FOLLOW-UP TO THE THEMATIC SEGMENT FROM THE 41ST PROGRAMME COORDINATING BOARD MEETING: ZERO DISCRIMINATION IN HEALTH CARE SETTINGS



26-28 June 2018 | Geneva, Switzerland UNAIDS Programme Coordinating Board Issue date: 29 May 2018 Additional documents for this item: *Documents: UNAIDS/PCB (41)/17.26; UNAIDS/PCB (41)/17.27; UNAIDS/PCB (41)/CRP1*

Action required at this meeting – The Programme Coordinating Board is invited to:

See draft decision points in paragraphs below:

45. Taking note of the background note (UNAIDS/PCB (41)/17.27) and the summary report of the follow-up to the thematic segment of the 41st PCB on "zero discrimination in health-care settings".

46. Recalling decisions 7.2 and 7.3 from the 41st PCB meeting on actions to reduce stigma and discrimination in all its forms, *call* on Member States, stakeholders and partners to:

a. improve measurements to track progress on ending discrimination;

b. strengthen and scale up multi-sectoral measures to address all forms of discrimination, including legislative and budgetary measures;

c. ensure supportive work environments for health-care workers to reduce discrimination both towards service users and other health-care workers integrating ethics and human rights, such as non-discrimination, free and informed consent, confidentiality and privacy, into pre- and in-service training curricula for health workers.

47. Request the UNAIDS Joint Programme to:

a. accelerate efforts to develop synergies and links with national, regional and global efforts to reduce discrimination in all its forms, including in health care settings, and with efforts to achieve relevant Sustainable Development Goals and to leave no one behind in the achievement of those goals;

b. support Member States, donors, civil society, networks of key populations and other partners, including national, regional and international human rights institutions and bodies, to integrate the measurement of discrimination in health-care settings into routine monitoring of the AIDS response and to consolidate and disseminate existing evidence on effective programmatic and policy responses to eliminate discrimination in health-care settings;

c. strengthen collaboration with the Global Fund and other donors to increase investments in programmes to reduce discrimination, including in health-care settings.

48. *Request* Members States and key donors to increase their investments to adequately address discrimination in health-care settings as part of a fully-funded global HIV response.

INTRODUCTION

- The thematic segment was devoted to ending discrimination in health-care settings. Presentations and discussions included empirical evidence and personal accounts of ongoing discrimination, accounts of successful interventions, and proposed actions for ending discrimination in health-care settings and beyond.
- 2. The PCB Chair, Kwaku Agyeman-Manu, Minister of Health in Ghana, introduced the thematic segment and emphasized the importance of the issue, highlighting that ending discrimination in health-care settings is a prerequisite for reaching the other HIV targets and reminded members that a strong body of good practices exists for reducing such discrimination.
- 3. The moderator, Mahesh Mahalingam, Director of Communications and Global Advocacy at UNAIDS, outlined the segment's three main objectives: review evidence of the impact of discrimination in health-care settings; identify and showcase good practices; and galvanize action to eliminate such discrimination.
- 4. Michel Sidibé, Executive Director of UNAIDS, reiterated the Joint Programme's commitment to set up a global compact on eliminating stigma and discrimination. He told the Board that the HIV response has always been about transforming the way public health is understood and practiced. The progress made to date stems from people's refusal to accept "things as they are". Activists pushed governments to act, they broke the conspiracy of silence, and they worked to make sure no one was left behind.
- 5. This has led to great progress, with more than half of people living with HIV now receiving treatment. However, the fear and reality of stigma and discrimination in health-care facilities continues to prevent many people, especially those belonging to key populations, from accessing lifesaving services. In some countries more than 40% of transgender persons report avoiding health-care facilities because they fear stigma and discrimination. Forced sterilization of women living with HIV is still being reported. Marginalized communities are often excluded from the public health system.
- 6. Such human rights violations are an affront to all: from Baltimore to Bamako, the right to health belongs to all, Mr Sidibé said. The vision for health set out in Sustainable Development Goal 3 cannot be achieved if countries do not confront stigma and discrimination, including in health care settings.

