring HIV among LGBT prisoners, who are the most likely victims of rape [98].
64. In a review of over 100 studies, low social protection access by key HIV populations in low-income countries was reported [99]. Although adequate data around key populations is limited, the need for specific strategies to support key populations living with HIV aged 50 and older is clear.

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#### Children born with and getting older with HIV

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Ageing is also relevant for children born with HIV, who are now able to grow older due to expanded access to ART. As a result of scaled-up HIV prevention services there was a 70% decline in the number of new HIV infections among children between 2000 and 2015. Despite this significant progress, the number of children becoming newly infected with HIV remains unacceptably high. About 150,000<sup>18</sup> children became infected with HIV in 2015 [3]. Of the 1.8<sup>19</sup> million children less than age 15 living with HIV, 86% live in sub-Saharan Africa, 11% live in Asia and the Pacific and the remaining 3% are situated in the rest of the world [3]. The majority of the 1.8<sup>20</sup> million HIV-positive children globally have perinatally acquired HIV. An estimated 640,000 of those children are aged 10-14.

Ageing with HIV is an issue that requires particular attention for this group who have been on ART for long periods of time and have substantial challenges as they age around mental health, reproductive health and child bearing for girls, disclosure and early onset of comorbidities. Children born with HIV not only deal with their own illness but are also highly affected living in a family with HIV. Children born with HIV experience a range of negative consequences that affect health, cognitive development, education, child mental health, exposure to abuse and adolescent risk behaviour, including sexual risk behavior, all of which have implications for HIV-prevention and support efforts [100].

ART is not curative which means that a young adult or a child born with HIV will need to take expensive and potentially toxic drugs for several decades or their whole life – this poses challenges for the individual and the health-care system [38]. A UNICEF report from Asia Pacific found that across the region, many children and adolescents living with HIV may be on sub-optimal treatment regimens, such as those that include use of d4T, that can contribute to a poorer quality of life, result in harsh side effects (including those which have physical manifestations associated with HIV such as lipodystrophy), and can contribute to treatment resistance and failure. Political will, updated pediatric guidelines and effective drug procurement and supply management are all important issues in ensuring young people ageing with HIV have access to optimal treatments [101].

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<sup>18</sup> uncertainty bounds [110,000 – 190,000]

<sup>19</sup> uncertainty bounds [1.5 million – 2.0 million]

<sup>20</sup> uncertainty bounds [1.5 million – 2.0 million]

Recent systematic reviews found evidence of cognitive delay in children both infected and affected by HIV [102]. This affects all domains of development including expressive and receptive language, memory, information processing, visual-spatial tasks, executive functioning and decision-making. The causal pathways for cognitive delay however, are yet unclear as to how much can be attributed to family background factors and how much could be related to antiretroviral exposure.

Children born with HIV go through the same stages of development in terms of adolescence into adulthood compared to their HIV-negative peers, but have many issues to face living with HIV including disclosure, stigma, illness, treatment adherence and side effects, sexual reproductive health, childbearing and parenting. They will experience different issues at different stages of development and interventions are required at all stages. Interventions to support perinatally-infected young people disclose their status has been identified as an urgent need [103]. A number of useful strategies and publications to support children born with HIV are referenced in a UNICEF document titled 'Lost in Transition' [101]. Sexual reproductive health is particularly important, as in addition to the need for regular comprehensive sexuality education about safe sex, relationships, STIs and unplanned pregnancy, these young people are experiencing their sexuality for the first time as people living with HIV. This is particularly important when considering the mental health needs of young people already susceptible to depression and struggling to cope.

The importance of social protection programmes has been highlighted by some studies pointing to the HIV prevention benefit of a basket of social protection including school feeding, cash transfers, school counselors, transport provision, food gardens and others [104]. It is also important to look at resilience and coping in children born with HIV and living in HIV-affected families [100].

## HEALTH, SOCIAL AND STRUCTURAL RESPONSES TO AGEING AND HIV

### Health sector responses

65. People aged 50 and over living with HIV are at increased risk of developing a broad spectrum of non-communicable diseases as a consequence of their HIV infection or as a result of side-effects from long-term treatment or ageing. This requires complex clinical and psychosocial management that pose a challenge to health systems in every country in the world.
66. Treating HIV as a chronic illness presents substantial challenges for health systems and includes uninterrupted access to ART, ensuring adherence and retention in care and dealing with multiple comorbidities. All of this requires a well-resourced and well-functioning health-care system [105]. Health-care systems in regions where most people with HIV live were designed to provide acute care only and are not well prepared or equipped to provide the chronic care and deal with the complex care and treatment that is now required [38]. Separating acute from chronic care is an essential step in the transition to a chronic-disease model [38].
67. To support preparedness of health systems transitioning to chronic care models and dealing with non-communicable diseases (NCDs) in general, the global, national and community responses to the HIV have valuable lessons to share. Many low- and middle-income countries have already developed and scaled up HIV prevention, care, treatment and support programmes to aid people living with HIV manage a chronic and lifelong condition. Non-communicable disease efforts can be integrated into these existing systems that have

already been strengthened by HIV investments [106]. Such approaches integrating NCD care into HIV programmes are already underway in a number of countries.

