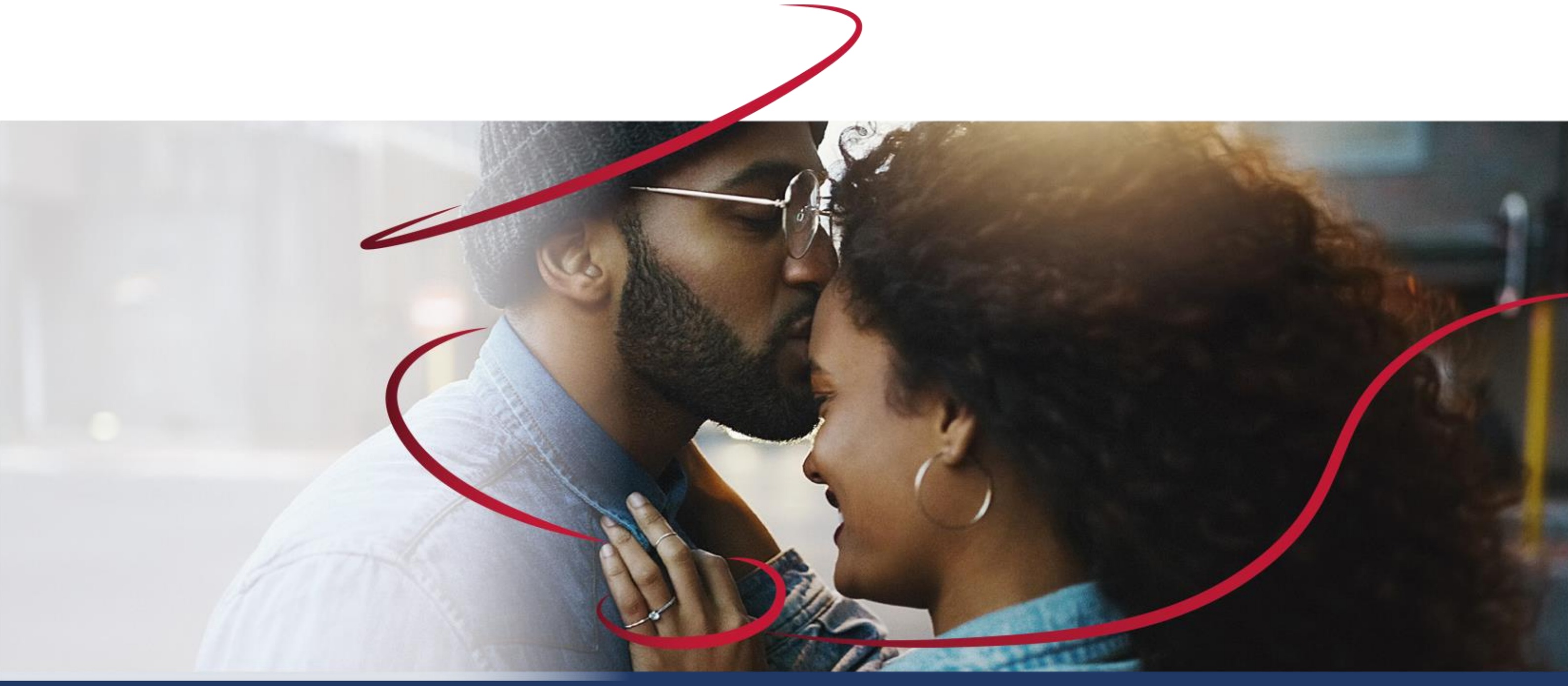

Building a national HIV action plan for all

Including people living with HIV to end new HIV transmissions in England

A briefing paper in support of England’s national HIV action plan

Rethinking LIVES IN HIV

UK-HIV-2021-02-0040 – DoP April 2021

Contents

Executive summary

The nature of the HIV epidemic in England has fundamentally changed in the past decade. Rates of new diagnoses are falling and people living with the virus can enjoy a near-normal life expectancy, meaning that HIV is increasingly a manageable long-term condition; a far-cry from the fatal virus that it once was.

With over 100,000 people living with an HIV infection in the UK, including 6,600 people in England who remain undiagnosed,[1] we cannot afford to be complacent. To successfully end new HIV transmissions, we must work together and place people living with HIV at the centre of a whole-of-society effort.

As we struggle to maintain services in the ongoing shadow of COVID-19, we neglect other health conditions at our peril, particularly other communicable diseases. HIV is both more preventable and more manageable now than it has ever been, but it would take only a short period without appropriate attention and funding to see transmissions soar again and the health of tens of thousands of people with HIV deteriorate.

