# UNAIDS

# UNAIDS PROGRAMME COORDINATING BOARD

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## THIRTY-FOURTH MEETING

**Date**: 1-3 July 2014

**Venue**: Executive Board Room, WHO, Geneva

**Agenda item 3**

## Update on the AIDS response in the post-2015 development agenda

**UNAIDS-Lancet Commission: Youth Online review**

**Defeating AIDS**
**Advancing global health**
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THE UNAIDS AND LANCET COMMISSION

# The UNAIDS and Lancet Commission:
# Defeating AIDS – Advancing global health
## Youth Online review: A summary of feedback from consultation on draft papers of Commission Working Groups

**25 November to 9 Dec 2013**

The Youth Online Review brought together young people concerned about the future of HIV and global health to examine the Commission's three Working Group draft discussion papers and enable the perspectives of young people to be included in the review process. 22 young people actively participated in the review, which was open to comments from a larger group.

**Key recommendations:**

- **Young people are a key population in their own right**. Young people have specific risks and vulnerabilities that impact their sexual and reproductive health, HIV testing uptake, treatment access (especially adherence) and care, and these deserve focused attention. In addition, young people make up a large proportion of many key populations groups.

- **Education in general and treatment literacy in particular is key** to increase treatment access, to support treatment adherence, and to empower youth as leaders and activists.

- **The shortcomings of political leadership must be recognized**, including the lack of political will to address the needs of key populations and to address drug use and taboos around adolescent sexuality. Leaders should be called to action to defend human rights and put an end to homophobic and other discriminatory laws that impede the AIDS response, especially among young people.

- **The involvement of marginalized communities and young people has to move beyond lip-service** towards transparent and systematic mechanisms which ensure meaningful participation of communities in investment, accountability and strategic priority-setting. This is critical for the legitimacy of the future global health architecture.

- **Data needs to be age disaggregated, more widely disseminated and better packaged** to inform and influence policy, particularly data on vulnerable and marginalized populations. Innovation in data collection including the use of mHealth is essential.

- **Countries must make full use of TRIPS flexibilities**. There is an urgent need to transfer knowledge from older members of civil society to a new generation of activists in order to ensure the continuation of effective advocacy in relation to TRIPS flexibilities/equitable trade agreements, and to challenge national patent laws.

# 1. Background

Launched in May 2013, *The UNAIDS and Lancet Commission: Defeating AIDS – Advancing global health* aims to ensure the effective positioning of AIDS in the post-2015 development agenda and to generate high profile advocacy for ending AIDS as a shared triumph of the post-2015 era. The Commission is a time-bound initiative that brings together a diverse group of HIV, health and development experts, young people, people living with HIV and affected communities, activists and political leaders. The Commission is expected to conclude in 2014 with three outcomes: evidence, in the form of a special report in *The Lancet* to present the Commission's findings; mobilization through a higher level of commitment to action on the part of individuals, civil society, businesses, institutes, and governments; and awareness among key thought-leaders of the contributions of the AIDS response to broader global health outcomes and sustainable development.

The Commission seeks to influence the post-2015 debate through deliberations framed against the following three central and overarching questions:

- **What will it take to end AIDS?**

- **How can the experience of the AIDS response serve as a transformative force in global health and development?**

- **How should the global health and AIDS architecture be modernized for the post-2015 development agenda?**

Three Working Groups, convened by Commissioners, drafted discussion papers that unpack and analyse each of the Commission's three framing questions. To stimulate global participation and debate on framing these papers, a consultative process was launched to engage and solicit inputs from stakeholders in all regions of the world. This consisted of regional, civil society and think tank dialogues, the youth online review and a public call for comments through *The Lancet*'s website (for full list of consultations, see Annex 2). The aim was to add participants' voices to the inputs to be considered by Commissioners at the Commission's second and final meeting in London, in February 2014.

