

25 April 2016

Excellency,

Further to my letter, dated 16 March 2016, informing Member States of the informal interactive civil society hearing that was held on 6 April 2016, on the preparatory process in the lead up to the 2016 high-level meeting on HIV/AIDS from 8-10 June, I have the honour to attach hereto the Summary of that hearing.

Please accept, Excellency, the assurance of my highest consideration.

Mogens Lykketoft

To all Permanent Representatives and Permanent Observers to the United Nations New York

# Summary of the President of the General Assembly on the Informal Interactive Civil Society Hearing in support of the preparatory process towards the 2016 high-level meeting on HIVIAIDS

## 6 April 2016 Trusteeship Council Chamber

## United Nations Headquarters, New York

The following is a summary of key issues from the Informal Interactive Civil Society Hearing in support of the preparatory process towards the 2016 high-level meeting on HIV/AIDS:

#### Overview:

In accordance with Resolution 70/228, a high-level meeting on HIV/AIDS will be convened from 8-10 June 2016 to undertake a comprehensive review of the progress achieved in realizing the Declaration of Commitment on HIV/AIDS and the Political Declarations on HIV/AIDS of 2006 and 2011, including successes, best practices, lessons learned, obstacles and gaps, challenges and opportunities. The meeting will include recommendations to guide and monitor the HIV/AIDS response beyond 2015, including concrete strategies for action to end the AIDS epidemic by 2030, as well as to promote partnership, cooperation and the continued commitment and engagement of leaders to accelerate a comprehensive universal and integrated response to HIV/AIDS.

In order to support the inclusive, active and substantive engagement of civil society and other relevant stakeholders in the process, the President of the General Assembly convened an informal interactive civil society hearing on 6 April 2016.

The hearing, organized in partnership with the Stakeholder Task Force for the high-level meeting (HLM) on HIV/AIDS and the Joint United Nations Programme on HIV/AIDS (UNAIDS), provided all relevant stakeholders with an opportunity to contribute to the ongoing preparatory process in a day of interactive panel discussions. The hearing was attended by Member States, as well as over 300 civil society representatives, non-governmental organizations, the private sector, academic and scientific community, and others.

The hearing focused on taking stock of the various aspects of the AIDS response and promoting an interactive exchange of views on key priorities for the HLM. It encouraged civil society and other stakeholders to share practical experiences from their work on the ground and to make recommendations for the HLM in order to support Member States in the preparatory process, including in the negotiations of the outcome document. It demonstrated the strength, diversity and commitment of civil society and other stakeholders in the response to the AIDS epidemic by discussing challenges and opportunities in the AIDS response and by proposing key actions that will make it possible to end AIDS within our lifetime.

#### **Opening Segment:**

The President of the General Assembly, H.E. Mr. Mogens Lykketoft, underscored the importance of a successful outcome of the HLM which he said is a critical step towards achieving the SDG target to end the AIDS epidemic as a public health threat by 2030. Furthermore, he emphasized that the HLM comes at a pivotal time in the global AIDS response when new HIV infection rates are falling too slowly and socially marginalized groups are often left behind and experience much higher HIV infection rates. He underscored that stigma, discrimination and other social and legal barriers exacerbate vulnerability to HIV and put life-saving services out of reach of millions.

The President of the General Assembly also noted that the international community, including development partners and national governments, must work to close the resource gap to be able to end the AIDS epidemic. He reiterated that civil society organizations, together with the private sector and the academic and scientific community, have been at the forefront of the fight against AIDS. Without civil society and other stakeholder advocacy, and without community-based treatment and prevention services, the response to AIDS would be a small fraction of the effort it is today.

The co-facilitator of the 2016 High Level Meeting on HIV/AIDS, H.E Mr. Jürg Lauber of Switzerland, speaking also on behalf of the co-facilitator H.E. Dr. Mwaba Patricia Kasese-Bota of Zambia, recognized the importance of securing an ambitious Political Declaration as an HLM outcome. They acknowledged the unprecedented commitment from the AIDS community in fighting the epidemic and stressed the importance of civil society contributions to the setting of bold targets to help end the AIDS epidemic. They also welcomed the hearing as a way to make civil society voices heard and to ensure they will have an opportunity to contribute to the HLM preparations.