At the same time, the COVID-19 pandemic reminded us of the importance of having a well-resourced voluntary sector. They have been taking a fundamental role in preventing, delaying and mitigating the negative impact of comorbidities among people living with HIV during times of uncertainty. Through the provision of welfare benefits advice, peer support, counselling and health and wellbeing services, the voluntary sector has enabled individuals to stay healthy and well. They often see people living with HIV more frequently than their doctors and as such, they must be supported, funded and included within any future action plans.

HIV stigma, discrimination and health inequalities continue to have a detrimental impact on how people living with HIV experience and access care. The number of people being diagnosed late remains too high, representing 42% of all new diagnoses.[2] People diagnosed late have an eight-fold increased risk of death.[3] In addition, inequalities across the prevention and care continuum have prevented progress being translated across all populations. Living well and getting older with HIV brings its own health and wellbeing issues and these vary starkly by protected characteristics, co-morbidities and lifestyle. The challenges include:

- **Quality of life –** for those living with HIV, whether it was acquired as an adult or at birth, health-related quality of life, self-rated health and life satisfaction all fare worse compared to that of the general population[4]
- **Co-morbidities and long-term conditions –** over half of people living with HIV report having a second long-term condition in addition to their HIV, and more than one in three were living with two or more other long-term conditions.[5]
- **Persistent stigma and mental health challenges –** around half of people living with HIV express mental health concerns, compared to just 24% of the general public.[6]
- **Continuing inequalities in the experience of care –** ethnicity, gender and other existing indicators of social inequality also impact HIV care: for example, some Black, Asian and minority ethnic people living with HIV are less informed about HIV and therefore less likely to extract maximum benefit from their care.[7]

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[1] Public Health England, Trends in HIV testing, new diagnoses and people receiving HIV-related care in the United Kingdom: data to the end of December 2019, November 2020
[2] Terrence Higgins Trust, HIV statistics, November 2018
[3] Public Health England, Trends in HIV testing, new diagnoses and people receiving HIV-related care in the United Kingdom: data to the end of December 2019, November 2020
[4] National survey of people living with HIV, Positive Voices, January 2020
[5] National survey of people living with HIV, Positive Voices, January 2020
[6] Public Health England, Progress towards ending the HIV epidemic in the United Kingdom, November 2018
[7] National AIDS Trust: HIV and Black African Communities in the UK, Policy Report, June 2014

- **Barriers to access –** issues relating to fragmented HIV service provision (both HIV and co-morbidity management) and barriers to accessing new and innovative HIV treatments mean that people living with HIV may not be receiving optimal health management. In addition, stigma and poor knowledge about HIV within the general healthcare system acts as a barrier to those in need of services.

The Government has committed to end new HIV transmissions by 2030, however in order to achieve this, the Department of Health and Social Care must develop a strategy and action plan that addresses the needs of people living with HIV. This action plan must tackle the issues highlighted above while also embedding the learnings from the COVID-19 pandemic.

With significant changes underway throughout the public health system in response to COVID-19 and the reorganisation of local and national public health services (including Integrated Care Systems, the UK Health Security Agency, and a new office of Health Promotion within the Department of Health and Social Care), now is the time for a comprehensive, fully funded and measurable national HIV action plan that places people living with HIV at its core. This is to ensure optimising access to life-saving innovations and services as well as to provide support for people living with HIV and those at risk of acquisition.

Living well and ageing with HIV brings its own health and wellbeing issues and these vary starkly by protected characteristics. This paper outlines several essential recommendations for national and local government to ensure that everyone with HIV in England is supported to live and age well. It should be read alongside the recommendations of the HIV Commission, which focus on ending new HIV transmissions by 2030.

The current situation presents opportunities to not only halt this threat but also to make significant improvements for people living with HIV and those at continuing risk of it that must be seized. A new national strategy is a vital baseline component of this. Gilead stands ready to work in partnership with the entire HIV. We look forward to working collaboratively with stakeholders across government, charities, professional organisations and interested groups to make these recommendations a reality.

Our recommendations

Recommendations: Getting to zero new HIV infections

- Ensure the HIV Commission’s recommendations to end new HIV transmissions by 2030 in England are fully implemented and funded by local and national government through an overarching and measurable national HIV Action Plan and Sexual Health strategy, including a continued focus on prevention, stigma reduction, quality of life and leadership

Recommendations: Living and ageing well with HIV

- Ensure that services are commissioned and measured based on the BHIVA standards of care for people living with HIV.
- Define and formalise measurements related to health outcomes for people living with HIV, including a ‘4th 90’ on quality of life.
- Ensure plans are developed that will enable health services to introduce innovative, and more effective treatments and technologies for people living with HIV.
- Make sure primary care professionals are trained to monitor and deliver regular comorbidity checks for people living with HIV.