68. In order to provide the comprehensive chronic care needed to support an ageing population of people living with HIV, greater integration, linking and coordination of HIV services with relevant health areas is needed, such as non-communicable diseases, sexually transmitted infections, broader sexual and reproductive health, substance use disorders, mental health, hepatitis, tuberculosis, blood safety, geriatric care and gender-based violence [4]. Greater integration can potentially reduce costs, improve efficiencies, simplify and streamline care for clients, and most importantly, lead to better outcomes for people living with HIV and lead to strengthened health systems. The model of integration will depend on the health system and country context and should also include health information systems, laboratory and diagnostic services, human resource planning and capacity building, procurement and supply chain management, and resource mobilization [4].

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#### Elderly People Living With HIV Programme, Brazil

Elderly people make up around 10.7% of the population of Brazil's São Paulo state, and national debate has taken place around a public health policy to help care for this population and assure the human right to dignity and quality of life. Between the 1980s and 2015, there were approximately 26,600 notified cases of AIDS among people over the age of 50, representing around 10% of all cases during that same period. However, these figures do not take into account those living with HIV who do not yet know their serologic status. The Treatment and Training Reference Centre (CRT) in São Paulo state created the Elderly People Living with HIV programme in 2011, in response to the increasing survival and improved quality of life of people living with HIV, and the rise in the proportion of conditions often associated with ageing, including cardiovascular and kidney diseases, diabetes, and bone disease. This programme prioritises the participation of people living with HIV over the age of 50, who are not yet enrolled in treatment, and focuses on comprehensive care, with input from professionals from related areas, including a geriatrician, a nutritionist, and a clinical pharmacist. However, the personnel involved in the programme are not exclusive to medical care for the 50+ age group, therefore the Centre has limited capacity and only supports attendance of two new patients, and two follow-up visits per week. Since its inception, the programme has reached approximately 350 people (65% male; 35% female), including a 93 year old patient, and it has contributed to knowledge and understanding of the specific needs among elderly people living with HIV. The Centre promotes professional integration and knowledge exchange, as well as creating opportunities to develop partnerships with civil society organisations, aiming to increase HIV testing, counselling, and peer education for the 50+ age group. The programme has helped highlight the shortage of qualified human resources to care for ageing people living with HIV, and also the need to build awareness among healthcare professionals around HIV and ageing.

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69. People-centred chronic HIV care services should include interventions across the continuum of care, including screening, assessment, monitoring and managing the most common health risks including non-communicable diseases and comorbidities experienced by people living with HIV, especially through primary care. These care services should be age-friendly. Effective pain management, palliative care and end-of-life care are also essential interventions to be included in HIV services [107]. Strengthening linkages, including with non-communicable disease services, will ensure holistic and integrated person-centred care, boosting the impact of programmes overall [107].

70. There are a number of elements that must be part of a robust health system to provide adequate HIV prevention and care services. These must ensure people of all ages can access effective HIV prevention services; can get tested, receive and understand their HIV test results; are referred to appropriate HIV prevention services or enrolled in care; are initiated promptly (as soon as possible) on antiretroviral therapy if diagnosed HIV positive;



are retained and adhere to effective treatment; are moved to alternative antiretroviral regimens if treatment fails; and can access chronic and palliative care, including prevention and management of major co-infections, non-communicable diseases and other comorbidities [107].

71. A number of key lessons from the response to HIV include: the active role of international, national and community leadership in cooperating to achieve a broad-based national response [108]; multisectoral national coordination mechanisms to coordinate policy and planning and engaging civil society organization as equal partners in the response. Integrating non-communicable disease services into the relatively well-developed HIV delivery systems in low- and middle-income countries offers some unique and important benefits [106].

### **Strategies for healthy living**

72. WHO guidelines clearly state that strategies for the prevention and risk reduction of cardiovascular diseases and associated risk factors, such as high blood pressure, smoking, obesity, unhealthy diet and lack of physical activity should be applied to all people living with HIV [21]. HIV chronic care should include integrated interventions such as dietary counselling and support, nutrition assessment, smoking cessation, exercise promotion, blood pressure and cholesterol management as this can both reduce the risks of non-communicable diseases and improve treatment outcomes for people living with HIV [109].

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#### **Health, Wealth, and Happiness, UK**

A 2010 report by the Terrence Higgins Trust (THT), Age UK, and the Joseph Rowntree Foundation highlighted the many disadvantages faced by older people living with HIV, ranging from poorer health, social care issues, and housing problems. This led to creation of the Health, Wealth, and Happiness programme in 2012. The programme supports the financial, emotional, and physical wellbeing of people over 50 living with HIV across 5 major cities in the UK, aiming to increase resilience to manage key life transitions. Example activities include peer support to address isolation and loneliness, provision of accredited financial advice across a range of areas, counselling and emotional support, and HIV training for mainstream organisations around HIV and ageing. The programme also aims to inform policy and practice through lobbying and campaigning using project evidence. The pilot programme worked with 192 people in London, and its national expansion has supported over 730 people. Among these, 328 older people living with HIV to date have been reconnected with their communities, made new social connections, and developed peer networks. 350 older people living with HIV have been supported by the programme's accredited advisors around welfare and financial matters, with a total of £430,000 in financial benefits for older people living with HIV being accessed in year 2 alone. In addition to these supports, the programme has also supported older people living with HIV to become peer mentors through mobilisation and skills building, to support those who are less able. Furthermore, 82 organisations have been provided with training to build their understanding of the needs of older people living with HIV, and ways to support them. THT has coordinated the programme, in partnership with the George House Trust in Manchester. The programme's third, and final, year has been financed by the UK National Lottery's Big Lottery Fund. Key factors contributing to the programme's success include its peer-led approach, and its access to a large network of partner organisations to provide expertise. However, challenges remain, such as changes occurring in the landscape of social care and welfare are now significantly impacting clients both financially, and in terms of care.

