

What Future Do We Want? 2023 Manifesto



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In 2022 there were 106,000 people living with HIV in the UK and an estimated 5,000 that still remain undiagnosed. In 2021 the UK met, for the first time, the UNAIDS targets of 95-95-95, with 95% of all people diagnosed, 99% of those in care on treatment, and 97% of those receiving treatment being virally suppressed (UKHSA 2021). The past three years of the COVID-19 pandemic have brought incredible disruption and change for all, including the way people with HIV access clinical services and support. As an organisation of people with HIV we believe it is critical to amplify our voices on what is needed for us to live well with HIV, beyond just controlling the virus.

In June 2022, Positively UK held the fifth National Conference of People Living with HIV. Attended by over 150 people with HIV, the conference was organised by a steering group of people with lived experience connected to community organisations around the country. Delegates from across the UK discussed and debated major issues affecting our wellbeing, given the fact that for those of us living with HIV improving quality of life is crucial. This manifesto is the result of those discussions.

The manifesto shines a light on how different issues are interconnected and calls for a collaborative response from all key stakeholders. This includes the people who are living with and are affected by HIV in all our diversity - policy makers, community leaders, the media, healthcare providers, commissioners, funders, pharmaceutical industry, artists, researchers and academic institutions.

What we highlight here can be a source of inspiration and further debate, contributing to a positive shift in public understanding and awareness of HIV. Through our manifesto we are inviting all actors to engage with us, and shape the changes needed to ensure the future people with HIV want - a future where we can be healthy, respected and involved in all decisions that affect us.



Foreword

Lloyd Russell Moyle MP
Vice Chair All Party Parliamentary Group HIV and AIDS

It has been 14 years since I was diagnosed HIV-positive. It has been a long journey from the fear of acceptance to today and, hopefully, advocacy, knowing that my treatment keeps me healthy and protects any partner that I may have. Since then, further developments have happened in the fight against HIV and AIDS and there have also been some setbacks.

We know that the number of older people living with HIV is growing for two main reasons: first, powerful HIV drugs are allowing many people to lead longer, healthier lives with HIV; and second, while most new HIV cases occur in younger people, people over 50 are acquiring HIV at increasing rates.

Many of the medical problems now faced by people living with HIV have more to do with aging than with HIV-related illnesses. People who have lived with HIV since the early days of the epidemic may face unique issues, both physically and psychologically.

Advances in developing HIV drugs have successfully kept people's immune systems healthy with fewer side effects and fewer pills than back in the 1980s. While these health challenges may seem discouraging, they show that the lives of people living with HIV are now long and healthy enough that they die of the same conditions as the general population. Because people living with HIV may encounter these medical issues earlier in their lives, it is important that both people living with HIV and their providers are aware of them. There is still plenty you can do to stay healthy and live a full life.

It is common for there to be stigma of living with HIV and the stigma of being older. This can make it difficult for older people to find support. First of all, they may be ashamed and hesitate to tell anyone that they live with HIV. Secondly, they may not be comfortable in support groups that include younger people.

The report the All-Party Parliamentary Group HIV and AIDS published, called "Quality of Life", addressed many of these issues and it is re-assuring that the report mirrors many of the policy asks this manifesto advocates.

The All-Party Parliamentary Group HIV and AIDS welcomes this report with the desire that the many recommendations made can be implemented and serve beyond England. The vision set out in the manifesto underpins our current path towards a much-needed transformation of health systems into person-centred healthcare delivery models that promote optimal wellbeing.

Foreword

Longret K
Co-Director, 4M Mentor Mothers Network CIC

My first ask after an advanced HIV diagnosis in 2012 was for peer support. Positively UK was the first structured organization I was directed to. There, I formed trusted relationships, trained as a peer mentor and started my journey as an HIV activist. Today, I am a co-director at the 4M Mentor Mothers Network CIC, an African migrant women HIV-led organisation. I am a product of the UK HIV community.

My remarkable journey has included change, intersecting challenges and successes. Similarly, each of the 106,000 people living with HIV in the UK have encountered unique experiences. While similar in many ways, we are different with unique needs.

