



Ending the Epidemic

An assessment of HIV-related policy in England and recommendations to improve the lives of those living with, and at risk of, HIV



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The report was compiled by KPMG LLP UK (KPMG) and guided throughout by an independent Steering Group comprising of policy, clinical and patient experts in HIV. The Steering Group had editorial control of the report.



01

Executive summary

The impact of effective antiretroviral therapy over the past 25 years has changed the face of England's HIV epidemic. The number of people dying of HIV related causes has fallen dramatically and fewer people are newly acquiring HIV^{(1), (2)}. Of the estimated 101,600 people living with HIV¹, the vast majority (87%) are virally suppressed which means they are not infectious and cannot pass HIV on to other people⁽³⁾.

But as the epidemic evolves, so do its challenges – challenges England must address if there is to be an end to the epidemic and if people who are living with HIV are to live long and live well.

Today the life expectancy of people with HIV is close to that of the general population and more people with HIV are reaching older age. In 2017 more than a third (37.6%) of people treated for HIV were aged 50 or over⁽⁴⁾, and this is expected to rise. Further, HIV is associated with higher rates of a number of other age related health complications, poorer mental health and a quality of life that is below that of the general population. Despite increases in HIV testing programmes, around 10,000 people living with HIV remain undiagnosed and unaware of their infection. At the same time 43% of people were first diagnosed with HIV at a 'late stage of infection'² which increases the risks of poorer health outcomes and of ongoing onward transmission. Late diagnosis is more likely amongst older people and people from black and ethnic minority communities highlighting issues of health inequalities. Despite biomedical progress HIV

remains a stigmatising condition and negative social attitudes towards HIV persist, including within healthcare settings^{(5), (6)}.

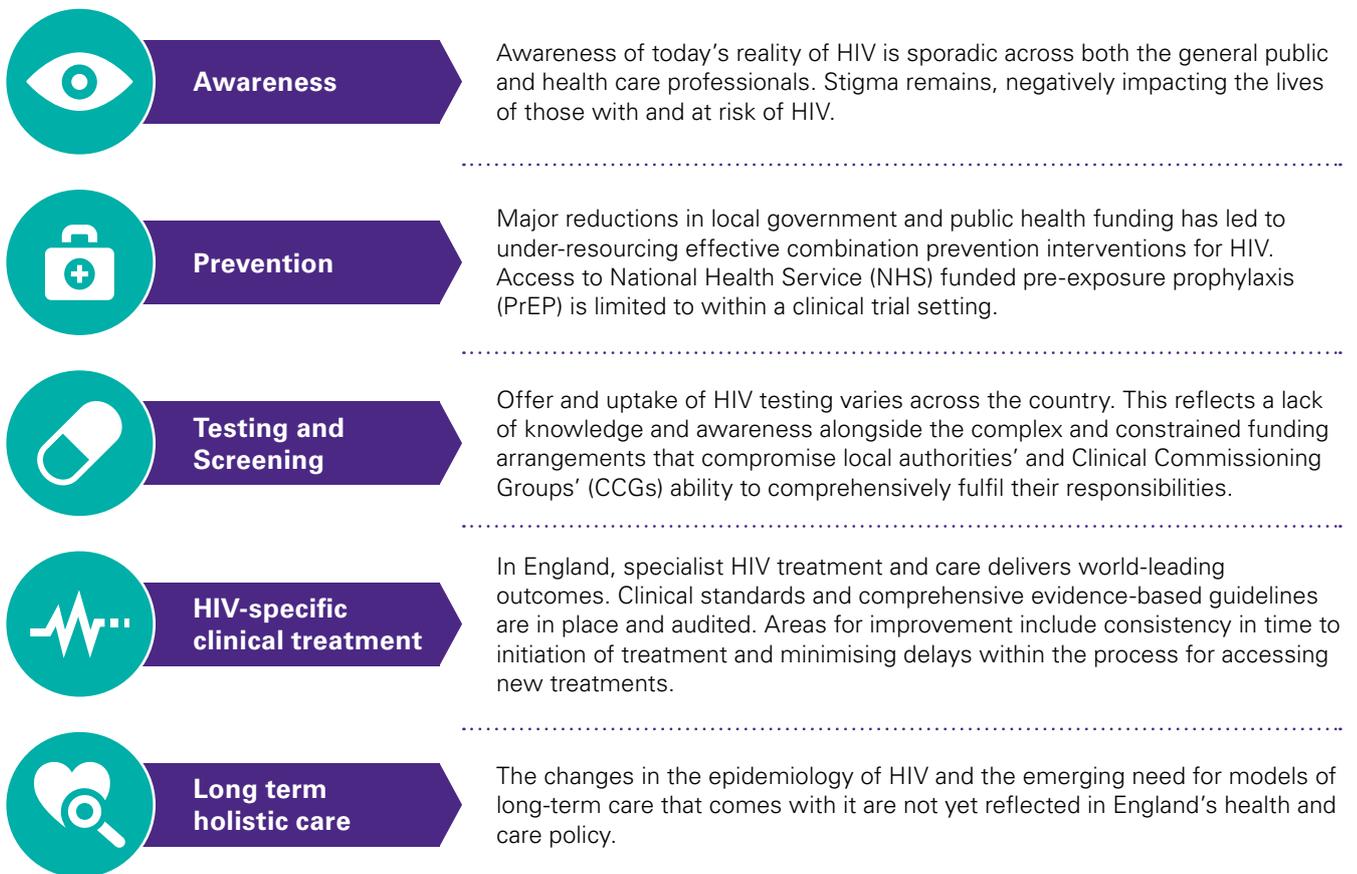
But England currently does not have a single nationally-defined policy or strategy on HIV to tackle these challenges. Instead, an assortment of standards, service specifications, clinical guidelines, and recommendations from accredited organisations address the HIV care continuum. The picture is further complicated by the fragmented responsibilities for commissioning and provision of HIV treatment and care services resulting from the changes set out in the 2012 Health and Social Care Act^{(7), (8)}. Although HIV is not specifically mentioned, the recently published "NHS Long Term Plan" sets out an intention to move to a more integrated service model and highlights healthy ageing as a key area of focus⁽⁹⁾. These, among other aspirations outlined in the plan, have potential to significantly impact other design and delivery of person-centred care for those living with HIV.

To tackle these emerging challenges, and meet ambitions for ending new HIV infections, policy and practice in England must evolve. To understand the effectiveness of England's current strategy, the Steering Group³ undertook an assessment. Working step-by-step across the HIV care continuum of Awareness, Prevention, Testing and Screening, HIV-specific Clinical Treatment and Long-Term Holistic Health, they identified areas of strength and those with room for improvement.

¹ Data for UK, 2017

² A late diagnosis is one which is made at a point in time after which HIV treatment should have been started. Currently, a CD4 cell count below 350 cells/mm³ at time of diagnosis is considered 'late'. Source: UNAIDS

³ For full list of Steering Group members, see European report, Methodology section, Table 1



To drive improvements in the lives of those with, or at risk of HIV in England, the Steering Group put forward a number of recommendations:

- **Develop a national plan for HIV addressing strategic areas of focus as a matter of urgency:** Department of Health and Social Care (DHSC) should lead a multi stakeholder panel including national (e.g., NHS England, Public Health England: PHE), local and community organisations to create a national strategy to provide leadership, direction and clarity to tackle key challenges of the epidemic.
- **Raise awareness of HIV among healthcare professionals:** NHS England should lead in the development and implementation of training for the health workforce, particularly those in primary care, to improve awareness and tackle stigma.
- **Address high rates of late diagnosis through widening access to testing:** PHE should work with community organisations to increase the delivery of highly targeted campaigns that raise awareness of HIV and provide access to various testing offers that are culturally appropriate and effective.
- **Use HIV as a model for person-centred treatment and care of long-term conditions:** NHS England, working through Clinical Reference Groups (CRGs) and building on existing frameworks, should integrate HIV into policies and initiatives (NHS Long Term Plan) under development, using lessons learnt from HIV to elevate long-term care as a whole.

02

HIV in England, the wider context

The HIV response in the UK has delivered major positive outcomes. There has been a sustained decline in HIV-related deaths and new diagnoses of acquired immune deficiency syndrome (AIDS). In the past two years, the number of people newly diagnosed with HIV has also dropped – most marked among men who have sex with men (MSM), with a decline of 31% (from 3,570 in 2015 to 2,330 in 2017). Of the 101,600 (1.7 per 1,000 population) people estimated to be living with HIV in the UK, approximately 92% (93,472) are aware of their HIV positive status, 98% of whom (91,603) were prescribed anti-retroviral therapy (ART), with 97% (88,854) of those achieving viral suppression^{[2],[3]}. This equates to approximately 87% of all people living with HIV in the UK having a suppressed viral load who are uninfected and cannot pass HIV to sexual partners. In the light of these outcomes, the UK has both met and exceeded UNAIDS 90-90-90⁴ targets (Figure 1). These successes mean that today more people than ever before are living with HIV in the UK and are living longer lives – in 2016, 37.6% of people seen for HIV care in the UK were aged 50 or over^{[4],[1]}. And this proportion is expected to rise. However, when compared to the general population there is increasing evidence that people living and ageing with HIV have higher rates of a number of major concomitant conditions as well

as a reduced health-related quality of life^{[10]-[12]}. A recent British HIV Association (BHIVA) over 50s audit indicated that people with HIV aged over 60 and 70 years were likely to have at least three comorbidities^[4]. The marked improvements in morbidity and mortality rates across the UK are not universal. Those who are unaware of their HIV infection and those diagnosed with more advanced infection have a poorer outlook. Despite increases in HIV testing, 10,400 or around 10% of people living with HIV were estimated to be living with an undiagnosed HIV infection in 2016^[13]. Similarly, a high rate of late diagnosis continues. In 2017, the overall “late diagnosis” rate was 43%, and is more frequent amongst heterosexual people and those from black and ethnic minority communities. People who are older are also more likely to be diagnosed late - with 61% of late diagnoses among the 50-64 year age group compared with 31% among people aged 15 to 24 years^[3].