DIALOGUE: THE IMPACT OF DISCRIMINATION IN HEALTH-CARE SETTINGS

- 7. Lillian Kyomuhangi Mworeko, Regional Coordinator of the International Community of Women Living with HIV in Eastern Africa, outlined the many ways in which women experience stigma and discrimination related to their health. Migrant women are especially likely to be denied HIV and other health services, she said. For pregnant women, it is often mandatory to be tested for HIV, yet many women avoid taking an HIV test for fear of violence or rejection from their partners. That reluctance is reinforced by the fact that some countries criminalize the transmission of HIV from mother to child. Women living with HIV are often denied their family planning choices and are sometimes subjected to forced sterilization.
- 8. Ms Mworeko reminded the meeting that important guidance documents have been developed and that countries can use them to address these violations. But it is equally important that women have the information they need to take the best decisions for themselves and their families.

- 9. Camille Anoma, director of Clinique Confiance in Abidjan, Côte d' Ivoire, told the Board that key populations experience intense self-stigmatization in addition to the stigma they face from others. People who are perceived to be gay experience stigma from families, on the street, from police and from health-care providers. Many are afraid to use health-care facilities. Clinique Confiance offers free and confidential health services and works with peer groups that provide primary prevention services. The clinic also engages with other health service providers around the difficulties key populations experience.
- 10. Abhina Aher, Associate Director for Sexuality, Gender and Rights at the India HIV/AIDS Alliance, recalled the multilayered stigma, discrimination and confusion she has experienced as a transgender person. As a former sex worker, she avoided health clinics due to the discriminatory attitudes she encountered and because it was unclear which services she—as a transgender person—should attend. Health-care systems are still not equipped to deal with transgender realities, she said, and few medical staff have sufficient knowledge to provide transgender people with the care they need.
- 11. Punitive laws are a major problem, she added. In Asia-Pacific, for example, 49 of 75 countries have laws that allow for the punishment of certain key population behaviours. Stigma against sex workers—and internalized stigma—adds to the difficulties. Even when sex workers do seek health care, the judgemental attitudes of doctors discourage them from disclosing their backgrounds and relevant medical histories. Self-stigma affects the ability and willingness of key populations, especially transgender people, to access services.
- 12. Winfield Tannis-Abbott, chair of Caribbean Regional Network of People Living with HIV and AIDS, speaking from the floor, highlighted the effect of stigma and discrimination on young people's willingness and ability to seek medical care, especially for people living with HIV. Mental health issues are a challenge for many young people living with HIV, and stigma and discrimination is often a contributing factor, he said. Although it is clear punitive laws legitimate stigma and discrimination, pressure from organized religion can make it politically difficult for governments in his region to reform such laws.
- 13. Jim Campbell, Director of the Health Workforce Department at WHO, focused on the need to ensure that health-care workers' rights are also respected so that they can uphold people's human rights. He reminded that health-care institutions reflect the power dynamics and relations of broader society. For example, in Ghana, he said, two thirds of health workers are women and about one quarter of reported cases of violence in work settings occur in health-care facilities. More than 50% of recently graduated female nurses reported experiencing violence, including sexual violence, within their first 12 months of work. The discussion about stigma and discrimination in health-care settings should take into account the fact that health-care workers have roles and responsibilities, as well as rights, he told the meeting.
- 14. In the subsequent discussion, Ms Aher suggested that the focus should be on improving attitudes and preserving people's dignity. Policies and laws could only lay the groundwork for changes in attitude. Ms Mworeko pointed to the importance of "healthy" health-care systems. Health workers could not reasonably be expected to safeguard patients' rights if their own rights were being violated. In addition to appropriate policies, adequate resources are needed to achieve the desired improvements, she said.
- 15. Mr Campbell suggested that much could be learned from efforts to strengthen health systems and that opportunities should be created to learn from communities. For example, traditional clinic-led approaches are not always the solution. At the same time, community-led approaches may require some flexibility with regard to policies and regulatory systems.

16. The Board was also told that good practices should be shared more widely. Ms Mworeko referred to "centres of excellence" that had been identified in her region and described how exchange visits were being used to share experiences among health-care providers in different countries. Her organization also stages dialogues between women living with HIV, health-care workers and decision makers. These sessions have revealed, for example, that health-care workers often believe they are acting in the patients' best interests, even when it is manifestly not the case. Greater understanding of patients' realities and needs is an important part of the solution, she said.