In the UK, laudable achievements have been made in HIV treatment, prevention, support and management. While it is vital to celebrate these successes, it is not nearly the end of HIV. This manifesto represents diverse communities living with HIV across the UK. It provides a guide focused on quality of life which is critical for living well with HIV today. We must address systematic disparities and intersectionality that are the cause or effect of inequalities the most vulnerable, disadvantaged and marginalised among us face daily. Health is not only about the absence of disease as such, therefore treatment is not the only solution.

HIV awareness within health, social care and the general public needs to improve, for an attitudinal change and stigma prevention. Resources including sustainable funding must be made available for accessible peer support which evidence shows is vital to living well with HIV. Those of us undiagnosed or unable to maintain undetectability must be supported. Living well with HIV in the post-COVID era, with people aging, young people born with HIV becoming adults, gender, health and social inequalities and stigma still rife requires an innovative and flexible approach. There must be continuous stakeholder dialogue, meaningful involvement, research and investment.

Person-centred, population-focused and community-based approaches looking at healthcare holistically, including the wider determinants of health must be utilised. A joined-up approach to co-morbidity management is crucial. Mixed method research focused on under-researched areas enhance the identification of nuances and complexities of lived reality.

There must be gender sensitivity in policies and programmes. Access to sexual and reproductive health and rights must be improved.

This is a clearly articulated manifesto with excellent recommendations for the future. It is a valuable and timely resource that will empower stakeholders who are strongly committed to human rights. It is important that the wealth of resources within the HIV community is recognised and utilised. The gains we have made must be preserved, sustained and improved. Apart from prevention and reduced cost of long-term social and health complexities, it impacts on quality of life - a human right. We know what our priorities are.

Let us work together using a multidimensional approach to address the future.
The time to act is now!

Diversity and inclusion of people living with HIV

People with HIV come from all backgrounds and we want to be recognised and understood in our diversity. We are old and young, some of us are born with HIV, we are gay, heterosexual, women, men, people from racially minoritized groups, we are trans and non-binary. Many of us belong to groups that have been historically marginalised, such as people who use drugs, people who do sex work, migrants without secure status, people who have gone through the criminal justice system and more.

Our health and wellbeing go beyond anti-viral therapy. Due to the complexities of our lives and the inequalities we face, we need healthcare that is holistic, person-centred and trauma informed. Our wellbeing cannot be reduced to biomedical markers. Just because someone has an undetectable viral load, does not make them a 'stable' patient. We need ongoing care, planning and coordination, and, as people with HIV, we should be involved and consulted in all aspects of our care.

Quality of life should be defined by more than a viral load number. Viral suppression does not mean eliminating all the other challenges that come with living with a chronic condition. Each individual living with and affected by HIV will have their own understanding of quality of life.

Patient choice and a person-centred approach must be developed in partnership with the community and implemented across the entire care pathway to improve quality of life and equip people living with HIV to make the best choices for them. This approach will help address barriers to accessing the best and most appropriate treatment.

**Rt Hon David Mundell MP – Co-Chair
All Party Parliamentary Group HIV
and AIDS**

Stigma

Stigma and discrimination persist 40 years after the first case of HIV was reported. In recent research commissioned by Fast Track Cities and the National AIDS Trust [1], researchers identified three themes contributed to people's negative attitudes and stigmatising views about HIV:

- People associated acquiring HIV through 'irresponsible' or 'taboo' behaviours, including condomless sex and promiscuity
 - Respondents had low knowledge of how HIV is transmitted, what the treatment is, and what the outcome of treatment is
 - Negative attitudes towards LGBT people, who remain associated with HIV
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We call for: peer-led research on our quality of life

We understand that HIV stigma does not exist in isolation – it overlaps and intersects with other forms of marginalisation, such as homophobia, transphobia, racism and anti-migrant sentiment, misogyny, classism, taboos towards sex and sexuality, and more. We call for more research on how systemic issues and inequalities affect our communities and impact on our health and quality of life.

We call for: education of healthcare providers on HIV

We recognise that some of us still encounter stigma when accessing health services outside of HIV clinics, including primary care.

We call for: participation in educational programmes and awareness activities

We acknowledge that the burden of challenging stigma should be shared, and not the sole responsibility of people living with HIV. However, many of us do want to play our part in educating the wider public and wish to work collaboratively with our allies in educational programs to address stigma across all sectors.

