

No-one left behind



A declaration on 'Whole Person Care' in HIV care and support

This project is funded and co-ordinated by MSD. The contents of this declaration are the result of a workshop held with Terrence Higgins Trust, NAT, British Association for Sexual Health & HIV, Positively UK and NAZ in April 2017 with the content of the declaration agreed on an equal basis between MSD and the partner organisations (additionally including British HIV Association). The project was co-ordinated, and the workshop hosted, by MHP Communications on behalf of MSD.



Overview

The UK has made significant strides in the treatment of HIV over the past three decades. Strong progress has been made towards meeting an international target set by UNAIDS for 90% of those living with HIV to have been diagnosed, with 90% of those diagnosed in treatment, and 90% of those in treatment having undetectable viral loads by 2020¹. Thanks to early diagnosis and better treatment, people living with HIV can have the same life expectancy as those living without it².

The UK now faces a new challenge: how to ensure that services adapt to the complex needs of people living with HIV. More people than ever are being diagnosed with HIV who are aged 50+³, and we are increasingly seeing those who have been treated with antiretroviral therapy (ART) able to grow older with the condition³. As a result, their care and support needs change with age, and services must therefore adapt to be more holistic in their approach.



This document outlines the concept of 'Whole Person Care', which we believe care pathways, service delivery and funding should be based around. Whole Person Care represents support and treatment that does not simply treat HIV from a medical perspective, but recognises the many other social, economic, employment, and physical and mental health needs that are associated with the condition. Crucially, Whole Person Care complements and supports the direction of travel set out in the NHS Five

Living with HIV can have a significant impact on other areas of health and wellbeing:

- A recent Positive Voices study of people accessing HIV care in England and Wales found that two-thirds of respondents reported having at least one long-term condition other than HIV, increasing to three-quarters of respondents aged over 50⁴
- Levels of poverty seen in people living with HIV aged 55+ are double those seen in the general population³
- A survey by Positively UK in 2013 found that of people living with HIV (PLHIV), three-quarters stated that they had suffered from either depression, anxiety or ongoing emotional distress in the past 12 months⁵

Year Forward View, particularly in regards to improving patients' control over their own care and placing more emphasis on both community services and public health.

It incorporates several principles – **care planning, parity of esteem, addressing care inequality and patient self-management**. These are detailed below, with a set of "I..." statements for each that we believe people living with HIV should be able to apply to their own care.

2/3



have one long term condition other than HIV



3/4



over 50 have one long term condition other than HIV

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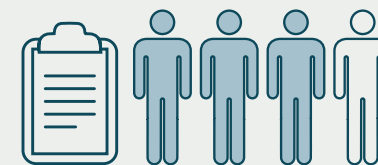
Poverty = 2x the general population



Levels of poverty seen in people living with HIV aged 55+ are double those seen in the general population³

3/4

are suffering from either depression, anxiety or ongoing emotional distress



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Care planning

As a result of reforms made through the Health & Social Care Act 2012, responsibility for HIV care in England is now split across NHS England, local authorities and clinical commissioning groups (CCGs)². This has led to fragmentation in the HIV care pathway, confusion in commissioning and wide variations in the availability of support⁶. Services are often not joined up around an individual living with HIV and there is often

a lack of clarity about who is responsible for each service and individual needs. There is a need for people living with HIV to have a clear care plan which is co-produced/jointly decided with the individual. Discussions on the care plan should include choices around what services are available, focus on long term objectives, and ensuring the needs of the individual are fully met in a way that works for them.

People living with HIV benefiting from Whole Person Care should be able to state that:

"I have an integrated care plan that is clear, practical and adaptable to my needs, and which incorporates the various providers of care."

"I am at the centre of my care, have discussed the options that are available to me, and have clear goals and outcomes."

"I have opportunities to input on how much time I need with clinicians and those providing support."

"I have access to clear, up-to-date information that enables me to make informed choices about my health care and treatment."