Recommendations: Tackling discrimination, stigma and mental health issues

- Renew and reinvest in public awareness campaigns, including a focus on Undetectable equals Untransmittable (U=U) and include U=U in clinical guidelines.
- All NHS staff must be trained to understand the complexity and diversity of the needs and requirements of people living with HIV.
- Introduce information on combination HIV prevention within the new curriculum for Relationship Education, Relationships and Sex Education and Health Education (RSE).
- Commit to the recommendations from the report ‘The missing link – mental health and HIV’[8] published in March 2020 by the APPGs for HIV/AIDS and for mental health.

Recommendations: Reducing inequality in the experiences of care

- Provide and enhance peer support services aiming to address the needs of key populations.
- Ensure a smooth transition from paediatric to adult services.
- Carry out further research to understand the disproportionate impact of COVID-19 on ethnic minority communities living with HIV.
- Women must be prioritised in any policy and research agenda in order to better understand their care needs.

Recommendations: Improving commissioning of HIV services

- Resolve the fragmentation of HIV care and commissioning and capitalise on the opportunities presented by integrated care systems.
- Ensure equality, diversity and inclusion assessments are carried out when commissioning services.

Recommendations: Preparing the system for innovation

- A person-centred approach should be implemented across the entire care pathway. This must be developed in partnership with community-based organisations to ensure individuals can access the best available innovation for prevention, treatment and care based on their medical and personal needs.
- Embedding person-centred approaches while also ensuring that prescribing guidelines are relevant, up-to-date and enshrine enough flexibility to appropriately support individualised care.

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[8] All Party Parliamentary Group for HIV and AIDS and the All Party Parliamentary Group for Mental Health, The missing link - mental health and HIV, March 2020

- Encourage the appropriate adoption of digital care technologies, while providing training for clinicians and people living with HIV, to ensure technology is used and standards maintained.

Recommendations: An effective long-term plan for HIV

- Ensure that a comprehensive HIV strategy is a core component of the Government’s future public health plans.
- Additional financial investment should be provided by national and local governments to meet the 2030 goals to eliminate new HIV transmissions while supporting people living with HIV.

Section 1: HIV in England

Since its peak in the 1990s, England, like the rest of the UK, can point to strong and sustained progress in bringing HIV under control through the roll out of several HIV and sexual health strategies. However, the most recent sexual and reproductive health and HIV: strategic action plan expired in 2019 leaving us without a national government strategic approach to our nation response to HIV.[9]

There have been improvements in prevention, care, diagnosis and treatment, and we have seen new infections fall steadily. We have also seen AIDS-related deaths drop to below a quarter of their 1994 level, with 98% of people diagnosed with HIV now receiving treatment and 97% of those on treatment having an undetectable viral load.[10]

As a result, in 2019 the UK overall and England individually was able to announce for the third consecutive year that it had met UNAIDS' 90:90:90 targets – 90% of people with HIV diagnosed, 90% receiving treatment, and 90% virally suppressed.[11]

However, amidst this broadly optimistic picture, serious challenges remain that will require continued attention and action from policymakers. Success in the HIV response has not translated equally across communities. Women, young people and ethnic minority groups have not seen the same level of success as other groups. The HIV Commission was convened in recognition of this, and we need to make sure that it's ambition to end HIV transmissions by 2030 is met. However, this cannot be the sole area for national focus; we require an overarching approach to also support those already living with HIV.

We know, for instance, that people living with HIV are disproportionately vulnerable to a wide range of other conditions, which complicate both care and everyday life. Indeed, people living with HIV are:

- 77% more likely to develop cardiovascular diseases and 84% more likely to have a heart attack than the general population[12]
- Four times more likely than the general population to develop chronic kidney disease[13]
- At greater risk of developing cancer at a younger age, particularly lung cancer, liver cancer and Hodgkin lymphoma[14]

Furthermore, research from Gilead and leading charities has revealed concerning disparities in the way that different sub-groups of the HIV population engage with, and benefit from their care.[15] For example, the survey shows that Black and minority ethnic people living with HIV feel less informed about their condition than non-ethnic minority groups, see figure 1 below. The survey also shows that this group are seemingly less content and comfortable with changes to their treatment programme than others: just 30% of ethnic minority people living with HIV reported being happy with a decision to change treatment, compared to 59% of non-ethnic minority people living with HIV.[16]