Challenges around stigma and negative social attitudes towards HIV remain stubbornly high and is even noted within healthcare settings. The PHE 2017 Positive Voices survey revealed one in nine (11%) of the 4,400+ participants felt they were treated differently when engaging with health services^[14]. Additionally, 18% of participants stated they had avoided seeking medical care for fear of being treated differently^[14].

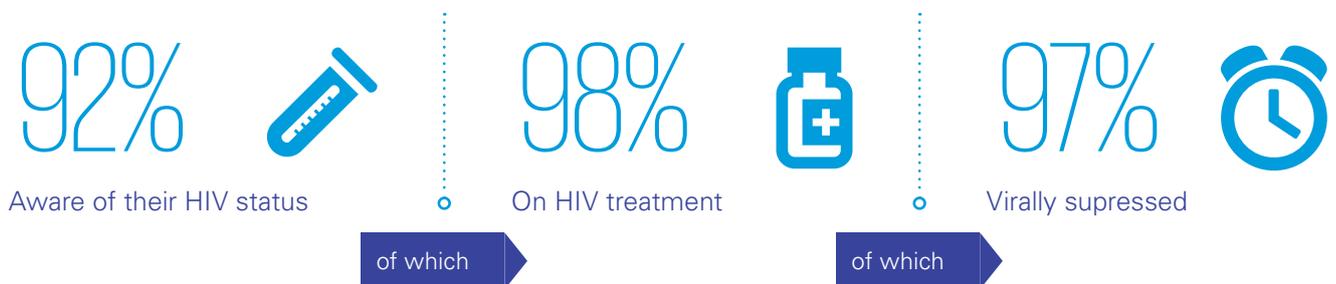
⁴ The UNAIDS 90-90-90 targets set in 2014 are targets for the treatment of people with HIV – 90% of people with HIV will know their status, 90% of people diagnosed with HIV will be receiving ongoing antiretroviral therapy, and 90% of people with HIV on treatment will be virally suppressed by 2020. These targets are based on the assertion that it is not possible to end the HIV epidemic without treating all of those with HIV that need it. Source: UNAIDS

Changing demographics and HIV related risk behaviours, for example an increase in sexualised recreational drug use “chemsex”⁵, mean that new approaches are needed. While comprehensive quantitative data on changing risk patterns are currently limited, a 2017 survey indicated close to 30% of MSM living with HIV reported sexualised drug use in the preceding year, with 10% reporting the use of injected drugs¹⁵.

These new and continuing challenges must be tackled if England is to meet its ambitions of ending the epidemic.

The recent commitment by the Health Secretary to end transmission of HIV in England by 2030 is a welcomed development, as it may mean a greater focus and efforts to tackle prevention, testing and treatment¹⁶. As well as HIV-related policy and strategies that form the current basis for action (see chapter 3), the wider legal and policy environment must also be considered, as it continues to influence the HIV response and in turn impact the lives of those living with, at risk of, and working in, HIV (see Box 1).

Figure 1. Performance towards the 90-90-90 targets



Source:^[3]

Notes: data for UK, 2017

⁵ Chemsex is the practice of consuming drugs recreationally in order to facilitate sexual activity – typically this refers to one or a combination of three drugs: methamphetamine (crystal meth), mephedrone (M-cat), and GHB/GBL (G). Consumption of these drugs reduces inhibitions and therefore increases risky behaviours, whilst also exacerbating an individual’s mental health. Source: UNAIDS



Box 1. The wider legal and policy landscape

As outlined in the Methodology section (see European summary), a deep assessment of the wider legal and policy landscape and its impact on the HIV response is not within the scope of this project. However, outlined below is England's current position on three common areas which typically impact the HIV response:



1) Legal protection against stigma and discrimination:

The 2010 Equality Act makes certain types of discrimination, such as discrimination against individuals with HIV, unlawful and applies in England, Wales and Scotland^[17]. However the UK Stigma Index, a survey of 1,576 people living with HIV (2015), found 3% of respondents reported losing their job or another source of income due to their HIV status in the preceding two months, and one in nine reported being denied insurance products (e.g., health, dental, life) in the last year. While just over half (59%) were aware of the Equality Act, many did not seek legal support for such instances of discrimination, often citing lack of confidence or feeling intimidated. The survey also found that people living with HIV continue to fear stigma in various aspects of life – for example sexual rejection due to their HIV-positive status^[67]. As mentioned above, the recent, large scale 'Positive Voices' survey also found people with HIV faced stigma and discrimination in health settings^[14].



2) Free, non-discriminatory access to healthcare:

In the UK, the National Health Services Act 2006 and the Health and Social Care Act 2012 (which replaced the National Health Service Act 1946) guarantees free access to healthcare for the population^{[18]–[20]}. Since 2012, HIV treatment and care has been extended without charge to everyone living in the UK, irrespective of migration status. Although further regulations on charging overseas visitors have since been implemented^[21], treatment of HIV is still exempt. However, other services, including mental health services, drug support and community care, are no longer exempt and are unavailable to migrants who are unable to make payments^[22].



3) Decriminalisation of behaviours such as sex work and drug use:

In England and Wales, while the act of prostitution itself is not illegal, a number of related activities (e.g., owning a brothel) are crimes under the Sexual Offences Act 2003^[23]. A 2016 report by the Home Affairs Committee called for the decriminalisation of soliciting by sex workers and sex workers sharing premises, citing improvements to the safety and wellbeing of sex workers, public health gains and a reduction of stigma. No changes however have been made as a result^[24].

With regards to drug use, the UK takes a "prohibitionist" approach (as opposed to the harm reduction approach taken by some countries such as the Netherlands and Canada), with a pre-existing framework based on the Misuse of Drugs Act (1971), Misuse of Drug Regulations (2001), and the recent Psychoactive Substances Act (PSA), which came into effect in May 2016. Within this framework, possession is a criminal offence only if it's an illegal drug under the Misuse of Drugs Act and not a psychoactive substance covered by the PSA, but the two may be indistinguishable. Reports show this has resulted in confusion and led to challenges in enforcement, with only a quarter of the UK public believing that the current policy is "effective at preventing harm to the public's health and wellbeing"^[25]. A 2019 report by the National AIDS Trust (NAT) indicated drug-related deaths (DRDs) have increased six years in a row, with 3,756 DRDs in England and Wales in 2017. The report calls, at a minimum, to reverse the cuts to drug treatment services over the last few years and for local authorities to be mandated in law to provide drug treatment services^[26].

03

Assessment of HIV-related policy in England

This chapter outlines the Steering Group's assessment of current HIV-related policy in England, and its effectiveness in tackling the new and continuing challenges of the epidemic. It is broken down by stages of the HIV care continuum: Awareness, Prevention, Testing and Screening, HIV-specific Clinical Treatment and Long Term Holistic Care.

3.1 Overview of HIV-related policy

No nationally-defined policy on HIV exists in England, other than high level aspirations for HIV awareness and testing set out in the 2012 Department of Health Framework for Sexual Health^[27]. Instead, a mixture of service specifications (e.g., NHS England's HIV specialised services for adults and children), clinical guidelines from accredited organisations (e.g., BHIVA and British Association for Sexual Health and HIV, BASSH) and recommendations (e.g., PHE's HIV: testing guidance) address the HIV care continuum and form the basis for action. In contrast, national-level strategies for prevention and management of HIV exist in Scotland, Northern Ireland and Wales^{[28]–[32]}.

The landscape for commissioning and provision of HIV care and services in England is complex. It has undergone major reconfiguration since April 2013, when the implementation of the Health and Social Care Act 2012 changed the commissioning landscape of the HIV care continuum^[20]. Public Health responsibilities (including sexual health services, HIV prevention and most HIV testing) moved from the NHS into local government; Primary Care Trusts (PCTs) were disbanded and replaced by CCGs; and NHS England was established with responsibility for commissioning specialist services, including HIV treatment. As a result, HIV care and support functions are now split between NHS England

(commissioning HIV treatment to a national service specification), CCGs (testing, diagnosis and long-term condition management) and local authorities (testing and prevention as part of public health as well as commission of broader sexual health services).

