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The HIV Outcomes UK programme is funded by Gilead Sciences and ViV Healthcare as co-sponsors

Unlocking synergies between Core20Plus5 and HIV response

November 2023

HIV Outcomes

HIV Outcomes UK is a coalition of HIV experts working to secure policy, practice and evidence changes to improve the health-related quality of life (HRQoL) for people living with HIV in the UK.

Working in partnerships, we are delivering policy projects focused on:

- **Tacking stigma as a barrier to care**
- **Driving better HIV care engagement, integration and coordination**
- **Better meeting the mental health needs of people living with HIV**
- **Improving approaches to information, data and confidentiality in the NHS**

The National AIDS Trust is proud to act as the secretariat for HIV Outcomes UK. We are affiliated with HIV Outcomes at a European level.

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Introduction

The reduction in HIV transmission and support provided for people living with HIV is a NHS success story. There has been a 44% reduction in new HIV diagnoses in England between 2015 and 2022.¹ England is also exceeding the UN's 95-95-95 targets for 95% people living with HIV knowing their status, being on treatment and having an undetectable viral load. Thanks to this progress, the UK Government's target of ending new HIV transmissions by 2030 could be in reach.

However, there are glaring disparities in progress on HIV between different groups. Whilst it is encouraging we are seeing falling HIV diagnosis amongst white gay and bisexual men, diagnoses have increased in the last year amongst heterosexual men and women, as well as gay and bisexual men of other ethnicities. To end all new HIV transmissions in England by 2030, action must be taken to end the disparities in HIV prevention, treatment, and care.

Integrated Care Systems (ICSs) will play a key role in determining whether we can reduce health inequalities, and HIV transmissions, by 2030. Action on the HIV response provides a key opportunity to complement ICS's work on the Core20PLUS5 approach. Core20PLUS5 is NHSE's approach to inform action to reduce healthcare inequalities at both national and system level.² The approach defines a target population – the 'Core20PLUS' – and identifies '5' focus clinical areas requiring accelerated improvement.

The Core20PLUS5 approach can be used to advance progress towards both targeted reducing of overall healthcare inequalities and glaring disparities in HIV outcomes. And with a history of innovation and community leadership in the HIV response, ICSs can use this approach as a blueprint for aligning innovation to tackle broader health inequalities alongside the national innovation for Healthcare Inequalities Improvement Programme.³

The HIV response is also an exemplar for person-centred, integrated care for long term conditions. People living with HIV are more likely to have multiple, long-term conditions that require support from different services. There are a lot of learnings from the HIV response for other long term conditions. Through work on the HIV response, ICSs have an opportunity to develop best-practice approaches for integrated care, long-term condition management and to deliver on the commitments made in the Major Conditions Strategy.⁴

As explored in the tables in the annexe, there are strong correlations between some of the characteristics of people living with HIV and both 'Core20PLUS' communities. The five priority clinical focus areas also overlap with the clinical conditions faced by people living with HIV. Core20 includes the most deprived 20% of the national population as identified by the national Index of Multiple Deprivation (IMD). Poverty and HIV outcomes are also inextricably linked, with individuals living in poverty facing a higher risk of acquiring HIV⁵ and experiencing more adverse health outcomes.⁶

People living with HIV are more likely to be living in poverty, with levels of poverty seen in people living with HIV aged 55+ double those seen in the general population.⁷

PLUS population groups should be identified at a local level and people living with HIV may share characteristics with the PLUS population groups. Given the intersectionality of people living with HIV in all their diversity, interventions will also help to address the broader health inequalities faced by these communities and 'inclusion health groups'. Inclusion health is an umbrella term used to describe people who are socially excluded, who typically experience multiple interacting risk factors for poor health. People in inclusion health groups tend to have poor experiences of healthcare services because of barriers created by service design.

Reducing healthcare inequalities is a NHSE priority and the Inclusion Health Framework is intended to help ICSs improve access, experience and outcomes for people in inclusion health groups.⁸

A key priority of the Government's HIV Action Plan is to improve the quality of life for people living with HIV and address stigma.⁹ As part of a combination prevention approach, efforts are taken to ensure that people diagnosed with HIV are referred into care promptly and stay in care.

The HIV Action Plan recognises that some people may experience challenges in prioritising their HIV care and adherence to treatment if they are experiencing personal, financial, housing, immigration, or mental health difficulties.¹⁰ ICSs should give particular consideration for interventions that improve people's health related quality of life (HRQoL) within the Core20PLUS approach.

