



One Voice

Manifesto of People Living With HIV 2015

There are now over 100,000 people living with HIV in the UK. Over 85,000 people are diagnosed and accessing care. In 2015 Positively UK held the third biennial Conference of People Living with HIV in London. Attended by over 100 people living with HIV from across the UK, delegates debated and discussed the major issues facing them today. This manifesto is the result of those discussions.

This Manifesto brings together the views of the diverse communities of people living with HIV on the challenges faced in daily life, health and care needs, and hopes for the future.

This Manifesto shines a spotlight on these issues. It is a campaign for change identified by the community of people living with HIV. It is a platform for discussion between people living with HIV, people affected by HIV, health and social care providers, policy makers, decision takers, community leaders and beyond. It is a foundation for collaboration to identify and implement solutions to ensure everyone living with HIV has the best possible health and wellbeing.

Campaigning

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HIV Stigma



A third of people living with HIV were worried about discrimination within primary health care and more than one in 10 felt they had been treated differently because of HIV status (Stigma Index 2015).

Stigma around HIV does not sit in isolation, but is compounded by discriminatory attitudes towards sex, sexuality, gender and ethnicity. Stigma exists in many settings from healthcare provision, the workplace, faith institutes and within our own communities.

We need to ensure that the range of staff across all healthcare settings feel confident in talking about sex and HIV and receive equal treatment and care.

We want to create opportunities for conversations around sex and HIV within our communities recognising cultural needs and tailoring approaches accordingly.

We seek to create alliances to tackle HIV stigma and discrimination. We want to work with institutions and community leaders who have the power to promote anti-discriminatory attitudes, create understanding and acceptance including government, health and social care organisations and faith groups.

With our allies we want to work across the general public and within our communities to engage in conversations, address misconceptions, and raise awareness and understanding of HIV.

We want to change the discourse on HIV, help people to see the reality of living with HIV, that people living with HIV are within our communities, are our family and friends.

We are concerned at the lack of support for people living with HIV in employment, despite legislation covering HIV from point of diagnosis. DWP, ESA assessors and employers need a greater understanding of fluctuating conditions and where the impact of a disability may be episodic. This will address both assessments in terms of work capability and reasonable adjustments in the workplace.

Treatments



The British HIV Association now recommend that, if individuals are able to commit, people living with HIV should commencing Anti-Retro Viral Therapies from point of diagnosis (British HIV Association Guidelines for the treatment of HIV-1-positive adults with antiretroviral therapy 2015).

We recognise that starting treatments as soon after diagnosis as possible is beneficial to health. But also that people with HIV have a right to make informed choices around treatment and start ARVs when they are ready. In order to prepare to initiate treatment, it is crucial that people have clear information, at a suitable level, peer support, and time to understand treatment options.

We will seek the best and most effective treatments of people living with HIV; to achieve this we will challenge criteria for medications based primarily on price and best value for commissioners, where this is at the detriment of people living with HIV.

We also recognise the role of treatments in enabling people to live with HIV as a long-term condition; as well as a means of preventing onward transmission of HIV, and with PrEP enabling people to prevent acquisition of HIV.

We will challenge the agenda around HIV prevention which is primarily driven by the use of condoms. We will promote greater

understanding of, and respect for, the complexity of people's lives, the decisions people make around sexual activity and sexual health, and constrains that prevent people making their own decisions.

We seek the implementation of a wider approach to tackling HIV prevention including the commissioning of PrEP.

We will develop new messaging around sex that is realistic, takes account of these issues, is non-judgemental and does not take a moralistic stance.

We want to improve messaging that those living with HIV, adhering to treatments and undetectable are not a risk of transmitting HIV; and seek support from policy makers, community leaders and healthcare professionals to promote this understanding.

We recognise that for someone living with HIV to initiate a discussion around treatment as prevention they need to have tools and information to be able to do so effectively.

Engaging



The NHS recognises the need “for a more engaged relationship with patients, carers and citizens so that we can promote well-being and prevent ill-health” (NHS Five Year Forward View, October 2014).

We believe that policies, services and societal attitudes can only be improved with the greater involvement of people living with HIV. However there are barriers to engagement. Firstly the landscape of health and social care is complex, particularly in England where services are fragmented, with HIV prevention, testing and support being commissioned on a local level by Local Authorities, while HIV clinical care is commissioned nationally by the NHS through Clinical Commissioning Groups.