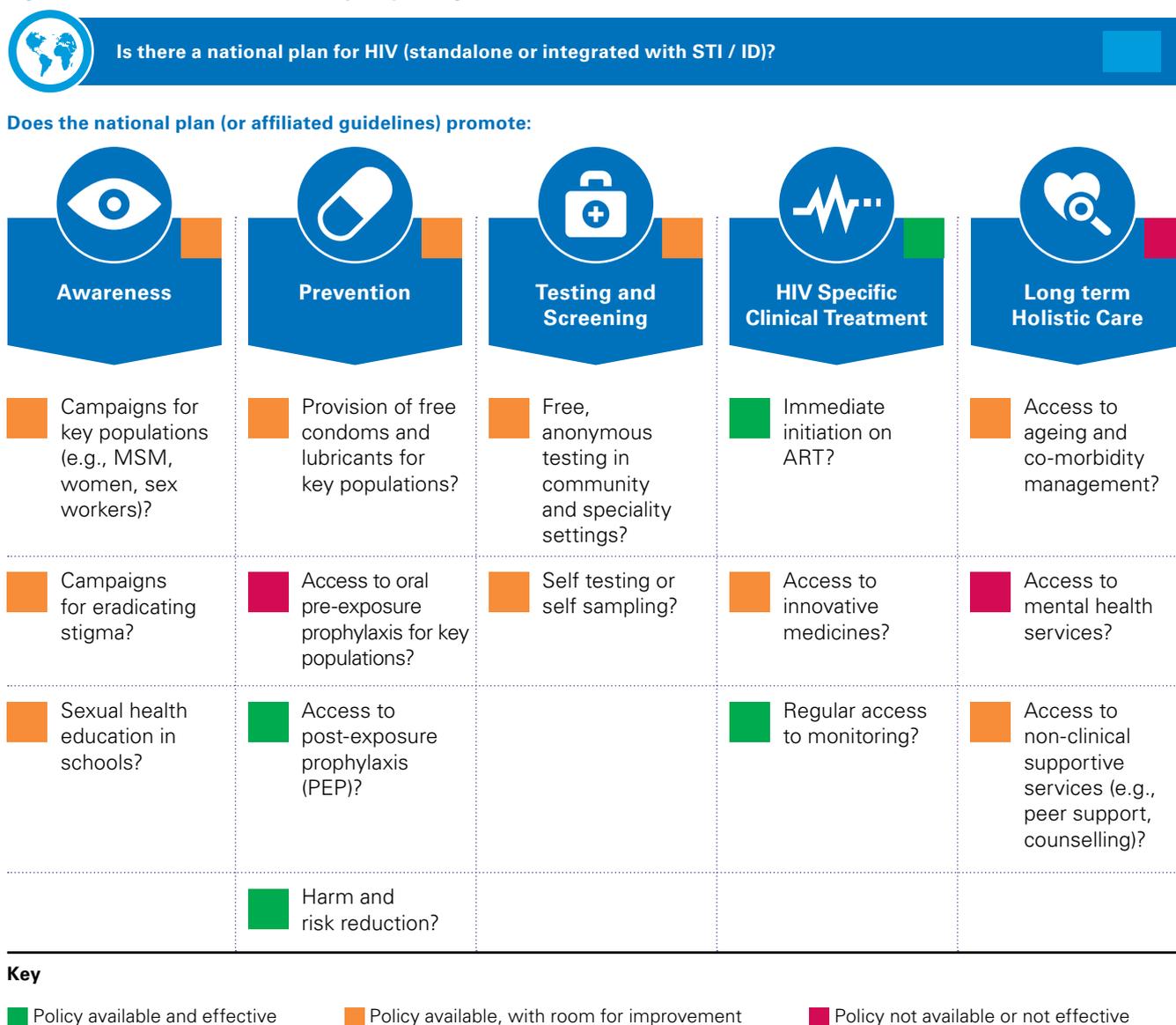
The fragmentation of budget lines, responsibilities and accountability introduced by these arrangements have resulted in significant challenges in the provision of holistic HIV care and services^[71,81]. Furthermore, while another major restructure of the health economy is not expected in the short term, the newly launched (February 2019) NHS Long Term Plan^[9], outlining the vision for the NHS over the next 10 years, may introduce further change. Among the most relevant changes proposed, the move to a new model through greater delivery of services via the community (including integrated teams of general practitioners, community health and social care staff) has the ability to greatly impact delivery of person-centred HIV services. On long-term condition management, the plan builds on the NHS Five Year Forward View, focusing on areas such as mental health and healthy ageing^[33]. Again, changes in the delivery of these services have the potential to impact the ageing population with HIV. The extent to which these proposed changes in the health economy will improve the lives of those with HIV remains to be seen.

Other challenges in delivery of care and services include the continued austerity measures, which have placed a significant pressure on the whole health economy and have reduced the capacity of the Department of Health (DoH) (including its policy-making bodies). Funding for the public health functions of local government has been significantly reduced with major consequences for the prevention and diagnosis of HIV and support for people living with HIV. There is also considerable uncertainty related to Brexit,

which may see a further reduction in NHS capacity and capabilities and impact the health economy.

To understand the ability of England’s approach in tackling the new and emerging challenges of the epidemic, the Steering Group undertook an assessment. Going step by step across the HIV care continuum, areas of strength and those with room for improvement were identified.

Figure 2. Assessment of HIV-related policy in England



Note on methodology: the assessment underlines the view of the Steering Group on current policy and its effectiveness, broken down by stage of the HIV care continuum. Additional in-country experts provided input, and findings were supplemented through secondary research. Full details of the policy, as related to stage of the HIV care continuum, is available in chapter 5.



Awareness



- Understanding of HIV and surrounding issues is lacking and inconsistent in the general population
- Funding for interventions to improve awareness tend to be sporadic
- Existing messaging risks missing important sections of the population, for example heterosexual men and newly arrived migrants

What is the policy position?

Policy on awareness in England is fragmented and spread across multiple documents by government bodies. DoH, PHE and the National Institute for Health and Care Excellence (NICE) have produced frameworks, strategic plans and guidelines to raise awareness of HIV in England, often in the wider context of sexual health^{[27], [31], [34]}. These documents emphasise the need to reduce the stigma associated with HIV both among communities and healthcare professionals^[34], promoting the development of interventions to help reduce discrimination and stigma in key populations^[31].

In contrast to England, Scotland has a dedicated national strategy for eradicating HIV stigma, which outlines best practices and highlights ways to address the causes of HIV-related stigma^[35].

Sexual health education in England has historically only been mandatory in state-run schools. However, recent changes will make it a statutory requirement for all schools from September 2019, though the new legislation does not specify the exact content to be taught^[36].



“It’s quite a fragile commitment, with upcoming general elections, and Brexit, who knows what will happen”
HIV Practitioner

What happens in practice?

Government funded programmes exist, and have been successful in establishing initiatives to help raise awareness of HIV and reduce associated stigma and discrimination. This includes the national HIV prevention program for England, HIV Prevention England (HPE), which has a variety of initiatives targeted at key populations such as MSM and black communities, and the HIV Prevention Innovation Fund to support organisations in reducing the impact of HIV through interventions targeting key populations^{[37], [38]}. Examples of government funded initiatives to reduce stigma and discrimination include:

- LOL@Stigma (KwaAfrica): A comedy-centred event with motivational speakers to reduce stigma and promote testing among black African communities;
- Sex Week on National Prison Radio (Prison Radio Association): Week-long schedule of radio programming regarding sex, sexual health and HIV to reduce stigma and promote testing;
- Using digital platforms to reduce HIV stigma and discrimination (The Martin Fisher Foundation): Developing digital content, videos and social marketing targeting higher risk communities.

In 2015/16, seven projects were funded through the HIV Prevention Innovation Fund, increasing to 13 projects in 2016/17^[38].

Sexual health education in schools, which plays a significant role in raising the awareness of HIV and associated issues, has also been found to have wide variation across England. In 2013, Ofsted, the official body that regulates schools in England, reported that curriculum provision for personal, social, health and economic education (PSHE) was only 'good' or 'better' in 2/3 of schools^[39]. Additionally, a survey on behalf of the Sex Education Forum in 2016 found that 46% of young people responding had not been taught 'how to tell when a relationship is healthy' in sex and relationship education (SRE) at school, a third had not been taught about sexual consent and a fifth rated their SRE provision as 'bad' or 'very bad'^[40].

What do the experts say?

The lack of cohesion in policy combined with fragmentation across several government bodies is exacerbated in practice due to devolution of implementation to local authorities. Despite best efforts, this lack of a national approach combined with limited resources at the local authority level has resulted in any attempts to raise the profile of HIV and reduce stigma to be sporadic and inconsistent across England.



“You find any attempt by PHE to artificially impose a national framework for uniformity across England onto what is a localised picture, ends up in duplication in some areas and absolute gaps in others”

HIV expert, UK

While sexual health education is available in schools, it is often viewed as inadequate due to variation in the quality of content and failure to tackle wider issues such as sexuality and gender identity. Further, education of HIV is often combined with other sexually transmitted infections (STIs), thereby at times missing the seriousness of the infection and its lifelong implications.



“When we talk about HIV education, it ties in very closely to sexuality and gender identity which aren't taught very well in schools”

HIV expert, UK

Reflecting current insufficient levels of awareness, a survey conducted by the NAT in 2014 found that only 45% of people could correctly identify all of the ways in which HIV is and is not transmitted^[41]. The ramifications of such misguided and under-informed perceptions is a considerable number of people in the UK still holding stigmatising attitudes to people living with HIV, with one in five people living with HIV having experienced verbal harassment or threats^[67].