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73. Interventions for smoking cessation need to be prioritized, to prevent increases in smoking-related mortality that will be seen as the population of people living with HIV on treatment ages [26]. This is particularly significant given the cardiovascular risk for people living with HIV, a risk that increases with age.

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#### Ageing with HIV – A Life Cycle Approach, European AIDS Treatment Group (EATG)

Many gaps persist in research and policy around care for people living with HIV as they age, and in getting that information to clinicians, policymakers, and people living with HIV themselves. Recognising this, the European AIDS Treatment Group developed a project to improve access to resources and support, and increase awareness to help mobilise action at local and national levels. It also aimed to provide networking opportunities for establishing collaborative efforts to advocate for priorities on HIV and ageing. The project addressed three age bands: people living with HIV aged 50+; children and young people under the age of 25 born with HIV or infected with HIV at an early age; and people aged 25-50 who have been living with HIV for more than 10 years. Activities included stakeholder meetings focusing on each age band, providing an overview on the latest research as well as networking opportunities. Communications media such as webinars and the project's website were used to distribute information, training packages, resource documents, stakeholder meeting reports, and policy recommendations. 116 people have attended the webinars to date, whilst the project's website ([www.ageingwithhiv.com](http://www.ageingwithhiv.com)) has over 3,800 users, and information shared on its Facebook page has reached 8,669 people across 27 countries. A 3-day conference was held titled "New Challenges and Unmet Needs of People Living with HIV/AIDS Aged 50+" to identify knowledge gaps and formulate actions, focusing on testing for over 50s, disclosure and stigma, wellbeing and quality of life, and palliative care. The conference gathered 85 attendees from 34 countries. A major strength of the project has been its partnership between clinicians, researchers, experts, and people living with HIV and the value of engaging people living with HIV in the development and delivery of programmes.

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#### Living Longer with HIV in Asia Pacific, The Asia Pacific Network of PLHIV (APN+)

The Asia Pacific Network of PLHIV (APN+) conducted research, to identify issues affecting ageing people living with HIV in the region, and inform policy and programming to help address their needs. To date, this has been the only project of its kind undertaken, with the research being conducted by people living with HIV themselves. The research aimed to 1) raise awareness and encourage discussion among people living with HIV in the Asia Pacific region around living longer with HIV; 2) create a body of knowledge around ageing with HIV within the region's culture and social context; 3) inform advocacy on good practice in responses around HIV and ageing; and 4) lead a positive community-centred response on living longer with HIV in the region. The programme was designed after wide community consultation, and research was conducted using an online. 360 individuals responded, drawn from 21 countries across the region. Results showed that only 60% of respondents were on treatment, with many having difficulty in accessing care; less than half of those who were on treatment had undetectable viral load; 43% of the respondents were suffering from depression, and there was also a high incidence of high blood pressure, non-depressive mental illness, sexually-transmitted infections, as well as moderate levels of kidney disease and cancers. Almost half of the respondents had not used any protection at their last sexual encounter. The majority of respondents were also experiencing economic difficulties. The research highlighted the fact that many ageing people living with HIV face health challenges which, although not directly stemming from HIV or its treatment, are inseparably linked to living with HIV. A key success factor was the involvement of older people living with HIV in the design and implementation of the project. The research provided strong evidence to help inform advocacy by national people living with HIV networks to call on their governments and other institutions for action. The current challenge is to secure further funding to implement recommendations.

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74. Nutritional interventions can improve the quality and span of life as well as support the effectiveness of medications and improve the person's resistance to infections [27]. In order to prevent frailty and improve immune parameters, preventive actions could include multiple strategies that include medical management, improving nutritional outcomes and increasing physical activity are important and include ARVs, treatment of infections, nutritional counselling, nutritional supplements, providing pharmacologic agents to stimulate appetite and exercise [30].
75. Palliative care remains a critical component of a comprehensive health sector response, helping to ensure dignity and comfort for people in managing their pain and other symptoms [107]. Although the prognosis is much better than ever before if treated with ART, HIV still causes death, particularly with late diagnosis and when people with HIV become frail, accumulate multiple morbidities and have to make end-of-life decisions without prior discussions with professionals [110]. Core interventions in HIV palliative care include the management of symptoms such as fatigue and pain, treatment of adverse effects such as nausea and vomiting, provision of psychosocial support, advance care planning and end of life care. A palliative approach to HIV care has been shown to support better patient outcomes and to improve adherence to ART [110].
76. Ensuring integrated and joint HIV and tuberculosis programming in countries with the highest burden of tuberculosis and HIV co-infection strengthens integration, enhances access to life-saving interventions, and at the same time maximizes efficient use of resources [107]. A recent MSF report highlighted the importance of providing systematic and free HIV testing and services within TB services, general hospital services and in therapeutic feeding centres [111].

#### **HIV risk reduction and prevention for people aged 50 and above**

77. For people aged 50 and above at risk of acquiring HIV, ensuring various options for HIV prevention and testing are made widely available should be a key strategy. Combination HIV prevention should include comprehensive sexuality education, male and female condoms, behaviour change communication, male circumcision and harm reduction for people who use drugs. In order to increase access to and uptake of testing, self-testing and improve linkages to care, clinic-based and innovative and targeted community testing strategies will be necessary. Community responses can also include 'know your status among 50+' in advocacy and programme efforts. Targeted prevention education efforts need to be prioritized that include information about pre-exposure prophylaxis (PrEP) and treatment as prevention (TasP) for ageing populations with HIV.
78. Comprehensive sexual and reproductive health and sexuality education and services specifically targeting people over aged 50 are not widely available. A systematic review including twelve studies highlighted possible programmes to reach older adults with HIV including use of older adults as peer educators for sexual education, providing training in sexuality counseling for an older age group and increased use of internet and mobile phone for education and support [112].
79. A number of responses at different levels are needed, including improved access to testing and an expansion of ART services to identify, target, retain and treat older individuals. This will ensure timely initiation of older people acquiring HIV start on ART and help respond to the issue of reduced immune reconstitution.