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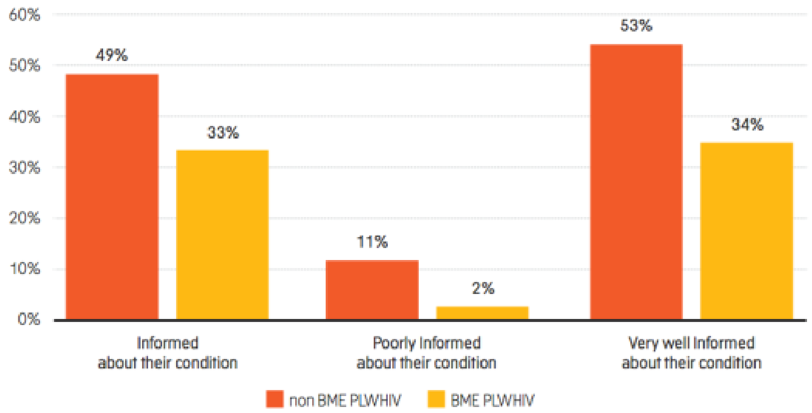
[9] Public Health England, Health Promotion for Sexual and Reproductive Health and HIV, December 2015
[10] Public Health England, Trends in HIV testing, new diagnoses and people receiving HIV-related care in the United Kingdom: data to the end of December 2019, November 2020
[11] ibid
[12] M. Daskalopoulou et al., "HIV as a risk factor in the initial presentation of a range of cardiovascular, coronary, cerebrovascular, and peripheral arterial diseases", UCL; Edinburgh, P178, April 2018
[13] V. Pourcher, et al., "Comorbidities in patients living with HIV compared to matched non HIV controls", IAS 2017. Paris, France. Poster #TUPEA0145, July 2017
[14] M.L. Nguyen et al., "Non-AIDS defining malignancies in patients with HIV in the HAART era", Current Infectious Diseases Reports, 12:46, January 2010
[15] Gilead Sciences, Striving towards health equalities in HIV, February 2019
[16] ibid



This disparity matters because individual engagement in care is an important component of successful long-term condition management.

Well-informed people living with HIV are better placed to work collaboratively with their clinician to tailor a care plan that suits their clinical and everyday needs. The survey found that lower levels of patient-information translated to poorer experience and worse self-reported outcomes for minority ethnic people living with HIV.[17]

Moreover, mental health, stigma and discrimination continue to be issues which have wide-ranging implications for those affected. In their 2020 report surveying 4,400 people living with HIV in England and Wales,[18] Positive Voices showed that of those surveyed:

- 49% of people living with HIV experienced mental health concerns compared to 30% of the general population. The biggest differences in proportions experiencing mental ill health for men and women were seen in those over 55.
- 16% are worried that they would be treated differently because they were HIV positive, a concern that was higher for men than women, and of those worried, 10% had avoided seeking healthcare when they needed it in the past year.
- 59% of those surveyed had been diagnosed with a long-term condition in addition to their HIV, with 42% on medication for these conditions, including mental health. As with the general population, these conditions increased in prevalence with age.
- 33% said access to HIV services had become more difficult over the past two years, more noticeably in London than in the North of England.
- When asked about unmet needs, 20% of participants said they had experienced this in the past year in HIV services, 45% felt it in other health-related services, and 62% in social and welfare needs.
- 14% of people living with HIV were unemployed which is more than triple that of the general population (4%), with unemployment highest in trans people.

The comprehensive national strategy for HIV should set out not only a roadmap to ending HIV transmissions by 2030, but also a bold, integrated approach to improving the quality of life of adults and children already living with HIV. By bringing together prevention and care policies in this way, such a strategy would fill the current policy-making gap and lay the foundations for a modern, world-leading approach to HIV.

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[17] ibid

[18] National survey of people living with HIV, Positive Voices, January 2020

Section 2: The importance of Getting to Zero

We strongly welcome the ambitions of the HIV Commission to end new infections by 2030. This is a positive step and shows the UK as a world leader in HIV provision. However, we are clear in this document that a focus solely on getting to zero new transmissions is just a first step, and in parallel the country needs to support all those living with HIV in the UK to live and age well.

Nonetheless, the ambition to get to zero new transmissions is admirably bold; an aim that will positively impact the lives of thousands of people in this country. We fully support this vision and believe that the outcomes and recommendations of the report from the HIV Commission should be a core component of a national HIV action plan and a Sexual Health strategy, alongside our proposals.

- **Recommendation: Ensure the HIV Commission's recommendations to end new HIV transmissions by 2030 in England are fully implemented and funded** by local and national government through an overarching and measurable national HIV Action Plan and Sexual Health strategy, including a continued focus on equitable access to prevention, stigma reduction, quality of life and leadership.

