LONDONASSEMBLY

February 2025

Health Committee

This document contains the written evidence received by the Committee in response to its Call for Evidence, which formed part of its investigation into HIV in London.

Calls for Evidence are open to anyone to respond to and in September 2024 the Committee published a number of questions it was particularly interested in responses to as part of its work, which can be found on page 2. The Call for Evidence was open from 13 September to 25 October.

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Questions asked by the Committee

1. What specific challenges to achieving the targets of ending new HIV infections, stopping preventable HIV deaths and eliminating stigma associated with HIV by 2030 is London facing?

2. What actions are being taken by local authorities, the NHS and the voluntary sector to meet the zero-HIV targets, and what impact are these having?

3. What role should the Mayor of London have in helping to meet these targets, and is there any further action he could take?

4. How can London's health system address HIV health inequalities amongst minority groups?

5. How does progress in London compare to other national and international cities in achieving its zero-HIV targets by 2030?

Ref No.001, Catholics for AIDS Prevention

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Brief submission for the HIV Commission: January 2020

re: HIV and Christian faith

Introduction: scope and limits of this paper

Some Commissioners will know the 'terrain of HIV and Faith' and be familiar with the challenges. Others may be unfamiliar with the ways in which Christian faith intersects with HIV as a personal, communal and public health challenge.

It is our intention to inform the Commission as to the current situation, from CAPS' perspective, in regard to HIV and Christian faith.

The goal to 'eradicate HIV' depends upon a combination of actions spanning a continuum of HIV prevention. Any plan must address community education; clinical provision; *and* the care and support of PLWH. As a Catholic charity we argue that those who are neglected, underserved or especially vulnerable deserve our special attention and particular care. One of the many lessons from HIV is that a healthy society (or a healthy Church) must address issues of equality and justice. Eradicating HIV requires a reduction in the social conditions which render people vulnerable to HIV.

Understanding the many ways in which Christian faith and HIV interact is no simple matter. This paper provides a basic outline of *some* of these issues. We will describe the situation, the dynamics, the challenges and opportunities. The experiences discussed in this paper are real. We necessarily use extreme examples occasionally to demonstrate a point clearly. Research is cited in notes as indicative. Additional evidence can be provided.

Throughout, we ***highlight in italics*** some of the main points. We introduce a wide range of issues relevant to several of the Commission themes. We address issues related to both care and support and HIV education. The subject area is vast. This paper reflects the breadth of the 'landscape' albeit 'thinly'.

Section 1 briefly describes CAPS and what we do. Section 2 considers the numbers of Christian PLWH and begins to 'complexify' the situation. Section 3 introduces religiously generated HIV stigma and why it matters to church members. Section 4 describes some challenges for HIV Prevention. Section 5 briefly argues that adequate faith-sensitive support for PLWH is both necessary and beneficial. Section 6 considers HIV-Faith interventions and raises questions about the existing approach. Section 7 concludes with recommendations for the Commissioners' consideration.

1. About CAPS

Formed in 2003 CAPS is the only national Christian charity in England and Wales dedicated to addressing issues at the intersection of HIV and Christian faith domestically. CAPS is truly a ‘grass-roots’ charity. We are open, inclusive and welcoming of all people regardless of religious affiliation, whilst specialising in faith-specific HIV interventions and services. We are committed to the Meaningful Involvement of PLWH. The majority of CAPS board are PLWH. Our services are devised, planned, managed and delivered by PLWH.[i]

Our stated aims are:

- To be a voice for PLWH in the Church and a Christian voice within the HIV sector

Broadly, we meet these aims in two ways:

1. **Pastoral Action** – responding to the pastoral, spiritual and actual needs of any PLWH is our priority through a national community peer support network of PLWH. Providing individual and group support, including peer support groups and residential ‘Retreat’ weekends.

2. **Education through ‘visible active presence’**

A. In the church. Through conferences, workshops, meetings and publications we raise awareness of the needs of PLWH within faith settings including ‘Institutional’/Hierarchical bodies; academia and educational settings; parishes and local churches. CAPS advises pastors in cases where HIV arises as part of ministry. These actions improve awareness of access to HIV testing and raise issues relating to sexual health and relationships which are often difficult to address within faith settings.

B. In the HIV voluntary and statutory sector. CAPS advocates for the needs of PLWH and the relevance of faith/religion for many PLWH within the voluntary and statutory sector. Faith-sensitive HIV peer support, was commissioned in South London boroughs, for Christian (and separately Muslim) PLWH as a result of CAPS advocacy. We provide support for health professionals undertaking HIV Prevention in churches. We provide support and guidance for clinicians and vol sector partners with patients/clients for whom religious belief is problematic and/or a barrier to effective treatment.