Parity of esteem

Receiving an HIV diagnosis can be a distressing and isolating experience. The UK Stigma Index 2015 Survey found that 15% of participants reported avoiding their GP altogether⁷, a problem that is exacerbated by the fact that stigma also exists amongst healthcare professionals (the same study revealed that 14% had received negative comments from a healthcare worker about their HIV status)⁷.

There is also a danger that the perception that HIV has been 'solved' affects funding of public health programmes, education and awareness. In the same way that the Department of Health has worked with patient groups to promote awareness of mental health, so too should it be working to ensure that HIV does not become an 'invisible' condition and that those who are diagnosed with the condition are aware of how to seek treatment and support.

People living with HIV benefiting from Whole Person Care should be able to state that:

"My condition is viewed with the same importance as other long-term conditions."

"I am easily able to access information about HIV services."

"I am clear about how I can report incidents of healthcare professionals making discriminatory comments, or engaging in discriminatory actions, concerning my HIV status, and I am confident that strong action will be taken against them."

"I feel confident that HIV services will be well-supported for the foreseeable future."



Addressing care inequality

It is vital that inequalities in access to HIV services are identified and addressed. However, there is currently a lack of reliable data and metrics against which the availability of HIV services can be assessed. It is difficult, therefore, to analyse where there are geographical, social or economic variations in access to treatment and support services.

In some areas, inequalities have been recognised and this has helped to identify where and how services should be improved. In diagnosis, for example, statistics show that African men have a late

diagnosis rate of 66% compared to 34% for men who have sex with men⁸. Similar statistics, collated through quantitative and/or qualitative research, could and should be regularly updated and assess variations in access to services across a range of demographics.

With those from ethnic minority populations – such as black African communities – more likely to face stigmatisation and discrimination in public services⁹, as well as obstacles such as insecure residency status⁹, it is vital that this does not affect their access to HIV services or the standard of their care.

People living with HIV benefiting from Whole Person Care should be able to state that:

"I have access to high quality services irrespective of where I live in the country."

"I am treated equally and with respect, regardless of my gender identity, ethnicity, sexuality or any other characteristic."



Patient self-management

People living with HIV should be at the centre of Whole Person Care development and implementation; they are the experts on their own needs and what will work for them. The health and social care system is moving towards co-production and this must be the ethos that underpins Whole Person Care for HIV.

However, those diagnosed with HIV often have very little knowledge about their condition. For people living with HIV to fully understand their condition and provide input into their own treatment they need to have the right information available to them. Where there is confusion or misunderstanding, there should be easily accessible services – outside of clinical treatment – allowing people living with HIV

to ask questions and acquire any further information they may need.

This is especially important for those who do not speak English as a first language, of which there are many amongst migrant populations and within Black African communities.

The success of Whole Person Care will depend on awareness and understanding among people living with HIV about their condition and what services they require to meet their own individual needs. Individuals should be encouraged to develop knowledge of their condition and be given the resources to do so, which in turn will help to facilitate patient empowerment.

People living with HIV benefiting from Whole Person Care should be able to state that:

"I have the resources and support available to allow me to take greater responsibility for the direction of my treatment pathway."

"I am well-placed to input on decisions made about my care."

"I am satisfied that clinicians and professionals involved in my treatment and support pathway have an appropriate level of understanding about the details and sensitivities of my condition, and they take on board my own views."

"I have, where appropriate, the right to translation services which will support my decision making on the best options for my care."



Further information

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Our call to action



Despite the significant gains that have been made in HIV treatment since the start of the HIV epidemic in the UK, it has become clear that current services are not sufficiently meeting the complex needs of people living with HIV (PLHIV).

We call on policymakers, healthcare professionals, commissioners, funders and local authorities to incorporate the principles of Whole Person Care into HIV treatment and care pathways. These principles should inform and guide changes to funding, commissioning and service delivery, which we hope will ensure that patients benefit from a more holistic and effective support framework.



Understanding the needs of PLHIV is now more complex than ever and it is vital that no one living with the condition is left behind.