



UNAIDS PROGRAMME COORDINATING BOARD

UNAIDS/PCB (33)/13.16
Issue date: 6 December 2013

THIRTY-THIRD MEETING

Date: 17-19 December 2013

Venue: Executive Board Room, WHO, Geneva

Agenda item 1.4

Report by the NGO Delegation to the PCB

Document prepared by the PCB NGO Representatives

Additional documents for this item: none

Action required at this meeting - the Programme Coordinating Board is invited to:

See decisions in paragraphs below:

65. Call upon Member States, UNAIDS and partners to:

- a. *Ensure* that any implementation/guidance on new biomedical preventative technologies proceeds with the full and meaningful engagement of key populations, guaranteeing informed and voluntary adherence to ARV, and respecting the diversity of perspectives between and within such communities.
- b. *Ensure* the potential impacts of treatment as prevention - recognized by an increasing body of evidence in support of the earliest possible initiation of ARV for people living with HIV - will be aligned to the principle of treatment being first and foremost to benefit those living with HIV;

66. Call on UNAIDS, co-sponsors and partners, as a matter of urgent priority

- a. *to intensify* coordinated technical support to governments, civil society and key affected communities, and UNAIDS to periodically report to the Programme Coordinating Board on progress in the effectiveness of technical support interventions at the country level in key areas specifically in implementation of the WHO Guidelines, key affected community and civil society engagement in decision making processes, community systems strengthening and roll out of the Global Fund New Funding model.
- b. *Request* UNAIDS and member states to call on the United Nations General Assembly to convene a High Level Meeting before September 2015 to assess progress towards those targets set out in the 2011 Political Declaration and to renew the commitments to achieve Universal Access to HIV prevention, treatment, care and support in the post- 2015 era.
- c. *Request* UNAIDS to engage key population representatives in the planning for the HLM – including those communities not reflected in the 2011 Political Declaration but that continue highly impacted by HIV, specifically the transgender community.
- d. Recalling the 26th PCB, *Agenda item 2: Ensuring non-discrimination in responses to HIV; Decision points: 7.3; 7.4; 7.5; 7.6 and 7.7^a*; Recalling the 30th PCB: *Thematic Session on Non-Discrimination: Decision point: 6.1^a*; *requests* UNAIDS and Member States *to report* at the 35th PCB on concrete actions (including support to strengthen national capacity, funds disbursed, the development of data, research and evidence, strengthening of enabling environments including reform to punitive laws and policy) taken to implement expanded programmes to reduce stigma and discrimination against key populations (including transgender people), at sufficient scale to improve the lives of those at risk of infection and people living with HIV.

THE EQUITY DEFICIT: UNEQUAL AND UNFAIR ACCESS TO HIV TREATMENT, CARE AND SUPPORT FOR KEY AFFECTED COMMUNITIES

I. INTRODUCTION AND METHODOLOGY

1. The 2013 NGO Report to the UNAIDS Programme Coordinating Board is *The Equity Deficit¹: Unequal and Unfair Access to HIV Treatment, Care and Support for key affected communities*. It responds to a context where antiretroviral therapy (ART) is once again a 'hot topic' – with multiple, exciting initiatives and opportunities emerging across the treatment landscape. The report argues however that the 'success story' of expanded ART is fundamentally flawed – with the communities of sex workers, men who have sex with men (MSM), transgender people and people who inject drugs (PWID) left far behind in treatment access. It warns that without concerted action and significant change the latest initiatives and emerging opportunities risk *exacerbating*, rather than resolving, the 'Equity Deficit'.
2. The report starts with an overview of the status of HIV treatment, care and support. It provides detail of the inequities in access and the multiple underpinning barriers experienced by key affected communities that contribute to this situation. It then presents five factors that, according to the NGO Delegation and its constituents, will 'make or break' the 'Equity Deficit' in the future. These factors are noted below. After drawing conclusions, the report ends by recommending 6 decision points for the 33rd Meeting of the Programme Coordinating Board. These decision points are noted in the preamble to the report. Five case studies are presented in Annex One. Each case study presents the perspectives and views of different key communities on the issues raised in the report.

'Make or break' factor 1: • **Human Rights and Ethics**

'Make or break' factor 2: • **Data and 'what works'**

'Make or break' factor 3: • **Financial investment**

'Make or break' factor 4: • **Meaningful involvement**

'Make or break' factor 5: • **Technical capacity**

3. The Report is informed by: interviews and group discussions with 40 stakeholders from the communities of sex workers, men who have sex with men (MSM please spell all abbreviations out when first introducing into this document), transgender people, PWID and treatment advocates from different regions of the world (see Annex 1); and systematic review of over 100 research papers, reports, and analyses sourced from across range of organisations and sectors. The report is not intended to be a total and comprehensive review but instead aims to be a critical contribution to current debates via consolidation of various viewpoints and through presentation of a number of priority messages from key affected communities.

II. THE EQUITY DEFICIT

4. The HIV treatment landscape is changing dramatically. As we near 2015 and the target of 15 million people on treatment, we have at our disposal: **new evidence^a**, **new guidance^{b 2}**; and **new initiatives^{c 3}**. These, alongside the recent development of good practice frameworks and approaches such as Treatment 2.0⁴ and the Strategic Investment Framework⁵ provide a unique opportunity to fundamentally change the course of the global pandemic and achieve universal access to treatment. These developments have emerged in the context of renewed global policy commitments. Most notable of these is the *Political Declaration on HIV/AIDS (2011)*⁶ which reiterates the Millennium Development Goal of universal access to HIV

^a For example: The efficacy of treatment as prevention (hereafter referred to as TasP)

^b For example: The 2013 Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection: Recommendations for a Public Health Approach (hereafter referred to as the 2013 WHO Guidelines)

^c For example: UNAIDS Treatment 2015

prevention, treatment, care and support and set a target of 15 million people living with HIV on antiretroviral therapy (ART) by 2015⁷. The current landscape also features critical opportunities for resourcing and recalibration of HIV and AIDS responses at the country level. These include the New Funding Model (NFM) of the Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund)⁸ and the *Blueprint: Creating an AIDS-Free Generation* of the President's Emergency Fund for AIDS Relief (PEPFAR)⁹.

5. These initiatives combined – some the result of persistent advocacy by people living with HIV and key affected communities¹⁰ - have the potential to yield extraordinary progress and results. That such potential can be realised is clearly evident in the significant progress made over the last decade. At end of 2012, an estimated 9.7 million people in low and middle-income countries were receiving ART, an increase of 1.6 million from 2011, the largest increase in a single year¹¹. This represents 61% of those eligible for treatment under WHO's 2010 guidelines¹² - and nearly two-thirds towards achievement of the 2015 target.
6. Although the rapid scale up of treatment must be celebrated as an unprecedented achievement across global health, there is an urgent need to critically reflect on, and respond to, fundamental flaws and weaknesses in this agenda. In doing so we need to question whether the benefits of the 'treatment success story' are equitably shared by all. It is without doubt the *availability* of HIV treatment, care and support that has increased dramatically but, as this report clearly illustrates, *accessibility* to treatment for many key affected communities remains grossly inequitable.
7. Reliable data on treatment access for key affected communities is scarce¹³. The current context is however made clear in the UNAIDS Report on the Global AIDS Epidemic 2013¹⁴. There it is emphasised that key communities experience "extremely low HIV treatment coverage" when compared to 'general' access rates. For example, in Swaziland, a country which has successfully achieved coverage of 87%, only 33% of MSM living with HIV receive ART¹⁵ 16. In the European region where PWID represent 59% of people living with HIV, WHO studies demonstrate that this community constitutes just 21% of the total number actually receiving ART. 17
8. The 'Equity Deficit' results from multiple and powerful barriers experienced by key affected communities, as structural and systematic barriers are common across many communities. 18 19 20They include intense stigma and discrimination within health care settings (as illustrated in ANNEX ONE).
9. According to a global study conducted by the Global Forum on MSM and HIV (MSMGF) in 2012²¹, homophobia is the most significant barrier to treatment for MSM living with HIV. Disaggregation of this data²² demonstrates that *young* MSM experience higher homophobia and violence than older MSM and, in turn, lower access to treatment. This finding – that young members of key affected communities are often hardest hit by the 'Equity Deficit' - was reflected across the literature and data informing this Report. For example, in focus group discussion amongst young MSM living with HIV in North America, it was emphasised that their access to services is seriously affected by factors such as homelessness and unemployment²³. Similarly, within some communities, women often experience heightened or specific challenges. For example, a study in Ukraine²⁴ found that women who inject drugs were less likely to receive ART than other women, while a study in India²⁵ found that female sex workers were often denied services for prevention of mother-to-child transmission.
10. The negative impacts of these barriers are not 'news'. They reflect recognised, ongoing, and much debated challenges in the response to HIV and AIDS. They have been highlighted for the Programme Coordinating Board in previous NGO Reports on Stigma and Discrimination in 2010²⁶; Legal Environments in 2011²⁷; and The Funding Crisis in 2012²⁸. However, these barriers remain as a major impediment to effective HIV responses and present as clear