This briefing for ICS representatives, NHS leaders and other stakeholders working to address health inequalities and the HIV response, highlights the synergies between Core20PLUS5 and the HIV response at a national and system level.

Considering the priorities of people living with HIV from 'Core20PLUS communities', **this briefing highlights practical actions that ICSs can take to support the Core20PLUS5 approach and also improve HIV outcomes.** It provides case-studies on cost effective interventions that address key health inequalities that ICS should consider to advance improvements in healthcare inequalities with aims of:

- **Re-engaging people in HIV care.**
- **Supporting mental health needs of people living with HIV.**
- **Preventing late HIV diagnosis.**

HIV Outcomes UK looks forward to working with ICSs in the mutually aligned fight of addressing health inequalities and ending HIV transmissions.

Delivering against Core20PLUS5 and HIV aims at a system level

Equity based interventions on the five clinical focus areas will lead to improved health outcomes for people living with HIV, a demographic that is disproportionately affected by worse outcomes in these clinical areas.

In addition to action on the five clinical focus areas, guidance stipulates that ICSs are 'expected to see a measurable improvement in healthcare service access, experience and outcomes on their Core20PLUS population, thus reducing avoidable mortality'.¹¹ Issues around HIV prevention, treatment and support can be a key issue for ICS' Core20PLUS' populations. As explored in the below case studies, equity based interventions in the HIV response will also enhance productivity and value for money. For example, through seeking to prevent late HIV diagnoses and re-engage people in care, it will help to reduce hospital admissions, onward HIV transmissions and opportunistic infections.

Across different ICSs there will be varying levels of HIV prevalence, and different Core20PLUS communities that are living with or at greater risk of acquiring HIV. This underscores the importance of working with partners (including voluntary sector organisations) to identify target communities and local priorities. UKHSA data¹² should also be considered and UKHSA should plan to develop ICS-level datasets. Even if an ICS has a lower HIV prevalence, testing and support for people living with HIV should be ensured. This is particularly pertinent given that in areas with lower HIV prevalence, people living with HIV may experience worse outcomes, including late diagnosis. This could be due to social isolation, health services being less equipped to respond to the needs of people living with HIV, and local HIV support services having closed.

To take forward work on Core20PLUS5, ICSs should identify the needs of people with HIV and plan interventions that reduce inequalities. This will also accelerate the delivery of other strategies including the HIV Action Plan and Women's Health Strategy.

Strategies should be locally informed and co-created but key interventions on addressing inequities in the HIV response that ICSs should consider include:

- Re-engaging people not in HIV care.
- Supporting mental health needs of people living with HIV.
- Preventing late HIV diagnosis.

Re-engaging people not in HIV care

The number of people living with diagnosed HIV but not in care in England could be higher than the number of people with undiagnosed HIV.¹³ This is expensive for the NHS and society, and threatens elimination of HIV transmission. People not in HIV care are disproportionately from Core20PLUS communities. This includes people from the most deprived parts of the country, Black communities, women, young people and people who use drugs.¹⁴

Poverty and poor mental health create barriers for engaging in HIV care. For example, some people living with HIV report not being able to afford transport to attend appointments. And those without a secure immigration status may not be aware that HIV care is free and confidential.

To end this health inequality and reach the target of ending new HIV transmissions, greater action should be taken to re-engage people back into HIV care. Interventions have shown it is possible to effectively keep and re-engage people from 'Core20PLUS communities' back into HIV care, and provide a strong return on investment.

Taking a Core20PLUS5 approach to re-engaging people in care, ICSs should work in partnership to ensure:

- **All clinics in the ICS are working with UKHSA to identify people out of care based on a transparent data collection and reporting process that maximises trust in the accuracy of the data.**
- **Use of Patient Association communication and engagement check-list when developing engagement plans related to re-engaging people in care.**¹⁵
- **Co-developed strategies and commissioning for work on re-engagement including adequate funding for HIV support services and peer support.**
- **Local HIV services meet the holistic needs of people living with HIV, are responsive to community feedback and co-creation and are delivered in a culturally competent way.**
- **Learning and evidence sharing with other ICSs, and supporting calls for increased central Government funding for work on re engagement.**