The Executive Director of the Joint United Nations Programme on HIV/AIDS (UNAIDS), Mr. Michel Sidibé, encouraged Member States to agree to a Political Declaration that includes strong commitments on financing, services and rights to end the AIDS epidemic. He called for a commitment to fully fund the AIDS response and underscored the need to increase the total investment to US\$26 billion annually by 2020. He further stressed the importance of a strong working partnership between governments and civil society. He referred to UNAIDS' estimates that investments in community mobilization must triple by 2020 and investments in community based ART delivery must see significant increases as well if we are to end the epidemic. He also added that outreach to key populations in low and middle income countries should account for about 7.2% of global investments by 2020, with many of these services provided by communities. Despite the treatment advances, prevention must not be neglected and human rights and gender equality need to remain central to a scaled up response.

L'Orangelis Thomas Negron, civil society representative and a person openly living with HIV, called for greater participation of civil society and an end to tokenism. She said the epidemic will only end if there is leadership from civil society, young people, and women. She underscored that the criminalization of key populations and people living with HIV makes people more vulnerable and reduces the state's responsibility to respond effectively to the social drivers of

HIV, including poverty, violence, displacement, stigma and discrimination. She urged Member States to commit to eliminating gender-based violence and to ensure comprehensive sexuality education and access to sexual and reproductive health and rights services to ensure that all women and girls, regardless of their HIV status can make informed decisions about their health.

#### Panel I: Financing the AIDS response and the cost of inaction

The first panel focused on the importance of sustaining funding and reforming resource allocation in order to deliver the best outcomes. Speakers stressed that without increases in funding for HIV programmes and improved efficiency in the use of resources, it would be impossible to achieve the 90-90-90 (90% of people know their HIV status, 90% of those living with HIV are accessing treatment, and 90% of all people receiving antiretroviral therapy are virally suppressed) and the SDG targets. They underscored that maintaining 2014 coverage service levels will prolong the epidemic indefinitely while, in many countries, the epidemic will rebound and grow, which would translate to an additional 17.6 million HIV infections and an additional 10.8 million AIDS-related deaths globally between now and 2030.

Panellists called on all governments to scale up their responses and to make clear commitments to finance community advocacy and services. Speakers stressed that the Political Declaration should commit to fully funding the AIDS response, including for the Global Fund to Fight AIDS, TB, and Malaria, as well as set clear funding targets. They added that Member States must make the necessary long term financial commitments to the global response to AIDS, based on scientifically validated assumptions and which include prevention and treatment innovation, research and development. Investment in civil society must run through all approaches. While increased domestic funding is necessary, as are new funding mechanisms, donor countries need to continue supporting the HIV response.

Speakers emphasized that countries face great disruption in their AIDS responses as they make the transition from low to middle income status as defined by World Bank classifications. They also noted that there is an increased reliance on domestic funding, increased gaps in the HIV response and resulting danger of cuts to essential services as donors leave middle income countries. In these scenarios, participants added, the burden falls on key populations (particularly for men who have sex with men (MSM), people who use drugs, sex workers, transgender women and migrants) but these are exactly the people it is the most necessary to reach in order to attain the 90-90-90 and SDG targets. For this reason, panellists recommended that aid levels for the HIV response be decoupled from World Bank country classifications and be based upon disease burden and needs instead. They further underscored the need for transition policies to be developed in collaboration with all key stakeholders to allow for a sustainable response to the epidemic.

Participants added that investments in universal health coverage are needed to ensure that groups left behind such as children and adolescents, indigenous people, and key affected communities are covered. They noted that smarter spending requires reallocating funds and that investments should be made in key populations, civil society, and community-led interventions. Financing should reflect community input in policy reviews, including harm reduction policies and legal reforms to remove barriers to access and end the criminalization of HIV transmission, same-sex

sexual activity, drug use and possession and sex work, in order to ensure that services are integrated into national health systems.