human rights violations. Their persistence contradicts and undermines the notion and necessity of ‘knowing your epidemic’ and the recognition that supporting responses amongst key affected communities is central to addressing both concentrated and generalised HIV epidemics. The evidence here is indisputable. According to various modes-of-transmission studies²⁹, high proportions of *new* HIV infections occur among such communities in countries as diverse as the Dominican Republic (47%), Kenya (about 33%), Morocco (80%), Mozambique (over 25%), Nigeria (51%) and Peru (65%)³⁰. Meanwhile, the barriers also work against the evidence that, despite common perceptions to the contrary, highly positive outcomes for treatment, care and support can be achieved and sustained among key affected communities, such as sex workers³¹ and PWID³². As concluded in recommendations developed by WHO, UNAIDS, UNFPA and the Global Network of Sex Worker Projects (NSWP)³³, *“it is not the issue of efficacy but of equitable access to ART which is important for sex workers.”*

11. The barriers can prevent a member of a key affected community from accessing voluntary HIV counselling and testing (HCT) and ever knowing their HIV status. For those living with HIV, they often act to delay, interrupt or totally deny the use of treatment. For example, studies show that barriers can lead to transgender women living with HIV having lower treatment outcomes³⁴ and sex workers living with HIV in Southern India having a 10 times higher mortality rate than other women³⁵. In countries such as Namibia, which report 91% coverage, there is strong anecdotal evidence that sex workers chose to die rather than face persecution at government ART clinics³⁶.

Box 1: The impact of barriers to treatment

According to the 2012 Global Men’s Health and Rights Study, just 14% of MSM living with HIV in low income countries consider treatment to be easily accessible.

Box 2: Barriers to equitable access to HIV treatment care and support for key affected Communities³⁷

Community and societal barriers:

- Compounded stigma, discrimination and intolerance that marginalises key affected communities and people living with HIV.
- Harassment and gender-based violence against key affected communities and people living with HIV.
- Fear of adverse consequences of key affected communities knowing their HIV status and accessing services.
- Poor knowledge of about treatment, care and support and where to access such services among key affected communities.
- Lack of community groups able to offer treatment, care and support to key affected communities.
- Lack of trained community workers able to support key affected communities living with HIV.
- Low self-esteem and self-stigma among key affected communities – causing late access to treatment, care and support.

Health systems and services barriers:

- ART side effects, especially where poor quality drug regimens are used for key affected communities.
- Lack of clear and appropriate treatment, care and support information for key affected communities.
- Lack of targeted HCT services for key affected communities to start the ‘treatment journey’.
- Time and financial costs for key affected communities to access distant, specialist services.
- Lack of specific and low-threshold treatment, care and support services for key affected communities.
- Difficult locations/opening times for treatment, care and support services for key affected communities.
- Particular lack of services in specific contexts, such as prisons, for key affected communities.
- Institutional stigma against key affected communities in services by government and religious organisations.

- Lack of treatment-related equipment (such as for CD4 counts) in services for key affected communities.
- Presumptions by providers that key affected communities are ‘bad patients’ and cannot adhere to ART.
- Lack of training and expertise in the specific treatment, care and support needs of key affected communities.
- Use of registries and monitoring systems that force key affected communities to declare their identity.
- Poor confidentiality and privacy at treatment, care and support services for key affected communities.
- Time and financial costs for key affected communities to access distant, specialist services.
- Poor continuity, such as with key affected communities mobilised for HCT, but without follow-up services.
- Poor quality counselling and psycho-social support for key affected communities living with HIV.
- Unequal distribution of existing treatment, care and support services, such as in urban/rural areas.
- Lack of guidelines/protocols on ART for key affected communities (such as addressing ART/OST interactions).
- Bureaucracy, such as that requires key affected communities to go to different places for different services.
- Interruptions in supplies of drugs and commodities for treatment, care and support services.

Policy and legal barriers:

- Lack of political support and leadership on treatment, care and support for key affected communities.
- Lack of ‘know your epidemic’ data to convince policy-makers about targeted treatment, care and support
- When ‘know your epidemic’ data available, it is not taken into account for policy and programming, the data is considered as non-representative, methodologies not adapted for sound studies on population size estimates.
- Laws that criminalise key affected communities or their behaviour and drive them away from services.
- Laws, such as on drug use, that cause high levels of incarceration/rehabilitation and limit access to services.
- Laws that criminalise HIV transmission and exposure and which, for example, force sex workers to conceal their HIV status.
- Lack of support to civil society and recognition of their role in treatment, care and support.
- Lack of opportunities for key affected communities to advocate on their treatment, care and support needs.
- Low government commitment/civil society knowledge about key initiatives, such as Treatment 2.0.
- Integration of HIV into broad health gender, human rights programmes, neglecting the specific needs of key affected communities.
- Lack of follow-up on the Political Declaration on HIV/AIDS and its commitments to key affected communities noting specifically however that transgender people’s ‘existence’ is not acknowledged in the declaration.
- Policies that prohibit comprehensive services for key affected communities, such as ART/OST for PWID.

Economic and Political barriers

- Decreasing overall funding for targeted responses to HIV, including treatment, care and support.
- Low understanding of the investment case for treatment, care and support for key affected communities.
- Lack of national allocation of resources to treatment, care and support for key affected communities.
- Perceptions that targeted treatment, care and support programmes are too expensive/poor value for money.
- High cost of treatment, including due to issues related to trade agreements and intellectual property

rights.

- Donor policies/bureaucracy that makes it difficult for key affected communities to access resources.
- Low knowledge among key affected community groups of the funding opportunities available.
- Donor policies that emphasise the number of key affected communities tested, not the quality of support.

III. THE 'MAKE OR BREAK' FACTORS TO END THE 'EQUITY DEFICIT'

12. Section III focuses on five factors that, according to the NGO Delegation and its constituents, will 'make or break' achievement of equity in access to treatment, care and support for sex workers, MSM, transgender people and PWID. The factors are:

1. Rights and ethics;
2. Data and 'what works';
3. Financial investment;
4. Meaningful involvement; and
5. Technical capacity.

13. For each factor, the text provides key messages, data, viewpoints and case studies (see Annex One) identified through the multiple sources of information used for the 2013 NGO Report.

14. Individually, each of the factors is crucial as countries adapt to the new treatment landscape, recalibrate their responses to HIV and prepare for the post-2015 agenda. Collectively, they could add-up to the concerted action and significant change that is needed to end the 'Equity Deficit' and fulfil the rights of key affected communities.