We want programmes established to develop the skills and knowledge of people living with HIV to meaningfully engage in policy and decision making.

We want to see the development and implementation of treatment and care standards addressing all aspects of health and social care, which are shared nationally and adopted by local authorities.

We want to engage GPs as an integral part of the care pathway to ensure that they are effective in supporting the health of people living with HIV.

We will develop formal and informal collaborative networks of advocates, activists and allies including politicians, and community activists from other causes to support the needs identified in this Manifesto.

We seek to work across all political parties and want cross-party collaboration to address the needs identified in this Manifesto.



Support Services

Peer communities are vital in enabling people to manage long-term health conditions (NHS Five Year Forward View, October 2014). While The Health and Social Care Act sets out clear aspirations for the voluntary and community sector as a provider of support and a partner in tackling health inequalities it also presents a number of challenges and risks (Kings Fund, The Voluntary and Community Sector in Health, 2011).

We want multi-disciplinary and integrated care, with innovative solutions to meet the needs of people in rural areas where there is a low prevalence of people living with HIV and low level of support.

We will work with clinical bodies including BHIVA, NHIVNA, CHIVA and HIV clinics to promote the value of peer support for people living with HIV. We will seek out champions from clinical bodies to act as advocates with their clinical colleagues in championing support services.

With people living with HIV being at greater risk of poor mental health, we want to see greater access to psychological support services, within the clinic and in the community, including counselling, talking therapies and peer support.

We seek the commissioning of peer support and as a community, define this as “support by and for people living with HIV”. We recognise the spectrum of peer support. Peer support is a professional role, undertaken by paid staff and trained volunteers

in providing structured support. We also recognise the value and contribution of peer support volunteers and the need to retain informal approaches such as social gatherings and their role in tackling isolation.

We want the voluntary and community sector to champion peer support across the UK, and within the four nations for local providers to form regional networks to enhance access and standards of care.

We want to see greater cross-partnership working between HIV organisations and other long-term condition charities to promote co-ordinated care and campaigning for those living with multiple conditions.

We seek greater co-ordination and integration of commissioning to support people living with HIV on the care pathway across testing, treatment, care and support provided by statutory, private and third sector agencies.

We want the government to hold a review of support services and funding available with many valuable services and organisations closing and further decommissioning of services on the agenda.

We want HIV clinics to include referrals to peer support and newly diagnosed courses as standard procedure, recognising the role of these services in improving overall quality of care.

We recognise care should address the needs of specific communities:

Gay Men: We need to address isolation within the gay community, develop better ways of engaging gay men and MSM, and support the community around drug and alcohol issues.

Heterosexual Men: We need to address the genuine lack of services for heterosexual men across the country, with organisations better responsive to the needs and interests of heterosexual men, to ensure they have access to effective support.

Young People: We need to create space for conversations in the home around health and HIV, provide better support for children living with HIV, including opportunities to be told early about their HIV diagnosis. We want to create resources tailored that can be used by all young people, including those living and affected by HIV, to be used in schools and their communities to promote understanding and conversations around HIV, treatments and treatment as prevention.

Women: We want to both retain and create more women only spaces and events to enable open dialogue and to support the multiple needs of women including HIV, their wider healthcare, gender based violence and sexuality. We want to promote women's participation in clinical and social research to ensure needs are captured, in conjunction with capacity building for women to be more involved in decision making, to ensure effective solutions are implemented.

advocating

People Ageing with HIV



There are now over 40,000 people living with HIV aged over 45 years of age; and nearly 20% are aged over 55 years of age (Public Health England, HIV New Diagnoses, Treatment and Care in the UK, 2015 Report).

People living with HIV face specific issues as they age. For many people family members will become the main carers, yet family may not be aware of the person's HIV status. A large cohort, in particular gay men, have no family or children, therefore rely on care institutions for support. With rising numbers of people living longer with HIV we need to ensure there are effective support and services to meet the needs of this ageing cohort.

We need later life care to reflect the diversity of people living with HIV and able to meet the physical, psychological, social and sexual health needs of people living with HIV.

We want to ensure there are people trained and able to advocate for the needs of people living with HIV when they can no longer advocate for themselves.

We want to ensure people living with HIV receive support in maintaining and establishing new relationships in later life including sexual relationships.

We need to work with institutes including the Care Quality Commission, to ensure people living with HIV are involved in establishing standards of care, delivering training, auditing and ensuring standards are upheld.

We are positive

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