Sexual and Reproductive Health Team
Department for Health and Social Care
sexualandreproductivehealthteam@dhsc.gov.uk

Dear colleagues,

1. Purpose of this letter

- To recommend actions to be included in the upcoming HIV Action Plan that will address the disparities in health-related quality of life of people living with HIV (see recommendations, below).
- To highlight the key challenges that undermine the health-related quality of life of people living with HIV, and put the support and the system in place to raise the standards for this patient community.

2. Background

HIV Outcomes is a cross-nation initiative seeking to improve the long-term health outcomes and the health-related quality of life of all people living with HIV (appendix 1 – About HIV Outcomes). As a multi-stakeholder Initiative, HIV Outcomes brings together patient representatives, clinicians, academics and industry. Our focus has been on health-related quality of life, and mental health support to help tackle HIV-related stigma and discrimination.

In England, our focus is on actions that will ensure that people living with HIV are able to enjoy good long-term health outcomes and health-related quality of life. We aim to do this through working with the existing HIV community that has already done so much successful work in improving the lives of people with HIV.

The HIV Action Plan offers a unique opportunity for policy makers to ensure a proportionate focus and access to the full suite of combination HIV prevention tools, including condoms, PrEP, treatment as prevention and HIV testing.

As important as ending new HIV infections is, so too is the provision of the highest standards of treatment and care for those living with HIV. People living with HIV with an undetectable viral load are unable to pass HIV to others, thereby breaking the transmission chain. Ensuring ongoing treatment and service provision for the nearly 100,000 people living with HIV in England must therefore remain a top priority towards our common objectives of ending new HIV transmissions by 2030.

This is closely linked to engagement and re-engagement of people with their care. People who are engaged with their care are likely to achieve better outcomes and a higher health-related quality of life. Provision of, and access to, holistic wrap-around services that will enable people living with HIV to effectively deal with the complexities of their condition, including social and psychological, will enhance engagement with their care and services, in turn creating a virtuous cycle. We believe this to be particularly relevant to achieving the 2030 ambition, as a mechanism to deliver services to people with diagnosed HIV that is not yet virologically suppressed and who are still able to pass HIV to others.

People living with HIV, who are able to access long term effective treatments when correctly treated, no longer face progression to AIDS and death. Instead, HIV has become a condition that requires long term coordinated management. This creates challenges, in that the work and actions previously required to deal with HIV may no longer fit the needs of people with HIV as they live into old age; and the challenges are significant. The needs of younger people with HIV, including children and adolescents must also be borne in mind, so that they can have the same life opportunities and experiences as any of their peers.

3. Context to our recommendations

Following a series of engagement sessions with key stakeholders, the HIV Outcomes steering group has put together recommendations organised into two areas:

- The need to achieve parity for quality of life for people living with HIV in England and to maintain a strong focus on ongoing treatment and services (alongside, not instead of prevention).
- The need to focus on the mitigation and eradication of the stigma and discrimination that people ageing with HIV can still encounter.

We are asking that you include these health-related Quality of Life recommendations in the HIV Action Plan and put clear objectives and milestones in place to deliver them.

4. Our recommendations

Achieving parity of health-related quality of life and maintaining a strong focus on top class treatment and service provision for people living with HIV

High quality, effective and accessible treatment must be at the core of any nationwide strategy. While the rollout of PrEP provision and HIV testing needs to remain a key priority towards ending new HIV infections, we must maintain full focus on the needs of people living with HIV. They require the best treatment and care possible, to ensure that they can achieve the highest standards of health-related quality of life and remain non-infectious.

The range of social complexities many people with HIV are also managing is significant, and service responses need to recognise this interrelated need and deliver holistic responses. People require an individualised response to their unique needs, so differentiated models of care may be needed; for example, recognising the specific needs of adolescents versus older people. If we are serious about helping people with HIV experience good health-related quality of life, and in turn realise more positive health-related outcomes in the future, these issues must be considered within the action plan alongside the resources and the multi-disciplinary teams that are pivotal to delivery.

An agreed-upon and generally accepted measure of what good health-related quality of life for people living with HIV looks like, is essential both as a benchmark and as a mechanism to monitor progress. Although not easy, a clear commitment to the design and implementation of such metrices will focus attention and resources and be a major step towards reaching HRQoL parity for people living with HIV. As a group, we are working to map existing UK work that is looking specifically at the issue of measuring health-related quality of life.

Recommendations:

- Optimising health-related quality of life of people living with HIV at all stages of life, should be a principal aim of the HIV Action Plan, with clear milestones for its achievement.
- The HIV Action Plan should capture a commitment to monitor, assess and benchmark health-related quality of life, using a measurement that is co-produced and agreed with the HIV community.
    - This should be as a prelude to work towards agreeing a method to systematically measure health-related quality of life of people with HIV to track progress and highlight success.

  - This work should aim to help ensure that people with HIV have a level of health-related quality of life that is at last equal to that of people with other long term chronic conditions/the wider public. [delete as appropriate]
- The importance of multi-disciplinary teams (MDT) to deliver the holistic support that is required can improve quality of life for people with HIV – the role of the MDT should be highlighted and encouraged.

Ending stigma for people living with HIV

People living with HIV may experience stigma and discrimination throughout their lives. Ageing is also associated with stigma and discrimination, which represents a potential double burden for older people living with HIV. Stigma and discrimination often lead to social isolation and marginalisation, which can significantly affect the health outcomes and health-related quality of life of people living and ageing with HIV. The experience of HIV associated stigma within healthcare settings is a major issue that impacts on access to and engagement with care as well as impeding prevention initiaves

Recommendations:

- The assessment and mitigation of stigma and discrimination in all areas of society, including in education and in non-HIV specialised healthcare settings, should be a policy priority within the HIV Action Plan.

The HIV Action Plan offers an opportunity to raise the health-related quality of life of people living with HIV up the agenda and include interventions that can make a real difference. HIV Outcomes UK has brought together a wide range of stakeholders with an interest in health-related quality of life and HIV, in order to identify the key areas where progress can and should be made.

We would welcome the opportunity to discuss these matters further and to provide additional information.

With best wishes

HIV Outcomes (UK) Steering Group

- Prof. Jane Anderson (interim Chair UK group, HIV Outcomes Co-Chair), Homerton University Hospital NHS Foundation Trust
- Prof. Richard Harding, Kings College London
- Prof. Caroline Sabin, University College London and Health Protection Research Unit Director
- Dr Yvonne Gilleece, University Hospitals Sussex and Chair of SWIFT
- CHIVA
- Positively UK
- Terrence Higgins Trust
- National HIV Nurses Association

Appendix 1 – About HIV Outcomes

The HIV Outcomes Initiative seeks to improve the long-term health outcomes and the health-related quality of life of all people living with HIV. The Initiative was originally established in 2016 at a pan-European level and has subsequently seen national Initiatives set up in Germany, Italy, Spain and Romania. As a multi-stakeholder Initiative, HIV Outcomes brings together patient representatives, clinicians, academics and industry. Our particular focus has been on health-related quality of life, and mental health support to help tackle HIV-related stigma and discrimination.

Here in the UK our focus is on actions that will ensure that people living with HIV are able to enjoy good long-term health outcomes and health-related quality of life. We aim to do this through working with the existing HIV community that has already done so much successful work in improving the lives of people with HIV. Across the four nations of the UK, different commitments and plans are in place to tackle HIV and related issues, and of course to try and end new HIV transmissions. In England, the national HIV Action Plan is a prime example of a strategy looking to build on the progress made in achieving the UNAIDS 90-90-90 targets.