'MAKE OR BREAK' FACTOR 1: HUMAN RIGHTS AND ETHICS

Key message

Any initiatives to expand the use of and access to ART must occur alongside concerted action to address existing barriers to equitable treatment, care and support for key affected communities, in particular stigma, discrimination and human rights violations. An enabling social, economic, policy and legal environment is critical to ensure that the 2013 Treatment Guidelines and strategies such as treatment as prevention (TasP) are further developed/rolled-out with full respect to equity and ethics.

15. As seen in Section II, stigma, discrimination and persecution – especially in health care settings - are fundamental barriers to equitable access to treatment, care and support for key affected communities. They fuel persistent weaknesses in the treatment cascade and present major obstacles to the continuum of care.

16. Human right as a principle underpins the commitments and frameworks that shape the current treatment landscape. These include the: 2011 Political Declaration on HIV/AIDS³⁸; Treatment 2015³⁹; and 2013 Treatment Guidelines (see Box 3)⁴⁰. However, to end the 'Equity Deficit', intentions are not

Box 3: The importance of rights and equity

“Global and national commitments require providing HIV treatment and prevention to everyone in need, following the human rights principles of non-discrimination, accountability and participation Key ethical principles of fairness, equity and urgency should also be observed in the process of reviewing and adapting guidelines. The design of effective and equitable policies implies that strategies should focus comprehensively on addressing barriers to access testing, prevention and treatment services, particularly those faced by key populations.”

Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection, WHO, 2013

enough. Instead, a human rights-based approach must be applied *in practice* within the daily lives of key affected communities. Required are enabling environments – where, for example, sex workers are protected and sex work is decriminalised, respected and recognised as legitimate work, people of all sexual and gender identities are legally recognised and protected, and policies enable PWID to access the full range of services that they need. The impacts here are emphasised by WHO⁴¹, “*stigma, discrimination and punitive laws are denying these key populations the multiple benefits of ART*”.

17. The 2013 Treatment Guidelines were developed in collaboration with different sectors, including a community consultation coordinated by the Global Network of People Living with HIV (GNP+) and International HIV/AIDS Alliance⁴². The resulting standards reflect the latest in scientific, medical and programmatic evidence. They present as a critical tool to fundamentally address the HIV and AIDS epidemic. However, many key affected community stakeholders are alarmed that – without action on the multiple barriers that they experience, especially in relation to rights – the Guidelines’ impact will be limited and potentially exacerbate existing inequity in treatment access. Given the current context these concerns are well founded. With a 9.2 million additional people eligible for treatment and the potential of an additional 3 million averted deaths⁴³ will not benefit key affected communities unless there is concerted action to rapidly address the factors that contribute to these inequities. As highlighted in diverse regions (see Annex One), if marginalised groups do not feel safe or comfortable to access services – or if governments do not wish to invest in or supply such support - WHO’s 2013 Guidelines will remain mere aspiration.
18. An illustration is provided by a 2013 report by the Foundation for AIDS Research (amfAR) and Johns Hopkins School of Public Health⁴⁴ on gay men and other MSM in six countries in Southern Africa (Botswana, Malawi, Namibia, Swaziland, Zambia and Zimbabwe). This concludes that “*while the global conversation focuses on novel approaches to HIV treatment and prevention, GMT [gay men and transgender people] struggle to obtain the most basic health services. They are isolated, criminalized, blackmailed, and beaten ... Real efforts to increase donor and national government engagement in preventing and treating HIV infection among GMT must include comprehensive human rights programming that addresses stigma and discrimination.*”
19. A further strong message is that the good, public-health orientated intentions of the 2013 Treatment Guidelines should not be used to ‘justify’ coercive strategies that, even inadvertently, abuse the freedoms of members of key affected communities (including those with CD4 counts under 500 or in sero-discordant relationships). They must, instead, be part of a systemic approach that strengthens treatment literacy and enables people to make informed decisions about their own health. No community member, of any identity, should be forced into testing, treatment, care or support, especially in contexts where association with such services risks *increasing*, rather than *decreasing*, their marginalisation.
20. The 2013 Treatment Guidelines must be applied in an ethical way – prioritising action on the *existing* barriers to equitable treatment over implementing *additional* strategies. This issue is most critical in relation to **TasP** – a strategy that raises passionate, sometimes different, opinions among key affected communities⁴⁵. Broadly speaking, the strategy is recognised for its significant potential to contribute to reversing and addressing the impacts of the HIV and

Box 4: Promoting, protecting and fulfilling human rights in the roll-out of TasP

“Key populations are groups at higher risk of being infected or affected by HIV; and in many countries, they are marginalised, stigmatised and discriminated against and often left out of the HIV response. Promoting their involvement in the HIV response and creating a supportive environment will ensure the widest possible access of voluntary HIV testing and treatment, increase confidence in negotiating safer sex and making use of harm reduction services and ensure retention to HIV care and support, making the most of the potential prevention benefit of ART.”

AIDS pandemic. However, a strong over-arching message is that ‘treatment as treatment’ should come first. As one PWID advocate puts it, *“the world can’t even do treatment for treatment so why on earth are we talking about treatment for prevention? It’s unethical to even discuss it”*.

21. Further common messages are that any intervention should be part of a package of support to key affected communities that, for example, existing evidence informed prevention programmes (such as condoms and lubricants, harm reduction and behaviour change communication). Also, any intervention should be safe for those that use it with many community members concerned about the potential side effects and resistance associated with the long-term use of ART.
22. A core principle is that the **primary purpose and goal of ART** is for someone living with HIV to benefit their own health. Preventive benefits are important, but in a context where many who urgently need treatment do not have access to it, these benefits must remain as secondary considerations. Likewise, public health benefits must not be prioritised over a respect for individual benefits and patient autonomy in decision-making. In a position paper on TasP⁴⁶, GNP+ emphasises that all people testing HIV-positive, including those from key affected communities, must receive full and appropriate counselling on what ART involves, including its potential side effects. Regardless of their individual medical need for ART, they must be provided comprehensive counselling on what is currently known (and unknown) about the potential preventive effects of ART. It stressed that decisions about when, or if, to start treatment must be made by the person living with HIV. Required to make such decisions is access to adequate and up to date information (including CD4 and viral load, treatment adherence, resistance to medications and potential side effects), in a format and language that the person can readily understand. Support systems, including support by peers from key affected communities, must be put in place and funded to ensure that a person living with HIV can access non-biased, non-judgemental, accurate and current information about treatment and prevention and can be supported in their decisions about ART initiation or deferral.
23. Implementation of TasP in all contexts must be imbedded within a **human rights-based approach**. It must never result in key affected communities being coerced to test, accept treatment or undergo unwanted procedures. As Barr et al⁴⁷ state: *“the use of antiretroviral treatment as prevention reinforces the value of basic principles related to the dignity and agency of people living with HIV to participate in the design and implementation of programmes, to be informed and to make informed decisions about their health and lives, to be protected from harm, and to have opportunities to seek redress and accountability for abuses.”*
24. Different key affected communities emphasise varying issues within the TasP debate. At a 2012 consultation with Asia Pacific MSM and transgender community representatives, priority treatment access related concerns were strengthening treatment literacy and adherence programs and the need to scale up and emphasise existing prevention efforts such as behavior change communication⁴⁸. For many from the PWID community the most pressing concern that prioritising TasP within a broader context, where investment in and coverage of proven harm reduction interventions remains wholly inadequate, will see this situation worsen.
25. For the sex worker community, the Global Network of Sex Worker Projects (NSWP)⁴⁹ has highlights that TasP risks reducing condom with pressure on sex workers exerted to abandon their use. This risk is noted by Overs in a recent research article⁵⁰ *“clearly the greatest risk concerning sex workers is condoms will be abandoned or become even more difficult to negotiate. Knowledge that ‘treatment is prevention’ will seep out from academic journals to sex workers, clients, policy makers and programme planners. Demand for unprotected commercial sex will certainly result from confidence that even if a sex worker is HIV+ she/he*

is likely to be on ART, and therefore not HIV infectious Crafting messages to encourage testing and treatment as a prevention strategy without discouraging condom use is an enormous challenge.”