Re-engaging people not in HIV care

South East London project to re-engage people in HIV care

In South East London, doctors observed that the majority of patients admitted with HIV related illness were known to have HIV and no longer in care rather than new diagnoses. A project involving three hospital trusts in South London sought to re-engage people living with HIV. Not being in care was defined as not attending clinic for > 12 months or being off treatment. Initial data on patients not seen for over a year was cross referenced by UKHSA to ascertain which patients were accessing HIV care at another UK clinic. Contact with patients who potentially left care was attempted by phone, text, email, coordination with the GP or community teams. Through reviewing UKHSA data and attempting to contact people (including finding people who had died or moved abroad), it was found that 824 patients had potentially left HIV care (out of 3 hospitals serving 8448 people living with HIV). As a result of the project, 153/824 (18.5%) patients were re-engaged back into care.

Highlighting the risk to their health, a third had a CD4 of <200 at re-engagement and half had a CD4 of less than 350 cells/ml. CD4 cell counts give an indication of the health of someone's immune system. The lower the CD4 cell count, the greater the damage to the immune system and the greater the risk of illness. People living with HIV who have a CD4 count below 200 are at high risk of developing serious illnesses.

'Core20PLUS communities' were more likely to not be in care - 45% patients came from the 1st and 2nd decile of most deprived areas in the UK, 74% of these were of Black ethnicity and 57% were female.

People leaving HIV care is driving considerable morbidity and mortality in South East London. Women, individuals of Black ethnicity, and people in the most deprived areas were disproportionately affected. As such people not in care represents a significant health inequality. A high proportion of reengaged patients had advanced immunosuppression. The project utilised significant clinical time. However this data demonstrates it is possible to reengage in HIV care, and the need for dedicated funding to ensure the most vulnerable are not left behind in the UK's HIV strategy.

George House Trust - Intensive Support

The need for targeted health and social care co-ordination for people living with HIV was identified by HIV clinical nurses in Greater Manchester as a gap in their 'complex care' provision.

Funded through Greater Manchester's Integrated Care System, George House Trust's Intensive Support Service provides person-centred social and wellbeing support to people living with HIV. The service is wholly focused on those who are experiencing significant challenges with their HIV treatment and care and the objective is to improve clinical and social outcomes and maintain engagement with care.

The one-to-one support follows a referral from the clinic for any patients with a detectable viral load. The support aims to address social problems in order to overcome barriers they face. The service recognises the impact of external factors on individuals that prevent the effective management of their HIV. Whilst these factors include adherence to medication, attendance at appointments and the effective management of other conditions that co-exist with their HIV that often have a negative impact on their HIV if not effectively managed, there are a much wider range of health and social impacts that complicate the situation for those referred to the service.

The programme works to support the individual in an accessible and straightforward way, with a single access point via the Intensive Support Worker. The ultimate goal is to place the individual in the position to improve their own circumstances with the right level of intensive support for them, which they can then eventually sustain on their own.

A critical element of the HIV Intensive Support Programme is embedding the workers within the HIV clinical multi-disciplinary teams, enabling a stronger understanding of the holistic needs of the individual, together with an understanding of their history and their barriers to engagement.

Progress and success are measured through a range of person-centred metrics including:

- **Medication adherence.**
- **Sustained undetectable viral load.**
- **Engagement with services.**
- **The Warwick Edinburgh Mental Health and Wellbeing Scale (WEMWBS).**

This best practice way of working, which takes a person-centred, integrated approach to meeting the holistic needs of people living with HIV, has very encouraging results. In the last 12 months, 57% of people supported through the programme had attained an undetectable viral load, meaning the levels of HIV are so low that the virus cannot be passed on. Furthermore, 95% had improved their engagement with clinical appointments and 78% reported an improvement in their emotional health and 83% an increase in their overall wellbeing.

Supporting the mental needs of people living with HIV

People living with HIV are disproportionately affected by poor mental health and interventions to support mental health are well aligned with the Core20PLUS5 approach. This applies to diagnosed mental illness as a common comorbidity with HIV, higher risk of low-level poor mental health that might require early intervention, and higher risk of severe mental illnesses such as schizophrenia.¹⁶

NAT found that the alternative, generic services provided through NHS Talking Therapies (NHS TT) are suitable for about half of people living with HIV experiencing mental ill health, while the other half need specialised provision.¹⁷ However, decommissioning of specialist HIV support services also means that peer support and community based HIV specialist counselling are not always available to those who need them. Despite this, there are successful examples of support services, often embedded in clinics in partnership with the voluntary sector.