We call for: HIV services that meet the needs of trans women and men, non-binary people, and other gender diverse folks

We know that trans and non-binary people face many barriers in accessing healthcare services, including HIV services, caused by transphobia and stigma. Gender inclusive services should address HIV in connection with hormonal therapies, psychological support, gender affirming surgery, and peer support.

[1] National AIDS Trust and Fast Track Cities Initiative, HIV Public Knowledge and Attitudes, July 2021

Stigma

We call for: accessible peer-support services, including in clinical settings

We are aware that for so many of us, stigma still has roots in our own minds in the form of internalised stigma.

Accessible community-based peer-support services, both face-to-face and on-line, where we can share lived experiences and learn from each other, are essential to nurture our self-esteem, confidence and ability to counteract stigma within ourselves and in the wider world. Equally, ensuring access to peer support outreach in clinical settings is key to reaching those for whom internalised stigma may prevent from accessing community HIV services.

We call for: equitable access to sexual and reproductive health

People living with HIV have a right to make their own decisions if, when and how we have a family, including access to fertility treatment regardless of sexuality.

We call for: peer-support services around being a parent and raising our babies including access to peer mentor mothers, non-judgmental information and strategies on how to safely breastfeed (if we choose to), in line with WHO and BHIVA guidelines.

We call for: a focus on positive and empowering language

We know that when we talk about stigma, language really matters, which is why we continue to support positive and empowering language.

We need more than 'Zero Stigma'. We need to focus on words that nurture and empower us, such as: respect, support, involvement, connection, value, equality.

We call on: faith and community leaders to be our allies and be more knowledgeable and outspoken around HIV and to support us openly in our communities.

We call for: contemporary stories representing the variety of people with HIV today

The arts, storytelling, images, films, books, podcasts and TV series can be powerful tools to dispel misconceptions about HIV. We want to have more of them represent our lives today, rather than focusing on historic challenges, and with a greater diversity of stories.

We call for: a national media campaign that portrays the reality of people living with HIV in 2023 explaining that HIV is a long-term manageable condition, that people can have rich and fulfilling lives, can become parents to children born HIV-free and that people living with HIV on effective treatment cannot transmit the virus to others - that Undetectable=Untransmittable. Too many people are still under the negative influence of the outdated 80's tomb stones adverts, which promoted fear and rejection.

Mental Health

People living with HIV are around twice as likely to have mental health problems compared to the general public. [2]

We know that people with HIV are disproportionately affected by poor mental health. This can also be linked to stigma, resulting in feelings of loneliness and isolation. Anxiety and depression have also been exacerbated for people with HIV during the COVID-19 pandemic. [3]

We call for: HIV awareness among mental health practitioners

We know that poor mental health can easily lead to difficulties with adherence to HIV treatment. Timely and sensitive support needs to be prioritised. Prompt access to mental health services via HIV clinics is essential, alongside access to professional peer supporters integrated in the multidisciplinary team. Mental health professionals need to be educated on HIV, so that we can feel confident accessing support outside of HIV clinics.

We call for: opportunities for people with HIV to be positioned as role models

We call for opportunities to support our mental health by normalising narratives around HIV. Providing opportunities to people living with HIV to be visible as positive role models is an important step. This can also improve mental health.

We call for: more opportunities to connect and engage, including local peer-led spaces

We believe that to improve our mental health we need opportunities to connect, to be part of a community, to be involved in local decisions, to feel valued by others and to use our lived experiences for mutual support.

We call for: specialised welfare advice to alleviate financial hardship

We recognise that financial security is essential to maintain good mental health. Poverty is an issue for many of us, and we call for access to employment and a fair and user-friendly welfare support system, when needed, so that we can ensure financial stability.

[2] [Positive Voices: The National Survey of People Living with HIV, 2017](#)

[3] [Addressing the Needs of Black, Asian And Minority Ethnic Communities in Relation to HIV, 2021](#)

Ageing

As people live longer, healthier lives with HIV, we have seen the number who are aged 50 and over increase in recent years. The age profile of those receiving HIV care in 2021 continues to reflect an ageing population living with HIV. Those aged 50 years or over constituted nearly half of all people living with diagnosed HIV in 2021 (48% 43,584 out of 91,432) compared with 25% (17,499 out of 71,253) in 2012. [4]

We are the first generation of people getting older with HIV and we are concerned about the future, as many of us have to manage additional health conditions as well as HIV.

