# FOLLOW-UP TO THE THEMATIC SEGMENT FROM THE 39TH PROGRAMME COORDINATING BOARD MEETING:

# **HIV and ageing**



27-29 June 2017 | Geneva, Switzerland UNAIDS Programme Coordinating Board Issue date: 25 May 2017

# Additional documents for this item: none

Action required at this meeting – the Programme Coordinating Board is invited to: (see decisions in paragraphs below)

30. *Take note* of the summary report of the Programme Coordinating Board thematic segment on HIV and ageing.

- 31. Recognize that:
  - a. Addressing HIV and ageing requires a lifecycle approach and age-sensitive strategies for each age group, includes responding to physical and mental health challenges as well as the need for social protection;
  - b. An ageing population of people living with HIV is a measure of a successful response to HIV and the resilience of people living with HIV, not a failure, and it is imperative to strengthen action now to pro-actively address the needs of current and future generations of people living with HIV who are 50 years and older;
  - c. Communities, Governments, political leaders, civil society and, in particular, people living with HIV 50 years and older have key roles in ensuring a coherent and effective response to HIV and ageing;
  - d. Systemic and structural barriers perpetuate stigma and discrimination against persons 50 years and older and hinder access to HIV information and services;
  - e. Continuous innovation and research in drug development for more simplified and less toxic ARV regimens, for medications addressing age-related conditions and their interactions are needed.
- 32. Request Member States to:
  - a. Invest in systems for health and social protection, and provide health and social workers with appropriate levels of knowledge and skills;
  - b. Support research to improve understandings of ageing with HIV, including the long-term effects of ART, the effects of interactions between ARV and medications for age-related conditions, and possible accelerated and accentuated ageing due to HIV;
  - c. Improve evidence gathering and monitoring systems to provide strategic information on people living with or at risk of HIV 50 years and older;
  - d. Support structural interventions, including legal and policy reform that removes barriers and increases access to services, comprehensive sexuality education for people 50 years and older, social protection and programmes that tackle the stigma and discrimination faced by people living with HIV and by other key populations;
  - e. Invest in age appropriate and evidence informed interventions to scale-up and promote testing and timely linkage to sustainable care with reference to the UNAIDS Fast Track Targets

33. *Requests* the Joint Programme, in cooperation with partners, to strengthen support to countries for integrating and implementing comprehensive programmes on ageing with HIV and for allocating resources.

## Cost implications for decisions: none

## BACKGROUND

- 1. The 39th meeting of the UNAIDS Programme Coordinating Board (Board) included a thematic segment devoted to HIV and ageing. The theme had previously been agreed at the 38th Board meeting in June 2016.
- 2. This report summarizes the presentations and discussions during the thematic segment of the 39th meeting. Rather than capture every intervention made during the session, the report summarizes the key themes and issues that emerged. It should be read together with the background document (UNAIDS/PCB (39)/16.26), which was prepared specifically to accompany this thematic segment.
- 3. In September 2015, the 2030 Agenda for Sustainable Development was adopted, along with a plan of action to leave no one behind. In May 2016, WHO Member States adopted the Global Strategy and Action Plan on Ageing and Health, 2016–2020, which recommends the establishment of national frameworks to facilitate healthy ageing. Those frameworks would address a need for evidence-informed policies and steps to combat ageism; for age-friendly environments that also foster older people's autonomy, thereby enabling their active participation in society; for promoting multisectoral action; and for aligning health systems to the needs of aging populations.
- 4. Of the estimated 36.7 million people living with HIV globally in 2015, approximately 5.8 million (2.5 million women and 3.3 million men) were aged 50 years and older. The proportion of people living with HIV who are at least 50 years old is projected to increase to 8.5 million in 2030, a trend that has significant cost implications for national budget planning and financing. The medical, social and psychosocial aspects of a growing aging population living with HIV highlight the urgency to Fast-Track a people-centred response that ensures that people living with HIV are able to reach and sustain good health throughout their lives.
- 5. People living with HIV 50 years and older, similar to other age groups, are diverse there is no typical older person. Their sexual preferences and sexual identities vary and they may also belong to key populations such as sex workers, people who use drugs, gay men and other men who have sex with men or incarcerated persons. As such, they have different needs and face different challenges, including the significant social, psychological and physical challenges that are associated with the ageing process.
- 6. For people living with HIV aged 50 years and older, the HIV-related and ageing-related health and social needs converge. HIV and ageing is also an important issue for people 50 years and older who acquire or are at risk of HIV infection. HIV and ageing is also relevant for children and young people living with HIV who will be managing their HIV infections for the rest of their lives.