Section 3: Living and ageing well with HIV

We know that for those living with HIV, whether they acquired it as an adult or were born with it, health-related quality of life, self-rated health, and life satisfaction all fare worse compared to that of the general population.[19] Quality of life has become widely accepted as a 4th branch of the existing UNAIDS 90:90:90 targets.

As the overall HIV population ages, new and complex demands will be placed on the broader healthcare system across both primary and secondary care requiring a significant shift in the structure and focus of HIV services. The British HIV Association (BHIVA) has set several proposed standards for the routine monitoring and assessment of people living with HIV, however, many are not being met, including those relating to bone fracture risk and ten-year cardiovascular risk.[20]

Providers, both HIV specialists and across the wider NHS, must be supported to better deal with the complex reality of extensive HIV-associated comorbidities. A failure to do so will not only be a disservice to people living with HIV, it will also place significant strain on other parts of the health system.

The Positive Voices report covers 29 different types of HIV health and social services which people living with HIV accessed in the previous year. [21] It also found that 49% needed information about living with HIV and 43% needed support in managing other long-term conditions. In order to support the system and individuals we need to:

- **Recommendation: Ensure that services are commissioned and measured based on the BHIVA standards of care for people living with HIV.**[22] Concrete commitments would make sure treatments are delivered promptly, enabling quality of life improvements by the most appropriate care provider.

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[19] National survey of people living with HIV, Positive Voices, January 2020
[20] Ekong, N, BHIVA National Clinical Audit, HIV monitoring and assessment in older adults, 2018
[21] National survey of people living with HIV, Positive Voices, January 2020
[22] A. Molloy et al., "Routine monitoring and assessment of adults living with HIV", BMC Infectious Diseases, September 2017

- **Recommendation: Define and formalise measurements related to health outcomes for people living with HIV, including a '4th 90' on quality of life.** England should lead the way in putting forward standards and targets to measure quality of life for people living with HIV. A '4th 90' focusing specifically on quality of life, to sit in conjunction with the existing UNAIDS' 90:90:90 targets, will be a critical success factor in supporting the care and treatment of people living with HIV.

- **Recommendation: Ensure plans are developed that will enable health services to introduce innovative and more effective treatments and technologies for people living with HIV.** Historically, the NHS has been slow to adopt and roll-out innovative treatments and technologies. Health bodies should ensure plans are developed that streamline the roll-out of new treatments with reduced side effects and more efficient technologies to help people live well with HIV as they get older

- **Recommendation: Make sure primary care professionals are trained to monitor and deliver regular comorbidity checks for people living with HIV.** Improving cooperation between primary and secondary care is an important first step. However, HIV services must improve the delivery of regular comorbidity checks by professionals fully and by supporting community-based services that reach key populations.

Section 4: Tackling stigma, discrimination and mental health issues

Evidence shows there are continuing issues relating to stigma, discrimination and associated implications around mental health for people living with HIV. For example, PHE has commented, using data from Positive Voices, that in every age group and each gender, people living with HIV reported worse mental health than the general public.[23] Furthermore, only 1 in 6 (17%) in the Positive Voices survey felt able or willing to disclose their HIV diagnosis beyond immediate friends, partners and family.[24]

Repeated surveys and reports of people living with HIV, including the Positive Voices survey, show that healthcare settings (not run by HIV specialists) continue to have some of the highest incident rates of stigmatisation and discriminatory experiences for this group.[25,26] One in ten respondents to the Positive Voices survey avoided seeking general healthcare in the previous year, in an effort to hide their HIV status.[27] These patterns of behaviour risk further health damage and convey the entrenched stigmatisation surrounding the disease. Indeed, almost 40 years after HIV was first seen in the NHS, people living with HIV continue to report ongoing educational deficits amongst those treating them, particularly among non-specialist staff such as GPs and nurses.[28]

It is also important to consider HIV through the lens of intersectionality. HIV variably affects different sub-groups of the population, including across gender, ethnicity, cultures, and sexuality. Many of those most at risk of HIV are also potentially facing other weighty and contentious social issues such as: substance abuse, economic inequalities and inequality of exposure to harm.[29] We know that stereotyping, discrimination and intersectional inequalities can both impact the mental health of people living with HIV from marginalised groups and reduce their ability to seek and access care.[30]

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[23] Public Health England, Progress towards ending the HIV epidemic in the United Kingdom: 2018 report, 2018
[24] National survey of people living with HIV, Positive Voices, January 2020
[25] National Aids Trust, Changing Perceptions – talking about HIV and attitudes , November 2018
[26] King's Fund, Tackling stigma in the health service, blog series, December 2018
[27] National survey of people living with HIV, Positive Voices, January 2020
[28] ibid
[29] Watkins-Hayes, C, Intersectionality and the Sociology of HIV/AIDS: Past, Present and Future Research Directions, Annual Review of Sociology, 2014; 40, 431-457, July 2014
[30] ibid

For young people, this is heightened by inadequate education on HIV and sexual health in schools. Although this is now under reform, these inadequacies currently put young people at risk and fuel stigma.