“People aren't always able to assess their risk, which comes down to a lack of awareness”

HIV clinician and policymaker, UK

HIV-related stigma continues to be a pressing challenge. The recently concluded Positive Voices survey – the largest survey of the lives and experiences of people living with HIV in England with 4,400 respondents – indicated a number of worrying findings, including one in six female respondents indicating they had not shared their HIV status with anyone outside of a healthcare setting. Even more worryingly, the study provided an indication of the level of HIV stigma within the NHS, with one in nine or 11% of respondents revealing they have been refused healthcare or delayed treatment because of their HIV status^[14].

Discrepancies exist between efforts targeting specific regions and populations. Awareness campaigns are most prolific in London, where the prevalence of HIV is highest, while other areas of England see a reduced focus. Similarly to geographic regions, not all subpopulations are targeted equally. MSM see significant focus in targeted campaigns and initiatives, reflecting policy documents which highlight their needs as a key population. However due to resource limitations, this means that other populations, such as heterosexual men and newly arrived migrants, may be missed and remain underserved.



“The way that HIV awareness and campaigns are structured towards black and ethnic minority populations...newly arrived migrants are not properly looked after at all in awareness”

HIV expert, UK



Prevention



- The government's austerity agenda means that overall national financial commitment to public health has fallen and is disproportionately affecting local government response
- The focus for prevention on key populations may result in others who are at risk being under-served
- Mechanisms to address emerging risks are absent or slow, with limited availability of public or private funded interventions
- Provision of PrEP continues to be an area of contention

What is the policy position?

A national, cohesive HIV prevention strategy is absent. A combination of policies and other mechanisms including research trials are in place for the provision of condoms, PrEP, post-exposure prophylaxis (PEP) and harm reduction.

Condom distribution is mandated in policy. NICE guidelines developed in partnership with PHE recommend the distribution of free condoms through a variety of settings, including commercial venues, community pharmacies and universities^[43].

Similarly, guidance from the DoH, NICE, Chief Medical Officers' Expert Advisory Group on AIDS (EAGA) and the BASHH outlines the free provision of PEP in a variety of settings following significant risk of HIV infection for both occupational and non-occupational exposure^{[44]-[47]}.

Existing policy documentation at a national level details harm reduction services in England, including needle programmes^[48] and opioid substitution therapies (OST)^{[49]-[51]}. Further, the Home Office's 2017 Drug Strategy document recommends PHE work closely with local authorities to promote effective practice in addressing the public-health challenges relating to all blood-borne viruses associated with chemsex^[49].

The provision of HIV-PrEP within the NHS is currently limited to the Impact trial. The trial, currently funded by NHS England, was launched following a ruling by the High Court of Justice that NHS England is responsible for the commissioning of PrEP in England. Through the trial – which has a limited number of places - the drug is made available at no cost to those at high risk of contracting HIV^[52]. In contrast to England, Wales, Scotland and Northern Ireland have free provision of PrEP to individuals who are HIV negative and at high risk of contracting HIV^{[53]-[55]}, though in Wales this is limited to a three year trial^[55].

What happens in practice?

HIV Prevention England (HPE), run by Terrence Higgins Trust (THT) and funded by PHE, is the national HIV prevention programme in England. It runs a number of programmes throughout the year, including awareness programmes such as It Starts with Me campaign and National HIV Testing Week^[56].

Condoms are available from a variety of settings in England, with an assessment of condom distribution schemes (CDS) in England during 2015/16 showing high levels of implementation of this policy, with CDS available in nearly all areas of the country^[57]. C-Card schemes are the most common type of CDS in the UK, in which young people can register for a C-Card, entitling them to free condoms from a variety of

distribution outlets^[57]. These schemes typically cover young people up to 19 years, or 24 years in some areas. Other CDS are used to target high risk subpopulations such as MSM, people who inject drugs (PWID) and sex workers.

The policy for PEP is widely implemented across England, with PEP available from a variety of settings, including sexual health clinics, Genito-Urinary Medicine (GUM) clinics and hospital Accident and Emergency (A&E) departments^[58].



“The NHS policy is there for PEP and it is paid for”

HIV expert, UK

Harm reduction interventions are available, however, implementation is patchy in many parts of England. A survey carried out for PHE in 2016 found that less than half (46%) of people in England, Wales and Northern Ireland who had injected drugs in the past 28 days had adequate needles, rising to 72% among people who had injected drugs in the past six months in Scotland^[59]. Alongside harm reduction, risk reduction is also a growing issue, with chemsex being of particular concern in larger cities such as London and Manchester.

PrEP is partially available through the Impact trial. As of January 2019, over 10,000 participants were enrolled in over 139 clinics^[60]. The trial has faced challenges, including oversubscription for MSM places and an under-representation from other communities^[60]. This led to an initial increase in the total number of places on the trial from 10,000 to 13,000, and a reallocation of ~1,000 of the non-MSM places on the trial to MSM. However, commissioners in London have requested more time to confirm what proportion of their full allocation they have the capacity to accept, due to funding shortages at local authorities which restrict the services they are able to offer^{[61],[62]}.

What do the experts say?

The current lack of a joined up approach and the continued austerity agenda has meant that despite best efforts, room for improvement remains (see case study). This is reflected in a 2018 BASSH and BHIVA member survey which indicated government funding cuts have left sexual health and HIV care at ‘breaking point’^[63].

CDS are available through the country, but despite this, a YouGov poll from 2017 indicated one in 10 sexually active young people had never used a condom^[64]. Corroborating this, PHE’s figures on STIs indicate highest rates of diagnoses continue to be seen in those 16 to 24 years of age^[65]. Further, the existing CDS primarily focus on young

people and high risk populations such as MSM and black African minority ethnicities, which means those who do not fall in to these categories (e.g., heretosexual men and women over 25) no longer have free access to condoms.



“You can get free access to condoms and good access until you’re 25 and then those free programmes stop, unless you are a key population, so it’s not for everyone”

HIV expert, UK

Harm reduction has room for improvement. A recent report by the NAT indicated the continuing funding cuts (including the Public Health Grant) and other wider cuts to support services, are creating challenges in provision of harm reduction services^[26]. Integrating changing patterns of risk is another challenge - chemsex is becoming an increasingly relevant issue, with a 2014 study finding that 21.9% of the HIV-positive population are using chemsex drugs (methamphetamine, GHB/GBL or mephedrone), going up to 32.7% in London^[66]. This finding was echoed in the recently concluded Positive Voices survey – in which nearly 30% of the responding gay men living with HIV reported chemsex in the last year^[14]. Despite this, interventions for addressing chemsex are not widely available. Studies have indicated traditional drug treatment or harm reduction services have limited uptake among MSM – possibly due to lack of identification with the target population (e.g., injecting drug users) or limited fit with the sexual nature of their drug use^{[66],[68]}.



“For chemsex, if you live in the right regions you have services, but it’s patchy and inconsistent as it has been delegated to local government and is not universal at all”

HIV expert, UK

With regards to PrEP, the Impact trial is a ‘work around’ to lack of a policy position, and debate continues over its funding and provision. In September 2018, a coalition of 32 organisations including BHIVA, BASHH, THT and NAT came together to insist PrEP be made routinely available through the NHS by 1st April 2019 (earlier than the timeline proposed by NHS England, which sees the PrEP trials concluding in 2020)^[69]. Aside from the increase in number of Impact trial places, no other response has been given by NHS England or other bodies.



“Unless people in England buy PrEP themselves or join the Impact trial, they can’t really access PrEP”

HIV expert, UK

Experts point to Scotland as being an example of how PrEP can be made freely available to at-risk populations, and how to implement policy successfully. HIV Scotland published a PrEP good practice guide^[70] and administered Scotland’s expert group, following PrEP being made freely available. This document contained prescribing criteria, cost assessments, and mapped the information and training needs of workers and the community^[70]. As a result PrEP uptake in Scotland has been rapid, exceeding the 1,000 places initially planned for the first year, with 2,517 PrEP prescriptions provided July 2017 – February 2018. This importantly reached people at high risk, many of whom were not previously engaged in care^[71].



Case study: London HIV Prevention Programme (LHPP)^[72]



What is it?

The LHPP is a London-wide programme, established on the basis of a 2013 needs assessment which indicated that 32 of the 33 London boroughs had a high or very high prevalence of HIV^[72].

The programme was funded and commissioned jointly by all 33 of the London boroughs, thereby bringing together the multiple local authorities for provision of consistent services.



What are the key features?

- Condom and lubricant distribution including personal or digital outreach to MSM (e.g., through apps such as Grindr, presence at priority MSM venues and events such as London Pride)
- Multi-channel communication campaigns for the general public, e.g., Do-it London promoting testing and safer sex
- Evidence collection, e.g., on-going review of effective condom distribution schemes in black African communities and research into chemsex



Why is it a good practice?

LHPP is an example of successfully overcoming fragmentation of responsibility and resources in public health to deliver effective, evidence-based interventions at scale. The impact of LHPP and its campaigns such as Do-it London have been recognised by multiple awards. An independent evaluation performed by Research Now showed that 66% of those surveyed believed the campaigns had influenced them to practice safer sex, whilst 68% reported it had influenced their behaviour towards HIV testing^[72].