# SHAPING THE DEBATE: OPENING DIALOGUE

7. Mr Michel Sidibé, Executive Director of UNAIDS, opened the thematic segment emphasizing that a demographic shift was underway, with increasing numbers of people who are living with HIV and are at least 50 years of age. He highlighted the need to apply a lifecycle approach to HIV that reflects the different needs of people at different ages. Stressing the importance of focusing on the experiences and needs of people aged 50 years and older who are living with HIV, he challenged the meeting to identify the appropriate approaches that should be implemented as part of the Fast-Track strategy. Those approaches would have to take into account people over 50 who are at risk of HIV, as well as those at risk of comorbidities, including noncommunicable diseases such as cancers, heart disease and dementia – all of which also complicate HIV treatment and care, and increase the costs of health care. Mr Sidibé noted that people living with HIV are 5-6 times more likely to suffer from noncommunicable diseases than HIV-negative people of similar age. He urged the meeting to propose ways for improving social protection for people living with HIV 50 years and older who need increased support as they age.

- 8. Ms Angeline Chiwetani, Director of Widows Fountain of Life, Zimbabwe, highlighted the importance of social protection issues for people who are ageing with HIV, including the need for pensions, ongoing social support and life insurance. She mentioned the specific needs of children who had been born with HIV as they enter adolescence and adulthood. While insisting that people living and ageing with HIV could have a good quality of life, she also underscored the importance of understanding the long-term effects of antiretroviral (ARV) drugs, the ongoing value of treatment literacy, the need to innovate simpler and safer medications, and the need for improved training for health care providers. She also emphasized the need to pay special attention to mental health issues and self-stigma.
- 9. Mr John Rock, representative from the community of people living with HIV shared his powerful personal story. An Australian, he has been living with HIV for 36 years and is now 72 years-old. He described the experience of living with HIV and taking the various treatments that were available to him during those 36 years. He emphasized that there is clear evidence that several associated ageing conditions are most likely at least in part a consequence of the inflammatory effects of HIV and especially those whose viral load has been elevated fort a long period, although this is not yet sufficiently understood. Depression, loneliness, low esteem, social isolation and survivor guilt affect many people living with HIV, Mr Rock told the meeting. He highlighted the stark differences that separate developed and developing countries, including the quality of their health infrastructure and availability of state-subsidized social protection, and noted the need to promote treatment as prevention, and reduce stigma and discrimination. He also addressed some of the specific issues that affect ageing key populations, such as gay men and other men who have sex with men, including a high association between HIV and anal cancer, and called for greater access to regular screening services. Mr Rock urged Member States to embrace the Fast-Track strategy, promote HIV testing, and support community groups so they can expand testing and potentially provide treatment themselves in their constituencies. He emphasized the importance of placing people living with HIV on robust first-line treatments as soon as possible after becoming infected in order to supress their viral loads. Doing so would also limit the emergence of other conditions that tend to occur as people with HIV grow older.
- 10. The panel discussion following the opening dialogue included several people living with HIV, as well as representatives from Ministries of Health and civil society. They discussed priority actions for ensuring that people living with HIV can live long and healthy lives. The days discussions were facilitated by Mr Andy Seale of the World Health Organization.

## AGEING WITH HIV: LIVE LONG AND LIVE WELL

11. Professor Peter Reiss, of the Amsterdam Institute for Global Health and Development in the Netherlands, presented a thorough overview of the status of the HIV epidemic and its impact on the physical and mental health of people living with HIV aged 50 years and older. After reminding the meeting that age is a major risk factor for a wide range of diseases, Professor Reiss said that the comorbidity burden is consistently elevated in people living with HIV. Cardiovascular disease, diabetes and various forms of cancer are among the most prominent comorbidities. He noted that the success of HIV treatment

means that increasing numbers of people living with HIV are aged 50 years and older. He emphasised the importance of early diagnosis and treatment for enabling people with HIV to live long and healthy lives.

