

Working together



The HIV Outcomes UK programme is funded by Gilead Sciences and ViV Healthcare as co-sponsors

HIV Outcomes UK briefing:

Positive Voices 2022 report

The UK's HIV response

The Governments of the UK have all committed to ending new HIV transmissions by 2030. Significant progress has been made in recent years on HIV, with a 35% reduction in new HIV diagnoses in England between 2014 and 2019. Treatment means that someone living with HIV now can expect to live as long as anyone else, and not pass the virus on. Effective preventative medicine means that people at risk of acquiring HIV can be protected against transmission.

However, progress on HIV has stalled, with the latest data showing stark and persistent inequalities in HIV – particularly for race and gender. Stigma and discrimination based on HIV are still prevalent, and urgent action is needed to support all living with HIV to have a good health-related quality of life (HRQoL). Ensuring people have good HRQoL supports engagement with HIV treatment and care. This is key to both sustaining the huge successes in long term morbidity and helps ensure that the 2030 targets are achievable.

The Positive Voices 2022 report published by the UK Health Security Agency and UCL is the largest UK survey of people living with HIV. It offers important insights into the way HIV impacts communities, inequalities and is a key resource to inform Government policy-making.

Key findings from Positive Voices 2022 include:

- Since 2017 there has been little change in life satisfaction and quality of life among people living with HIV. Overall, compared to the general population, people living with HIV continued to fare slightly worse.
- 2 in 5 of people living with HIV have been diagnosed with at least one mental health condition, substantially higher than the general population.
- Stigma remains a major issue for people living with HIV. 1 in 3 people reported low self-esteem due to their HIV status and 1 in 9 were afraid to attend healthcare services in the last year due to concern that someone may learn their HIV status.
- 9 in 10 people living with HIV were aware of U=U, however only 6 in 10 believed strongly in the concept.
- Significantly poorer health and wellbeing among trans and gender diverse people.
- More than half of people living with HIV do not routinely have enough money to easily cover their basic needs, with significant differences between groups. The report highlights that poverty impacts strongly on health and wellbeing.
- Wider needs (psychological, social, welfare, lifestyle) often remain unmet.

Key reflections on Positive Voices 2022

Positive Voices highlights the importance of addressing inequalities and supporting all communities to live well with HIV. Connecting people to HIV treatment and care in a way that works for them and designed around their needs, improving accessibility and availability of peer support, and a greater emphasis on supporting the interventions that improve quality of life are all required.

The inequalities and issues raised in the Positive Voices report are not only important to address to improve the lives of those with HIV but also have an impact on the HIV Action Plan's ambition to end HIV transmissions by 2030. The HIV Action Plan, which is due to be updated in 2025, provides

an opportunity to respond to the holistic and changing needs of people living with HIV. Integrated Care Systems and local leadership will also be of increased importance as commissioning structures change.

Whilst the Positive Voices report provides important insights to those accessing HIV care, Government policy-making should also be responsive to those who do not know their HIV status and those who have disengaged from HIV care. Given that there could be over 10,000 people in the UK with diagnosed HIV but not linked to care, programmes are urgently needed to find, re-engage and support everyone living with HIV to stay in care.

Recommendations

HIV Outcomes UK is working to secure policy, practice and evidence changes to improve the HRQoL for people living with HIV in the UK. Informed by the findings of Positive Voices, to ensure we can meet the holistic and evolving needs of people living with HIV, we recommend the following to the Governments of the UK:

Ensure better HIV care engagement, integration and coordination

- Embed the findings from Positive Voices to inform needs assessment and planning of future health and social care services for people living with HIV. It should also be used to inform national programmes to find, re-engage and support everyone living with HIV to stay in care.
- Prioritise, support, and champion programmes that address HIV stigma.

Tackle healthcare inequalities

- Ensure commissioning of HIV peer support services.
- Ensure provision of social welfare support services. These services are vital in mitigating the impact that financial insecurity, claiming benefits and the immigration system can have on people's health and wellbeing.
- Ensure community organisations are meaningfully consulted and commissioned at national and local levels. Community organisations play key roles in addressing inequalities and supporting people to live well with HIV.

Meet the mental health needs of people living with HIV

- Ensure that people living with HIV have access to appropriate mental health care that is stigma free and meets their needs. This should include ensuring psychosocial support in clinics, optimising pathways between HIV clinics and mental health services, and ensuring provision of peer-support.

How to support

Please support HIV Outcomes UK to tackle inequalities and improve the HRQoL of people living with HIV.

You can do this through:

- Emailing this briefing to your local MP and request that they ask the Government what steps it is taking to respond to the findings from Positive Voices 2022.
- Writing to your local NHS Integrated Care System or care board to ask what steps they are taking to address healthcare inequalities and support people living with HIV to have a good quality of life.
- Signing up to the HIV Outcomes mailing list to stay connected with our work and partner on future projects.
- Sharing this briefing with your networks.