**Youth online review participants**

The perspective of young people has been included in the various regional dialogues held to inform the Commission's work, but the youth online forum was a venue dedicated exclusively to young people as a forum in which to discuss the Commission's three Working Group papers, focussing on the needs and agenda of young people and bringing their unique insights. Participants were nominated to participate either by a PACT[1] member, a UNAIDS Youth Advisory Forum member, a UNAIDS-Lancet Commission youth member, one of UNAIDS' cosponsor organizations or by the UNAIDS Secretariat. The review opened on 25 November and closed on 9 December, 2013, during which time a total of 22 participants commented on the papers, which were available for comment to a larger group (see Acknowledgements section for full participants' list).

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[1] The PACT was formed at *the Youth and UNAIDS: a PACT for Social Transformation* meeting in Hammamet, Tunisia from 20-22 May 2013. The PACT is open to new member organizations that fit six criteria including being youth-led or youth serving, having HIV as focus or major programmatic area, and working with young people living with HIV and young people belonging to key populations at higher risk.

Participants[2] came from all regions of the world and ranged in age from 15-35. 38% of participants identified as male, 57% as female, and 5% as other. Participants self-identified as people living with HIV, transgender, sex workers, men who have sex with men, out-of-school youths, community workers, and people affected by HIV and AIDS (e.g., those with family members living with HIV, or who have high prevalence rate in their community).

In all there were more than 300 comments from participants, with most of the comments concentrated on the Working Group 1 paper on the question 'What will it take to end AIDS?'

This document summarizes the key themes that emerged during this online discussion, both in terms of the priority issues that were raised under each of the three papers, and also with regard to the critiques provided on each paper – for example, what was considered over-emphasized, under-represented or missing.
A full record of all comments can be accessed through the following links:

- Working Group 1: What will it take to end AIDS?

- Working Group 2: How can the experience of the AIDS response serve as a transformative force in global health and development?

- Working Group 3: How should the global health and AIDS architecture be modernized for the post-2015 development agenda?

All comments provided by participants in this review have been sent to Working Group chairs, for incorporation in their papers at the chairs' discretion. A synthesis report of feedback received from all dialogues, including this youth online review, will be shared with Commissioners by way of summary at the second and final meeting of the Commission in London, in February 2014.

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[2] Data on participants is from a survey which was circulated together with the invitation to join the online review and which collected key demographic information on participants'.

# 2. Key recommendations from the youth online review

This section of the report outlines a summary of key recommendations emerging from the youth online review of the three UNAIDS and Lancet Commission draft Working Group papers.

## 2.1 Working Group 1 discussion paper: What will it take to end AIDS?

### i. Young people's specific needs must be addressed

*"If we can prepare [adolescents] better for the environment of peer pressure, changing bodies, hormones, sex and relationships, and community challenges, we will have a better equipped group of youth."*[3]

Across the three papers, a critical point raised was the need to fully consider the physiological, physiological and social changes that adolescence as a period entails across all cultures. In turn, participants made the case that young people must be recognized as key population in their own right. In addition, young people make up a large proportion of many key populations groups. They have specific risks and vulnerabilities that impact their sexual and reproductive health, HIV testing uptake, treatment access (especially adherence) and care, and these deserve focused attention. As young key populations, they face structural vulnerabilities that impede access to treatment and care, because unlike other older counterparts, they are less likely to have an independent income and stable housing.

Specific suggestions include:

- Highlight issues relating to the transition from paediatric to adult care, including psychosocial support, disclosure support, self-management of disease etc. If these issues are not addressed, there is an elevated risk that young people drop off treatment in the transition period.
- Address treatment adherence challenges for a clear course towards zero new AIDS-related deaths. Such challenges are common among young people living with HIV and non-adherence is an extremely complex issue, particularly for young people going through adolescence. Showcase programmes and services which take into account the family community and structural drivers of risk as children transition into adolescence and go through puberty.
- Highlight the need for comprehensive health services including mental health and support in particular for young key populations, and the need to further invest in programmes that address homophobia and violence.