Participants urged Member States to agree on a strong Political Declaration and commit resources for system reforms including disaggregating data to assess the burden of HIV faced by transgender persons separately from MSM, and to address gender-based violence. Panellists emphasized the need for intellectual property agreements to expand affordable access to medicines through mechanisms like TRIPS flexibilities.

Participants also underlined the need for tuberculosis (TB) diagnosis and treatment to be integrated within HIV services. Tuberculosis is the leading killer of people living with HIV and one-third of all people living with HIV have latent tuberculosis which further illustrates the critical importance of early access to treatment for HIV in reducing TB risk.

#### Panel II: Who is being left behind in the AIDS response?

The second panel examined what is necessary to deliver effective programming with and for key populations. Participants outlined how social, structural, and political drivers of HIV, including poverty, inequality, stigma and discrimination increase vulnerability to HIV and these areas must be addressed if we are to achieve SDG Target 3.3.

Panellists reflected that barriers to ending the AIDS epidemic are well known and common across all key affected groups, underscoring that these barriers are structural and arise because of the way societies are organized to deliberately exclude and stigmatize vulnerable communities. They highlighted barriers based on discriminatory laws and policies, for example laws that criminalize same sex relations, sex work and drug use instead of policies that promote gender equality, implement harm reduction approaches, and ensure young people have access to youth friendly sexual and reproductive health information and services. Speakers underscored how these barriers violate respect for basic human dignity and rights and lead to marginalization and exclusion from equal access to HIV services.

Several speakers emphasized that key affected populations, including indigenous communities, are left behind and are the very people who must be reached if the world is to achieve the fast track targets and SDG target 3.3 to end the epidemic. They called on Member States to adopt approaches to meaningfully involve the marginalized among the marginalized, including indigenous groups and people belonging to minorities within key affected communities. These communities risk becoming "the 10-10-10," a reference to the ones left behind as the world is striving to meet UNAIDS 90-90-90 targets. They also called on Member States to commit to strengthening the capacity of families, the community level child care workforce, and the social welfare workforce, so that together they can meet the developmental needs of children living with and affected by HIV, from pregnancy to early childhood and into adolescence.

Several participants noted that strong evidence indicates that community-led services are effective, but there is little political will to support indigenous groups and key affected communities, specifically transgender people, men who have sex with men, sex workers, people who use drugs, migrants and prisoners.

They called on Member Stated to clearly define, based on scientific evidence, which populations are the "key population" groups. They added that the language needs to be specific, consistent and inclusive. Member States must also develop specific targets appropriate for key populations. These should include investing in research for women and children, testing and treatment of children, community-led services, expanding access to services for key affected communities and investing in innovation including combination prevention tools.

Participants also added that decriminalization is the single intervention that would have the greatest impact on HIV across all nations. Member States should undertake policy reform to promote anti-discriminatory laws, abolish all remaining restrictions on migration for people living with HIV, and decriminalize sex work, same-sex sexual relations, drug use and HIV transmission. Harm reduction, particularly needle and syringe exchange programmes and opioid substitution therapy are the most effective ways to prevent HIV transmission among people who use drugs, but it is also an issue for which there is little political will.

#### Panel 3: Innovation introduction – new and improved tools, approaches and policies

Participants highlighted that Member States must commit to a comprehensive innovation agenda in commodities, technologies and delivery systems for HIV prevention and treatment. This requires increased investment, both from the public and private sectors, in research and development as a critical tool in the development of new prevention and treatment, in particular vaccines. A number of internationally respected investment frameworks for the long-term AIDS response have been developed, including the UNAIDS Lancet Commission Report, which should be used as a basis for updated estimates. Participants raised concern regarding the recently updated cost estimates for the HIV epidemic and the extent to which these take into account scientifically validated assumptions regarding costs related to innovation and research needs, calling for the cost estimates to be updated to include these necessary associated costs. The important role the private sector and foundations have as part of these multi-disciplinary efforts was also noted.