- 12. Importantly, Professor Reiss cautioned against generalizations about the association between HIV, HIV treatment, comorbidities and ageing. The interactions between those various factors were still insufficiently understood, he said. It is not clear, for example, whether people living with HIV are indeed experiencing accelerated ageing. However, HIV infection and ART toxicity (particularly toxicity associated with ARV therapies used during the early years of HIV treatment) may be contributing to the prevalence and intensity of certain chronic comorbidities in people living with HIV. Research studies (including the AGEhiV and Cobra cohorts) are providing important new data on these questions. Current data suggest that the risk of comorbidities appears to be associated with the duration for which a person experiences low CD4 cell counts, rather than overall exposure to ART. Professor Reiss stressed that the promotion of healthy lifestyles, along with early diagnosis and treatment of HIV infection, is of key importance since it can reduce the negative effects of the interactions and reduce the burden of comorbidities.
- 13. Ms Ekaterine Gardapkhadze, head of the board of the ACESO International Organization for Women in Georgia, outlined the challenges faced by people who are living with HIV and who use drugs, particularly older drug users, when accessing services. She highlighted the role of violence and stigma, the lack of information about ageing with HIV while receiving substitution therapy, and a shortage of health professionals who are experienced in dealing with issues related to ageing and HIV. Since older people tend not to use social media as a regular source of information, other methods are needed to reach them with the information they may need. Ms Gardapkhadze stressed the importance of harnessing the experiences of older people living with HIV. She also noted a lack of medical and social services within prison systems to deal with comorbidities such as cardiovascular diseases. In particular, services for incarcerated female drug users are absent and these women's confidentiality is not protected. Social isolation, stigma and discrimination can be more destructive than HIV and drug use, she noted.
- 14. Mr Stephen Ayisi Addo, programme manager of the National AIDS Control Programme in Ghana, told the meeting that 8% of people living with HIV in that country are at least 50 years-old and many of them encounter barriers when accessing services. With support from the Global Fund to Fight AIDS, TB and Malaria, the Government in Ghana has set up chronic care clinics to ensure that services are available and to reduce the stigma surrounding HIV. The clinics support various groups, including adolescents, and people older than 50 years. He called for more studies to improve understandings of the long-term effects of different ARVs, so that children living with HIV can avoid any negative effects associated with their treatment. He also called for further research into the care and related needs and experiences of older people who are living with HIV and comorbidities.
- 15. Mr Clive Blowes, National Coordinator of the Health, Wealth and Happiness Project of the Terrence Higgins Trust in the United Kingdom, described a 2010 study that guided the development of the project. The study had found that although people living with HIV were receiving quality clinical care, they experienced twice as many long-term conditions compared with HIV-negative people, and that there was scant information about how the conditions interacted. The research also highlighted financial challenges, particularly for older people living with HIV who did not have pensions, received limited state benefits and had made little provision for their financial futures. High levels of depression, anxiety, stigma and self-stigma were found, along with loneliness, loss of friends and social isolation. A pilot programme was established in 2012 and rolled out nationally in

2014. The programme provides financial advice, income support, emotional and psychosocial support, medical information and a back-to-work service. Mr Blowes stressed the importance of social protection and linkages to services, and called for greater recognition of the different needs and issues faced by people in their fifties and older.

- 16. Ms Norlela Mokhtar, chairperson of the International Community of Women Living with HIV, Asia Pacific, shared her experiences working with the Wahidayah Shelter, a community-led initiative in Malaysia. She outlined the vulnerabilities of women living with HIV, in particular sex workers, drug users and widows, who are often shunned by their communities and families and end up needing housing and other support as they grow older. She reminded the meeting of the importance of reliable health information so that people who are ageing with HIV are able to understand and protect their health.
- 17. The concluding discussion highlighted the value of early diagnosis and treatment of HIV. Speakers called for strengthened livelihood support and employment programmes, and noted the gendered nature of social protection gaps, with women more likely than men to grow old in poverty. Medical staff need training on HIV and ageing, and there is a need for research and programmes that address the underlying structural factors shaping the experiences of people living with HIV 50 years and older. It was suggested that reformed health insurance systems could facilitate improved HIV care, especially for older persons, while the management of HIV and comorbidities in large numbers of older people could serve as a model for other health conditions. Ghana was noted as an example where integrated care for diabetes, hypertension and HIV screening is provided. Speakers also emphasized a need for ongoing sexual and reproductive health services for people 50 years and older who are living with HIV.