Many of us do not have access to care from our families, as we have been cut off because of HIV stigma or because we belong to historically marginalised groups, as previously mentioned. Many of us have been separated from our family and support network through migration, or other reasons. Thus, a large number of us will have to rely on community and institutions for support later in life. We know that in this context peer support is a lifeline.

We recognise that older people with HIV may face more obstacles using digital platforms to access support, including digital poverty, and that face-to-face and telephone services continue to be an essential way of providing support.

We call for: standardised HIV-friendly care approach

We believe that providers of elderly care need to be educated so that they treat us with kindness and respect. We want to work on a 'Charter of Care' for people living and ageing with HIV, backed by Care Quality Commission & NHS. We want to contribute to delivering training, auditing and ensuring standards are upheld.

We call for: women-centred services and research

Women have specific needs as they get older, especially around transitioning through menopause. We live in a society that devalues older women, especially when they come from racially minoritised groups. We need women-centred services that meet the needs of the diversity of older women with HIV, understanding the intersecting impact of ageism, racism and gender inequalities. We also need more research with and about older women with HIV.

[4] [UK Health Security Agency, 2022](#)

We call for: a holistic approach to healthy lifestyle support and co-morbidities prevention

We need a life-course approach to optimising our wellbeing and ageing: younger and older people alike need to be supported to develop healthier lifestyles in order to prevent co-morbidities, including better nutrition and access to opportunities to be active and exercise in a way that is enjoyable and accessible.

We call for: support services that are peer-led and can empower us to self-care or can advocate for our needs if we are no longer able to do it for ourselves.

We call for: older people with HIV to be recognised as sexual beings and have access to support and safe spaces, to enable us to have fulfilling relationships and sexual pleasure later in life.

We call for: ongoing support for young adults who were born with HIV

Many of us born with HIV are now young adults. Because of the unique circumstances we have grown up with, we face complex challenges as we move into adult life. As young people with HIV, we do not want to be defined by our diagnosis, and we want to be meaningfully involved in the design and delivery of support services for us.



Treatments

We recommend that people living with HIV are given the opportunity to actively contribute to decisions about their treatment. [5] As people with HIV, we recognise the importance of treatment to keep us healthy and to prevent transmission to our partners and babies.

We call for: a chance to make informed choices about our treatment

We recognise that clear and open communication with our HIV doctors about our treatment is fundamental. If there is any change in our treatment, we need to be consulted and offered the opportunity to make informed choices. We will challenge treatment choices made exclusively on price, where this is to the detriment of people with HIV.

We call for: sharing of treatment information that is easy to understand

Treatment information needs to be supplied in easy to understand language and we need to have access to peer treatment advocates who can help us understand the information and support us in making our own decisions.

We call for: our clinicians to be proactive and tell all their patients about U=U

We recognise that the U=U message needs to be promoted as part of a holistic approach within well-funded sexual health services that also address other key issues linked to sexual health, such as Chemsex, intimate partner violence, sex work, inclusivity and access for marginalised communities, especially trans and non-binary people.

We call for: young people with HIV to have access to young peer mentors who understand their challenges with treatment without any blame.

We recognise that the U=U message is critical for the wellbeing of young people born with HIV and needs to be communicated clearly and in an empowering way by doctors, with support from youth peer mentors.

We call for: ongoing treatment research and innovation

We recognise the importance of innovation in treatments and are keen to work together with the research community to find new and better treatments, including longer acting injectables, implants and patches. We also support home viral load testing options.

We call for: wider inclusion of (ageing) women in clinical trials

We recognise that women are still under-represented in clinical trials and advocate for more clinical trials that consider the needs of women, especially around issues relating to ageing and the menopause, such as osteoporosis.

[5] [BHIVA guidelines on antiretroviral treatment for adults living with HIV-1 2022](#)

We call for: mechanisms to report on and guidelines around side effects of treatment

We recognise that all treatments come with some side effects and we want easy ways to report these, and for our concerns about side effects to be taken seriously. This includes the link between weight gain and certain treatments, especially in certain groups. We would welcome clearer guidance and solutions on how to deal with weight gain, based on empathy and trust, rather than blaming lifestyle choices and reinforcing stigma.