Testing and Screening



- Funding constraints undermine the ability of local governments and CCGs to fulfil their responsibilities
- Healthcare professionals are not yet consistently operating in line with NICE guidelines
- Late diagnosis rates, a key marker of a lack of testing, remain high

What is the policy position?

The national policy on HIV testing is dependent upon multiple documentation from various accredited bodies, including BHIVA, BASHH, NICE and PHE.

NICE and PHE's detailed guidance (2016) aims to increase uptake of testing and repeat testing within the undiagnosed and high risk populations. It outlines the frequency with which HIV tests should be offered to individuals in primary and secondary care, based on the prevalence of HIV in the locality as well as the risk status of the individual. For areas of extremely high prevalence, guidelines indicate opportunistic testing in general practice (GP) surgeries, routine testing in clinical settings (e.g., following hospital admittance) and in A&E Departments^[34].

Additionally, the BHIVA/BASHH National Guidelines for HIV testing (2008) covered the frequency at which tests should be offered as well as recommending which settings they should be offered in, such as sexual health clinics, antenatal services, pregnancy termination services, drug dependency programs and healthcare services for those diagnosed with tuberculosis, hepatitis B, hepatitis C and lymphoma. Recommendations for offering testing for high risk populations, including those with indicator conditions, are also available from the European Centre for Disease Control (ECDC).

Both self-sampling and self-testing kits are available in England, with a change to UK law making self-testing kits available in 2014^{[73]-[76]} and self-sampling launched in 2015.

Routine HIV screening is recommended only in pregnancy.

What happens in practice?

HIV testing is available in a range of community and clinical settings, and uptake continued to increase in 2017 (compared to 2016). PHE data indicate a total of 116,071 MSM and over 67,000 heterosexual men and women who were of black African ethnicity or born in a high prevalence country were tested in 2017^[3]. Across these population groups, HIV positive rates were stable, or declined compared to 2016^[3]. Free testing is also available through general practices, and a 17% increase in testing was seen during 2014-2016.

In 2017, nearly 130,000 HIV tests were obtained online or carried out in community settings, including the national self-sampling service, community providers or privately purchased self-testing kits.

Since launch in 2015, a total of 13,356 self-sampling kits have been tested and 134 reactivities identified from users who had never had an HIV test before^[77], indicating efficacy in engaging individuals who have never tested for HIV. However, availability of self-sampling remains

patchy – a report in 2017 indicated only 87 local authorities had signed up to the service since its launch in 2015^[77]. Even where available, heterogeneity in the level of service exists, such as kits being free versus requiring a fee. Finally, a lower adoption of self-sampling has been noted in black and other ethnic minority communities, indicating the need for greater outreach^[77].



“Self-sampling for HIV testing shouldn’t be a lottery of where you live – it should be everyone that can access for free”

HIV public health expert, UK

Implementation of self-testing is less well established when compared to self-sampling. As of November 2015, self-testing kits were available on the market. In August 2018 a large UK retailer became the first to start selling HIV self-testing kits, at a cost of £33.99^[78].

Innovative outreach programmes (see case study) and testing in high risk settings including ‘opt-out’ testing in prisons is also available, with around 40,000 tests conducted in 2017/2018^[3].

In some areas, secondary care, comprising in-patient services and A&E departments are also enabled to deliver HIV testing. The latter saw a 118% increase in HIV tests from 2014-2016^[79]. Screening for HIV in antenatal services is highly successful, with uptake increasing to 98% of all women engaged in care by 2015. As a result, the rates of vertical transmission of HIV in England are extremely low, with the proportion of pregnant women passing on the virus to their babies at a new low of 0.27% in 2012-2014^[80].

Community HIV testing initiatives led by non-profit organisations (NGOs) provide important routes of access, particularly for populations that may not use traditional health services. A range of very successful programmes to increase HIV testing have been developed and supported through PHE’s Innovation Fund^[42].



What do the experts say?

Substantial guidance exists on where and when to implement HIV testing, and continued efforts by local government, CCGs, statutory (i.e. NHS England) and community providers are seeing an impact, reflected in both the rising number of HIV tests carried out year on year and the declining rate of new HIV diagnoses.

However, significant challenges remain. These include evidence of significant variability in both the population impact and geographical reach of existing initiatives, the stubbornly high rates of late diagnosis and the heterogeneity of those at risk

A key contributor may be the lack of consistency among healthcare professionals in implementing NICE/ BHIVA guidelines, due in part to poor awareness of guidelines and limited capacity and capabilities. As a result, multiple missed opportunities for the diagnosis of HIV are being documented. In 2016, a national audit conducted by BHIVA demonstrated up to 46% missed opportunities in a cohort of 773 adults with advanced infection (CD4 <200 cells/mm³) at/shortly after diagnosis^[81]. This is echoed in data from PHE, showing that nearly 350,000 attendees at Sexual Health Services (SHS) were not offered a test for HIV in 2017, despite being recorded as eligible. Particularly within older age groups, where current data indicate high levels of late diagnosis, numerous barriers to the offering and uptake of testing have been documented, including low perceived risk and clinical preconceptions about older people^[82].

Despite national recommendations for regular testing amongst some populations the offer and uptake of repeat testing remains a key challenge, with reports indicating 77% of MSM diagnosed with HIV at a SHS had not had a test in the previous year at that clinic^[79].

Common across the entire HIV care continuum, and the wider health and care economy, severe austerity measures are hampering efforts by local authorities and CCGs to fulfil their responsibilities, resulting in regional variation in the level of services offered, e.g., a 2017 report by NAT indicated a quarter of local authorities in England did not commission any primary HIV prevention or testing^[83].



“NICE guidelines say that if you live in a certain area you should get a test, but it’s not being tracked and audited”

HIV expert, UK



Case study: HIV self-test vending machines at a Brighton gay sauna^{[84][85]}



What is it?

A touch-screen vending machine to dispense HIV self-tests was installed at a gay sauna in Brighton. The initiative is funded by PHE's HIV Prevention Innovation Fund 2016-2017 and is in collaboration with the Martin Fisher Foundation and other stakeholders (e.g., designers, clinicians and researchers)^{[84],[85]}.



What are the key features?

- HIV self-tests dispensed without charge
- Results available via finger prick test in minutes
- Staff at the premises that contain vending machines trained to offer appropriate support and advice following test results



Why is it a good practice?

- Provides convenience and discretion
- Targets a high risk population in a social setting, thereby contributing to normalising HIV testing while increasing awareness and risk perception



HIV specific clinical treatment



- Clinical standards for care of HIV are in place and audited
- The process of accessing new treatments is complicated, and may risk creating delays

What is the policy position?

Policy is available for clinical management of HIV, with a national HIV service specification from NHS England. The importance of early treatment initiation is recognised and NHS England has developed policies recommending immediate initiation of anti-retroviral drugs (ARVs) upon diagnosis^{[86]–[91]}. The national ‘Standards of Care for People Living with HIV 2018’ from BHIVA has reinforced this recommendation, noting that “people newly diagnosed with HIV should be informed of their CD4 status and the opportunity to discuss management, starting ART and opportunistic infection prophylaxis (if indicated) within two weeks of an initial assessment (i.e. within one month of initial diagnosis).”^[92].

NHS England develops policy documents as treatment approaches evolve and as newer agents come to market that have been shown to be more efficacious, reduce side effects or are required when other lines of treatment fail^{[96]–[92]}. The BHIVA standards highlight “safe and effective prescribing of appropriate ART is crucial to maximise benefits, minimise adverse effects, avoid drug interactions and reduce the emergence of drug resistance”^[92].

Access of new and innovative HIV medication, in contrast to most pharmaceuticals, is determined via an NHS England policy process rather than NICE approval^[93]. Decisions on access to HIV drugs are informed by two sets of guidelines: the HIV treatment guidelines developed by

BHIVA, which are NICE accredited, and the commissioning policies published by NHS England which detail the medications that will be paid for by the specialised commissioning budget, and under which circumstances.

Monitoring is comprehensively covered, with NHS England’s service specifications for specialised HIV services outlining how monitoring adherence of medication is a requirement in people living with HIV^[94]. Additionally, BHIVA guidelines provide extensive recommendations on methodologies for monitoring patients at different stages of HIV, both on and off ART, with appropriate auditable targets^[95]. These guidelines take into consideration when additional adherence support may be required, for example for PWID who are taking ART^[95].

What happens in practice?

Immediate initiation on ART is generally well implemented in England, with ART coverage in 2017 being at 98%^[2]. Expert consensus is that the vast majority of patients discuss treatment options and are ready to start ART within two to three weeks of diagnosis, in line with the most recent Standards of Care published by BHIVA. However, national-level data on the time to initiation is not available, and anecdotal evidence indicates timelines may be longer. Good practice examples of rapid linkage to care is available (see case study).

Monitoring is also conducted effectively, with the BHIVA national audit in 2015 finding that 93.4% of patients were undergoing annual adherence monitoring, surpassing the target of 70% and 90.1% had received a viral load measurement within the past six months^[96].

What do the experts say?

Experts concur that specialist clinical management of HIV delivers excellent outcomes in England. Policy is available and robust, with detailed accompanying guidelines which are well implemented across the country. While general consensus is that immediate treatment initiation is well implemented, anecdotal evidence exists of longer timeframes – however, data on this is not currently available.