## **Structural interventions, including those addressing stigma and discrimination**

80. Structural interventions are urgently required to address the underlying causes of vulnerability, inequality and inequities faced by older women and men living with HIV and to create an enabling environment for HIV prevention, care and support; this is of particular importance for key populations, including those living with HIV. There is a specific need for programmes that promote human rights, remove punitive laws and practices, and that tackle stigma and self-stigma, gender-based discrimination and gender-based violence.
81. To better support people ageing with HIV, there is an ongoing need for education and anti-stigma interventions [62]. Interventions to reduce and cope with stigma, self-stigma and shame should include programmes in health care institutions, in schools for children living with HIV, in workplaces for people aged 50 and above living with HIV, and in elderly care homes and the community for older men and women living with HIV.

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### **HIV & Older Adults: Working Together Across Canada**

A needs assessment conducted by Realize (formerly the Canadian Working Group on HIV and Rehabilitation) found that only 22% of service providers offered sexual health education for older adults, and only 14% offered support programming targeted towards the needs of people living with HIV who are over 50 years of age. 70% of respondents had never received any training on HIV and ageing. To address this need, the Working Together project was developed, via collaboration with advisory committees comprising over a dozen stakeholders. It aimed to increase knowledge of the needs of older adults living with or vulnerable to HIV, facilitate the delivery of high-quality care, and reduce HIV and ageing-related stigma, among service providers. The intervention takes the form of an interactive workshop co-facilitated by a national trainer and a local service provider and/ or an older adult living with HIV, in addition to four online self-study modules. 37 learners took part in the course pilot in 2014, and in 2016, 90 participants from three cities engaged in a revised version of the course. Average scores for HIV-related prejudice, stereotyping, and discrimination all decreased, and several participants self-reported feeling more comfortable and confident providing care and services for clients with HIV following taking part in the intervention. Participants reported increased confidence in their ability to help older adults living with HIV to navigate the health and social service systems, and increased confidence in their ability to recognise the signs of poor mental health among older adults living with HIV. Contributing factors to the programme's success include adequate allocation of staff time and resources to evidence-based course development and technical support, and attention being paid to identifying strategies for participant engagement and retention. The use of a web-based format also helped provide flexibility, allowing learners to study at their own pace, and schedule learning around other responsibilities. The engagement of an advisory committee throughout the course was instrumental to its development and monitoring and evaluation.

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### **Directory of Promising Programmes and Services for Older People Living with HIV in Canada**

Coordinated by the Toronto HIV/AIDS Network, seven agencies came together to develop a directory of available programmes and services for older people living with HIV. A cross-sectoral committee, including people living with HIV, was formed to conduct a needs assessment of older people living with HIV and a review of existing service systems used by this population. The aim was to develop coordinated models of care for ageing people living with HIV focused on improved health outcomes and sustaining stable housing. A directory was produced that included existing and promising programmes and services that include health, home and practical care, support groups, educational and informational programmes and national coordination activities.

More information is available at: <http://bit.ly/2e4nqCl>

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## Equipping healthcare providers

82. Complex treatment needs in people aged 50 and over living with HIV co-infections and comorbidities makes geriatric and gerontological education an urgent need among health and social care professionals, community health workers and should be included in medical education at under- and post-graduate levels. Healthcare providers may fail to recognize the clinical manifestations of advanced HIV infection in people aged 50 and over, that can present as encephalopathy and wasting syndrome [18]. A study in the US found that when people aged 50 and over are hospitalized with *pneumocystis jirovecii* (PCP), one of the most common AIDS-defining opportunistic infections, they are less likely to be evaluated for HIV infection, less likely to receive timely PCP prophylaxis and treatment and are less likely to survive hospitalization [113]. While training in geriatric and gerontological health care is already been provided in countries such as Cambodia, Cameroon, Canada, Indonesia, Japan, Kenya, Nigeria and South Africa [23], there are fewer than 25 geriatric clinicians in all of sub-Saharan Africa, and in most of the region's countries there are none [114]. Clinicians in HIV service organizations typically do not receive ongoing education about the complexity of HIV in older patients [114].

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### Age-friendly Primary Health Care Centres Toolkit, WHO Kenya

WHO has developed a toolkit to assist health care workers in the diagnosis and management of the chronic diseases and the four areas that often impact people as they age: memory loss, urinary incontinence, depression and falls/immobility. The toolkit's purpose is to:

- Improve the primary health care response for older persons.
- Sensitize and educate primary health care workers about the specific needs of their older clients.
- Provide primary care health workers with a set of tools/instruments to assess older people's health.
- Raise awareness among primary care health workers of the accumulation of minor/major disabilities experienced by older people.
- Provide guidance on how to make primary health care management procedures more responsive to the needs of older people's needs.
- Offer direction on how to do environmental audits to test primary health care centres for their age-friendliness.

The toolkit comprises a number of instruments including evaluation forms, slides, country guidelines, and screening tools that can be used by primary health care workers to assess and address older persons' health.