SETTING THE SCENE: DISCRIMINATION IN HEALTH-CARE SETTINGS AS A BARRIER TO REACHING THE FAST-TRACK TARGETS

- 17. Luiz Loures, UNAIDS Deputy Executive Director, introduced this session with a reminder that stigma and discrimination has been a problem since the earliest days of the HIV epidemic and that it helped catalyze a social movement that has brought treatment to more than half of the 36.7 million people living with HIV. But that achievement also highlights the challenge that remains, which is to ensure that everyone who needs treatment can access it.
- 18. About 80% of new HIV infections outside sub-Saharan Africa are in key populations who are already vulnerable and discriminated against in numerous ways, he told the meeting. In sub-Saharan Africa, a large percentage of new HIV infections are in young women, many of who are also subject to violence and inequality. The current patterns of the HIV epidemic spotlight the persistence of stigma and discrimination, and of the violence it often leads to.
- 19. What should be done? The UNAIDS Deputy Executive Director emphasized the need for accurate, disaggregated data and for data that captures the availability and equity of services. Such data would reveal more clearly the costs of stigma and discrimination, including the economic costs to societies.
- 20. Strengthened training and capacity building on stigma and discrimination is needed for health-care providers and affected communities should be involved centrally in such training. Health-care workers' rights must also be protected. More appropriate laws and policies will make a difference, including changes to laws that require young people to obtain the consent of their parents before they can use health-care services. Getting to zero discrimination will require reaching deeper into society, into faith-based organizations and communities, he added.
- 21. In discussion, PCB members applauded the UNAIDS Secretariat for arranging this thematic focus and welcomed the proposed global compact on stigma and discrimination.
- 22. Members described their efforts to reduce stigma and discrimination, including through decentralizing health services and the greater use of community-based services. They urged countries to take practical steps to end stigma and discrimination, such as enhanced education and training for health-care workers, using peer support methods, creating mechanisms for reporting rights violations and achieving redress, and by introducing procedures that are gender-responsive.
- 23. Important legal challenges are being mounted against stigma and discrimination in some countries. However, other changes are also needed, including improving women's knowledge of their rights and enabling them to claim those rights. The rights to confidentiality and to informed consent must also be respected.

- 24. Speakers stressed that a rights-based approach has to underpin the HIV response and reminded that human rights must be protected more widely in social and economic life. Stigma and discrimination cannot be tackled solely within the realm of health; realizing people's right to health requires safeguarding a broad range of human rights. It is part of the pursuit of universal health coverage and the push toward greater social and economic equity.
- 25. The experiences of transgender people were highlighted. For example, Brazil's first nationwide study among transgender people in 2016 found HIV prevalence of 20% and syphilis prevalence of 50%. The Ministry of Health is now adapting its data collection systems to capture the realities of transgender people and improve the design of health services accordingly.
- 26. Also emphasized was the role of stigma and discrimination—and of punitive laws that criminalize drug use—in causing many people who inject drugs to shun health services. Decriminalization was singled out as an important step towards reducing discrimination against this key population and reducing the harm associated with drug use.
- 27. UNAIDS Cosponsors reiterated their commitment to reach the target of zero discrimination in health care. Noting that women and girls experience multiple forms of stigma and discrimination, they described some of the education and training programmes, as well as engagements with legislators, they are using to reduce stigma and discrimination.

FROM CHALLENGES TO SOLUTIONS: PROGRAMMES TO REDUCE DISCRIMINATION IN HEALTH-CARE SETTINGS

- 28. Taweesap Siraprapasiri, Acting Senior Advisor for Preventive Medicine in Thailand's Ministry of Health, described some of the steps taken by his Government to reduce stigma and discrimination in health-care settings. A system for monitoring stigma and discrimination was introduced at national and subnational levels after being piloted in two provinces in 2013. Results showed that stigma remained prevalent. Based on those findings, special participatory training programmes for health workers were introduced in 2015. The results have been positive, with health-care staff less anxious about possible infection and less likely to take unnecessary precautions. The approach has shown that stigma and discrimination can be monitored and measured, that monitoring can inform effective actions, and that interventions can be scaled up if they are incorporated into existing systems.
- 29. Charafa Boudries, Medical Examiner at Algiers Central University Hospital in Algeria, described some of the steps Algeria has introduced since the late 1990s to counter stigma and discrimination in health-care settings against people living with HIV. The measures included HIV training for medical personnel. Existing legal texts, including the ethical code for medical professionals, were used to enforce patients' rights. An association of people living with HIV has advocated for reduction of discrimination in the general surgery, ophthalmology and other medical services, since it appeared that people living with HIV tended to experience discrimination mostly when using health services other than HIV services. The association also plays an important role in linking medical professionals and patients.
- 30. In her presentation, Frederike Booke of the International Federation of Medical Students' Associations emphasized the importance of a perspective that is people-centred rather than disease-centred. That requires recognizing that people's health is intertwined with their social, legal and economic standing in society. Her organization promotes such a

holistic understanding of health and seeks to attune the medical profession to the needs and experiences of key populations and other marginalized communities. She called for fundamental changes in health systems, including more inclusive and rights-sensitive curricula for medical education.