We call for: the U=U message to be part of comprehensive sexual and relationship education in schools; alongside information around pleasure, consent, sexuality, gender, gender identity, and of course STIs and HIV.

We call for: tolerance and understanding around achieving and maintaining undetectable viral load

The Undetectable=Untransmittable (U=U) message is extremely empowering for us and can be used to improve our intimate relationships and sex lives, which are key components of good quality of life. However, **U=U should not be used to stigmatise those of us who cannot achieve an undetectable viral load.**

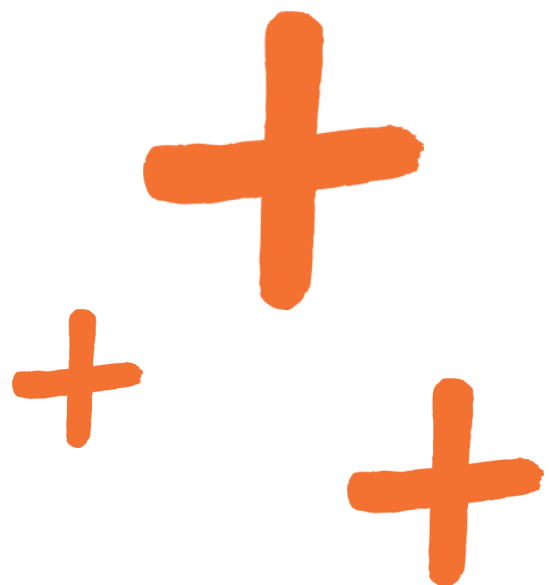
We call for: improved communication between HIV clinics and other healthcare services

Many of us live with more than one health condition, on top of HIV, and need to access different specialists or additional support from our GPs. Our experience is that the different specialities are not well connected, and that communication is poor.

Quality of life is a multidimensional concept; the HIV voluntary and clinical sectors must come together to agree on both what we mean by quality of life and how we can measure it.

As the response to ending HIV continues into its fourth decade, our work is not just about prolonging the lives of people living with HIV. It is about ensuring that those lives are healthy, happy and fulfilled. Quality of life is not a 'luxury' or 'optional extra'. It is a human right – one that is more important than ever.

Baroness Barker – Co-Chair All Party Parliamentary Group HIV and AIDS



Geographical Disparities

In 2021, 39% of people seen for HIV care were living in London and 61% elsewhere in the UK. [6]

We recognise that people living with HIV living in rural areas face challenges relating to lack of local access to community support and have concerns that Integrated Care Systems may not recognise or prioritise HIV support in low prevalence areas.

We call for: national and regional organisations to support the integration of peer navigators within local clinical services to improve whole-person care, reduce stigma/isolation and bridge to external support agencies.

It is crucial that the recommendations for effective pathways to peer support included within the [2018 BHIVA Standards of Care](#) for people living with HIV are followed by all clinical service providers. In areas where there are no local HIV voluntary sector organisations, provision of in-house peer support should be prioritised, or at least there should be a clear referral pathways to regional or national voluntary sector peer support services.

We call on: national and regional charities to do more to provide and publicise virtual services.

We recognise that the use of digital support, which has increased significantly during the COVID-19 crisis, can improve access to community support to those most isolated, especially in rural areas.

We call for: BHIVA to audit the peer support recommendations contained within the 2018 Standards of Care to assess how they are being implemented.

The 2018 BHIVA Standards of Care provide numerous clear recommendations and auditable outcomes in relation to ensuring access to peer support. We understand that in many areas these are not being achieved. An audit would help identify gaps and provide an opportunity to engage those services who are not achieving them to improve their service offer.

We call for: the Clinical Reference Group (CRG) to review the HIV service specification and include peer support as an integral component of HIV care.

We believe that including peer support within the service specification has the potential to provide an additional impetus for services to explore new and innovative ways of ensuring that everyone in the UK has equitable access to high quality peer support.

[6] [UK Health Security Agency, 2022](#)

We call for: the CRG and BHIVA to undertake the necessary work to ensure that Patient-Related Outcome Measures (PROMs) can be implemented in all HIV services. Effective whole-person care in HIV requires a more holistic approach than blood tests alone. Undertaking regular wellbeing and quality of life measures should be urgently prioritised, so that any challenges identified can facilitate access to additional support or onward referral to address unmet needs.



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