Source: <http://www.who.int/ageing/publications/Age-Friendly-PHC-Centre-toolkitDec08.pdf>

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## Ageing and health-management programmes addressing HIV in Latin America and the Caribbean

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To address the primary health-care challenges, including HIV, that accompany the ageing population, the Pan-American Health Organization (PAHO) has partnered with the Inter-American Centre for Social Security Studies (CIESS) and the Latin American Academy of Medicine for Older Persons (ALMA) to increase human resources in primary health care for older persons in Latin America and the Caribbean.

### *Specialization in health management of seniors*

This regional initiative develops leadership in ageing and health to better align policies and health services with the needs of older adults. The programme is a theoretical and practical, online education course aimed at current managers and professionals interested in managing programmes and services for older persons and seeking to improve their skills in quality health management for the older population. Managers undertaking the training receive accreditations leading to better management of services and the establishment of minimum standards in the selection and evaluation of administrators of programmes and health services for older people in the region. Between 2009 and 2012, 128 students of various professions from 14 countries in the Americas graduated with the specialization, which is available in Spanish, Portuguese and English.

### *Master's programme in ageing and health management*

PAHO and CIESS have promoted the organization of the University Consortium in Public Health and Ageing with more than 18 universities. The Master's programme was created to train competent, motivated, and skilled professionals capable of seeking viable solutions to the health problems of the older adult population. The focus is on finding formulas for promoting health and preventing disabling diseases, including living healthy with HIV, and improving the quality of life of this population group, and anticipating the demographic, epidemiological, economic, environmental and current health challenges.

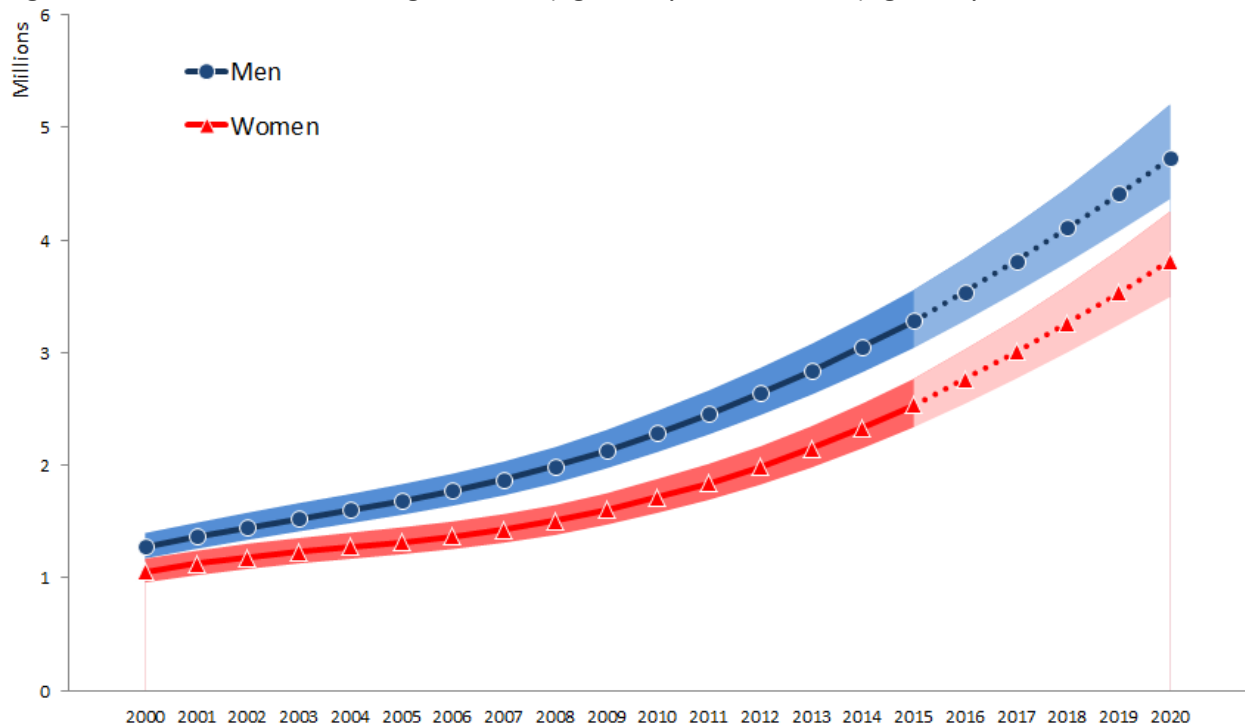
By encouraging collaboration between universities and schools of public health in the region, the Master's programme promotes integration, continuity and complementarity with the specialization course and increases the human resources available to address the primary health-care needs of the ageing population [23].

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Sustaining ARV production, procurement and delivery

83. The costs of providing ARV treatment to support an ageing population with HIV are considerable and need to be factored into national budget planning and financing. Globally, people living with HIV aged 50 and over will increase from an estimated 5.8 million<sup>21</sup> in 2015 to an estimated 8.5 million<sup>22</sup> in 2020 (see Figure 3) [3]. Sustaining ARV treatment coverage for an ageing population of people living with HIV, including key populations living with HIV will require focused efforts and resources.

Figure 3: Men and women living with HIV (aged 50 years and over), globally, 2000–2020



Source: UNAIDS 2016 estimates. Projections 2016-2020 are based on an assumed scale-up of ART to reach 81% coverage by 2020.