- 31. Richard Elliott, Executive Director of the Canadian HIV/AIDS Legal Network, provided examples of the use of law and legal processes to challenge discrimination in health-care. He distinguished between two categories of discrimination: direct discrimination in the delivery of health services (e.g., involuntary sterilization of women living with HIV) and discriminatory laws and policies that have the effect of denying or impeding access to health care (e.g., for people who use drugs). With respect to direct discrimination, he outlined a lesson learned from litigation on involuntary sterilization of women in Namibia. Although the case marked a victory in so far as the court recognized the autonomy of women living with HIV over their reproductive choices, the court did not accept that the women in question had been involuntarily sterilized because of their HIV status. The verdict showed the importance, in litigation, of invoking a multiplicity of the interdependent and indivisible rights that are being violated, Mr Elliott said. He also called for improved documenting of the practice of involuntary sterilization of women living with HIV.
- 32. With regards to laws and policies that may deny or impede access to health services, Mr Elliott gave two examples. One involves a number of applications pending before the European Court of Human Rights challenging the continued criminal prohibition by the Russian Federation of methadone as opioid substitution treatment (OST). There is also an ongoing court case in Canada challenging the refusal by the federal prison system to implement evidence-based harm reduction services which amounts to a discriminatory denial of HIV prevention services to prisoners (contrary to the Mandela Rules, the minimum standards of treatment for prisoners adopted by the UN General Assembly). He stressed the need for "know your rights" programmes, along with greater access to legal services and support to vindicate rights, including through litigation where necessary to overcome discrimination in health care settings. Finally, while litigation is an important strategy for challenging discrimination in health care, it is essential to create a legal environment that is enabling and protective of rights, including by decriminalizing drug use and possession for personal use.
- 33. Members shared other country-level experiences of countering stigma and discrimination. For example, the Board was told that the health code in France now explicitly protects refugees' and migrants' right to confidentiality when using health services. Non-Francophone patients also have the right to access health care related to transmissible diseases in their own language (via free interpretation services).
- 34. In Germany, action is being taken to reduce stigma and discrimination against people living with HIV when seeking dental care. The results of the Stigma Index study made it clear that public campaigns and progressive laws had not done enough to counter misconceptions about HIV among dental care providers. In response, the information on the website of the national dental association was updated to reflect the actual risks of HIV transmission, while additional information and training material was distributed to some 30 000 providers, along with training and monitoring interventions.
- 35. Although Norway has already reached the 90–90–90 targets, cases of HIV-related stigma and discrimination are still being reported there. Most complaints relate to breaches of confidentiality, which appears to stem from ignorance or oversight rather than outright discrimination. Other members said that health-care providers often misunderstand the actual needs and concerns of adolescents around HIV, which can lead to discriminatory behaviour.