If the general population were to become more aware through public messages about the realities of HIV, especially the U=U principle (which shows that undetectable levels of HIV render it untransmittable), it would greatly reduce the psychological toll on those who live with the virus.

For many living with HIV, the first time they hear about U=U is during discussions with their HIV clinicians. However, these discussions are limited and some people living with HIV still report not having discussed U=U with their health care professional. Evidence shows that those who do have such discussions have favourable health outcomes as such conversations should be mandated in clinical guidelines.[31]

The All-Party Parliamentary Group (APPG) on HIV and AIDS and the APPG for Mental Health 2020 joint report '*The Missing Link – HIV and mental health'*,[32] outlined a number of urgent recommendations for Government and public bodies across health, education and employment policy. It also reinforced the need for a national strategy to overcome the major challenges faced.

Mental health-related addiction issues are also frequently seen in HIV clinics, including dependency on recreational drugs to enhance sex (chemsex). This often falls through commissioning gaps as drug and alcohol services are commissioned by local authorities but do not necessarily treat non-traditional chemsex drugs or associated mental health issues. A study found that 20% of gay and bisexual men with HIV had engaged in chemsex in the past three months.[33]

There is a need to have a wider spectrum of mental health services and support available, some of which are currently delivered by the voluntary sector making it more accessible to people living with HIV. The spectrum ranges from buddying, peer support, counselling, psychology and health and wellbeing related services. Having a wider range of funded services would help have a more preventative approach avoiding the need for escalation.

- **Recommendation: Renew and reinvest in public awareness campaigns, including a focus on Undetectable equals Untransmittable (U=U) and include U=U in clinical guidelines**. These campaigns need to build on the work currently done by the voluntary sector. This would not only reduce much of the stigma and misperceptions of HIV that people living with HIV endure throughout their lives, it would also likely result in people living with HIV improving their understanding of the importance of adherence to treatments

- **Recommendation: All NHS staff must be trained to understand the complexity and diversity of the needs and requirements of people living with HIV**. This will reduce unintentional stigma and discrimination and enhance the likelihood of positive messages about healthy living with HIV, also improving clinical interactions

- **Recommendation: Introduce information on combination HIV prevention within the new curriculum** for Relationship Education, Relationships and Sex Education and Health Education (RSE)

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[31] National Aids Map, Third of people living with HIV have not discussed U=U with their healthcare provider, September 2020

[32] All Party Parliamentary Group for HIV and AIDS and the All Party Parliamentary Group for Mental Health, The missing link - mental health and HIV, March 2020

[33] National survey of people living with HIV, Positive Voices, Jan 2020

- **Recommendation: Commit to the recommendations from the report '*The missing link – mental health and HIV'*** published in March 2020 by the APPG for HIV/AIDS and the APPG for Mental Health as this covers health, education and employment policy to tackle stigma, discrimination and mental health issues for people living with HIV

Section 5: Reducing inequalities in the experience of care

Despite continuous medical advances over the past 30 years, there have been, and continue to be, inequalities in the experience of care across those groups most impacted by HIV. We know for instance, that there are specific and separate concerns around rates of transmission, access to care, and late diagnoses within marginalised groups across the population including gay and bisexual men, Trans communities, migrants, children, women, Black, Asian and other minority ethnicities, and older people.

The reproductive health needs of women living with HIV remains a neglected area of study. For example, there are many gaps on data around their menopause experience, a women's quality of life and their ability to adhere to health-sustaining behaviours.[34] Other gaps in data are about the experiences of ethnic minority groups. Current data collection systems do not capture the ethnic diversity present in England. For example, Latino Americans and people from the Middle East continue to be recorded as 'mixed/others' impacting our understanding for their care and needs[35].

We also know that late HIV diagnoses are associated with a tenfold increase in mortality, with Black African heterosexual men being disproportionately more likely to be diagnosed late in England (65% diagnosed late).[36] Regional variations in HIV which underline many inequalities are made clear by HIV Lens, an online tool providing clear regional data across England.