**Social sector responses**

84. As the number of people aged 50 and over increases, including people living with HIV, so will the need for financial and social support. In sub-Saharan Africa older people are generally cared for and supported within extended families, with a significant burden of care placed on women, and there are currently no or limited pension programmes [115]. This is an important issue for consideration by policy makers as they assess and put in place measures to provide support through existing or new old-age pension and social care systems [46].

<sup>21</sup> uncertainty bounds [5.4 million - 6.3 million]

<sup>22</sup> uncertainty bounds [7.9 million - 9.4 million]

### Ugandan Grandmothers Gathering

Across sub-Saharan Africa, many grandmothers now play a key role in providing care for their orphaned grandchildren. They provide leadership, care, and support, whilst themselves overcoming their own challenges of grief, sickness, and poverty. In October 2015, the first National Grandmothers' Gathering was held in Uganda, bringing together 473 grandmothers from across the country to raise national awareness of the issues they face, and to advocate for recognised rights and increased support. The Gathering was led by a dedicated committee of six key Ugandan community-based organisations whose work focuses on grandmothers and their dependents. Taking place over three days, the Gathering acted as a staging ground for grandmothers, and the organisations supporting them, to develop agendas to advance grandmothers' rights in areas such as old age pensions and cash transfers; housing, land and inheritance; protection from violence; and improved access to HIV treatment and care. Members of the Gathering's organising committee also created an NGO, the National Grandmothers' Consortium, with a mandate to follow up on local, regional and government commitments made at the Gathering and to garner continued resources and opportunities for ongoing advocacy by and for grandmothers. The inclusion of community-embedded grassroots organisations was critical to the Gathering's success. These organisations brought considerable expertise to help mobilise logistical and financial support to rapidly stage such a large event, as well as providing ongoing support to grandmothers to attend. In addition, the organising committee was greatly strengthened by inclusion of grandmothers themselves, and the agenda for the Gathering was guided by their input.

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85. HIV-sensitive social protection is recognized as a key enabler of the AIDS response to reduce the disadvantages, inequities and inequalities that make people vulnerable to HIV and can help in overcoming barriers in access to treatment, reduce HIV risk behaviour and mitigate the impact of HIV on households [99,116]. It is important that people living with HIV aged 50 and above remain part of the productive workforce for as long as possible and are supported to acquire adequate insurance and pension benefits where possible. People living with HIV who are employed are, on average, 39% more likely to continue with ARV treatment than those who are unemployed [99].
86. Social protection enhances resilience and supports people ageing with HIV to continue life-long treatment [117]. A study in Guatemala, Indonesia, Rwanda and Uganda found that even when health/medical insurance and other services are available, there are formidable barriers to access and usage that must be addressed. These barriers are particularly challenging for people living with HIV and key populations. Across all four countries, social protection is closely linked to the formal economy and yet 61% of people living with HIV and other key populations worked in the informal economy and 7% were unemployed. Barriers to access and uptake of social protection include lack of information about available types of social assistances or services; complex procedures to access social protection; discrimination and self-stigma; the cost of living with HIV [99]. The most common social protection benefit was health insurance schemes and free access to medical care.

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**Seniors Fulfil Their Dream While Knowing Their Rights: Building Capacity for Promoting Older People's Rights and Income Security in Thailand**

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Building capacity for promoting older people's rights and income security in Thailand, in cooperation with the Older People's Group (OPA) in Ban Thi District, Lamphun Province, organized a volunteer team which works with government agencies to promote knowledge about older people's rights and to encourage, monitor, and protect those rights. The project operates in 10 pilot villages, comprising a total of 4,838 people, among whom there are 870 (393 male; 477 female) older persons. Each village has an older person's club, and the project engages 150 of the older people to drive club activities to address problems and needs of older people living with or affected by HIV. Following a participatory needs assessment, the Foundation for Older Persons' Development provided seed money for members to start income generating activities. Club members were trained on project management, including monitoring and evaluation, proposal formulation, narrative report writing, basic financial management and reporting. Workshop-style meetings are used to help educate older people around their rights and entitlements in accordance with Thailand's Older Persons Act of 2003, and provide information around daily living, access to health services, and the Elderly fund provided by the government. The volunteer team also disseminates information via word of mouth during special occasions such as Buddhist holidays. As a result of the project, older people have been empowered to access health services, and to negotiate with government organizations for funding to support their groups. The work of the older people's groups has been recognized by local authority and provincial government departments, and the OPA has acted as a testing ground for the integration of community-based age care in systems for health, and to generate better understanding of the needs of families of people living with HIV. The project has been successful in reducing isolation among older people living with and affected by HIV, who have been re-engaged in community activities, in particular income-generating activities. The project has highlighted the value of integration of activities and resources with local authorities, community hospitals, and other related government departments. UNAIDS/PCB (39)/16.25 CRP1

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87. A number of issues have been identified for people living with HIV aged 50 and over relating to income support, employment and retirement transitions that need to be addressed in social sector policies. For instance, financial uncertainty stemming from the initial belief that people living with HIV did not expect to live long lives (when ART was not available), the uncertainty of transitioning into retirement where chronic illness is expected and the concerns with appropriate long term housing for older adults living with HIV that may also be influenced by social stigma [62]. In addition, the reality of living with episodic illness influences the psychological ability of people to plan longer term. An analysis of life insurance policies for people living with HIV in 23 countries found huge differences in what was available. Some countries have insurance specifically for people living with HIV, others offer insurance on an individual basis where criteria are not clear and high premiums can be expected and others simply do not provide insurance options [118]. Given that the life expectancy of a person living with HIV on ART is nearly the same as that of an HIV-negative person, access to life insurance should be prioritized [119]. As social isolation is a risk factor for ageing in general, it is important to develop programmes to promote social interaction and support for those ageing with HIV [62].