‘MAKE OR BREAK’ FACTOR 2: DATA AND ‘WHAT WORKS’

Key message:

To better understand the scale and details of the ‘Equity Deficit’, stronger – but also participatory and rights-based – systems are needed to collect and analyse data on access to treatment, care and support for key affected communities. Further, there is a critical need to identify and recognise – and make political, financial and technical investment in - ‘what works’ for such groups, especially comprehensive programmes and community-based services and support.

26. The 2013 UNAIDS Report on the Global AIDS Epidemic⁵¹ states that “reliable HIV treatment coverage estimates are not available for men who have sex with men, people who inject drugs, sex workers or transgender individuals”. There is a **lack of data** about: the number of key affected communities living with HIV; the number accessing treatment, care and support; and the barriers to access. While some countries may routinely disaggregate ART coverage data across the demographics of sex and geography, very few do so according to affected communities⁵². **This is evidences in a recent** systematic review by Mathers et al⁵³ which found that from 98 countries that reported drug use and provided data on the number of ART sites, only 47 offered estimates of the number of PWID receiving ART. The situation for transgender communities is, at best, equally unclear. This community is entirely ignored within gender disaggregated ART data on contexts that refuse to recognise their ‘existence’ and actual and legitimate identity⁵⁴.

27. In many contexts, the lack of data – combined with a lack of political will –see communities such as transgender people and PWID as entirely ‘invisible’. The consequences here are significant. Without this data, program priorities and budget allocations proceed inadequately reflecting the realities and priorities of communities on the ground. In reality, data is vital to ‘knowing your epidemic’ and developing/prioritising effective national strategies, investment cases and proposals, such as to the Global Fund. As such, there is a need to strengthen data collection and analysis systems, while also ensuring that they are rights-based, grounded in strong ethical standards, and with the full and meaningful engagement of communities at all stages of the research process.

Box 5: Prioritising key affected communities

“Give priority to scaling up in key settings and populations with disproportionately high unmet need for HIV treatment.”

Treatment 2015, UNAIDS, 2013

28. The UNAIDS Treatment 2015⁵⁵ framework strongly recommends that countries establish specific targets for key communities – such as sex workers, MSM, transgender people and PWID – particularly where HIV treatment access remains low. It maintains that such targets must be used to ensure “expedited progress towards equitable access for all populations.” It further recommends that all such efforts should be accompanied by a review that identifies and addresses the bottlenecks to scale-up – paying particular attention to key affected communities.

29. Action on the ‘Equity Deficit’ – such as through the roll-out of the 2013 Treatment Guidelines –requires focus on and investment in ‘what works’ for reaching, mobilising and supporting key affected communities. This includes **evidence-informed, comprehensive programmes** that move beyond sole bio-medical responses and act to address the full needs of communities

and the structural drivers which see them disproportionality impacted by HIV and AIDS. These involve looking at the full range of determinants of health for key affected communities, including socio-economic factors, such as income, food security and housing status. This is essential to ensure that treatment, care and support packages meet the full clinical, psychosocial and other related needs of people living with HIV, their sexual partners and family members.

30. ART for prevention must be considered part of a *combination* prevention package, along with access to information about how HIV is acquired and transmitted, male and female condom use, harm reduction interventions for PWID, vertical transmission services, and that promote and ensure protection of human rights, the reduction of HIV-related stigma and action on gender-based violence. All People living with HIV must be supported to understand and be allowed to make choices from this package that suits their individual circumstances.
31. A specific example of comprehensive programmes is seen for PWID living with HIV for whom treatment should - as recommended by WHO – be provided as part of a package that integrates ART with harm reduction strategies (opioid substitution therapy (OST) and needle and syringe programmes (NSPs) and addresses co-infections, notably TB and Hepatitis C. This draws on the clear evidence that ART outcomes improve among PWID who are accessing OST⁵⁶. A meta-analysis of studies in Asia, Europe and North America⁵⁷ found that providing OST is a critical facilitator for adherence to ART by PWID – and was also associated with a 54% reduction in the risk of acquiring HIV infection among such community members. However, global coverage of OST remains low, being estimated at just 8% in 2010 compared to a target of 40%. Worldwide, as many as half of the countries that report HIV cases among PWID do not provide OST services. While some countries are expanding access to OST, in many others, the programmes remain small in size and limited in scope, with weak links between OST services and HIV testing, treatment, care and support services.
32. ***It has been clearly demonstrated that community-based*** services and support are important and effective approaches for key communities. The evidence here and the critical role key communities' play in responses to HIV is overwhelming. For example, a 2012 study by the World Bank, United Nations Population Fund (UNFPA), Johns Hopkins Bloomberg School of Public Health and Global Network of Sex Work Projects (NSWP)⁵⁸ found that a **community empowerment** approach to HIV prevention, treatment and care for sex workers not only has significant impact, but is cost-effective. Meanwhile, commitment to community-based approaches is articulated throughout international commitments and strategies. These include the: 2011 Political Declaration on HIV/AIDS (see Box); Treatment 2015 (see Box); and Treatment 2.0 (with a goal that *“people living with HIV and key populations are fully involved in the demand creation, planning, delivery and evaluation of quality assured, rights-based HIV care and treatment programmes in all LMICs”*⁵⁹). Community-centered design and delivery is also a critical enabler of an investment approach⁶⁰.

Box 6: Commitments to community-based services

33. Community-based structures and systems can be especially important for sex workers, MSM, transgender people, PWID and young people – who, as outlined in Section II, face multiple barriers to equitable access. Such communities want services that are, among other factors, local, confidential, affordable and provided by people who they trust and who understand their context and needs.

“Recognize the role that community organizations play, including those run by people living with HIV, in sustaining national and local HIV and AIDS responses, reaching all people living with HIV, delivering prevention, treatment, care and support services and strengthening health systems, in particular the primary healthcare approach.”

Political Declaration on HIV/AIDS 2011, UN General Assembly

“The health system extends deep into communities... because vulnerable populations are often the hardest to reach, we need to leverage and strengthen the systems that are best positioned to effectively deliver services to them. In many cases that means partnering closely with and strengthening civil society...”

Mark Dybul, Report of the Executive Director, 29th Board Meeting, the Global Fund to Fight AIDS, Tuberculosis and

34. Community-based (HIV counselling and testing) HCT has received particular attention as a means to start the 'treatment journey'. A 2013 systematic review and meta-analysis of community-based HCT by Suthar et al⁶¹ found that – although further research is needed to improve the acceptability for key affected communities – such approaches achieve high rates of uptake and good linkage of people to care. The 2013 Treatment Guidelines⁶² promote the use of a wider and more dynamic range of service delivery models, including that *"in all HIV epidemic settings, community-based HIV testing and counselling for key populations, with linkage to prevention, care and treatment services is recommended."*
35. However, the role of community-based responses in **decentralisation** of services and support for key affected communities goes well beyond HCT. There is increasing evidence of their critical contribution in a range of areas such as distributing ART and supporting adherence. This is confirmed by WHO⁶³ which cites dramatically improved retention, adherence and outcomes following pilot programmes and trials report which have engaged community-based groups in ART delivery. The 2013 Treatment Guidelines clearly recommends community-supported ART delivery to expand care for people receiving ART who are clinically stable.
36. Efforts relating to treatment care and support should be **integrated** into existing work by and within key affected communities, rather than be new or additional services. However, alongside the enthusiasm for community-based services, there is caution. As illustrated by Case study 4 (Annex One), communities – especially groups by and for key affected communities – already face multiple demands and require further recognition, resources and capacity building to play their full role. Also, the greater involvement of communities in service delivery should be coupled by a step change in mainstream services being 'key affected community inclusive'⁶⁴. For example, if a community group is only able to offer HCT services, there is a need for assurance that referral services for treatment, care and support are fully inclusive of key affected communities.
37. Fulfilling the key aspects of 'what works' for key affected communities requires more and better attention to **Community Systems Strengthening (CSS)** – as described under 'Make or Break' Factor 5. It also requires progressive thinking, such as about **human resources**. For example, in the community consultation to inform the 2013 Treatment Guidelines⁶⁵, stakeholders, including members of key affected communities, supported 'task shifting/sharing'. However, they emphasised that such measures could not 'just happen', but should be accompanied by training, protocols and remuneration.
38. There is the potential for such measures to not only improve the efficiency of services, but their effectiveness, such as through the recruitment of community health workers among sex workers, MSM, transgender people and PWID - who have a strong understanding of the real needs of community members. This can be especially the case in highly specific and marginalised groups, as indicated by a study among Kothi and Aravani in India⁶⁶. This recommended that the training and use of such community members is critical for addressing their inequitable access to services.
39. **Further research** is needed into the issues and dynamics that shape the 'Equity Deficit'. While prevention among key affected communities has been the subject of multiple research projects, treatment, care and support remains largely neglected. A review of interventions for sex workers in sub-Saharan Africa⁶⁷ failed to identify *any* published studies specifically aimed at improving sex workers' access to ART. In particular, more evidence is needed of how to tackle the persistent weaknesses in the treatment cascade among such communities.

