

Alignment workshop with UNAIDS

How to define Health-Related Quality of Life for People Living with HIV ?

Notes of the meeting

24 February 2021

Context

The meeting was the second of two meetings hosted by HIV Outcomes to support the development of the new UNAIDS Strategy. The focus of the first meeting was to understand the relative importance of issues beyond viral suppression and to make the recommendation to UNAIDS to include this as a domain in the new Strategy. This second meeting took this commitment to Health-Related Quality of Life and to developing relevant metrics for inclusion in the final version of the Strategy.

Introduction

HIV Outcomes Co-Chair Nikos Dedes welcomed participants and introduced the audience to the agenda of the day.

The Secretariat updated Workshop Members on progress to date in relation to the work of HIV Outcomes in feeding into the upcoming UNAIDS Strategy.

Update on UNAIDS draft Global AIDS Strategy

Presentation by Vinay Saldanha - Special Adviser to UNAIDS' Executive Director Winnie Byanyima

- The **overarching theme** of the new Strategy will be **reducing inequalities** and disparities that drive the AIDS epidemic and prevent progress to ending AIDS as a public health threat by 2030.
- The Strategy will maintain the **three zeros approach** of eliminating HIV/AIDS:
 - Zero new HIV infections
 - Zero AIDS-related deaths
 - Zero discrimination
- The Strategy will be articulated around **three Strategic Priorities**:
 1. Maximise **equitable and equal access to HIV services** and solutions with the aim to achieve a **95% coverage** for each affected community across a core set of evidence-based HIV services by 2025:
 - 95–95–95 testing and treatment targets achieved among people living with HIV within all sub-populations and age groups.
 - 95% of women of reproductive age have their HIV and sexual and reproductive health service needs met; 95% of pregnant and breastfeeding women living with HIV achieve viral suppression; and 95% of HIV- exposed children are tested.
 - 95% of people at risk of HIV infection use appropriate, *prioritized*, person-centred and effective combination prevention options.

2. **Break down societal and legal barriers** to accessing HIV services with the aim to achieve the so-called **10-10-10 targets** by 2025:
 - Less than 10% of countries have punitive legal and policy environments that deny or limit access to HIV services
 - Less than 10% of people living with HIV and key population experience stigma and discrimination
 - Less than 10% of women, girls, people living with HIV and key populations experience gender inequality or violence.
 3. Fully resource and sustain efficient HIV responses and **integrate HIV responses into systems for health, social protection, humanitarian settings and pandemic responses.**
- The Strategy will focus on **cross-cutting issues**, including:
 - Human Rights
 - Women’s rights
 - Multisectoral cooperation
 - Community-led responses
 - Data-driven innovation
 - The Strategy explicitly aims to **optimise quality of life through integrated people-centred services.**
 - **Next steps:**
 - The organisation of the **2021 High-Level Meeting on HIV/AIDS** was approved by the 75th Session of the United Nations General Assembly (UNGA)
 - The meeting will take place during the next **UNGA on 8-10 June 2021.**
 - UNAIDS will gather support for the adoption of a **Political Declaration on the Global AIDS Strategy.**

Quality of Life Partnership

Presentation by Rebekah Webb (Consultant for the Partnership)

- The Quality of Life (QoL) Partnership gathers several organisations to build synergies to support integrated, person-centred, peer-led and community-led interventions that optimise the health and wellbeing of people living with HIV globally.
- While HIV is the core focus, the Partnership aims to expand its scope of action beyond HIV-specific issues to look at the broader components of QoL. The Partnership therefore champions a **holistic concept of QoL**, looking beyond health from a person-centred perspective.
- **Stigma and the social determinants of QoL** are a crucial focus of the Partnership.
- The Partnership has explored numerous topics linked to the QoL of people living with HIV, including:
 - The root causes of poor QoL among people living with HIV
 - How to assess and measure the QoL of people living with HIV
 - The rationale behind the quest for better QoL for people living with HIV
 - Best interventions and policies to improve the QoL of people living with HIV
- The Partnership visualises the **different components of QoL** into three macro-areas:
 - HIV-specific aspects, related to access to treatment, adherence and quality of care