“NHS England has set out national service spec on how HIV should be managed, that is out there and we know what we’re doing”

HIV expert, UK

In general, clinicians are free to prescribe optimised treatments regimes for patients, taking into account key considerations (e.g., efficacy, intolerance, side effects, and adherence). Measures on cost-effectiveness are increasing, particularly in the use of generics or breaking up single tablet regimens into constituent agents, however careful consideration of switch choices and ensuring patient engagement are also important in helping maintain high quality clinical outcomes.

Where room for improvement exists is in access to new and innovative medicines, where England often lags behind the Europe5 (particularly France and Germany). The lengthy approval process often results in delays (e.g., up to a year), and may place restrictions on prescribing (i.e., delineating specific patient populations/clinical scenarios for treatment options).



“The policy for new formulations is a bit clunky, but it’s there”

HIV expert, UK



Case study: rapid linkage to care at Dean Street Clinic Soho London^{[97],[98]}



What is it?

56 Dean Street is a central London clinical service which is a constituent part of the Chelsea and Westminster Hospital NHS Foundation Trust, the largest HIV service in Europe (2017). The clinic specialises in the rapid outpatient diagnosis and treatment of HIV and other STIs^{[97],[98]}.



What are the key features?

- Free NHS sexual health service from two locations on Dean street, one which provides rapid testing services (Dean Street Express)
- Full outpatient HIV clinic services, as well as advice and support on a range of sexual health issues, for example chemsex advice, HIV PEP, HIV PrEP support etc.
- Provision of immediate access and treatment for urgent issues, those under 19, and immediate access to PEP in a preventative effort against HIV



Why is it a good practice?

- The clinic works in close collaboration with Soho’s gay community. In 2011 it set the World Record for most HIV tests performed in one location on World Aids Day at G-A-Y Bar in Soho, London
- The clinic offers people newly diagnosed with HIV a medical review within 48 hours and immediate ART which is in line with best practice standards for clinical management
- Offers late evening appointment slots and is one of the few London clinics open on Saturdays. The increased convenience allows more testing and earlier intervention to prevent transmission



Long Term Holistic Care



- Although HIV is now a long-term condition it doesn't appear in long-term management strategies
- While the cohort of people living with HIV is ageing and has changing needs, this is not addressed in policy
- The quality of life for people living with HIV is below that of the general population

What is the policy position?

The recognition that both ageing and long-term conditions are a growing issue for the health economy is evident in the newly published NHS Long Term Plan. It identifies healthy ageing as a key area of focus, and although it does not specifically mention HIV, it outlines a number of steps that have the potential for positive impact on people living with HIV, including routine assessment by primary care networks to understand unwarranted health outcomes (e.g., using the Electronic Frailty Index), and enabling home-based and wearable monitoring equipment to predict and prevent events^[9].

Despite this, specific policy does not yet exist on the long-term management of people living with HIV. Management of comorbidities is addressed in BHIVA guidelines 'For the routine investigation and monitoring of adult HIV-1 positive individuals 2016' and 'Standards of Care for People Living with HIV 2018', which highlight that people living with HIV should have access to services to safely manage comorbidities, in collaboration with the appropriate non-HIV specialist team and/or primary care^[92,195]. While policy for chronic care exists, including the House of Care framework for long-term conditions and NICE guidelines on multi-morbidity, care for people with HIV is not specifically included^[99,1100].

Supportive services, both clinical (including mental health) and non-clinical (such as peer support) are more comprehensively covered in policy. Clinical guidelines and NHS England's national service specification for HIV specialised services clearly set out that supportive services are an essential part of the care pathway^[92,194]. NHS England's service specifications states that all people living with HIV should have access to peer and psychosocial support^[94]. In addition, BHIVA guidelines recommend that people newly diagnosed with HIV should be able to access psychological and peer support within two weeks of receiving their HIV positive result^[92].

Further guidance and support on long-term well-being also exists. The BHIVA standards detail that HIV outpatient units should have an agreed pathway to enable access to peer support as well as financial and housing advice and support^[92]. The Housing Act of 2004 states that people with disabilities, which includes people living with HIV, are one of the groups given priority when allocating housing^[102]. Additionally, the Welfare Reform act of 2012 established Personal Independence Payments (PIP), a welfare benefit available to those with a long-term health condition, such as HIV, in replacement of Disability Living allowance (DLA)^[102,1101].

What happens in practice?

Common comorbidities such as high blood pressure or diabetes are typically assessed or recognised in HIV clinics, with the 2018 BHIVA audit on monitoring over 50s indicating multiple targets for routine comorbidity and laboratory testing (e.g., monitoring of viral load, blood pressure) were met. However, the same audit indicated targets for monitoring long-term health, well-being (e.g., mood / mental health, memory and cognition) and sexual and reproductive health were often missed^[4].

Availability of mental health support services varies. There are gaps in the implementation of policy guidelines, with discrepancies in the extent to which mental health screening is conducted as well as access to relevant mental healthcare services when needs are identified^[92]. This includes regional variability in support services in England, with some rural areas lacking any HIV-specific support services^[92]. Poor implementation is in part likely due to funding being substantially reduced for support services in recent years (by 28% between 2015/16 and 2016/17)^[103].



“HIV patients are noticing a change from a Rolls Royce psychiatric service to just about functional due to the tremendous financial strain on the NHS”

HIV expert, UK

Similarly, non-clinical supportive services are inconsistent across HIV clinics and regions, and are often heavily reliant on third sector organisations such as charities and community groups to plug the gaps. Continued austerity measures have had a strong impact on the output of these organisations, reducing the number of services that are available^[63]



“London does better in terms of support services, there are whole areas, e.g., rural areas, that have very few services around support”

HIV expert, UK



“There are terrible cuts in the support services for people living with HIV... it means a very broken situation whether you get peer support, or support on how to deal with stigma or how to disclose your status”

HIV expert, UK

Difficulties with implementation are also seen for welfare benefits. A report in 2017 stated that people living with HIV who previously claimed DLA were less likely to be awarded PIP after reassessment^[104]. One particular concern is that access to PIP for people living with HIV may be limited due to the fluctuating nature of the condition, which can affect eligibility and the level of support accessible.

What do the experts say?

Experts concur that a lack of an overarching policy which pulls together disparate documents and mandates their implementation is harming efforts in the long-term care of people living with HIV. There continue to be gaps in services across the country, and while this is recognised (see case study), the devolution of responsibility has resulted in a lack of concentrated effort to drive long-term care onto the policy agenda.



“The issue is that you have guidelines developed by clinical bodies that get the rubber stamp, but there is nothing that mandates for these to be followed”

HIV expert, UK

Austerity measures are again being felt, with a significant number (20) of HIV clinics reporting an unmet need for a specialist ageing service^[95], suggesting both new policy and implementation are required. Some areas are already forging ahead with the introduction of new clinics and HIV ageing services being proposed^[105].



Case study: Positive Voices survey^{[14],[84]}

Closer collaboration between primary and secondary care is critical in ensuring high quality, long-term management of people living with HIV. A 2018 BHIVA audit of monitoring in over 50s indicated a lack of communication between specialists HIV clinics and GPs, with 89.7% of HIV clinics sending communications to GPs over the last 15 months, with only 7.4% receiving communication back. A lapse in knowledge among primary care providers (nurses and GPs) of guidelines and requirements for long-term management of people living with HIV needs to be overcome^[41].

At present a policy document is being drawn up on chronic care conditions, but it is not clear whether that will include HIV. Multiple stakeholders, e.g., civil organisation and patient groups, have started working with charities engaging within wider healthcare to develop a united front on common issues, however the outcomes of these are yet to be seen. A key challenge is that any conversation on ageing or long-term care inevitably collides with wider issues (e.g., social services). However, integrating HIV care within policies for chronic care is a necessary change to ensure high quality management of the ageing cohort of people living with HIV.



“One key policy thing we’ve got to get right is HIV joining other conditions to get long-term care right”

HIV expert, UK



What is it?

Positive Voices, implemented by PHE, aims to routinely monitor quality of life of people living with HIV through surveying a representative sample of the HIV population. An advisory group of clinicians, social scientists, commissioners, survey experts and people living with HIV have been established to guide the project^[84].



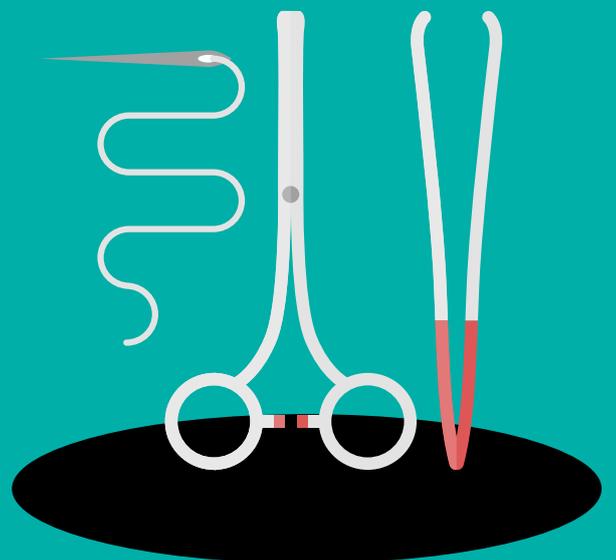
What are the key features?