A key population who continue to experience inequalities are Trans people who consistently report the lowest health-related quality of life compared to other people living with HIV and the general population. They are also the group most likely to not disclose their HIV status to anyone outside a health care setting, at 20% non-disclosure rate.[37]

Evidence suggests that lower socioeconomic status can also lead to poorer virologic outcomes on treatment in the UK.[38] The reasons for this may include competing responsibilities and stress, uncertain living situations, food insecurity, increased prevalence of mental health issues or less knowledge about the importance of treatment adherence.

The COVID-19 pandemic has contributed to highlighting existing inequalities and, similarly to HIV, has had the greatest impact on those who are already marginalised, such as ethnic minority groups.[39] The continuing strain which this presents in contributing, alongside other factors, to a general economic downturn which will inevitably impact NHS and social care services and increase pressure for service reforms.

There must be a renewed effort to strengthen HIV services for everyone, with specific support for the different groups affected. We have highlighted those for ethnic minority groups, women and older people above, but the following should also be included:

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[34] Tariq S, Delpech V, Anderson J. The impact of the menopause transition on the health and wellbeing of women living with HIV: A narrative review. Maturitas. Mar 18

[35] HIV Commission, England, December 2020.

[36] Morriss, E, New online tool pinpoints HIV health inequalities in England, Pharmafield, June 2020

[37] National survey of people living with HIV, Positive Voices, Jan 2020,

[38] Burch, L.S et al., Socioeconomic status and treatment outcomes for individuals with HIV on antiretroviral treatment in the UK: cross-sectional and longitudinal analyses, The Lancet Public Health, November 2016; 1, 26-36

[39] Public Health England, Beyond the data: Understanding the impact of COVID-19 on BAME groups, June 2020

- **Recommendation: Provide and enhance peer support services aiming to address the needs of key populations**. Peer support services are essential in addressing the mental health needs of key populations and supporting adherence to effective HIV treatment. This includes those from lower socioeconomic backgrounds, communities where English may not be their first language, and groups with high HIV prevalence

- **Recommendation: Ensure a smooth transition from paediatric to adult services**. Young people who have acquired HIV from birth are particularly vulnerable to mental health crises for a number of reasons and there is great concern that as adolescents are moved into adult services, where there is less specialised care, they are at a trigger point for a mental health crisis

- **Recommendation: Carry out further research to understand the disproportionate impact of COVID-19 on ethnic minority communities living with HIV**. This should seek to ensure any learnings are taken forward in the HIV pathway.

- **Recommendation**: **Women must be prioritised in any policy and research agenda in order to better understand their care needs**. The experiences of women living with HIV are under-addressed and under-recognised. It is essential to ensure that women's needs are understood but also to explore how individuals and communities are coping, and where this can be better supported. Importantly, this should include community, and not just an individualised understanding of what it means to live and age with HIV.

Section 6: Improving commissioning of HIV services

The 2012 Health and Social Care Act weakened the relationship between HIV clinical services and sexual health services causing disruption to care by separating commissioning powers.[40] Over the past two years Integrated Care Systems (ICS) have been formed across England. These bodies have large local footprints and seek to create an integrated care system, with NHS organisations in partnership with local councils and others, taking collective responsibility for managing resources, delivering NHS standards, and improving the health of the population they serve.[41]

Any endeavour to improve collaboration and integrate different elements of the health and care systems should be welcomed and supported. They should consider the following recommendations to ensure that the commissioning of HIV services removes barriers to accessing care and treatment and ensures that inequalities are tackled. This will help resolve any delays in diagnosis and bottlenecks caused inadvertently by the system.

- **Recommendation: Resolve the fragmentation of HIV care and commissioning, and capitalise on the opportunities presented by integrated care systems.** Any reforms to the health system should seek to bridge gaps in commissioning and set out clearly how there will be seamless co-operation between different components of the HIV care pathway. Commissioning must be done against national standards to avoid inconsistencies in outcomes.

- **Recommendation: Ensure equality, diversity and inclusion assessments are carried out when commissioning services.** To ensure equality across the different protected groups living with HIV, an equality impact assessment (EQIA) needs to be carried out when commissioning and contracting services

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[40] The All-Party Parliamentary Group on HIV & AIDS, The HIV puzzle: Piecing together HIV care since the Health and Social Care Act, 2016
[41] NHS England, Integrated Care System, last accessed February 2021

Section 7: Preparing the system for innovation

Over the course of the last four decades we have seen continual advances in HIV care and treatment, including an exponential increase of life expectancy for people living with HIV. Anti-retroviral therapies (ARTs) have been transformative and innovations such as triple therapy and single tablet regimens have been at the heart of this trend. Furthermore, there have been longer term benefits from innovative ARTs which minimise viral load, require less clinical monitoring, and are well tolerated by people living with HIV. This supports adherence, decreases footfall of people living with HIV in clinical settings and reduces the burden on healthcare professionals. Similarly, advances in the technology of testing have enabled us to improve access and cost-effectiveness.