RECOMMENDATIONS FOR ACCELERATING ACTION TO END DISCRIMINATION IN HEALTH-CARE SETTINGS

- 36. Doina-Ioana Straisteanu, a human rights lawyer in the Republic of Moldova, discussed the country's National Equality Council, a national human rights body that was set up to deal with rights violations. The Council monitors the implementation of the equality law and makes recommendations on concrete action to public and private actors. Although the Council lacks enforcement powers, its decisions are publicized and serve to promote public debate and corrective actions, she said.
- 37. José Zuniga, President of the International Association of Providers of AIDS Care (IAPAC), discussed the important role professional associations can play in promoting the right to health. IAPAC is advocating that clinical guidelines used by professional associations should promote practices that are free of stigma and discrimination and should support both the reporting of stigma and discrimination and the provision of legal redress. Associations should also train their members on rights-based approaches to clinical practices and include stigma-free delivery of care in their clinical guidelines. Associations can also hold practitioners accountable for providing stigma- and discrimination-free health-care services.
- 38. Julian Kerboghossian, a member of the board of the Global Network of People Living with HIV, described the stigma and discrimination which young people living with HIV experience when trying to use health-care services. In some cases, young people opt against HIV treatment for fear that their families would discover their status and ostracize them, he told the meeting. Some have lost their employment because of their HIV status. Young people need greater psychological support to overcome self-stigma and to deal with stigma and discrimination, he said.
- 39. Simón Kawa, Deputy Director-General of the Commission of National Institutes of Health in Mexico, reminded the meeting that the most vulnerable groups in society tend to experience the most severe stigma and discrimination. In his experience, many health-care providers lack sufficient knowledge about key populations, especially lesbian, gay, bisexual and transgender persons. Guidelines for protocols and methodologies have been developed and distributed to health-care providers, and back-up training is being provided. Although not sufficient, these are important first steps towards eliminating stigma and discrimination, he said.
- 40. Kate Thomson, Head of the Community, Rights and Gender and Civil Society Hub of the Global Fund, said that the Global Fund was undertaking a five-year programme to expand programmes to address human rights-related barriers to HIV, tuberculosis and malaria services in 20 selected countries, 13 of them in Africa. This includes programmes to reduce stigma and discrimination in health care. The Fund is providing catalytic funding which countries are expected to match. Countries are being supported to conduct baseline assessments, document human rights-related barriers, assess what programmes are already in place to address such barriers and determine how much it would cost to systematically tackle the barriers. Five-year action plans will be developed on the basis of the findings, with mid- and end-point monitoring.
- 41. Ten assessments have been completed, with initial findings showing that, despite nondiscriminatory laws and policies, people living with HIV and/or tuberculosis routinely experience stigma and discrimination from health-care providers and have a poor understanding of their own rights. Breaches of confidentiality are a major problem for key populations and adolescents. While some countries are trying to address such barriers, actions tend to be isolated and are often limited to one-off capacity-building

interventions. Ms Thomson said that capacity building is needed beyond health workers: comprehensive efforts should include access to legal services and actions that address legal and policy barriers. The Global Fund is working jointly with UNAIDS in the 20 selected countries to transform human rights principles into routine practice, with many countries devoting increased resources to those efforts.

CLOSING SESSION: THE WAY FORWARD

- 42. Introducing the closing session, Ms. Booke urged countries to pursue "100–100–100" targets to ensure that no one is left behind. This could be done if representatives from key populations participate actively in policymaking and if health facilities provide stigmaand discrimination-free services.
- 43. In his closing remarks, UNAIDS Deputy Executive Director emphasized the importance of empathy: "We have to see ourselves in the lives of others," he told the meeting. Achievements in the realm of health care could have a much broader impact across society. He said the world should not lose sight of the fact that some 100 million people regularly have to choose between feeding themselves or seeking and paying for health care. He confirmed that UNAIDS would move towards establishing a global compact on stigma and discrimination.
- 44. After thanking the outgoing Chair for his dedication and commitment, the Deputy Executive Director welcomed the United Kingdom as incoming PCB Chair.

DECISIONS

The Programme Coordinating Board is invited to:

45. Note the background note (UNAIDS/PCB (41)/17.27) and the summary report of the follow-up to the thematic segment of the 41st PCB on "zero discrimination in health-care settings".

46. Recalling decisions 7.2 and 7.3 from the 41st PCB meeting on actions to reduce stigma and discrimination in all its forms, call on Member States, stakeholders and partners to:

- a. improve measurements to track progress on ending discrimination;
- b. strengthen and scale up multi-sectoral measures to address all forms of discrimination, including legislative and budgetary measures;
- c. ensure supportive work environments for health-care workers to reduce discrimination both towards service users and other health-care workers integrating ethics and human rights, such as non-discrimination, free and informed consent, confidentiality and privacy, into pre- and in-service training curricula for health workers.
- 47. Request the UNAIDS Joint Programme to:
 - a. accelerate efforts to develop synergies and links with national, regional and global efforts to reduce discrimination in all its forms, including in health care settings, and with efforts to achieve relevant Sustainable Development Goals and to leave no one behind in the achievement of those goals;
 - b. support Member States, donors, civil society, networks of key populations and other partners, including national, regional and international human rights institutions and bodies, to integrate the measurement of discrimination in health-care settings into

routine monitoring of the AIDS response and to consolidate and disseminate existing evidence on effective programmatic and policy responses to eliminate discrimination in health-care settings;

c. strengthen collaboration with the Global Fund and other donors to increase investments in programmes to reduce discrimination, including in health-care settings.

48. Request Members States and key donors to increase their investments to adequately address discrimination in health-care settings as part of a fully-funded global HIV response.

[End of document]