- Survey outputs show a set selection of important met and unmet needs of participants for the last 12 months, e.g., range of HIV related services including peer support, treatment advice, stress management, smoking, alcohol, weight management to housing support



Why this is good practice?

- First time data on quality of life for people living with HIV has been collected at scale
- Provides granularity on met and unmet needs, e.g., despite excellent levels of medical and clinical outcomes for HIV treatment, the survey indicated a lack of social and welfare support dealing with loneliness and isolation being the single greatest unmet need



04

Recommendations



4.1 Develop a national plan for HIV addressing strategic areas of focus as a matter of urgency

What is the challenge?

There is no overarching government strategy for tackling HIV in England. Instead, responsibility is fragmented across multiple national and local bodies, resulting in both variable services and the quality of care provided to people living with HIV.

There is a need for direction and leadership at the national level, which will help prioritise and drive efforts at the local level while minimising variation in the level of services and care currently experienced by people living with HIV. It will also enable ambitions towards tackling HIV to be realised, including the recent commitment to ending HIV transmissions by 2030^[16].

What is the recommendation?

Develop a national strategy for HIV and provide government leadership across all relevant departments to ensure implementation. The DHSC should be the primary stakeholder, convening other national bodies, including, NHS England, PHE, and where relevant, other bodies (e.g., Health Education England). Input should be sought from a wider range of additional stakeholders, including local authorities and the community (e.g., NGOs).

The strategy should focus on a number of key areas including:

- Elimination of stigma in all healthcare settings;
- Engagement of all relevant communities in HIV awareness;
- Prevention of new HIV infections;
- Provision of support services;
- Recognition and management of HIV as a long-term condition.



4.2 Raise awareness of HIV among healthcare professionals

What is the challenge?

Awareness of HIV among healthcare professionals, particularly those in primary care, can be varied – resulting in missed opportunities for early diagnosis and provision of best in class treatment and care. It may also contribute to the persistent levels of stigma found within healthcare settings.

What is the recommendation?

NHS England should develop and mandate training on HIV awareness and tackling stigma for the NHS workforce. Close collaboration with DHSC, PHE, civil society (e.g., organisations such as THT and NAT and others), other statutory bodies (e.g., CCGs), and local authorities should play a role in their development, and build on existing work, PHE metrics and the stigma index.

Areas of focus should include:

- Early recognition of HIV (e.g., symptoms, risky behaviours, indicator conditions);
- Elimination of stigma.

Together with training, routine assessments should be conducted in the form of surveys (of both healthcare professionals and service users) to measure impact and effectiveness.



4.3 Address high rates of late diagnosis through widening access to testing

What is the challenge?

While the number of new infections of HIV have stagnated, the rates of late diagnosis are not falling in a meaningful way. Further, while efforts targeting certain at-risk populations (e.g., MSM or BAME) have had an impact, certain populations remain hard to reach. These include certain ethnic minorities, newly arrived migrant populations and older people.

What is the recommendation?

Reaching these varied populations will require highly targeted campaigns that raise awareness of HIV and provide access to various testing offers (e.g., self-tests, self-sampling, testing through sexual health clinics, testing in the community) that are culturally appropriate and effective. To enable this, PHE should identify and engage community service providers who are delivering/able to deliver effective, targeted and local campaigns. In addition to access to testing, behavioural support, in the form of counselling – including in the instance of a negative test – should also be provided.

Close monitoring of all programmes should be conducted by PHE in conjunction with the service providers, to assess impact and ensure the sustainability and scale up of those that are most effective.



4.4 Use HIV as a model for person-centred treatment and care of long-term conditions

What is the challenge?

Management of HIV as a long-term condition is not yet addressed in policy. This includes clinical management, for example, through the management of comorbidities, as well as support services to ensure a good quality of life beyond viral suppression.

There are many lessons learnt from the management of HIV both in England and other countries which can be used as good practice in setting up commissioning and service models for long-term care. Greater collaboration across the management of multiple long-term conditions will provide several advantages, including cost benefits as more services move to the community, and more convenient, person-centred care for individuals, thereby improving their quality of life.

What is the recommendation?

NHS England should incorporate HIV into all long-term condition planning, and use HIV as an example of evolving needs in provision of long-term person-centred care. This requires close collaboration with the relevant Clinical Reference Groups (CRGs, including mental health and blood and infection, while building on existing frameworks such as House of Care. Working alongside the NHS Long Term Plan will be critical for successful implementation of any changes recommended.

To specifically support people living with HIV, it could include:

- Everyone living with HIV in the UK should be assessed for comorbidities at least once a year, and be able to receive treatments for these in locations convenient to them;
- A quality of life indicator should be established and routinely measured for people living with HIV to ensure healthy ageing;
- Increased training on HIV should be offered to all health and social care workers across the UK, covering HIV awareness and issues related to ageing with HIV.

05

Appendix

Is there a national plan for HIV? No

From April 2013, implementation of the Health and Social Care Act 2012^[20] disbanded Primary Care Trusts, fragmenting all care commissioning. This included HIV care and support functions which were split between NHS England (treatment and clinical care), Clinical Commissioning Groups (long-term condition management) and local authorities (public health and social care). Alongside the devolution of HIV care, there have been continued cuts to the Department of Health's (DoH) policy making bodies.

As a result, there is no nationally defined policy on HIV in England. Instead, a conglomeration of guidelines and recommendations by government bodies (e.g., Public Health England's (PHE) guidance on HIV testing, NHS England's commissioning HIV treatment to a national service specification) and accredited organisations (e.g., British HIV Association's (BHIVA) guidelines for the routine investigation and monitoring of adult HIV-1 infected individuals) are used to form an overall strategy.

In contrast, there are national strategies in place for HIV in Scotland, Northern Ireland and Wales, either standalone or as part of policies in sexual health. The Scottish Government published a national strategy for HIV in 2009, covering HIV prevention, treatment and care^[29]. Following this, a Sexual Health and Blood Borne Virus Framework for 2011-2015 was released, and updated in 2015, integrating the key aims of the HIV action plan and further developing them for specific areas of focus in the near future^{[30],[106]}.

The HIV strategy for Wales is integrated into the Sexual Health and Wellbeing Action Plan for Wales 2010-2015^[28]. This strategy is currently undergoing a review by Public Health Wales, commissioned by the Welsh Government^[107].

In Northern Ireland, the HIV strategy is also integrated into the overall sexual health strategy, the Sexual Health Promotion Strategy & Action Plan 2008-2013, which was updated in 2015^{[31],[32]}. This sexual health strategy includes referencing to UK-wide guidance documents, such as those from the National Institute for Health and Care Excellence (NICE), British Association for Sexual Health and HIV (BASHH), and BHIVA.

Does the national plan (or affiliate guidelines) promote?

Awareness

**Campaigns for key populations?**

PHE's 'Health Promotion Strategic Action Plan for Sexual Health, Reproductive Health and HIV 2016-2019' outlines ambitions to decrease HIV incidence in key populations and reduce rates of late and undiagnosed HIV^[31]. This national strategy includes the aim of improving individual's knowledge of sexual and reproductive health and services^[31].

It is the role of local authorities in England to implement strategies to raise awareness of HIV in key populations, which are produced by PHE.



Campaigns for eradicating stigma?

The DoH's 'Framework for Sexual Health Improvement in England' sets out the need to 'continue to tackle the stigma, discrimination and prejudice often associated with sexual health matters'^[27].

PHE's 'Health Promotion Strategic Action Plan for Sexual Health, Reproductive Health and HIV 2016-2019' states that interventions should be developed to help reduce discrimination or stigma in key populations^[31].

Additionally, guidelines developed by NICE and PHE 'HIV testing: increasing uptake among people who may have undiagnosed HIV' highlights the need to reduce the stigma associated with HIV, both among communities and healthcare professionals - citing it as an issue to consider when implementing other HIV related policy^[34].

The 'Sexual Health and Wellbeing Action Plan for Wales 2010-2015' addresses HIV stigma in Wales, tasking the All-Wales Sexual Health Network and the third sector with action^[28].

The original 'Northern Ireland Sexual Health Promotion Strategy' also contains actions for tackling stigma, however, the 2013 update did not contain any further information or detail any specific actions^[32].

HIV Scotland formed a consortium to develop a national strategy for eradicating HIV stigma, resulting in a roadmap^[108]. This policy document outlines best practices and highlights relevant research, helping to identify the causes of HIV-related stigma and how to address them. This forms the foundation of a future document, Scotland's HIV Anti-Stigma Strategy Action Plan 2018-2027, which is expected to be published in 2018.



Sexual health education in schools?

In England, state schools have been required to provide SRE, but this has not been mandatory for independent schools and academies^[109].

Recently, it has been made a statutory requirement for secondary schools in England (state, independent or academies) to provide relationship and sex education, which will come into effect from September 2019, following a consultation period^[36]. This legislation does not specify the exact content of the subjects to be taught, but refers to government-endorsed advice by the PSHE Association, which outlines that pupils should have the opportunity to learn about STIs, including HIV/AIDS^{[110],[111]}.

In Scotland, sex education remains a non-statutory part of the Scottish curriculum^[112].