'MAKE OR BREAK' FACTOR 3: FINANCIAL INVESTMENT

Key message: Ending the 'Equity Deficit' requires a significant increase in investment in treatment, care and support for sex workers, MSM, transgender people and PWID – groups that, to date, have been grossly under-funded. This will require affordable medicines and political mobilisation, combined with sound investment approaches that demonstrate both the human and financial benefits of such resourcing and how it is critical to achieving the 2013 Treatment Guidelines and an 'end to AIDS'.

40. The opportunities presented by the current treatment landscape do not come for free. Despite being 'very cost effective' according to global criteria, the 2013 Treatment Guidelines will require an estimated 10% increase in the annual **investment** in the global response to HIV (above the US\$ 22-24 billion cited in the Political Declaration on HIV/AIDS). More specifically, to fulfil the Guidelines and address the 'Equity Deficit', significantly more investment will be needed in programmes for and by key affected communities.

Box 7: Under-funding for key affected communities

"Given the severity of the challenge, HIV prevention programming for people who inject drugs is badly under-resourced."

"Notwithstanding sex workers' disproportionate risk of acquiring HIV, prevention programmes for sex workers account for a meagre share of HIV prevention funding globally."

"Inadequate resources impede efforts to reach men who have sex with men with essential HIV prevention services."

UNAIDS Report on the Global HIV Epidemic 2013, UNAIDS, 2013

41. This comes at a time when funding for HIV has flat-lined⁶⁸ and the track record of investment in key community groups and responses has been appalling (see Box). Research for the 2013 NGO Report could not identify specific financial data on treatment, care and support for such communities. However, data on HIV prevention serves as a useful proxy. Data here demonstrates that targeted interventions have been systematically and grossly under-funded. According to UNAIDS⁶⁹, programmes to reach key affected communities currently receive 4% of investments in basic HIV prevention and treatment programmes globally, while an optimal response in 2015 would require 14%. Taking PWID as a specific example, worldwide, just 1% of HIV prevention expenditure targets such community members – a level that, according to UNAIDS, should be increased 20-fold⁷⁰.

42. Key affected communities are concerned about the incongruences between donor policies and funding patterns. For example, PEPFAR and the Global Fund have made clear a commitment to investments in interventions for communities such as MSM and transgender people (through the Blueprint for an AIDS-Free Generation and the Strategy in Relation to Sexual Orientation and Gender Identities (SOGI) respectively). However, actual allocations have come nowhere close to upholding the policies in practice. A study by the Foundation for AIDS Research (amfAR) and Johns Hopkins School of Public Health⁷¹ found that, in six Sub-Saharan African countries – that collective comprise 10% of all PEPFAR funding between 2007 and 2011 - four of the annual budgets contained no programming for

Box 8: The public health mandate for investment

"Resources need to target the most effective interventions, based on sound evidence ... This means focusing on some of the hardest-to-reach and most stigmatized populations, including sex workers, people who inject drugs, and men who have sex with men. The public health urgency to address these key populations is consistent with the human rights imperative to include those most in need of HIV prevention, treatment, and care."

Chris Beyrer, Director, Johns Hopkins Center for Public Health and Human Rights

MSM. In the countries where such allocations existed, *“budgeted amounts were difficult to decipher, frequently miniscule, and often shared among multiple populations, reducing the certainty that MSM were reached at all.”* There was no mention of transgender people. Meanwhile, a similarly concerning pattern can be seen in the US\$1.5 billion allocated by the Global Fund to the same six countries since 2001, with only 0.07% allocated to programs specifically targeting MSM and transgender people.

43. Stakeholders also express concern that investment in responses for key affected communities come largely from external funding sources, with the lack of domestic investment often reflecting countries' oppressive policies and restrictive legal environments. This scenario emphasises the need for further attention to **investment approaches** and the prioritisation and resourcing of interventions for key affected communities. A report to the 31st Programme Coordinating Board⁷² stated that the investment approach has already been used in at least 29 countries, including generalised and concentrated epidemics. The approach has also become central to the strategies of leading agencies. Critically, this includes the Global Fund. Maximising investment (including by focusing interventions on the key drivers of epidemics and the most vulnerable populations) is central to the mechanism's Strategy for 2012-16 and New Funding Model⁷³. For the latter, country applications can be based on a national strategy or investment case and, alongside service delivery interventions, must include action on 'critical enablers' such as programmes to address human rights-related barriers to access⁷⁴.
44. Research for the 2013 NGO Report – which included reports of community consultations on the approach, conducted by UNAIDS and International Civil Society Support (ICSS)⁷⁵ - indicates that the investment approach remains a *potentially* significant tool to /strengthen effective, evidence-based treatment, care and support interventions that address inequities in funding. Alongside other resources, the approach puts beyond doubt that programmes and advocacy for and by key affected communities are key to accelerating an 'end to AIDS'.
45. However, there is concern that, while funding for programmatic interventions has been limited, investment in '**critical enablers**' is even more lacking. A 2012 community consultation in Bangkok⁷⁶ emphasised that, to apply the investment approach within concentrated epidemics, community groups – including key affected communities – do not just require increased resourcing, but funding must be *flexible* and available for advocacy and other interventions on 'critical enablers'. Sex worker community advocates concur⁷⁷ noting that the hard work of changing repressive policies and raising awareness of sex workers' rights among communities, community leaders and law enforcement authorities remains grossly under-resourced.
46. To address the 'Equity Deficit', it is critical that – as its use is expanded and adapted, including to support implementation of WHO's 2013 Treatment Guidelines - the investment approach does not become reduced to simply a menu of biomedical interventions. It needs to be a dynamic process that, as advocated in a discussion paper on the approach by the International HIV/AIDS Alliance⁷⁸, understands the *“range of needs, struggles and problems shaping the lives of people who are detained, denied services, who are subject to violence, breaches of privacy, hate crime, discrimination and other violations, who live far from health services, who have uncertain immigration status or who are poor, young, old or socially isolated.”*
47. Action in this 'make or break' factor requires significant political advocacy to convince governments and donors of the value of investing in key affected communities. This should emphasise human rights, while also presenting a convincing public health and economic rationale. For example, a 60% reduction in the unmet needs of PWID for ART, OST and NSPs would reduce HIV incidence in Odessa, Karachi, and Nairobi by 41%, 43% and 30% respectively⁷⁹.