In line with delivering Core20PLUS5 priorities, ICSs should work to ensure that people living with HIV across the UK have access to appropriate mental health care and support that meets their needs. Key to this is ensuring effective local pathways to or in-clinic provision of specialist care. This underscores the importance of ensuring ICS integration beyond physical health services. Through ICSs developing pathways and supporting other interventions to support mental health of people living with HIV, it will also help to develop learning and best practice for meeting the mental health needs of people living with other long term conditions.

Taking a Core20PLUS5 approach to supporting the mental health needs of people living with HIV, ICSs should work in partnership to ensure:

- **NHS TT practitioners take the e-learning training module on HIV. The training has been developed by NHS England with the involvement of several HIV Outcomes UK members and will be published in January 2024.**
- **Use of the Patient Association communication and engagement check-list when developing engagement plans related to mental health.¹⁸**
- **Mapping of what support services are available for communities living with HIV within an ICS.**
- **Optimised pathways designed for referral between HIV clinics and voluntary sector services and NHS Talking Therapies, prioritising clinics without specialist mental health provision.**
- **Funding for HIV support services, including peer support.**

NHS Staffordshire and Stoke on Trent Talking Therapies' Pathway for people living with HIV

Within South Staffordshire, a specialist pathway has been developed to offer a direct referral route from HIV services into the local NHS TT service.

A designated Long-Term Conditions trained cognitive behavioural therapist (CBT Therapist) is co-located within the sexual health clinic to offer assessments and therapy to people who may find it difficult to access the NHS TT service via usual referral routes. This has helped to forge closer links between the services and enable a seamless pathway where patients are not needing to tell their story multiple times. The CBT therapist attends the HIV clinic team meetings to discuss cases and is able to offer training to the clinic staff around identifying anxiety disorders and depression.

This best practice way of working, that looks to meet the integrated care needs of people living with HIV, has encouraging indicators. Initial feedback from patients who have used the pathway is positive as they are able to choose from face to face or remote consultation appointments according to their preference. To support those experiencing digital poverty, the service is supported by the Trust Digital Team to use the novel Komp devices (User friendly and secure technology for photo sharing, text messaging, and video calls) which can be loaned to patients who do not have smart devices to enable them to attend video consultation appointments for the duration of their therapy.

Patients may also refer into the core TT service via the usual self-referral routes and the CBT therapist is able to offer supervision and consultation to other clinicians in the service to support the work they are carrying out.

Embedding a CBT therapist into a sexual health clinic can be an effective way to help ensure that people living with HIV receive care that is coordinated and joined up between different parts of the system. It has however been noted that there is a high cancellation and non-attendance rate for TT assessments and reasons for this are important to understand to reduce the barriers. There is further work needed to reduce stigma associated with an HIV diagnosis and encourage people to access talking therapies if they feel this will benefit them. The Communications Lead is working with the clinical team with regard to how reaching out through social media could support this.

Preventing late HIV diagnosis

Late diagnoses remain stubbornly high with UKHSA data for England showing that 44% of new diagnoses in 2022 were late.¹⁹ Those diagnosed at a late stage in England in 2021, were 5 times more likely to die within a year of their diagnosis.²⁰ Aligned to 'Core20PLUS communities', the rates of late diagnosis are highest for heterosexuals, people of Black African ethnicity, older people and those who live outside London.

Opt-out testing has proven to be an incredibly effective tool in identifying people with HIV who are disproportionately affected by higher rates of late diagnosis. In the first 12 months of an opt-out testing programme in London, Manchester, Brighton and Blackpool A&E's, more than 2000 people have been found with HIV, Hepatitis B and Hepatitis C.²¹

In the first 100 days, the programme in the highest prevalence areas, cost £2 million but saved the NHS an estimated minimum of £6-8 million in care costs.²² In line with ICS objectives to enhance productivity and value for money, opt-out testing has relieved pressure on other parts of the health service. For example, for Croydon University Hospital, when they first started opt-out testing the average hospital stay for a newly diagnosed HIV patient was 34.9 days.²³ After two years of opt-out HIV testing, the average stay is now just 2.4 days.^{24,25} In November 2023, the Government confirmed the expansion of routine opt-out HIV testing to hospital emergency departments in all 32 areas of high HIV prevalence in England. With this more than doubling HIV testing capacity in England, ICSs should optimise care pathways and linkage to care, including through the provision of culturally relevant support services like peer support.