### ii. Education in many forms plays a key role

Scaling up education initiatives is critical, as youth reviewers hold that there are still many misconceptions about HIV in communities across the world.  Moreover, education was seen as critical in relation to sexual and reproductive health and treatment literacy. Education was also called for within the AIDS movement to transfer knowledge from older members of civil society to a new generation of activists who now need to take the

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[3] Throughout this report, illustrative quotes from individual reviewers have been used. Attribution of these quotes are provided in Annex 1.

baton in relation to TRIPS flexibilities/equitable trade agreements, and challenging national patent laws.

Specific suggestions include:

- Treatment availability does not always equate to treatment access, and treatment literacy/education is key to connect the two.
- It is important to link education with access to and uptake of youth-friendly sexual and reproductive health services. Highlight the fact that community preference is peer-led awareness/IEC-based prevention interventions.
- Education is important to empower young people to advocate for affordable drugs by transferring knowledge from establish AIDS civil society to youth-led organizations about intellectual property issues.

### iii. Why 'ending AIDS' and what does it really mean?

The term 'ending AIDS' is controversial and this should be acknowledged according to the youth reviewers. Some specific issues raised include:

- Recognizing that 'Ending AIDS' has sparked complacency within political leadership, and a media surge around this phrase.
- Confusion over why ending AIDS vs. ending HIV is chose as the term, which suggest this needs to be explicitly addressed in the papers.
- The need for the concept of ending AIDS to explicitly include a focus on key populations.

### iv. Call to action on human rights

Political leaders must be called to action to defend human rights and put an end to homophobic and other discriminatory laws that impede the AIDS response, especially among young people. Across the papers, youth reviewers questioned the rosy picture painted in relation to political leadership. They noted that often politics and election cycles are precisely what stands in the way of effective responses, in relation to key populations, as well as adolescents more broadly, given that adolescent sexuality is still taboo and subject to social control in many societies.

Specific suggestions include:

- The paper need to strongly sound the alarm on political leaders in countries where there are homophobic laws and laws that criminalize HIV transmission.
- The papers offer an important opportunity to outline that the criminalization of sex between same-sex couples is an obstacle to universal development and increases the risk of acquiring HIV especially among young people
- Recommend that parliaments should establish systems based on the protection, promotion and respect of human rights governance of all people, especially those who often have to face stigma and discrimination from society as a whole.
- Further highlight in the papers how the HIV response is a key example of how social change can lead to better health outcomes – much of which is founded on the demand for governments to recognize and guarantee their citizens' human rights.

## 2.2. Working Group 2 discussion paper: How can experience of the AIDS response serve as a transformative force in global health and development?

### i. Beyond lip-service to affected communities

*"We have established recognition of the importance of community involvement, now we must establish the mechanisms for implementing it properly."*

While the youth reviewers recognized that advances have been made in ensuring the participation of communities within decision making structures and research and programme design cycles, they emphasized that much work remains to be done. Communities are frequently used to rubberstamp pre-determined agendas, or they are railroaded through processes that they have no say over according to participants. It was felt that the involvement of marginalized communities now has to move beyond lip-service and the appearance of community involvement, with rigorous structures for community participation created.

Specific suggestions include:

- Include recommendations for the establishment of transparent systematic mechanisms to ensure meaningful community involvement in determining priorities for investment and strategies for prevention and treatment scale-up. This also has bearing on the global health architecture debate, as noted in the following section.
- Strongly highlight the need to engage communities in setting research priorities to ensure that the research which urgently needs to get done is done, rather than asking the same, often academic and far removed, questions that have been answered many times before.

### ii. Community activism works but has its limitations

*"For too long, the AIDS establishment has relied on a patchwork of independent advocacy organizations working on a shoestring budget to hold the entire response accountable."*

The HIV epidemic has been a game changer for civil society and this must be articulated, participants said. In many ways, the global AIDS architecture has facilitated civic engagement and encouraged more participatory governments. The HIV response has led the way in patient-to-patient advocacy, with even pharmaceutical companies courting patient advocates and activists. However, the current role of activism in the AIDS response has its limitations and should be recognized in the papers so as to advance the dialogue on the role of civil society in the AIDS response.