48. A specific concern is the **geographic balance**

in the investment of resources for key affected communities. For example, domestic and/or overall targeted funding is sometimes at its lowest in the very regions where it is most needed – such as in the case of MSM in the Middle East and North Africa. Meanwhile, a report by the Civil Society Action Team (CSAT) hub in the region⁸⁰ voices extreme concern that even such minimal levels of investment will not

be maintained following changes to the eligibility of middle-income countries within the Global Fund's New Funding Model. At a recent conference on Controlling the HIV Epidemic with Antiretrovirals - organised by the International Association of Providers in AIDS Care and British HIV Association in partnership with UNAIDS and Public Health England⁸¹ - the World Bank warned that decisions about allocating money to TasP will be especially pressing in concentrated epidemics, where treatment already claims the majority of HIV budgets.

Box 9: The importance of affordable medicines

"One day the FTA will be imposed and we'll have to pay... the pharmaceutical companies will have to impose their patent fees and we may no longer enjoy free medication."

MSM living with HIV in Malaysia, quoted in
Treatment Access for Positive MSM
in the Asia Pacific, APN+, 2011

49. A critical component of the financial feasibility of scaled-up treatment is the **cost and affordability** of HIV-related medicines and commodities. Advocacy by people living with HIV and other stakeholders has long highlighted the harmful role of measures by the World Trade Organisation's Agreement on Trade-Related Aspects of Intellectual Property (TRIPS) and Free Trade Agreements (FTAs), as well as the failure of the current incentive structure for research and development to address the priority health needs of developing countries. Such issues are especially pertinent to key affected communities living with HIV. As stated in a briefing paper by NSWP+⁸² (a platform provided by the Global Network of Sex Worker Projects for HIV-positive sex workers), *"bearing in mind that sex workers already share a feeling of being 'last in line for treatment' ... the impact of these trade rules has the potential to be devastating."* As highlighted in a 2013 working paper⁸³ by a group of global key affected community networks, the impact of affordability risks, once more, being especially acute among key affected communities in middle income countries.

50. Combined, these multiple limitations in investment add up to unacceptably poor coverage of programmes for key affected communities. For example, a 2011 review⁸⁴ estimated that, worldwide, as few as 1 in 10 MSM receive a basic package of HIV prevention interventions.

51. As concluded in a briefing produced by amfAR⁸⁵ on the positioning of key affected communities in the changing global health landscape, *"despite the unparalleled vulnerability of these groups to HIV, national governments and international donors have routinely short-changed most-at-risk populations, preferring to allocate scarce funding toward programs targeting low-risk individuals. The end result of meagre investments and bureaucratic obstacles is extraordinarily low coverage levels for HIV prevention and treatment services for the populations most heavily affected by the epidemic."*

'MAKE OR BREAK' FACTOR 4: MEANINGFUL INVOLVEMENT

Key message: To address the 'Equity Deficit', key affected communities must have a 'place at the table' of all relevant decision-making and resource-allocation forums related to the treatment landscape, such as processes to roll-out the 2013 Treatment Guidelines. Such involvement should be both meaningful and comprehensive, including all relevant groups and sub-groups.

52. It is essential that – as a matter of both principle and practice – key affected communities have a **'place at the table'** in the decision-making and resource-allocating forums that shape the treatment landscape at all levels. Such involvement brings multiple benefits, from

enabling other stakeholders to better understand the barriers that shape the 'Equity Deficit' to enabling key affected communities to influence the design and delivery of strategies, programmes and budgets that address their needs. Involvement is especially important in areas such as TasP which, as already noted, raise passionate - and sometimes very different - opinions among key affected communities. It is vital that further work, such as the application of TasP in different regions or development of guidelines for specific populations, actively involve relevant communities every step of the way.

53. Involvement should be **meaningful** and comprehensive - recognising the specific and different issues of, for example, transgender people and MSM. It should also be mindful of those who experience especially inequitable access. For example, specific measures may be needed to involve *young MSM* and *women who inject/use drug user*. NSWP⁸⁶ emphasises the importance of sex workers being present at policy-making and planning meetings that will guide the introduction of all new prevention tools. As they say, "*without involvement, there is no assurance that the positive impact of new prevention technologies will be realised, and that negative impacts will be minimalised.*" For such involvement to be successful, there is a need for both: resources for sex worker organisations to maintain adequate capacity to engage in the development of new tools; and policy-makers to be convinced that the involvement of sex workers' groups is essential to achieving public health goals.
54. As seen in Case study 5 (Annex One), the changing treatment landscape highlights the need to maximise, but also continue to strengthen, existing platforms for key affected communities, such as related to the Global Fund. Meanwhile, further development and implementation of the 2013 Treatment Guidelines should – in keeping with the principles that they promote – be based on on-going community consultations are genuine, wide and deep. For example, they should go beyond international and national representatives and attempt to engage community members 'on the ground'. They should also recognise that, within forums for people living with HIV, the specific experiences of groups such as sex workers living with HIV have often been rendered invisible⁸⁷.

'MAKE OR BREAK' FACTOR 5: TECHNICAL CAPACITY

Key message: Well-coordinated, appropriate and high quality information and technical support is vital for both: enabling groups of key affected communities to play their full role in treatment, care and support; and supporting all stakeholders to recalibrate national responses to HIV that - such as through sensitive and rights-based roll-out of the 2013 Treatment Guidelines and development of TasP - end the 'Equity Deficit'. The critical and significant role key community organisations and networks play in providing technical support and must be recognised, respected and resourced.

55. Achieving the multiple opportunities outlined in this report – such as fulfilling the 2013 Treatment Guidelines and using the investment approach - requires not only financial and political support, but technical capacity. As a starting point, there is an immense need for clear **information** about the recent developments in the treatment landscape and their implications for key affected communities. Currently, stakeholders report that community members living with HIV - especially those not directly engaged in national or global advocacy – know little about the critical decisions being taken and strategies being developed that will affect their lives. There is a need for shorter versions of extensive global documents, as well as practical tools – such as that developed to implement comprehensive programmes for sex workers⁸⁸ – to support specific key affected communities to implement the recommended initiatives.
56. Beyond information, well-coordinated, appropriate and high quality **technical support** is needed to support all relevant stakeholders to recalibrate national responses to HIV so as to, for example, better: collect relevant data and 'know your epidemic'; develop investment cases

for programming for key affected communities; and roll-out the 2013 Treatment Guidelines in a way that respects human rights and addresses the 'Equity Deficit'. There is significant concern that technical support strategies, 'menus' and provisions have fallen behind the treatment landscape and are not able to respond to the current, let alone future, needs in this area.

57. In addition, technical support is required to enable groups by and for key affected communities to play their full role in relation to decision-making, programming and advocacy on treatment, care and support. As concluded by a 2013 consultation convened by UNAIDS on the role of community systems in expanded access to treatment⁸⁹, this should be provided within **CSS** (Community Systems Strengthening) – a framework conceived to acknowledge, develop and support the full range of roles of the community sector, including key affected communities, in the design, delivery, monitoring and evaluation of services and activities related to HIV and other health issues. CSS is based on six building blocks⁹⁰ and informs the work of a growing number of agencies, including being part of the Global Fund's core package of 'community sector-friendly' policies.
58. CSS responds to the reality that community-based services do not 'just happen' and organisations by and for key affected communities often lack the resources (financial, technical, human, etc.) to address the needs that they are all too aware of. However, there are challenges. A 2013 discussion paper on CSS and key affected communities, produced by the GFMSM⁹¹, notes on-going ambiguities about what the framework means and continued scepticism about it from some governments and health sector leaders. Community stakeholders voice on-going concerns about how CSS will be fully integrated and operationalized within the Global Fund's New Funding Model – with multiple strategies 'competing' for space within national proposals. Furthermore, there is concern that CSS should not only be about programmes, but enabling key affected communities to engage in local and country-level decision-making structures⁹².
59. For example, to strengthen community systems and engage in the roll-out of the 2013 Treatment Guidelines and further development of TasP, key affected communities may need technical support in areas as varied as: advocacy; financial planning; human rights programming; supply chain management; and resource mobilisation. Meanwhile, stakeholders emphasise that not only more, but better support is needed – in terms of coordination, quality and appropriateness for key affected communities. To date, such groups have often found it hard to identify and/or access the type of support that meets their needs.
60. Technical support needs to be nuanced, rather than 'one size fits all'. For example, in some contexts, groups for communities such as PWID may be more nascent, have much less capacity and have fewer training tools and guidelines than those for other communities (such as sex workers). In turn, they may need intensive support to play an active role. It must also be recognised that in many instances key affected community organisations and networks, and civil society more broadly, also act as highly effective technical support providers – work that often goes under or unfunded and unrecognised. Without adequate recognition and resourcing, the sustainability of the critical role of key affected community organisations play in providing specific and unique expertise and support to their constituencies, UNAIDS, co-sponsors, national governments and partners remains fragile.