As further innovations arise, the UK health system must be flexible, promoting the uptake of value-added treatments and designating funds to ensure that people living with HIV who choose to access these new innovations can do so, and ensuring clinicians have the ability to prescribe them.

Innovation does not apply to treatment alone. The COVID-19 pandemic has led to global and unprecedented disruption for health systems, economies and everyday life. People living with HIV, who have been unable to access treatment or were told to shield, have been disproportionately impacted by these changes. To deal with this disruption, we have seen great shifts in our healthcare systems with positive changes emerging, such as the rapid introduction of new technologies.

Digital services such as telemedicine, for both HIV prevention and management, can remove barriers to care, including by reducing travel times, offering convenient alternatives to attending clinics and avoiding any stigma associated with seeking HIV care – particularly for younger people living with HIV.[42]

Throughout the pandemic, people living with HIV who were vulnerable and in need of shielding have been able to use digital appointments and tele-health to ensure they continued to be supported. For people living with HIV, the offer of these digital services should continue as health services recover from the pandemic alongside measures to ensure that the minority who do not have access to technology or who need a more traditional approach can still obtain treatment and care.

- **Recommendation: A person-centred approach should be implemented across the entire care pathway**. This must be developed in partnership with community-based organisations to ensure individuals can access the best available innovation for prevention, treatment and care based on their medical and personal needs.

- **Recommendation: Embedding person-centred approaches while also ensuring that prescribing guidelines are relevant, up-to-date and enshrine enough flexibility to appropriately support individualised care.** People living with HIV must be put at the centre of their care, and it is paramount that as innovative treatments come through the pipeline, the system is flexible enough to adopt new innovations and ensure that people living with HIV receive the treatments that are right for them in a timely way.

- **Recommendation: Encourage the appropriate adoption of digital care technologies, while providing training for clinicians and people living with HIV, to ensure technology is used and standards maintained.** Since telemedicine holds the potential to make outpatient services more convenient and efficient, NHS Digital should look to support the development and/or utilisation of self-care management apps for people living with HIV,

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[42] Samuel, K, Is telemedicine for HIV here to stay?, NAM aidsmap, June 2020

and health practitioners should be supported and trained to use the tools available. For example, the national adoption of Patient Activation Measure (PAMs) and Patient Reported Outcome Measures (PROMs) will enable services to tailor specific support for patients.

Section 8: An effective long-term plan for HIV

The Health and Social Care Act 2012 saw cuts to public health funding and since then concerns have existed around pressure on services and a lack of investment in HIV prevention and testing.

In 2015/16, the public health budget was cut by £200 million[43] and this led to a further 12% drop in HIV prevention funding during that period.[44] A joint report from the World Health Organization and the European Centre for Disease Prevention and Control highlights the financial challenges presented to HIV prevention programmes following the withdrawal of funding from the Global Fund to Fight AIDS, Tuberculosis and Malaria.[45] If funding continues to be cut, the chances of ending the epidemic, or getting to zero new transmissions by 2030, will be at significant risk.

To ensure success in taking this strategy forward, there needs to be full and appropriate funding to ensure that 2030 goals are reached and people living with HIV receive the treatment, interventions and innovations they need to live well. Furthermore, a national strategy should include an action plan setting out measures for delivery.

The recent government announcement of a reorganisation of responsibilities for public health policy in England also adds uncertainty around the future policy direction and national responsibility for HIV.

As the Government develops its future approach to public health policy, it is vital that the need for a national strategy for HIV is recognised and appropriately funded, with clear roles and responsibilities defined across the health system.

- **Recommendation: Ensure that a comprehensive HIV strategy is a core component of the Government's future public health plans.** Any national strategy must include an action plan setting out measures for delivery.

- **Recommendation: Additional financial investment should be provided by national and local governments to meet the 2030 goals to eliminate new HIV transmissions while supporting people living with HIV**. We cannot meet our goals without specific funds to do so, and people living with HIV should not be forgotten. Specific funds should be allocated to meet these parallel aims. These can look to recover the impact of cuts to public health budgets since 2015 which have disproportionately affected sexual and reproductive health services,[46] whilst also improving future outcomes for people living with HIV.

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[43] Gold, D et al., Investment in HIV prevention and testing in England, National AIDS Trust, May 2017
[44] ibid
[45] World Health Organization, HIV & AIDS, surveillance in Europe 2019 – 2018 data accessed November 2020
[46] Bayliss, A et al. The future of HIV services in England – Shaping the response to changing needs, The Kings Fund, April 2017

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