In Northern Ireland, the Department of Education requires all grant-aided schools to develop their own policy on how they will address SRE within the curriculum^[113].

In Wales, SRE is a compulsory part of the basic curriculum in secondary schools, under the Education Act 2002^[114]. Additionally, primary schools are also required to have a policy on SRE.

Key

■ Policy available and effective

■ Room for improvement

■ Policy not available



Prevention



Free condoms for key populations?

NICE guidelines, developed in partnership with PHE, recommend distribution of free condoms with lubricant to people most at risk of STIs through a variety of settings, such as, commercial venues, community pharmacies and universities^[43]. NICE categorises condom distribution schemes (CDS) into three types 1) single component schemes which provide free condoms; 2) multicomponent schemes which offer free condoms as well as additional services such as support and training (e.g. C-Card); 3) cost-price sales schemes^[43].



PrEP for key populations?

In England, there is no policy for the provision of PrEP. An ongoing PrEP feasibility trial is being conducted by NHS England, following the high court ruling that NHS England is responsible for the commissioning of PrEP in England. The PrEP Impact trial makes PrEP available at no cost to those at high risk of contracting HIV, but has a limited number of places^[52].

In Wales, Scotland and Northern Ireland, PrEP is freely available to individuals who are HIV negative and at high risk of contracting HIV^{[53]-[55]}, though in Wales this is limited to a three year trial^[55]. Scotland was the first of the UK nations to approve the provision of PrEP by the NHS to prevent HIV^[53].



Occupational and non-occupational access to PEP?

PEP is available on the NHS for free in England if certain guidelines are met, which recommend prescribing PEP where there is 'significant' risk of HIV infection upon non-occupational exposure^[44].

Upon occupational exposure, guidelines recommend testing the source and prescribing PEP if they are found to be HIV positive or if the source is either known to be HIV infected, or considered to be at high risk of infection, but where the result of an HIV test cannot be obtained^[45].

Following changes in 2015, guidelines produced by NICE and BASHH no longer recommended the use of PEP following exposure if the source is on ART with an undetectable viral load, both in occupational and non-occupational situations^{[44]-[47]}.

Key

■ Policy available and effective

■ Room for improvement

■ Policy not available



Harm and risk reduction (e.g., needle and syringe programmes (NSP), opioid substitution therapy (OST), chemsex)

Extensive policy documentation exists from the government and NICE which details harm reduction services in England, including NSPs^[48] and OST^{[49]–[51]}.

The Home Office's 2017 Drug Strategy document highlights that PHE should be working closely with local authorities to promote effective practice in addressing the public health challenges associated with chemsex. This includes close collaboration with sexual health services and community groups. While there is reference to blood-borne viruses, no specific clause exists for HIV^[49].





Testing and Screening



Free anonymous testing through specialty / community settings?

Detailed guidance published by NICE and PHE in 2016 outlines the frequency that HIV tests should be offered to individuals in primary and secondary care^[34]. The guidelines use the prevalence of HIV in the locality as well as the risk status of the individual to determine the frequency at which testing should be offered, such as opportunistic testing in GP surgeries within areas of extremely high prevalence^[34]. Clinical settings are used to promote HIV testing in extremely high prevalence areas, as people being admitted to hospital have blood taken for other reasons, making it a cost-effective initiative^[34].

Additionally, BHIVA have produced UK National Guidelines for HIV testing (2008) which cover the frequency at which tests should be offered as well as recommending which settings they should be offered in, such as, sexual health clinics, antenatal services, pregnancy termination services, drug dependency programs and healthcare services for those diagnosed with tuberculosis, hepatitis B, hepatitis C and lymphoma.



Self-testing / sampling?

In 2015, PHE launched a nation-wide self-sampling service for most at-risk populations (MSM, black African populations) for HIV acquisition with the support of local authorities^[77]. In 2016, the service was devolved to participating local authorities who have since taken responsibility for implementing the service in their areas^[77].

The law on the sale of self-testing kits for HIV within the UK was changed on 6 April 2014, making it lawful to sell and advertise HIV self-testing kits in England, Scotland and Wales^{[73]-[76]}.

Key

■ Policy available and effective

■ Room for improvement

■ Policy not available



HIV specific clinical treatment



Immediate initiation on ART? ■

NHS England has produced a number of policies, including 'Immediate ART for treatment of HIV-1 in adults and adolescents', which recommend immediate initiation to combination ART upon diagnosis^{[86]–[91]}. This recommendation is also made by the British HIV Association (BHIVA) in the recent 'Standards of Care for People Living with HIV 2018'^[92].



Access to innovative medicine? ■

In England, new HIV drugs entering the market go through the NHS England policy process. Through this method, NHS England have produced policy documents on a number of alternatives to traditional ART that have been shown to be more efficacious, reduce side effects or are required when other lines of treatment fail^{[86]–[92]}.

In England, HIV drugs are not subject to NICE approval^[93]. Instead, decisions on access to HIV drugs are informed by two sets of guidelines; the HIV treatment guidelines developed by BHIVA, which are NICE accredited, and the commissioning policies published by NHS England (mentioned in the above paragraph) that outline which medications will be paid for by the specialised commissioning budget under different circumstances.



Access to regular monitoring (e.g., viral load, adherence, co-infections)? ■

NHS England's service specifications for specialised HIV services stipulate the monitoring of medication adherence to be a requirement for people living with HIV^[94].

Additionally, BHIVA guidelines provide extensive recommendations on methodologies for monitoring patients at different stages of HIV, both on and off ART, with appropriate auditable targets^[95]. These guidelines take into consideration when additional adherence support may be required, for example for PWID who are on ART^[95].

BASHH guidelines state that both asymptomatic and symptomatic patients should be offered screening/testing for HIV (and syphilis)^[115]. Additionally, patients already infected with HIV should be tested for Hepatitis A and Hepatitis B, and for HIV-infected MSM (and their partners), Hepatitis C^[115]. Another BASHH report recommends MSM in general should be tested for HIV, gonorrhoea, syphilis, Hepatitis B, Hepatitis C and chlamydia, given their increased risk of acquiring these STIs^[116].

Key

■ Policy available and effective

■ Room for improvement

■ Policy not available



Long term care



Ageing and co-morbidity care?

In England, policy refers to the management of comorbidities and long-term care as a general health concern, rather than specifically for people living with HIV; such as the House of Care framework ‘a model of care which takes into account the expertise and resources of the people with long-term conditions (LTCs) and their communities to provide a holistic approach to their lives and help them achieve the best outcomes possible’^[99].

NICE guidelines on ‘multimorbidity: clinical assessment and management’ provide recommendations on managing multimorbidities, however, HIV is not specifically mentioned^[100].

BHIVA guidelines ‘for the routine investigation and monitoring of adult HIV-1 positive individuals 2016’ and ‘Standards of Care for People Living with HIV 2018’ both make recommendations in the context of considering comorbidities in people living with HIV^{[92], [95]}. This includes factoring comorbidities into decision-making when selecting appropriate ART treatment regimens^[95] and recommending that HCPs, such as pharmacists, receive training in HIV-related areas and associated comorbidities, reflecting the proportion of their role allocated to HIV clinical care^[92].

BHIVA guidelines highlight that people living with HIV should have access to services to safely manage comorbidities, in collaboration with the appropriate non-HIV specialist team and/or primary care. Services should seek to agree local arrangements for the management of comorbidities where the roles and responsibilities of different agencies are clear, and lines of communication are robust. Clear pathways should exist for entry into more specialist services where people have less common or more complex problems^[92].

BHIVA will soon be releasing the results of their 2018 national audit of HIV monitoring and assessment in older adults.



Mental health services?

NHS England’s service specifications ‘for specialised HIV services (adults)’ state that all people living with HIV should have access to peer and psychosocial support^[94]. Extensive recommendations are also present in the ‘Standards for psychological support for adults living with HIV’, which outline a stepped care model for psychological support provision^[117].

For people living with HIV, it is recommended that following diagnosis or other changes in circumstance (e.g. changes to ART, difficulties with adherence) a mental health assessment is carried out. This is in addition to an annual assessment, a review of mental health management and promotion of mental health services^[92]. The target is to reach 90% of all new patients, with documented evidence of discussing peer and emotional support and signposting to appropriate services as required.

Both clinical guidelines and NHS England’s national service specification for HIV specialised services^{[92], [101]} clearly set out supportive services as being an essential part of the care pathway.

Standards detail that immediate emotional support should be given from the practitioner reporting the test result, and if more in-depth counselling or other support is urgently needed, rapid referral to an appropriate provider should be offered if this is beyond the competence or capacity of the test provider^[117].

Key

■ Policy available and effective

■ Room for improvement

■ Policy not available



Supportive services?

BHIVA guidelines recommend that people newly diagnosed with HIV should be able to access psychological and peer support within two weeks of receiving their HIV positive result^[92].

The BHIVA standards of care for people living with HIV outline that HIV outpatient units should have an agreed pathway to enable access to peer support as well as financial/housing advice and support^[92].

The Housing Act of 2004 states that people with disabilities, which includes people living with HIV, are one of the groups given priority when allocating housing^[102].

Additionally, the Welfare Reform act of 2012 established PIP, a welfare benefit available to those with a long-term health conditions, such as HIV, in replacement of DLA^{[102],[101]}.



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