Specific suggestions include:

- Recognize that the AIDS movement in some parts of the world has become stagnant in terms of the AIDS response particularly for men who have sex with men and transgender people, and that a new wave of activism is needed to get to the end of AIDS.
- Ensure the papers highlight the need to secure funding for civil society that enables civil society to remain independent and play the critical watchdog and accountability function that is often asked of them. Current funding sources and streams are inadequate.

- Highlight the need to ensure the safety of advocates – key populations are criminalized in many countries and many activists are taking huge personal risks. The AIDS response must find innovative ways to provide support to these activists across national borders.

### iii.  AIDS can be an entry point to comprehensive health approaches

In the same way that health has been an entry point to discuss human rights, HIV has been an entry point to discuss a more comprehensive idea of health, particularly for key populations, e.g., mental health.  Specific issues raised include the need to articulate how HIV offers a lens through which to see the kinds of structural issues that must be addressed to ensure better health outcomes. For example, the HIV response has been critical in ensuring that vulnerable populations have access not just to HIV prevention and treatment, but also to a wide range of comprehensive health services. This is particularly crucial as the world shifts its attention to a more comprehensive health approach.

### iv.  Data needs to be youth-oriented

Youth reviewers noted that there is a need for the disaggregation of data.  In addition, participants emphasized that data on specific young key populations as well as young people's treatment access is often missing.

Specific suggestions include:

- Highlight how approaches to data collection can harness young people's early adoption of technology, e.g., using mobile phone applications (mHealth tools) to gather data on sexual and other health behaviours, as well as facility data.
- Further explore the benefits of including young people in all parts of the research cycle - from priority setting to study design, data collection and analysis - to ensure that critical issues are raised and data interpretation is accurate.
- Innovate in the way data is packaged with the end-user in mind. Ensure wide dissemination.

### 2.3 Working Group 3 discussion paper: How should the global health and AIDS architecture be modernized for the post-2015 development agenda?

### i.  Linkages and differences need more detailed exploration

Geographical issues are poorly addressed in the paper, with no distinction as to the needs of middle-income vs. low-income countries. According to reviewers, the percentage of HIV infections in low-income countries will drop by 2020 – a cause of concern because middle-income countries have different problems that are currently not highlighted in this paper, e.g., hepatitis C co-infection.

Specific suggestions include:

- The geographical transition that will take place over the coming years will place new demands on the global health and AIDS architecture. This should be further explored in the paper.

- The discussion on health architecture would benefit from more direct reference to inter-linkages between HIV and non-communicable diseases, as people living with HIV and on treatment are at much greater risk of developing non-communicable diseases.
- Recommended that migration be taken into consideration as it will be hugely demanding on the global health infrastructure of the future.

## ii. What works needs to be maintained and strengthened

Participants noted that the paper should also place emphasis on what works in the current architecture, articulate what needs to be maintained and improved.

Specific suggestions include:

- Include an economic analysis to highlight the value of investing in health systems strengthening so as to offer a stronger political incentive to invest in health over the coming 15 years.
- Explicitly mention community systems and their role in addressing HIV, particularly among key populations where general health systems have repeatedly failed.
- Highlight the need to invest in data including by investing in capacity building in the field of in-country epidemiology, for example through the scale-up of programmes such as the European Programme for Intervention Epidemiology Training (EPIET) and other field epidemiology programmes, and through support for health informatics.
- Stress the need to invest in epidemiological data collection among/with vulnerable populations, as well as the need to ensure dissemination of what is already available.
- Highlight that governments continue to leave out data available on key populations when it comes to decision-making, interventions and investment in situations where reliable data already exists.
- Provide a stronger link between health and non-health regimes such as international trade as a more sustainable approach to ensure treatment access. These links should be weaved in throughout this paper.

## iii. Sustainable and effective funding

The issues of sustainable financing for the AIDS response drew numerous comments, including criticism of lack of national responsibility in financing.