2. HIV and Christian faith in context

Christians living with HIV

Data collection in regard to religious belonging and/or faith is a relatively recent and welcome addition to HIV research in the UK. CAPS has argued for the relevance of this demographic data for over a decade.[ii]

Public Health England (PHE) funded research indicated that 70% of PLWH are religious or spiritual, 52% of whom identify as Christian. 49% said their religion is very or fairly important to them.[iii] Other research found that 41% of PLWH had been active members of a religious community, of whom 78% identified as Christians.[iv] Amongst Black Africans receiving treatment in London, a 2012 study found that 90.9% of 246 participants identified as Christian (35.2% Roman Catholic and 55.7% other Christian traditions).[v]

Within the population of PLWH Christians are significantly over-represented and are more 'religious' when compared to the general population[vi]

However, further findings complexify the significance of faith and religious belonging. Questions are raised as to what 'HIV + faith + religious belonging' *actually means* for PLWH.

The first study above, also revealed that 18% of people who said religion is very important to them have not shared their HIV status with anyone. Of those who said religion was not important, rates of non-disclosure were lower at 10%.

The second study found that of those who had ever actively belonged to a religious community 15% had become more actively involved after diagnosis; 13% had become less active and 7% had left their faith group completely.

3. Religiously generated HIV stigma

HIV stigma remains a significant factor for PLWH, and inhibits testing and prevention interventions.[vii] Within Christian communities, HIV stigma is expressed and reinforced, unsurprisingly, in particular religious forms. It is impossible here, to fully discuss the complex dimensions of HIV stigma within the churches. In this section *some* of the causal factors and conditions within which religiously generated HIV stigma thrives are described. Why HIV stigma within Christian communities needs to be addressed is sketched.

It is important to note that Christianity in Britain is not mono-cultural.

The religious 'roots' of HIV stigma and it's expression will vary across denominations and local congregations, depending variously on the theological stances taken and how these are practically applied within a given church or faith community e.g. a school.

At the risk of being too simplistic - three basic examples:

1. Churches with a literalist interpretation of scripture who place a high emphasis on sexual morality, are likely to be more stigmatising environments for LGBT+ people than those that do not take a literalist approach to scripture and emphasise, for example, aspects of social justice in preaching and teaching before individual sexual morality.

2. Any Christian diagnosed with HIV who has been taught that God can cure them if they have sufficient faith, may believe that ARV medication should they take it, demonstrates a lack of faith, and will therefore deny them the healing (cure) that is on offer within their church. In our pastoral experience, it is very rare (but has happened) that Christian PLWH

refuse medication, but a version of this belief can delay treatment or effect adherence for some people.

3. Similarly, a theological emphasis upon a God who rewards the ‘righteous’ and punishes the ‘wicked’ intensifies the internalised stigma of a person diagnosed. The consequent negative social and psychological damage (including the ability to adhere to HIV treatment), will inevitably be more problematic for the person with this belief, than for a person who understands God differently or has no belief in God.

These short examples provide clues as to why HIV stigma within churches remains challenging.

The importance of belonging and fear of exclusion

Within all faith settings norms of acceptable behaviour and ‘right belief’ are reinforced by teaching and practice, and combine to create powerful cultural and social environments. In turn, these norms are markers of inclusion and exclusion - who is ‘in’ and who is ‘out’ – not only within the particular church, but also according to some theologies, who will be granted salvation or access to heaven. This may seem ridiculous to someone without faith. Transgression of church norms risks exclusion from the community of faith.

For the person with religious belief the attachment to a particular church community is often very powerful and should not be underestimated.

For those marginalised in society because of immigration status, poverty, poor mental health, etc… the church may be their most important locus of actual support. Psychologically and emotionally, especially for vulnerable people, the sense of belonging to a community that is ‘blessed by God’, or ‘chosen’, may be an important source of dignity and hope within a hostile society.

For the gay man raised religiously, diagnosed with HIV, acceptance in church may be both the most important emotional need he has; and at the same time, a threat to his psychological and spiritual well-being.

4. Some challenges for HIV Education and Prevention

Church norms are reinforced formally in preaching and informally through conversation. They are also maintained by silences. Example (1) above indicates how a culture of silence is produced. A strong emphasis on sexual morality based upon scripture will fore-close discussion of gay sexuality or sex outside marriage for example. Discussing HIV and sexual health is taboo.

Talk of sexual health and relationships is threatening in most churches because it may challenge church doctrine, the authority of the Priest or Pastor, or the sense of communal identity.

Religion makes some people more vulnerable to HIV infection than they might otherwise be.

A false sense of protection may be cultivated within individuals by the so called 'Prosperity Gospel' (See example (3) above) by which God protects the church-going person. The possibility of HIV as a danger to oneself is simply not considered. With a lack of openness about HIV, forms of religiously inspired denial may be a contributing factor in some cases of late diagnosis.[viii]

5. Some challenges for care and support

After diagnosis, the support of the church is important for any Christian. But, non-disclosure results from a reasonable fear of judgement within the church. As a woman attending a CAPS Retreat once put it: 'I have not told anyone in my church or my family. They would think I have been a bad wife'. For this woman, her HIV status remained a shameful secret and asking for support was impossible.[ix]

The Christian diagnosed with HIV

If the PLWH does not address faith-related stigma, including that which rests upon flawed theology, it persists as a kind of deep wound or affliction, with obvious negative consequences for health and wellbeing.[x] For example, research shows that views of God are predictors of disease progression.[xi] However, appropriate support, is not available in most of our churches. Even those clergy who intend to help, are often simply unsure or ill-equipped to respond.

