

UNAIDS' Focus Group Discussion Final report

Summary:

The need to formalise a commitment to **look beyond viral suppression** and bio-medical interventions has been emphasised throughout the Focus Group Discussion. Participants have aligned on the need to extend the scope of the new Global Strategy to matters relating to the broader quality of life and health outcomes of those living with HIV, **expanding our focus to the management of co-morbidities as well as to the social and psychological repercussions of HIV on people and various communities.**

The input gathered from this Focus Group Discussion can be summarised in **six recommendations for action:**

1. Formalise the **commitment to prioritising quality of life, multi morbidity and discrimination by calling for the establishment of specific metrics, targets and methods.**
2. Take forward this commitment on an equal basis to the 90-90-90 Treatment Target.
3. Encourage policy makers to develop an **integrated, patient-centred, rights-based, multidisciplinary and long-term approach to HIV care.**
4. Determine which metrics and tools are best suitable to measure health-related quality of life in a standardised way, while improving monitoring by increasing reliance on community-gathered data.
5. **Empower the HIV communities to participate** in decision-making processes by improving government **engagement with key populations (ensuring that community organisations are well represented when involving non-governmental actors, e.g. sex workers, migrants, LGBTI communities)**
6. **Promote human rights by removing all social and legal barriers to access HIV services that result from stigma and discrimination** in healthcare systems and beyond (e.g. punitive laws criminalising risk behaviours such as sex work and drug use) and improving social acceptance of HIV overall.

The results of the discussion:

➤ How do we see the current situation?

- **Persisting HIV-related stigma and prejudice, especially in healthcare settings.** This creates **barriers to access to services** for fear of discrimination and ultimately leads to **late diagnoses** – due to reluctance to seek treatment
- **Burden of co-morbidities**
- **Psychological impact** of being diagnosed and living with HIV – exacerbated by the impact of COVID-19 on HIV communities
- **Social repercussions of HIV** – PLHIV are more likely to live in communities that face discrimination and/or economic hardship, thus affecting their well-being

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OBSERVER MEMBERS

- European AIDS Clinical Society (EACS)
- European Center for Disease Prevention and Control (ECDC)
- Fast Track Cities
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- **Limited government support** for community driven programmes
- Current policies are geared to address **illnesses rather than individuals**

➤ **What concerns us?**

- **Lack of healthcare services integration** – including for mental health support
- **Stigma and discrimination** directed at both people living with HIV and key populations (e.g. sex workers, drug users, LGBTI community)
- **Legal barriers and criminalisation of risk behaviours** (e.g. sex work and drug use) – Discriminatory laws have recently been adopted in many countries worldwide directed at specific key populations disproportionately affected by HIV, breaching human rights and impacting equitable access to healthcare services
- **Impact of COVID-19 pandemic:**
 - **Disruption of HIV services**
 - Rising burden of comorbidities as **people are less likely to get diagnosed** because of lockdowns and service disruptions.
 - Exacerbation of **psychological and mental health issues** due to isolation (depression and suicides).
- **Lack of information and health literacy.**
- **Lack of government engagement with key populations**
- **Excessive reliance on government-gathered data** rather than community-provided data
- **Excessive focus on biomedical interventions** and **lack of social focus** (e.g. social barriers to access to treatment and care)
- **Narrow-minded approach to PrEP** – not enough focus on actual accessibility of PrEP for key populations, such as sex workers

➤ **What gives us hope?**

- **Intensification of discussions on 4th 90 and quality of life.**
- **Community-led initiatives**
- **Digital health solutions**
- Intensification of **discussions around inequality** as a result of the COVID-19 crisis
- Positive examples of decriminalisation (e.g. New Zealand)

➤ **What constrains our ability to achieve our goals?**

- **Lack of political will and of country-level funding** for HIV prevention and HIV treatment services.
- **Lack of involvement** of HIV communities in the development of **prevention plans and other health policies.**
- Lack of patient-centered, multidisciplinary approach to care
- **Lack of data and metrics** to measure health outcomes and quality of life of people living with HIV
- The COVID-19 pandemic.
- Gender ideology movements and constant attacks directed at key populations.

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- The legal environment
- Rising nationalism and local violence directed at vulnerable groups

WORLD CAFÉ

➤ What should we continue doing?

- Focusing on **decriminalisation** of risk behaviours (in particular of sex work) and addressing **discriminatory laws** against people living with HIV
- Persevere in the achievement of the three 90s targets
- Pressuring government and policymakers to improve health literacy

➤ What should we start doing?

- **Involving communities** in data collection and taking onboard community-led responses
- Addressing **structural inequalities** and moving from **tolerance to acceptance**.
- Going **beyond bio-medical care**
- Addressing **co-morbidities and mental health issues**
- Focusing on (access to) **primary care**
- Monitoring **Health Related Quality of Life**
- Implementing a **person-centered strategy** based on a **tailored human rights-based approach**.
- Develop **tailored approaches** to meet the needs of specific population groups
- Supporting **multi-lateral policy reform across countries**

➤ What should we stop doing?

- **Stop the blanket approach** and stop aiming low
- **Stop ignoring social issues** such as gender equality
- **Stop neglecting community-led actions**
- **Stop stigmatising people living with HIV** – as well as key populations

➤ What is the one key recommendation you want to reiterate for strong consideration?

- We need **bold leadership** to develop an **integrated outcomes-based approach** focused on **wellbeing and human rights**, involving **communities** and vulnerable populations.

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