Panellists underscored that innovation, including research and development requires rolling out pre-exposure prophylaxis (PrEP) and new medications in developing countries as well as developed countries. They also called for communities to be involved in the design and implementation of research and emphasized that key populations, in particular women, should be partners in the development and implementation of research protocols; making the case that this will lead to greater efficacy and uptake because new developments will have been made to accommodate the specific needs of women.

Participants also emphasized that children face unique challenges based on age restrictions for testing and treatment and that ensuring paediatric treatment requires policy change. Speakers noted that many children are not receiving testing, with under half of infants living with HIV being tested within the first two months of their lives. Participants recommended that testing be decentralized in order for children to be tested and that adopting child-specific targets (for example, at least two million children living with HIV diagnosed by 2020) in the Political Declaration could facilitate required policy changes. The need to encourage testing among older children and adolescents was underlined because many adolescents living with HIV were not diagnosed as children because they were not tested at the time. Speakers called on Member

States to commit to achieving and sustaining by 2020, the elimination of mother-to-child transmission of HIV; to reach under 40,000 new HIV infections among children; and to take steps towards achieving WHO certification of elimination of mother-to-child HIV transmission. They also called on Member States to commit to a 75% reduction in HIV-related maternal mortality in the Political Declaration.

Some participants said that while innovation in accelerating access to HIV prevention, diagnosis, treatment, and monitoring was essential, innovation alone was insufficient as multiple barriers exist to ensuring that newer and better medicines get to people in low-income settings. Speakers highlighted the need for a broad range of innovations, including to remove intellectual property barriers to expand access to medicines. Participants called for the costs of research and development to be delinked from the price of the resulting health products.

Participants urged Member States to commit to ambitious targets on anti-retroviral treatment (ART) scale-up, including reaching more than 30 million people with life-saving ART by 2020 and increasing the number of new people on ART by 20% on an annual basis. Speakers highlighted how the pace of increasing access to ARTs will have a direct correlation with reducing morbidity and mortality, and lowering the rate of new infections. Member States must act to ensure that the Political Declaration expands access to medicines through patent and price flexibilities, in order to prevent bilateral regional trade agreements that limit TRIPS flexibilities.

Recognizing that research, monitoring and evaluation all generate data, speakers called on governments to be more open to operational data and to safely sharing data in order to promote transparency and accountability for effectiveness. Participants underlined that new technologies have much potential but are often underutilized, sharing examples when these can be effective such as using SMS to remind people about appointments or medicine regimens.

Speakers also noted the need for innovation in ways to overcome stigma and discrimination and as a requirement to ensure better access to care for men who have sex with men, disabled people, prisoners, and other key populations. They added that reaching these groups will contribute to the realization of the SDGs and the promotion of human rights.

Finally, participants called for a new research and development paradigm that includes global strategies to support inclusive research for innovative health technologies, including preventative HIV vaccines, new prevention technologies and HIV cure research, and reaching a point at which patent agreements are no longer significant barriers to ending AIDS as a public health threat.

# <u>Panel 4: Partnerships for success and the role of community responses for resilient health systems</u>

The final panel examined how to improve collaborative partnerships, including the need for an enabling environment to foster sustainable partnership. Panellists recognized that community-driven interventions are effective and have saved millions of dollars and countless lives, but also that their work is often unpaid and unrecognized and that communities often perform this work in unsafe conditions where key populations are criminalized.

During this session, the critical role of young people in the response was highlighted - as advocates for the needs of their peers, in delivering services within their community and in tackling stigma and discrimination. The lack of youth engagement in policy and programming development was lamented and it was pointed out that this continues to occur in practice despite claims from donors and policy makers regarding the need for greater youth participation.