Community testing is another effective way to engage communities with higher rates of late diagnosis and prevent late HIV diagnosis. This is partly due to sexual health services being not always accessible or acceptable to populations at increased likelihood of acquiring HIV.²⁶ Community testing is often led by community organisations, delivered outside of traditional healthcare settings, and is designed to engage specific populations. Community testing can overcome many of the barriers to testing and reach those who may be less likely to engage in sexual health services, including some 'Core20PLUS communities'.²⁷

To prevent late diagnoses, ICSs should work in partnership to ensure:

- **Expansion of opt-out HIV testing across the ICS, including in primary care, to reduce late diagnosis and onward transmissions. ICSs should optimise care pathways and implement facilitators to linkage to care for both newly diagnosed and those previously diagnosed to ensure the opportunities offered opt-out testing initiatives are not wasted. Part of this approach should be support for community and voluntary sector initiatives, including peer support.**
- **Collaboration with Local Authorities to ensure that there are tailored and culturally-competent interventions for HIV testing, including scaled up community testing.**
- **Collaboration with Local Authorities to ensure provision of online and self-testing which has been shown to more effectively reach some 'Core20PLUS' communities.**
- **Use of Patient Association communication and engagement check-list when developing HIV testing strategies.²⁸**

London HIV GP Champions

One Health Lewisham (OHL), the GP Federation in Lewisham, ran a project to identify new HIV diagnoses in primary care and re-engage individuals living with HIV who were out of care. This was funded through the Elton John AIDS Foundation (EJAF) Social Impact Bond. Several tools were used to achieve the outcomes, but the key behind the project's success was the local leadership provided by a GP HIV Champion.

To encourage early HIV diagnosis, an opt-in approach to HIV testing was introduced in GP practices. Healthcare professionals were prompted to request an HIV test through computer-based reminders, making testing a routine part of patient care. Posters and information leaflets about routine HIV testing were also placed in waiting rooms for patients to understand why they were being asked for a test.

To further increase testing and reduce HIV stigma, educational events were arranged. These included webinars with local HIV clinicians to reinforce collaboration between primary and secondary care. They also included educational sessions for non-clinical primary care staff and GP trainees, working also with patient advocates.

Between April 2021 - March 2022, there were 12,342 HIV tests requested across all GP practices in Lewisham. This was a 387% increase to the tests requested in same period between 2017 - 2018 before the project began. With the project contributing to higher levels of testing, between June 2019 - December 2021, 17 people were newly diagnosed with HIV, and 17 people were re-engaged in HIV care. The median CD4 count was 286, constituting a late HIV diagnosis and putting people at risk of developing serious illnesses (the definition of late HIV diagnosis currently used in the UK is a CD4 count below 350).

EJAF's funding also facilitated the creation of three other GP HIV champion roles across South East London. This network served as a platform for sharing ideas, best practices, and challenges. The collaboration extended to secondary care colleagues, resulting in the formation of an even larger network focused on bridging gaps in care, especially concerning patients lost to follow-up.

A significant outcome of this collaborative effort was the development of HIV Prevention England's practical guide for primary care teams. This guide serves as a valuable resource for optimising HIV testing and re-engagement with HIV prevention.

Partnership between ICSs and voluntary sector

Guidance for the Core20PLUS5 approach notes that ICSs should work collaboratively with the wider stakeholder effort to address health inequalities. Learning from the national and system level work on the Core20PLUS5 approach, there are meaningful lessons on reducing inequalities which may include co-creation and commissioning to HIV voluntary and community organisations.

The HIV community sector is a precious local asset and resource which should be supported to address healthcare inequalities. Commissioning services from HIV voluntary and community organisations can also support this aim. For example, community organisations can effectively reach marginalised groups and deliver person-centred and culturally competent services. This can include community testing and peer support. Community organisations can also provide advice and expertise to ICSs on the best ways to reach and support 'Core20PLUS' communities.

ICS' partnerships and commissioning model should also reflect the diversity of the Core20PLUS communities that they seek to work with. This could mean working to ensure that specialised community-led interventions working on the frontline are adequately resourced. ICSs should also review whether, and to what extent, organisations representing different 'Core20PLUS' communities are commissioned to deliver services within their area.

Whilst Core20PLUS5 describes NHSE's contribution to reducing health inequalities, ICSs should continue to support wider efforts to address the social determinants of health. This could involve more actively sharing data, learning and engaging in policy development.