- Health-related aspects, covering multi-morbidity, mental health, sexual and reproductive health and rights etc
- The wider social, economic and legal context and its impact on individual overall wellbeing

Breakout sessions on Health-Related Quality of Life

- HIV Outcomes Co-Chair Jeffrey Lazarus introduced the discussion on the definition of health-related quality of life, its domains and metrics.
- Participants were divided into **three breakout rooms**, to discuss the **physical, emotional and social components** of health-related quality of life.
- In the breakout rooms participants identified core challenges to health-related quality of life and discussed potential metrics to quantify and measure the health-related quality of life of people living with HIV.
- **Challenges** identified in the **physical** breakout room included:
 - Co-morbidities management – need to look at co-morbidities holistically, breaking silos among diseases areas and trying to always have in mind the overall wellbeing of patients
 - Energy and fatigue
 - Pain and discomfort
- **Challenges** identified in the **emotional** breakout room included:
 - Mental health and wellbeing (including disorders/ICD10).
 - Sexual health and wellbeing
 - Self-stigma, self-esteem and negative feelings
- **Challenges** identified in the **social** breakout room included:
 - Stigma.
 - Discrimination.
 - Isolation.
- **Metrics** identified included:
 - Self-reported outcomes
 - Denial of medical care
 - Psychological resilience

Conclusions

HIV Outcomes Co-Chair Jane Anderson concluded the meeting informing the audience that the work on defining the HRQoL will feed into the upcoming UNAIDS Strategy beyond 2021 and will also be leveraged into further developments as:

- the study from the European Parliament Research Study on the HRQoL for people living with HIV
- the input in the Green Paper on Ageing
- HIV Outcomes' asks when engaging with European policy makers.

Participants

UNAIDS representatives:

1. Vinay Saldanha
2. Jantine Jacobi
3. Celia Keller

WHO

4. Andy Seale

Steering Group Members:

5. Jane Anderson (HIV Outcomes Co-Chair)
6. Jeff Lazarus (HIV Outcomes Co-Chair)
7. Nikos Dedes (HIV Outcomes Co-Chair)
8. Ann Isabelle von Lingen (EATG)
9. Vladimir (ECUO)
10. Antonella D'Arminio (EACS)
11. Mario Cascio (EATG)
12. Yuri de Boer (AFEW)
13. Claire Albano (Gilead)
14. Rhon Reynolds (ViiV)

General Members:

15. Amanda Ely (CHIVA)
16. Dr. Patrizia Carrieri
17. Richard Angell (Terrence Higgins)
18. Alejandro Berto (ADHARA)
19. Diana Barger (University of Bordeaux)
20. Igor Gordon
21. Lars Eriksson (Karolinska Institute)
22. Marian Said
23. Kyriakos Soulioutis (University of Peloponnese)
24. Anna Mia Ekstrom (Karolinska Institute)
25. Maria Jose Fuster (SEISIDA)
26. Roberto Perez Gayo (Correlation – European Harm Reduction Network)
27. Lorraine Sherr (University College London)
28. Luis Mendao/Ana Montrond (GAT Portugal)
29. Caroline Sabin (University College London)
30. Shaun Whatson (National HIV Nurses Association)

Observer Members:

31. Bertrand Audouin (Fast-Track Cities)
32. Amish (UNITE)

In country colleagues/ steering group members:

32. Gregoriana Tudoran (Secretariat - HIV Outcomes Romania)
33. Roxana Cernat (Steering Group Member - HIV Outcomes Romania)
34. Dr. Mariana Mardarescu (Steering Group Member - HIV Outcomes Romania)
35. Johannes Fleischmann (Secretariat - HIV Outcomes Germany)

Quality of Life Partnership:

36. Mike Podmore (STOPAIDS)
37. Simonha Cuniffe (STOPAIDS)
38. James Cole (STOPAIDS)
39. Rebekah Webb
40. Maureen Ndawana (African Health Policy Network)

HIV Outcomes Secretariat:

42. Sorina Chivu
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44. Jesus Olivares-Guerrero
45. Enrica Obizzi

INITIATIVE PARTNERS



OBSERVER MEMBERS

- European AIDS Clinical Society (EACS)
- European Center for Disease Prevention and Control (ECDC)
- Fast Track Cities
- UNAIDS
- UNITE

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