IV. CONCLUSIONS

61. The 2013 NGO Report has confirmed that, within the world's pre and post-2015 agenda, it is critical to grasp the momentum for action on HIV treatment, care and support. The multiple initiatives and opportunities are sincerely welcome. The Report has highlighted that the future

trajectory of treatment should not just be about scale, but equity. Key affected communities must not be left behind.

62. The 'Equity Deficit' is real, significant and complex. It presents a threat to the health, rights and lives of many millions of people from key affected communities throughout the world. It results from multiple, sometimes entrenched, challenges within the response to HIV and has no 'quick fixes'. Instead, it requires concerted action on all five of the 'make or break' factors discussed here. None are optional. Without such action, current international initiatives – from the Political Declaration on HIV/AIDS to the 2013 Treatment Guidelines and Treatment 2015 – will remain aspirations, rather than realities for such communities. If applied without respect for rights, they could even *exacerbate*, rather than resolve, the 'Equity Deficit'.
63. The UNAIDS Programme Coordinating Board is uniquely placed to drive action on the 'Equity Deficit' and ensure the political, financial and technical support necessary to fulfil the rights of sex workers, MSM, transgender people and PWID to full and equitable access to treatment, care and support.

V. RECOMMENDATIONS

64. The NGO Delegation calls upon the 33rd Meeting of the UNAIDS Programme Coordinating Board to make and, with urgency, fulfill the following decision points :
65. *Call upon Member States, UNAIDS and partners to:*
- a. *Ensure* that any implementation/guidance on new biomedical preventative technologies proceeds with the full and meaningful engagement of key populations, guaranteeing informed and voluntary adherence to ARV, and respecting the diversity of perspectives between and within such communities;
 - b. *Ensure* the potential impacts of treatment as prevention - recognized by an increasing body of evidence in support of the earliest possible initiation of ARV for people living with HIV - will be aligned to the principle of treatment being first and foremost to benefit those living with HIV;
66. *Call on UNAIDS, co-sponsors and partners, as a matter of urgent priority*
- a. *to intensify coordinated technical support to governments, civil society and key affected communities, and UNAIDS to periodically report to the Programme Coordinating Board on progress in the effectiveness of technical support interventions at the country level in key areas specifically in implementation of the WHO Guidelines, key affected community and civil society engagement in decision making processes, community systems strengthening and roll out of the Global Fund New Funding model.*
 - b. *Request* UNAIDS and member states to call on the United Nations General Assembly to convene a High Level Meeting before September 2015 to assess progress towards those targets set out in the 2011 Political Declaration and to renew the commitments to achieve Universal Access to HIV prevention, treatment, care and support in the post- 2015 era.
 - c. *Request* UNAIDS to engage key population representatives in the planning for the HLM – including those communities not reflected in the 2011 Political Declaration but that continue highly impacted by HIV, specifically the transgender community.
 - d. *Recalling the 26th PCB, Agenda item 2: Ensuring non-discrimination in responses to HIV; Decision points: 7.3; 7.4; 7.5; 7.6 and 7.7^a; Recalling the 30th PCB: Thematic Session on*

Non-Discrimination: Decision point: 6.1^a; requests UNAIDS and Member States to report at the 35th PCB on concrete actions (including support to strengthen national capacity, funds disbursed, the development of data, research and evidence, strengthening of enabling environments including reform to punitive laws and policy) taken to implement expanded programmes to reduce stigma and discrimination against key populations (including transgender people), at sufficient scale to improve the lives of those at risk of infection and people living with HIV.

[Annexes follow]

Annex 1

Case study 1: The impact of stigma against sex workers in HIV health care settings – Zimbabwe

In Zimbabwe, HIV prevalence is 14.7% in the general population⁹³, but 50% among female sex workers⁹⁴. A 2013 study⁹⁵ highlights how - despite well-attended targeted services - social and systems barriers contribute to inequitable access to treatment, care and support for sex workers living with HIV. In the study site, fewer than half of women diagnosed with HIV took up referrals for assessment and ART initiation, while just 14% attended more than one appointment. Extreme stigma and discrimination within mainstream health services was a particularly powerful barrier. For example, a 32 year old sex worker shared how: *“She opened my file and I saw her face just changed instantly and she actually frowned and looked at me like I was disgusting her. Her first words to me were, ‘so you are a prostitute and you actually have the guts to come here to waste our time and drugs on you?’”*

Case study 2: Barriers to services for MSM and transgender people living with HIV - Asia Pacific

By 2020, the majority of new HIV infections in Asia Pacific will be among MSM and transgender people⁹⁶. A 2011 study by the Asia Pacific Network of People Living with HIV (APN+)⁹⁷ explored the context for such communities in India, Indonesia, Malaysia, Myanmar, Nepal and Singapore. It found that many MSM and transgender people living with HIV experience discomfort in accessing HIV services, with levels as high as 78% in Nepal. A broad range of barriers contribute to levels of access to ART as low as 39% in Indonesia. The study’s conclusions included that:

- The constant interplay between infrastructural barriers and the socio-cultural environment impacts on the healthcare options and treatment access of MSM and transgender people living with HIV.
- Unethical disclosure of sexuality and HIV status by staff perpetuates distrust in local healthcare infrastructure.
- Strong cultural norms about sexuality impede the availability of accurate treatment information, create the fear of disclosure and cause an increased chance of social isolation and loss of social support.
- Gender-based discrimination and violence makes treatment access an additional challenge for transgender people.

Case study 3: The importance of human rights in rolling-out the 2013 Treatment Guidelines and developing TasP - Latin America and the Caribbean⁹⁸, Eastern and Europe and Central Asia⁹⁹ and North America¹⁰⁰

In **Latin America and the Caribbean**, key affected communities represent a large proportion of the (respectively) 1.5 million and 250,000 people living with HIV¹⁰¹. In the Caribbean, adult HIV prevalence is estimated at 1% - a higher level than any other region outside of sub-Saharan Africa.

Here, stakeholders from key affected communities emphasise that, while welcome, the 2013 Treatment Guidelines cannot ‘just happen’. They will require a sea change in the political environment for key affected communities in many countries in the region – where sex workers, MSM, transgender people and PWID face daily and systematic abuse and prejudice. To halt HIV epidemics and enable those living with HIV to access services and support, countries need to remove punitive laws and take policy measures to stop stigma, discrimination and violence against such communities. As cited by the Global Commission on HIV and the Law, in Caribbean countries where homosexuality is criminalised, almost 1 in 4 MSM is HIV-positive, compared to 1 in 15 in countries where it is not¹⁰². Policy action on such issues will need to be complemented by intensifying efforts to ensure that mainstream treatment, care and support services are

'human rights aware' and 'key affected communities inclusive' – helping to plug critical gaps in the treatment cascade, such as supportive HCT for sex workers and MSM.

In **Eastern Europe and Central Asia**, a large proportion of HIV cases relate to injection drug use. Here, against global trends, the number of new HIV infections and AIDS-related deaths are *increasing*, with 1.4 million people now living with HIV. As of 2012, over 20% of PWID in Ukraine and 50% in Estonia were HIV-positive¹⁰³.