By ICSs aligning their HIV response with the Core20PLUS5 approach, it presents a powerful pathway to address pervasive health inequalities. This approach can also be used as a blueprint for ICS approaches for long-term condition management and integrated care. Without addressing inequalities in the HIV response, we will fail in the target of ending HIV transmissions in England by 2030. HIV Outcomes UK looks forward to working with ICSs in the mutually aligned fight of addressing health inequalities and ending HIV transmissions.

Annex

Synergies between HIV and Core20PLUS5

Core20

Core20 include the most deprived 20% of the national population as identified by the national Index of Multiple Deprivation (IMD). Poverty and HIV outcomes are inextricably linked, with individuals living in poverty facing a higher risk of acquiring HIV and experiencing more adverse health outcomes associated with HIV.

People living with HIV in poverty are more likely to be diagnosed late, not be retained in care, have a detectable viral load and experience stigma and discrimination. People living with HIV rate their health much worse when they also do not have enough money to meet their basic needs.²⁹

People living with HIV are more likely to live in poverty. In 2017, 37% of people living with HIV had an annual household income between £0 - £19,999.³⁰ Levels of poverty seen in people living with HIV aged 55+ are double those seen in the general population.³¹ Almost half of women living with HIV in the UK live below the poverty line.³² Similarly, 57% of those of black African ethnicity had a household income less than £20,000 per year compared to 36% of those of white British/Irish ethnicity.³³

There is a link between destitution experienced by migrants living with HIV and the poorer quality of life many of them expressed.³⁴ Policies such as No Recourse to Public Funds and restrictions on permission to work place additional pressure on the already limited Asylum Support Rate.

The cost of formula milk can also grossly disadvantage some women and birthing parents living with HIV. Some women go hungry in order to afford formula for their infant – compromising their own health and potentially compromising the effectiveness of their HIV treatment.³⁵

PLUS

PLUS population groups should be identified at a local level and include ethnic minority communities; people with a learning disability and autistic people; people with multiple long-term health conditions; other groups that share protected characteristics as defined by the Equality Act 2010; groups experiencing social exclusion, known as inclusion health groups coastal communities (where there may be small areas of high deprivation hidden amongst relative affluence). People living with HIV may share characteristics with the PLUS population groups.

ICS should take an intersectional and person-centred approach when identifying and working with these communities in all their diversities. This should recognise that people living with HIV will experience the same health consequences that the general population faces from issues such as ageing and racism, but living with HIV can create additional challenges and lead to intersectional discrimination. Inclusion groups to consider in relation to work on HIV and Core20PLUS5 include:

- **Women:** The most recent UKHSA data underscores a concerning disparity in HIV outcomes for women.³⁶ There is a significant shortfall in the number of women being offered or accepting HIV tests; and a higher proportion of late HIV diagnoses amongst women. Moreover, the potential benefits of the HIV prevention drug PrEP remain underutilised among women - no local authority report more than a handful of female PrEP users.³⁷ To enhance the accessibility of HIV testing and PrEP amongst women, there should be targeted, person-centred interventions across services that women are more likely to engage with.

There is also significant unmet need and poor mental health among women living with HIV.³⁸ Nearly half of women living with HIV express a desire for mental health support, which they currently cannot access.³⁹ This and other structural barriers, including poverty, contribute to women living with HIV being more likely to have left their HIV care.⁴⁰ Trans women living with HIV encounter further structural barriers. This includes transphobia, discrimination, and mental health challenge.

Addressing needs of women living with HIV is vital to advance the objectives of the Women's Health Strategy and Women's Health Hubs. HIV screening is included as a service for consideration in the Government guidance for Women's Health Hubs. As part of NHSE's combination HIV prevention approach, it should therefore be a priority to advance the HRQoL of all women living with HIV.