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National responses to ageing populations living with HIV, Ethiopia, Mozambique, Thailand, Cambodia, Tanzania, Kenya, Botswana, US

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Older people are included in some national strategies and policies on HIV, and HIV is included in some ageing plans and policies. For example, in Ethiopia, older persons are identified as a major group, both as beneficiaries and contributors, within the Strategic Framework for the National Response to HIV/AIDS. Similarly, in Mozambique, ageing is mainstreamed into the National Strategic Plan for HIV/AIDS 2005-2009.

In Thailand, the 10th National AIDS Plan (2007-2011) includes older persons as a specific target group for interventions. In Cambodia, HIV is addressed in the 2003 Policy for the Elderly. Also in South Africa, HIV is addressed in the South Africa Older Persons Policy of 2006. In Tanzania too, specific reference to HIV is made within the National Ageing Policy of 2003. In Kenya, the National Policy on Older Persons and Ageing of 2009 refers to HIV, and persons aged 50 to 64 are included in the Kenya National AIDS Strategic Plan (2009/10-2012/13). Some national surveys are now including prevalence and infection data for people aged 50 and above, including the AIDS Indicator Surveys in Botswana, Kenya and Mozambique.

In the United States, the White House Office of National AIDS Policy has highlighted HIV issues in older Americans. Also in the United States, the Office of AIDS Research within the National Institutes of Health in 2011 set up the Working Group on HIV and Ageing. This has initiated a research programme that includes collecting evidence on mechanisms and triggers of functional decline, predictors and surrogate markers of outcomes, intervention research and societal infrastructure, mental health and substance abuse issues [23].

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88. Due to the persistent societal norms on women's role in society, older women often find themselves bearing the bulk of the care work in the context of HIV. Older women who provide care should receive targeted economic, technical, and social support. The priorities of caregivers in households and communities must be included in national strategic plans and budgets and should include HIV-sensitive social protection schemes. Safe spaces should be secured for older women living with HIV to engage in the design, implementation and monitoring of the national HIV responses. Leadership skills and capacity of women aged 50 and over living with HIV should be strengthened to organize, participate and access sustainable financing for their work and their lives.

89. A longer living population with HIV can support families and society with social cohesion, improved child care and greater flexibility of middle-aged family members to temporarily migrate for more lucrative work opportunities [46].

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Older people's associations: harnessing the power of older age, South East Asia

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Older people's associations are an innovative approach to taking community-based action. These organizations empower people in later life, using their skills, capacities and willingness to actively engage with and serve their communities. Their importance in promoting the well-being of older people, including those who are poor and disadvantaged, has been recognized by the Association of Southeast Asian Nations, the United Nations, WHO and governments throughout Asia [120]. For example, China recently issued a policy promoting the improvement and expansion of their 490 000 associations to align them better with their development goals. Older people's associations are multifunctional and conduct a wide range of activities, the most common of which focus on improving incomes through microcredit and income-generating activities; providing health and care for older people, including through community-care programmes aimed at care-dependent older people; providing social and cultural activities as well as disaster preparedness; and enabling social participation.

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The associations may also provide social assistance in the form of money, food and labour for those in the community who are most in need of them. The associations work closely with public authorities not only to ensure that their community members are receiving the services they are entitled to, such as social pensions and health insurance, but also to advocate for the development and expansion of the services and resources provided by the local authorities. The associations also work to ensure their own financial sustainability, and in Viet Nam, associations have demonstrated their capacity to fundraise.

Older people's associations have great potential for fostering Healthy Ageing. For their members, they organize regular health check-ups, carry out health-education activities and regular physical exercise sessions, as well as conveying knowledge about healthy living and preventing and managing noncommunicable diseases. In South East Asia the associations are developing a holistic community-care approach to support the increasing numbers of older people who are highly dependent and need help with activities of daily living, have a limited income or lack adequate care from their families. Community activities include recruiting, training and managing home-care volunteers to provide personal-care assistance to older people who need it. The associations can also help pay for transportation to health stations when required, and offer links to complementary services, such as those that provide assistive devices or rehabilitation. Some associations also mobilize resources and labour to modify and repair homes, and in disaster-prone areas they ensure that all at-risk older people have a designated emergency buddy to support them in times of danger. Older people's associations have been effectively drawing on the resources inherent in older populations to mobilize entire communities [4].

## A LIFECYCLE APPROACH TO AGEING WITH HIV: AREAS OF FUTURE ACTION

90. Inherent to the SDG target to end the AIDS epidemic by 2030 is the need to focus on populations that have been left behind by the HIV response – one of these populations is older people [116].
91. It is time to recognize the ageing HIV epidemic in the context of ending AIDS by 2030 and to ensure integrated services for people living with HIV aged 50 and over are available, accessible and appropriately meeting the needs of such a growing number of people to ensure the health of a diverse population of people living with HIV. Moreover, as access to quality treatment expands and countries begin to approach universal access, life expectancy for people living with HIV should continue to increase and potentially reach that for HIV-negative people. Responses to HIV at global and national levels must anticipate the ageing of people living with HIV populations, making the successful shift from acute to integrated, chronic care and ensuring quality and affordable antiretroviral medicines within integrated health systems as well as ensuring the human rights of older people are respected. Based on the analysis presented above, a number of priority areas for action emerge:

### Research and development areas

92. To better inform policies and programmes, more research is required to understand ageing with HIV, including: the long-term effects of ART; better understanding of comorbidity related to the ageing process and other co-infections and NCDs; efficacy and modifications of regimens in different age groups; drug resistance; the impact of early or late initiation on ageing; and the body's ageing process with HIV in general for women, for men, for children born with HIV and for key populations.