Here, stakeholders from key affected communities recognize the *potential* of TasP, but have strong concerns about how it will be translated into practice among PWID in contexts that lack political support for such groups. There is concern that TasP will divert attention and resources away from the right to harm reduction, including NSP and OST - which is critical in its own right, but has also proven to increase the efficacy of ART. A further concern is that TasP will be applied as a coercive policy within, as described by one stakeholder, an increasingly "*brutal*" process to manage HIV cases, rather than support people. This is especially important against a track record of such communities receiving low quality drug regimens and being stigmatized in health care settings. A PLHIV community representative from Ukraine expresses that: "*My partner and I are a discordant couple and I did not infect my partner and was able to have healthy children only because I have been taking ART for many years So I realize the importance of this strategy But I am categorically against any compulsory strategies, against forcing all HIV-positive people to take ART. Because I believe that all things compulsory always have an ugly underside. There should be high-quality motivational counseling and a person's own voluntary motivation to take ART as a preventative measure. It's one thing when you need therapy to preserve your health and save your life. It's an entirely different thing when a person realizes that, to a large extent, they are taking this unpleasant chemical cocktail ... to be safe for others.*"

In **North America**, HIV prevalence is estimated at 8% among MSM, compared to 0.5% among the general population. The region is home to a total of 1.3 million people living with HIV¹⁰⁴.

Here, stakeholders are concerned that, among key affected communities, little is currently known about TasP. The information that exists is often confusing, even conflicting. There is, however, acknowledgement that TasP could provide a useful *additional* HIV prevention option, particularly for people for whom condoms are not suitable. Overall, there is concern that the strategy will detract from universal access to treatment, care and support for people living with HIV - by failing to address the existing inequities in access. Many stakeholders question whether TasP is an appropriate ambition within a context where ART is not currently available to all people living with HIV and where many such community members, especially those that are young, lack capacity or opportunity to make informed decisions about their treatment. As Ginny Shubert, HIV Research and Programs Consultant, summarises: "*Treatment as prevention will not work in the US until resources are devoted to meeting the basic subsistence needs of every person living with HIV. We simply cannot achieve high levels of viral suppression as long as homelessness, hunger and extreme poverty continue to make it difficult or impossible for many PLWHA to access and adhere to HIV care that meets clinical standards. For persons with HIV who are struggling simply to find a safe place to sleep and food to eat - or who are unable to access harm reduction services or treatment for behavioural health issues - TasP is simply irrelevant to their daily lives.*"

Case study 4: Access to community-based testing, treatment, care and support for sex workers - Asia Pacific¹⁰⁵

In Asia Pacific, the majority of the approximately 5 million people living with HIV are from key affected communities¹⁰⁶, including female, male and transgender sex workers.

Here, stakeholders from key affected communities cite how community-based HCT has a potentially vital role in scaling-up support for sex workers living with HIV. It can, among other benefits: increase the number of places for and convenience of testing; enhance the quality of counselling; and, in time, improve the uptake of and retention in treatment, care and support. However, there remain challenges. HCT for and by sex workers often receives little political support or funding. Where it exists, it often lacks appropriate or comprehensive follow-on treatment, care and support services for those testing HIV-positive. As a result, community members are forced to access government services – which commonly lack the knowledge or skills to address the needs and rights of sex workers. Stigma (related to both sex work and HIV) remains high – highlighting the need for any testing, treatment, care and support services to maintain high standards of safety and confidentiality.

Within the region, community-based HCT could be increased through more funding and technical support to local sex worker groups to build their capacity and provide services themselves. This could ensure a continuum – rather than separation - between HCT and treatment, care and support if, for example, sex worker health workers/peer educators were trained in areas such as ART adherence and psycho-social support. Critically, such programmes should be complemented by changes to national laws and policies – to support (rather than criminalise) sex workers and enable HCT, treatment, care and support to take place in and by their communities. To make this happen, it is critical that UNAIDS fulfils its role as the main technical partner of the Global Fund. This includes: coordinating and providing technical support on community-based HCT, treatment, care and support; ensuring that there are seats for key affected communities on CCMs; supporting such representatives to access training; and advocating for the inclusion of community-based HCT, treatment, care and support for key affected communities in national proposals. UNAIDS should further identify and promote evidence-based models of community-based services for key affected communities – providing case studies that demonstrate the efficacy, alongside practical tools on ‘what works’. It should also use its leadership role to advocate to governments on the rights of communities such as sex workers and the value of – and investment case for – community-based initiatives to support them. Advocacy should also call on governments and donors to stop policies and practices that focus on the *number* of key affected communities receiving HCT and, instead, focus on the *quality* of services and the availability of follow-up.

Case study 5: Involvement of key affected communities in Global Fund CCMs

A 2013 report by the International Council of AIDS Service Organisations (ICASO)¹⁰⁷ reviews the involvement of civil society, including key affected communities, in CCMs, in light of the Global Fund’s New Funding Model. It finds that, while civil society involvement will continue to be promoted as a prerequisite for well-functioning CCMs, in practice, the sector often has limited ability to influence actual decision-making. ICASO recommends that, as the Global Fund re-assesses how to work with civil society and key affected communities, it should establish strong accountability mechanisms for the meaningful involvement of the sectors in CCMs. It should also prioritise ways to address information and capacity gaps, such as through technical support for representatives of key affected communities to function effectively and accountably and to build consensus among their constituents.

Annex 2: Participants in interviews and focus group discussions

The following lists the participants involved in interviews and group discussions carried out by the NGO Delegation to inform the 2013 NGO Report.

Name	Organisation/Country/Region
Asia Pacific:	
1. Thailand	Global Action for Trans Equality (based in Bangkok)
2. Malaysia	Asia Pacific Network of Sex Workers
3. Thailand	Asia Pacific Network of Sex Workers
Europe	
4. Ukraine	Eurasian Network of People Who Use Drugs (ENPUD)
5. Russia	Andrey Rylkov Foundation, Russia
6. Moldova	Credinta, Moldova
7. Russia	Project "April", Russia
8. Ukraine	Association of Participants of Opioid Substitution Treatment (ASTAU), Ukraine
9. Ukraine	Right to Life, Ukraine
10. Georgia	Awakening Power, Georgia
11. Russia	Eurasian Network of People Who Use Drugs (ENPUD), Russia
12. Moldova	Pulse, Moldova
13. United Kingdom	International Drug Policy Consortium, United Kingdom
14. The Netherlands	The Correlation Project, The Netherlands
15. Denmark	AIDS-Fondet, Denmark
16. The Netherlands	AIDS Foundation East-West (AFEW), The Netherlands
Latin America and the Caribbean:	
17. Brazil	Grupo de Incentivo À Vida and ABIA, Brazil
18. Guatemala	ITPC, Guatemala
19. Peru	Independent Consultant, Peru
20. Argentina	International HIV Alliance, Argentina
21. Trinidad and Tobago	Caribbean Network of People Living with HIV, Trinidad and Tobago
Africa	
22. Namibia	Positive Vibes, Namibia
23. Zambia	Friends Of Rainka , Zambia
24. Kenya	ISHTAR, Kenya
25. Kenya	ISHTAR, Kenya
26. Cameroon	Anon
North America:	
27. USA	Anon
28. USA	USA
29. USA	USA
30. USA	HIV Research and Programs Consultant, USA
31. USA	Treatment Action Group (TAG), USA
32. USA	via Housing Works
33. USA	via Housing Works
34. USA	via Housing Works
Global	
35. Kenya	International Treatment Preparedness Coalition (ITPC), Kenya
36. Kenya	International Treatment Preparedness Coalition (ITPC), Kenya
37. USA	Global Action for Trans Equality (GATE)
38. United Kingdom	International Network of People Who Use Drugs (INPUD)
39. Scotland	Global Network of Sex Work Projects (NSWP)
40. USA	Global Forum on MSM (MSMGF)

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