

## IAS Conference – Satellite Symposium

### Supporting Health-Related Quality of Life for people living with HIV. Lessons and learning from the COVID-19 pandemic.

20 July 2021

Moderated by:

**John Bowis**, President, HIV Outcomes

#### Purpose of the event

The purpose of the event was to explore the long-term impact of COVID-19 and HIV/AIDS and to assess:

- What can be learnt from the response to the COVID-19 pandemic for people living with HIV
- Whether people living with HIV may be additionally impacted by COVID-19 including Long Covid
- What learning there may be from the treatment and care offered to people living with HIV for the treatment and care of those with Long COVID

#### Welcome remarks

**Prof. Jane Anderson**, Co-Chair, HIV Outcomes

- **HIV Outcomes** – The HIV Outcomes initiative was created in 2016 to reflect a widespread recognition that broader issues relating to the health and social inclusion of people living with HIV received insufficient attention from policy makers and healthcare providers. The initiative aims to make these elements integral to the overall response to HIV.
- **Health-Related Quality of Life (HRQoL)** – HIV Outcomes seeks to improve the HRQoL of people living with HIV across Europe. HRQoL is a broad concept that covers aspects related to a person's health and wellbeing and is focused beyond clinical outcomes.
- **HRQoL beyond HIV care** – The concept of HRQoL is increasingly being incorporated into clinical settings to help deliver patient-centred care. The application of such a framework may also be helpful to analyse and address the consequences of COVID in a holistic and horizontal way.

#### Setting the scene: The impact of COVID-19 on the HRQoL of people living with HIV – perspectives of a person living with HIV and a clinician

**Mario Cascio**, HIV Outcomes Italy and Chair of the EATG Programme on Quality of Life

**Prof. Streeck**, HIV Outcomes Germany

- The COVID-19 pandemic has had a major impact on people living with HIV.
- Although the full extent of the effects of the pandemic on people living with HIV is only starting to be identified, some outcomes are clear. Since the beginning of the COVID-19 emergency, severe issues have emerged:
  - **A drop of up to 50% in HIV testing** due to lockdowns and confinement measures
  - **Poor adherence to anti-retroviral therapies (ART)**
  - **Virus-related stigmatisation** – In the case of people living with HIV, this is aggravated by the double stigma of being HIV positive *and* having tested positive to COVID-19. Policymakers should channel their efforts into stopping the 'blame game' and help reshape the messaging around the fact that 'the virus' is the problem, not 'people'.
  - **Mental health issues** – the COVID-19 pandemic has brought about a significant increase in mental health disorders and related issues, such as anxiety, depression, sleeping and eating disorders, social isolation and loneliness. The mental health of people living with HIV has long been neglected and the pandemic has exacerbated these issues. Community-based organisations have stepped in to fill gaps left by healthcare

and support systems. However, these interventions have only highlighted the structural failures of modern healthcare systems, which have proved ill-equipped to provide continuous and holistic care.

## The importance of Health-Related Quality of Life in COVID times

Prof. Georg Behrens, HIV Outcomes Germany

Prof. Jeffrey Lazarus, Co-Chair, HIV Outcomes

- HRQoL is an approach which, in the case of HIV, encompasses:
  - Bio-medical aspects – such as multimorbidity, pain management and fatigue
  - Issues related to the overall personal wellbeing – such as mental health, stigma and discrimination, Including self-stigma and blame
  - Sexual and reproductive health and rights
  - Social isolation and marginalisation
  - Denial of medical care
- **The concept of HRQoL is in line with** existing metrics used in health technology assessment, such as **patient reported outcomes (PROMs), and links to the growing demand for individualised and person-centric care.**
- In circumstances where effective treatment and prevention is available and yet multiple barriers remain, HRQoL provides a tool to fully assess health status and a means to support the provision of holistic care.
- **The application of such a conceptual framework to assess the impact of a disease such as COVID-19 can be particularly helpful to analyse and address the consequences of COVID in a holistic and horizontal way.**
- This is particularly relevant given the impact that COVID-19 has on the lives of those who experience it – repercussions that do not disappear once a person tests negative and that go beyond the merely physical aspects of the disease.
- In particular, the importance of the concept of HRQoL in tackling the consequences of COVID is twofold:
  - In general terms, the assessment of HRQoL can help healthcare providers identify the factors affecting the overall wellbeing of people with COVID and Long Covid and recognise the aspects of COVID-19 management that need to be enhanced to improve the HRQoL of patients.
  - In terms of HIV response, the assessment of HRQoL can help quantify the impact of COVID on people living with HIV and its potential impact on aspects such as mental health, access to HIV services, management of co-morbidities etc.