93. There is an urgent need to understand the drivers of HIV incidence among women and men aged 50 and over in order to respond with supportive interventions and policies.
94. Investments are needed for research on new and improved ARVs for those on long-term treatment, ideally with less risk of toxicity and drug interactions, as well as investments in research for a cure and vaccine. Clinical trials should involve both women and men.

### **Age-sensitive strategic information**

95. To meet the needs of people living and ageing with HIV, age-sensitive and sex-disaggregated strategic information is necessary. Understanding the epidemiology of HIV infection in people aged 50 and over can lead to practical interventions to make the older years safer, more enjoyable [9] and improve general quality of life. Currently, there is a striking lack of surveillance or other strategic information on older men and women living with HIV [121]. National surveys which include the collection of data on HIV prevalence traditionally collect data among women 15-49 and men 15-54 limiting the data available to track prevalence and risk behaviours in the populations ages 50 and older. For example, out of 30 Demographic Health Surveys (DHS) between 2004-2009, only 13 surveys included older males and none included older females [9].
96. Sex-disaggregated data on incidence of HIV among people 50 years and older is equally important and also lacking. Incidence could be determined via case reporting, serologic incidence assays or modelling. Developing countries often have limited case-reporting systems, but industrialized countries do better [9]. In addition a number of global indicators that focus on HIV risk behavior, focus on the populations less than age 50.

### **Health, social and structural responses**

97. Integration of services related to coinfections and comorbidities is key when considering ageing and HIV. People-centred systems for health and social protection (including food and nutrition, employment) are needed to shift to treating HIV as a chronic illness that requires a lifecycle approach.
98. Integrated healthcare for people living with HIV aged 50 and above is needed and should include screening and management of cardiovascular diseases and other NCDs and lifestyle factors such as smoking, alcohol and nutrition. Antiretroviral treatment must be integrated with care systems for other chronic diseases. Health-care providers must be trained to respond to the specific needs and challenges of this population. Health services must respond to the reproductive, ageing and HIV health changes facing women living with HIV over 50.
99. There is a need for development of age specific guidelines for HIV. As well as including guidance on HIV clinical management and care, the guidelines should provide recommendations on screening programmes and also additional monitoring of biomarkers, especially from the comorbidities that occur more frequently with age. People aged 50 and over living with HIV could be seen by general health care providers and only referred to HIV specialist clinics when viral loads are unsuppressed or for management of complex co-infections or co-morbidities. In this way, they could also receive integrated care addressing lifestyle, cardiovascular disease and other chronic diseases as well as deal with ARV-associated complications such as drug-drug interactions [119].

100. Structural interventions including programmes tackling gender inequality, self-stigma, stigma and discrimination, gender-based violence, discrimination faced by key populations and legal rights for older men and women living with HIV in all their diversity should be prioritized.
101. Given the high prevalence of depression, as well as alcohol and drug abuse among people living with HIV (including older populations), the impact of these conditions on retention and ART adherence, and the limited availability of treatment for these conditions, it is critical that the health and social sectors develop and implement approaches to address these key mental health challenges. WHO has highlighted recommendations and priorities for action to address the combined challenge of HIV and mental health globally [122].
102. Special attention must be given to providing psychological and medical support as well as concrete social protection for people living with HIV over 50 in all their diversity.
103. Age appropriate and gender-responsive sexual health and comprehensive sexuality education programmes should be prioritised to support aged 50 and over living with and at risk of HIV.
104. Gender-sensitive programmes for key populations living with HIV aged 50 and above must be adapted to be age-appropriate, in particular services that reach women, people who use drugs, sex workers, gay men and other men who have sex with men and transgender people living with HIV. Age-appropriate harm reduction services are also critical for people who use drugs.
105. ART production, procurement, and delivery systems must be strengthened to ensure affordable, adequate and uninterrupted supply of ART to a growing ageing population of people living with HIV.
106. In May 2016, WHO Member States adopted the Global Strategy and Action Plan on Ageing and Health 2016-2020 that recommends the establishment of national frameworks towards healthy ageing that include evidence-based policies and combatting ageism; developing age-friendly environments that include fostering older people's autonomy, enabling their active participation and promoting multisectoral action; and aligning health systems to the needs of older populations. These are important recommendations towards strengthening the health sector response to HIV and ageing.

### **Political agenda**

107. Putting HIV and ageing on the international agenda includes increased political leadership and commitment, an active movement, stronger health systems, a greater commitment to trained human resources and improved clinical infrastructure and expertise and budgets to support research and programmes on older people living with HIV.
108. Civil society organisations together with governments can advocate for reduction of high costs of medication for diseases occurring late in life, including many cancers and end-stage organ diseases as they did for ART [114].

**Meaningfully engaging and learning from people living with HIV**

109. Ensuring greater involvement of people living with HIV aged 50 and over in the decisions, strategies and responses to their needs is crucial.
110. It is important to focus on the immense strength and resilience of people living with HIV aged 50 and over. Many people living with HIV have learned how to cope with hugely adverse psychological, social and physical challenges and can act as positive role models and leaders to show others how to live positively with HIV.

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