# PREVENTING HIV IN PEOPLE 50 YEARS AND OLDER: RISKS AND RESPONSES

- 18. This panel opened with the screening of two short TV campaign videos from Brazil, which creatively highlighted HIV prevention among women and men 50 years and older. Ms Shirley Hankerson, co-chair of the Positive Women's Network in the United States of America, spoke of the invisible issues of sexual reproductive health of women 50 years and older, and shared her personal experience of being diagnosed with HIV at 58. She called for improved education of older adults about HIV, especially women who may have lost a partner to death or divorce and who are sexually active, yet lack knowledge of HIV and other health risks. Older women often head their families and can become powerful advocates among their children, she told the meeting.
- 19. Ms Kay Thi Win, regional coordinator of the Asia-Pacific Network of Sex Workers, Myanmar, spoke of the elevated risks which key populations living with HIV experience due to punitive laws, restrictive policies and lack of services. Sex workers are ten times more likely to acquire HIV than the general population, she said. Older sex workers are at even greater risk because they tend to be forced out of sex work venues and onto the street, where they are vulnerable to higher levels of violence and harassment. They also receive less money for their services and face high levels of stigma and discrimination as they age. Condom distribution programmes tend to miss older sex workers. Ms Win said information, education and support programmes should take into account ageing sex workers who need condoms, sexual health information and other services, as well as support to secure alternative income sources.
- 20. Ms Adele Benzaken, director of the Department of STDs, AIDS and Viral Hepatitis at the Ministry of Health in Brazil, said that the sexual lives of older people are a priority for the Government of Brazil. There are more than 40 million people older than 50 years in

Brazil, and a 2013 national household survey estimated that more than 20 million Brazilians aged 50–64 years were sexually active. Among them, 20% reported having had one sexual partner in the year prior to the survey and 6% reported having had more than five casual sexual partners in that period. Only 25% of the sexually active respondents had ever been tested for HIV and almost 90% of them believed they were at low risk for HIV infection. Condom use with casual partners was rare. Ms Benzaken said it was not yet clear how best to address sexual health and HIV prevention among older people, but added that these issues can be raised with older people when they present to health services with other illnesses. Health care programmes for the elderly have included sexual care for older adults, but the sexuality for older people remains a taboo for many health professionals, she noted.

- 21. Mr Kenneth Mugayehwenkyi, Executive Director of Reach One Touch One Ministries, Stephen Lewis Foundation, Uganda, spoke of the needs and rights of older people. He relayed the story of Edwina, a 76 year-old grandmother, who lost her husband in 1998 and then lost her son and daughter soon afterwards. The family had spent a great deal of its resources to care for her husband and children, which eventually left her with no property, income or social security. A programme in Uganda now supports women such as Edwina in accessing medical care and earning an income by providing care for orphans. Mr Mugayehwenkyi described how grandmothers living with HIV have forged strong movements for change in their villages and communities, and have been instrumental in the development of stronger social protection in national policies. He told the meeting that grassroots organizations require funding to provide care and support to older people in their communities and to mobilize them to advocate more effectively for their needs.
- 22. The panel discussion noted the significance of intergenerational relationships for the HIV prevention agenda, as well as the need for strengthened social protection. The absence of adequate social protection, particularly for older women caring for family members with HIV, was highlighted. Speakers urged that information campaigns and sexuality education target men and women in their fifties and older. They also pointed to a need for specialist support from clinicians for women living with HIV who are in menopause.