## What impact has the COVID-19 pandemic had on the Health-Related Quality of Life of people living with HIV and what particular challenges do they face in relation to Long COVID?

MP Andrew Ullmann, German Parliament

Prof. Adrian Streinu-Cercel, HIV Outcomes Romania

Nikos Dedes, Co-Chair, HIV Outcomes

Winnie Seruma, HIV activist

- The onset of **the COVID-19 pandemic bore many similarities with the early days of the HIV pandemic**, including:
  - General uncertainty on the origins of the infections and its transmission routes
  - Generalised disease-related stigma
  - Exacerbation of existing inequalities and discrimination of marginalised communities
- Forty years on, **some of the problems which negatively impacted on HIV care also hamper the COVID-19 response**, such as:
  - The lack of a holistic and horizontal approach to health and care
  - The lack of coordination across healthcare services and support facilities
  - The lack of international solidarity and collaboration
  - The lack of funding and investments
- The COVID-19 pandemic has had a **severe impact on HIV care** and the daily lives of people living with HIV, causing:
  - Disruptions and/or delays in the provision of routine healthcare services, with other treatment or vaccination programmes lagging behind or collapsing due to the reallocation of resources to tackle the COVID emergency
  - Poor treatment adherence and/or patient drop-out from follow-up programmes

- Double discrimination issues, i.e. combination of HIV-related and COVID-related stigma and discrimination
- Dramatic increase in mental health disorders among the general population, and especially among people living with HIV, e.g., exacerbation of anxiety and depressive disorders
- Immediate **action** needs to be taken to address the following issues:
  - Improve coordination and referral systems among health services and specialists to address the issues of people living with HIV in a holistic and horizontal way
  - Establish EU-wide healthcare networks to facilitate cross-border access to health and care for people living with HIV
  - Align on HRQoL metrics to monitor progress and assess systems performance such as the uptake of PROMs in clinical and non-clinical settings
  - Coordinate and align on clear messaging around COVID and HIV to avoid stigmatising behaviours and discriminatory practices in healthcare settings and beyond
  - Link community-led initiatives and healthcare services to close the gap between the healthcare system and communities, especially marginalised population groups, and tackle existing – and growing – inequalities.
  - Increase funding and support investments to strengthen the resilience of HIV services also in times of crisis

## Closing remarks and next steps

**Prof. Jeffrey Lazarus, Co-Chair, HIV Outcomes**

- It is clear that a paradigm shift is needed, not just in HIV care, but in healthcare systems more broadly.
- The COVID-19 crisis has shed light on issues that have long been apparent:
  - Healthcare systems need to move away from the acute care paradigm and adopt a long-term approach to care.
  - Compartmentalisation and fragmentation of care prevent healthcare systems from looking at patient's health and wellbeing in a holistic way, taking account of possible comorbidities and the impact of a disease on a person's overall wellbeing.
  - Patient centricity and HRQoL are crucial concepts in this much needed paradigm shift towards a multidisciplinary, holistic and long-term approach to care.
- In order to drive this paradigm shift and embed HRQoL in healthcare, it is essential to:
  - Reach a consensus on the conceptualisation of HRQoL and the factors impacting it.
  - Break silos and look at challenges holistically.
  - Clearly define challenges and objectives to develop accurate metrics to measure progress and performance in improving HRQoL.
- The work of the HIV community on the conceptualisation of HRQoL is not only essential to improve the lives of people living with HIV. It can also set an example and help drive a broader transformation of healthcare systems across disease areas.

### 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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