- **Black communities:** People of Black ethnicities have higher rates of late diagnosis and disengagement from care.⁴¹ Studies have found that people from black communities had a lower CD4-count upon presentation than white populations.^{42,43} This makes this community more susceptible to poorer health outcomes.
- **Migrants:** 62% of all new HIV diagnoses in the UK (including people previously diagnosed abroad) were among migrants in 2019.⁴⁴ Half of these diagnoses were late, making them more susceptible to worse health outcomes.⁴⁵ Migrants face a unique set of barriers that often prevent them from engaging with HIV testing, treatment, and prevention when they reach the UK.
- **Gay and bisexual men:** Men who have sex with men are disproportionately affected by HIV. They are also more likely to have other health conditions that require prevention and support. For example, gay and bisexual men living with HIV are more likely to be diagnosed with a bacterial STI.⁴⁶ LGBTQ+ communities face other structural barriers that can limit their health access. For example research highlights that around one in seven LGBTQ+ people avoided treatment for fear of discrimination.⁴⁷
- **Sex workers:** Globally, sex workers are disproportionately affected by HIV. In countries where data is available, the prevalence of HIV is nearly 21 times higher among sex workers than for the population as a whole.⁴⁸ Sex workers living with or affected by HIV face an increased risk of violence and other health conditions because of entrenched gender discrimination, intersecting and structural inequality.
- **People who use drugs:** Viral suppression is lower in people who probably acquired HIV through using drugs than the general population.⁴⁹ This community is also more likely to not be in HIV care. There is also often a lack of adequate service provision for people who use drugs.
- **People with multiple long-term health conditions:** Three in 5 people with HIV had ever been diagnosed with another LTC in addition to HIV.⁵⁰ Comorbidities can have an impact on someone's employment, social isolation and self-care.
- **Older people:** Approximately half of people with HIV living with HIV in the UK are aged over 50. This diverse community has holistic and social care needs which NHSE should support in an integrated, person-centred way.⁵¹ 58% of people living with HIV over 50 are living on or below the poverty line (double levels of poverty seen in the general population) and this community on average has three times as many long-term health conditions as the general population.⁵²
- **Young people:** The vast majority of children and young people growing up with HIV in the UK acquired HIV via vertical transmission. Their life long experience brings more complex medical management, and by the time they enter adult care they have significant treatment experience. There is evidence of HIV impacts on the developing brain in young people which can affect cognitive functioning, particularly for those with poor history of treatment experience or an AIDS defining event in early childhood.⁵³ Children and young people experience HIV in a family context, many have experienced parental/sibling loss and wider social context challenges, as such young people entering adult care from paediatrics need to be understood as having specialist needs, and possibly require differentiated service provision to address these.
- **People in contact with the justice system:** The UK prison system is an environment that presents risk for both acquiring HIV and experiencing worse treatment outcomes. In line with wider proposed actions in the Health and justice framework for integration 2022-2025⁵⁴, ICSs should develop a shared understanding of the needs of people living with HIV in the criminal justice system and implement interventions that are informed by this.

5

HIV intersects with the five clinical focus areas of Core20PLUS5, with implications for maternity care, severe mental illness (SMI), chronic respiratory disease, early cancer diagnosis, and hypertension case finding. Research highlights that people living with HIV may be disproportionately affected by these conditions and can experience worse health outcomes.

Definitions

AIDS

(Acquired Immune Deficiency Syndrome) is the most advanced stage of an HIV infection when the immune system can no longer fight infections. Someone with AIDS has both HIV and at least one of a specific list of 'AIDS-defining' diseases, which include tuberculosis, pneumonia and some types of cancer.

HIV

HIV (Human Immunodeficiency Virus) is a virus which attacks the immune system - the body's defence against diseases. HIV stays in the body for life, but treatment can keep the virus under control and the immune system healthy. Without medication people with HIV can develop AIDS.

Intersectional discrimination

Acknowledges that discrimination is complex and there are many experiences and identities that combine and interact to determine how discrimination affects different people. People at-risk or living with HIV also experience discrimination because of groups they belong to and/or ways they self-identify. Racism, sexism, homophobia, and transphobia interact and combine in how the HIV response is experienced by different people.

PrEP

PrEP (pre-exposure prophylaxis) is a pill people can take regularly to prevent them getting HIV from sex or injection drug use. When taken as prescribed, PrEP is highly effective for preventing HIV.

U=U

Undetectable = Untransmittable (U=U) is a campaign explaining how the sexual transmission of HIV can be stopped. HIV medication increases a person's CD4 count and reduces their viral load. Treatment is now so effective that it reduces someone's viral load to undetectable levels within about 6 months, maintaining a healthy immune system and ensuring that they cannot pass on the virus.

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NATIONAL AIDS TRUST

Securing rights
Stopping HIV

We're the UK's HIV rights charity. We work to stop HIV from standing in the way of health, dignity and equality, and to end new HIV transmissions.

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