#### AGE-SENSITIVE SYSTEMS: WHAT THE FUTURE LOOKS LIKE

23. Introducing the discussion on age-sensitive health systems for the future, Mr Gottfried Hirnschall, Director of WHO's Department of HIV and the Global Hepatitis Programme, told the meeting that health systems are poorly adapted to cope with ageing populations of people living with HIV. Services tend to be highly specialized (and expensive) in highincome countries, but are weak in most low- and middle-income countries. The fact that the latter countries are undergoing rapid demographic changes makes systemic improvements especially challenging. Changes introduced in high-income countries over the course of many decades, and in relatively favourable fiscal circumstances, now have to be applied in low- and middle-income countries much more quickly and typically with much less funding. Strengthened health work forces are essential for supporting growing numbers of people that experience multiple health complications, and health systems will also have to interface more systematically with social and financial protection systems. Mr Hirnschall drew attention to WHO's Global Health Sector Strategy on HIV, 2016-2021, which also addresses HIV and ageing. He encouraged Member States to develop strong national HIV frameworks that incorporate ageing, and highlighted the distinct care and support needs of people of different age groups who are living with HIV. He advised a move towards more holistic and integrated care, and added that the increased collection of age-disaggregated data was needed to inform resource allocations that could strengthen health systems.

- 24. Mr Kenichi Komada, Deputy Director of the International Affairs Division in Japan's Ministry of Health, Labour and Welfare, said that the country has one of the oldest populations in the world, with one in four people older than 50 years. Approximately 20% of people newly diagnosed with HIV are older than 50 year.
- 25. Life expectancy among people living with HIV rivals that of HIV-negative people, and people with HIV are covered by the same insurance systems and receive the same services as everyone else. However, research has revealed low levels of HIV knowledge and acceptance of HIV-positive people in health facilities. In response, the Government has introduced health education training on HIV within the network of hospitals, while also training and assigning social workers to promote greater acceptance among health professionals of people living with HIV.
- 26. Ms Carmen Pérez Casas, HIV strategy manager for UNITAID, drew attention to several challenges, including the need to further reduce the costs of ART and improve treatment regimens in order to avoid having to switch patients to expensive second- and third-line regimens. She said the effectiveness and safety of existing therapies has to be safeguarded, for example through viral load testing, so regimens can be corrected timeously to avoid drug resistance and to limit the switching of patients between regimens. Given the rising numbers of people receiving HIV treatment and the increasing need to change regimens, treatment costs are growing making it more important than ever to advocate and strategize for cheaper drug prices. She also emphasized the need to develop improved ARV formulations with less toxicity. Ms Casas pointed to innovations such as HIV self-testing that are breaking down barriers to stigma and discrimination, and urged that pre-exposure prophylaxis be made more widely available.
- 27. Finally, Ms Erika Castellanos, Executive Director of C-NET+, Belize spoke of the different priorities of younger and older people who are living with HIV. She emphasized the need to protect the rights of people living with HIV, including the right to a household, to buy insurance and to plan for older age.
- 28. In the discussion that followed, members and panellists called for a world in which people ageing with HIV are fully supported by strong health and social systems by 2030, and stressed that human rights concerns should guide decisions and policies. Participants shared accounts of resilience that have strengthened responses to HIV.
- 29. Closing the thematic discussion, Dr Luiz Loures, UNAIDS Deputy Executive Director, Programmes, reiterated the need to apply a human rights approach across the entire lifecycle and called for continued discussions to ensure that the issue of HIV and ageing is kept high on the agenda.

## RECOMMENDATIONS

The Board is invited to:

- 30. *Take note* of the summary report of the Programme Coordinating Board thematic segment on HIV and ageing.
- 31. Recognize that:
  - a. Addressing HIV and ageing requires a lifecycle approach and agesensitive strategies for each age group, includes responding to physical and mental health challenges as well as the need for social protection;
  - b. An ageing population of people living with HIV is a measure of a successful response to HIV and the resilience of people living with HIV, not a failure, and it is imperative to

strengthen action now to pro-actively address the needs of current and future generations of people living with HIV who are 50 years and older;

- c. Communities, Governments, political leaders, civil society and, in particular, people living with HIV 50 years and older have key roles in ensuring a coherent and effective response to HIV and ageing;
- d. Systemic and structural barriers perpetuate stigma and discrimination against persons 50 years and older and hinder access to HIV information and services;
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  - c. Improve evidence gathering and monitoring systems to provide strategic information on people living with or at risk of HIV 50 years and older;
  - d. Support structural interventions, including legal and policy reform that removes barriers and increases access to services, comprehensive sexuality education for people 50 years and older, social protection and programmes that tackle the stigma and discrimination faced by people living with HIV and by other key populations;
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- 33. *Requests* the Joint Programme, in cooperation with partners, to strengthen support to countries for integrating and implementing comprehensive programmes on ageing with HIV and for allocating resources.

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