Participants underscored the alarming growth of the epidemic in certain regions and sub-regions and that donor investment is more urgent than ever. Speakers highlighted the need for a combination of political will, shared financing between national and international sources, and emergency funds which respond to the complexities of challenging operating environments. They underscored the increased need for partnership and coordination to minimize disruptions in HIV service and treatment delivery in areas saddled with conflict, and the need for programmes focused on gender equality to be put in place for women living with and affected by HIV. There is also an urgent need to ensure that HIV-related services (including sexual and reproductive health and youth-friendly services) for key populations are protected and scaled up, and civil society is a critical partner to create this service coverage. This, along with access to HIV services for all, will be a key to achieving the SDGs.

Participants voiced concern that more countries are imposing regulations that make it harder for civil society organizations to register, receive funding or function effectively. For partnerships in the HIV response to succeed, speakers urged governments to ensure policy space for advocacy and to remove barriers to the full engagement of communities and civil society in the HIV response. It was noted that partnerships with communities will not be fully realized if those same communities face criminalization and that stakeholders must be vigilant against tokenism, exclusion, arbitrary decision-making and unrealistic expectations of what communities can deliver. Instead, it was stressed that partnerships must be based on principles that foster inclusion, transparency, mutual respect and accountability.

Participants stressed the critical role played by communities and civil society in creating demand for services and access to treatments, underlining the integral role of communities in scaling up access to treatment, monitoring of treatment roll-out and quality of service delivery, particularly in low-income countries. They also stressed the need for partnerships with non-traditional stakeholders, including faith-based communities and the private sector, particularly to end the epidemic of sexual and gender-based violence.

A central message that emerged from this panel was the greater involvement of people living with HIV must remain a cornerstone in the HIV response and that complexities and challenges to the implementation must not deter governments from ensuring that people living with HIV are meaningfully engaged in all aspects of the HIV response and at all levels. It was repeatedly emphasized that people living with HIV should be politically and financially supported as essential actors in areas of policy development and decision making on funding allocations, programme and research design, advocacy and evaluation. Speakers called on Member states to commit to ensuring stronger accountability mechanisms, with an emphasis on community-based monitoring, advocacy and mobilization, accompanied by sufficient funding.

It was also noted that in many places, people of faith and faith-based organizations partner and engage with communities, such as migrants, transgender people and indigenous communities

who are too often on the margins of the marginalized. However, it was also noted that religious and associated institutions can play a role in obstructing or hindering policy processes that relate to sensitive topics such as sexual and reproductive health and rights and comprehensive sexuality education.

A key message was that partnerships in the AIDS response require a community-centred, multi-sectoral approach that includes key affected communities, governments, donors and civil society to ensure sustainable programming that will achieve lasting outcomes in line with the 2030 Agenda. However, it was also noted that, for decades, communities have been subsidizing the AIDS response and that unless there is greater investment, communities will doubt the validity and authenticity of these partnerships. Participants highlighted that communities and civil society organizations must be equal partners in the development of HIV strategies and programming. They underscored that in order to foster genuine collaboration, partnership with communities must be based on respect and recognizing and valuing the contribution of communities to the HIV response.

Participants added that the international community needs a clear investment target in the Political Declaration. It has been proposed that this target should be at least US\$26 billion a year. Between 15% and 20% of this must be invested in communities and civil society.

#### **Closing segment:**

The President of the General Assembly closed the hearing by highlighting key points emerging from the session, including collaborative financing, leaving no one behind, innovative technologies, and promoting effective partnerships. He emphasized that the high-level meeting and the Political Declaration must set clear targets for prevention, treatment and respect for human rights, and that there must be a stronger commitment to comprehensive sex education and youth friendly services. He highlighted that increased investments are also needed to protect future generations from HIV, especially vulnerable communities like women and girls; and that ending the epidemic will require platforms for mutual accountability.

Expressing deep appreciation to all speakers and participants in the hearing, the President of the General Assembly concluded by encouraging all participants to work closely with Member States to ensure that the HLM is a success and that the international community continues to work together to achieve the targets set out to end the AIDS epidemic by 2030.