Specific suggestions include:

- The papers should place greater stress on national responsibility for financing, drawing attention to the fact that most countries in Africa are not meeting their pledge under the Abuja Declaration to spend 15% of GDP on health.
- Include a stronger discussion on the role of private vs. public healthcare provision, as well as more exploration of innovative funding sources, such as the huge value of committing to financial transaction taxes.
- Recognize that current financing mechanisms have largely failed key populations and community systems in general - few funders track their investments in key populations, making it impossible to follow disbursements among the most vulnerable groups. With stigma and discrimination rife throughout funding chains, even funds that are earmarked for key populations often get siphoned off to

other priorities.
- The report should encourage the development of systems to ensure that the most marginalized and vulnerable receive the funding they need.


## Acknowledgements

## Annex 1 – Attribution of quotes highlighted in text

"There is a disconnect in access to care during the transition period from pediatrics to adult care and this can be a hindrance to care retention and access." Lorraine Anyango.

"The jump from primary into secondary school is immense and if we can prepare them better for the environment of peer pressure, changing bodies, hormones, sex and relationships, and community challenges, we will have a better equipped group of youth." Lorrie Faire

"My experiences are that those young people that have access to medication and support packages are still dying from non-adherence as this is an extremely complex issue that we really have not got on top of yet." Magda Conway

"Young people could be pushing their governments to apply for TRIPS Flexibilities/equitable trade agreements, and challenge national patent laws." Hannah Smith.

"I think that besides treatment and prevention, we need to move an extra mile and advocate strongly for the cure. The force for the cure is too lenient yet we are sure that it's possible." Jackie Kemigisha

"Communities are frequently used to rubberstamp pre-determined agendas, or they are railroaded through processes that they have no say over." Jack Beck

"For too long, the AIDS establishment has relied on a patchwork of independent advocacy organizations working on a shoestring budget to hold the entire response accountable." Jack Beck

"The silo-ed advocacy community needs to be tied to wider movements around health and social justice." Mike Kalmus-Eliasz

"In many the global AIDS architecture has facilitated civic engagement and encouraged more participatory governments." Daniel Townsend.

"With stigma and discrimination rife throughout funding chains, even funds that are earmarked for key populations often get siphoned off to other priorities. As we forge ahead, we will need to develop systems to ensure that the most marginalised and vulnerable receive the funding they need." Jack Beck

## Annex 2 – List of all consultations convened

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| 3 November | **Regional Dialogue for Africa**, during Africa Regional Consultative Meeting on the Sustainable Development Goals, co-hosted by the United Nations Economic Commission for Africa, the African Union Commission and the African Development Bank, Addis Ababa |
| 19 November | **Regional Dialogue for Asia and the Pacific,** during the 11th International Congress on AIDS in Asia and the Pacific, Bangkok |
| 25 November | **Civil Society Organisations' Dialogue for Eastern and Southern Africa**, Johannesburg |
| 25 November-9 December | **Youth Online Review** |
| 26 November | **Southern African Development Community National AIDS Commission Directors meeting,** Johannesburg |
| 27 November | **High-level panel at the European Development Days**, Brussels |
| 27 November-31 December | **Papers available for public comment** through *The Lancet* website |
| 29 November | **Regional Dialogue for West and Central Africa,** Dakar |
| 2 December | **Think Tank Dialogue**, hosted by the Institute of Global Governance and the Institute of Global Health, University College London, London |
| 4 December | **Virtual Regional Dialogue for Latin America** |
| 4 December | **Regional Dialogue for the Caribbean**, Kingston |
| 7 December | **Regional Dialogue for Africa,** during the 17th International Conference on AIDS and STIs in Africa, Cape Town |
| 13 December | **Virtual Regional Dialogue for Eastern Europe and Central Asia** |
| 10 January | **Think Tank Dialogue**, hosted by the Kaiser Family Foundation, Washington DC |
| 28 January | Dialogue with Non-State Actors, New York |

**Other feedback included in this report was received from:**

- UNAIDS Reference Group on HIV and Human rights
- UNAIDS Secretariat and Cosponsors