Any person with religious faith needs faith-sensitive pastoral support to successfully navigate the challenges of an HIV diagnosis.

In addition, Christians living with HIV report misunderstanding of their faith when accessing HIV services. For example, a clinical nurse is probably not equipped to address the belief that HIV is a punishment from God. Understandably within peer support groups, religion may be treated with derision or hostility by some PLWH. However, recognizing the religious or spiritual commitments of patients is an important component of care.[xii]

Christian PLWH are doubly isolated. In church they cannot speak about HIV, and in the HIV sector their faith is not understood.

In the absence of adequate pastoral support CAPS facilitated the first peer group in 2004. Since then PLWH have assisted each other to work through the challenges of religiously-generated stigma. In addition to beneficial social support, evidence suggests that compassionate service for others upon which our model relies, may have survival benefits for PLWH.[xiii]

The good news is that faith and spirituality as integrated aspects of life for any PLWH result in beneficial health outcomes.[xiv]

6. Strategies and interventions

Other than a very small allocation of funding for CAPS' peer support ministry, to our knowledge, there are no statutory resources allocated specifically for programs of faith-sensitive Christian pastoral support for PLWH.

The vast majority of funding has been directed towards HIV education for Church ministers, and community testing events led by mainstream HIV agencies. At various times CAPS has been involved in a supportive role. The Commission may know exactly how much HIV Prevention funding has been allocated.

To date, HIV Prevention within churches has focussed upon attempts to engage Church Pastors as 'influencers' and 'gate-keepers' within churches.

We question whether this is an appropriate or effective strategy.

Is community testing within faith-settings value for money?

What is the evidence that targeting Church Leaders has resulted in a reduction of stigma within churches? We see no evidence of more sensitive pastoral support.

Logically, an HIV agency focus is often driven by HIV testing targets. Do secular agencies have the theological expertise, resources or commitment to engage meaningfully with Church leaders? We suggest not.

There are ethical issues that need considering. Here we mention just two.

It has been reported to us, that within one church, after engagement with an HIV agency the Pastor was requiring that all engaged couples present him with their HIV test results before he would consent to marry them in church. We do not know what his motives were, but we do know that this created serious issues regarding confidentiality for the newly diagnosed couple. It points at very least to a failure of appropriate HIV training in his regard.

There is properly, a comprehensive route to follow-up clinical support as part of community testing. However, there is no comparable faith related follow-up. HIV testing in BAME majority churches for example, is justified upon the assumption that within the church there may be those who are infected but undiagnosed. As we have argued most churches remain stigmatising environments, and most Pastors are ill-equipped to respond appropriately. Yet an assumption is made, that the newly diagnosed person will access spiritual and pastoral support, which we have argued is so essential for any Christian PLWH, within the same church. As shown above for many Christian PLWH this is neither reasonable nor sufficient.

7. further considerations and recommendations

In light of all the above, the Commission has an opportunity to bring fresh thinking and insight into how we support initiatives at the intersection of HIV and Christian faith.

To achieve the elimination of HIV by 2030 and beyond, requires that we find ways to provide faith-sensitive support for Christian PLWH alongside continuing HIV educational activities including the access to HIV testing. A more joined up strategic approach is possible as a continuum of HIV prevention.

The reduction of religiously-generated stigma within churches, is complex and not easily achieved. It remains a significant factor that increases vulnerability to HIV infection for some people; leaves many Christian PLWH unsupported; and inhibits testing and prevention interventions. We suggest that a longer term and more sophisticated approach will be needed to begin to create HIV aware church communities.

The greater visibility of LGBT+ people over many years, contributes to a change in attitudes in society and many churches. We also know that this effort continual. A similar strategy empowering Christian PLWH to become more visible and actively present within the churches is likely to effect lasting change. If enabled, Christian PLWH can become the solution within faith communities.

We believe that inter-personal encounters are usually more affective and effective in achieving the reduction of stigma, prejudice and ignorance.

We recommend the following:

Strategic planning:

- **Rec: Research into the effectiveness of past and present HIV interventions. At least a review of how resources are directed. To seriously inquire what works?**

- **Rec: A faith engagement strategy based upon evidence. Establishing a new approach, properly resourced, theologically informed, including robust evaluation. The aims clearly defined. The strategy will distinguish methodologically between, for example, outcomes showing a reduction in stigma and others relating to HIV testing.**

Research identifies problematic and beneficial aspects of faith, religion and HIV. We know the challenges. Research, particularly from the USA, has identified the conditions that are favourable for engagement with HIV prevention and support projects.[xv] As community-based organisations churches have the potential to reach and support the most vulnerable people in society. Faith communities can be mobilised as partners with Health services, but this is yet to be actualised.

Resourcing Christian peer support ministry

- **Rec: As the only faith sensitive pastoral support available nationally for Christian PLWH CAPS peer support ministry should be supported and funded.**

CAPS ministry enables Christian PLWH to transition from a problematic state of internalised stigma towards an integration of faith and HIV. This model of Christian HIV peer support based upon adult discipleship and service for others is proven. This community of PLWH are also ‘the Church’, and have found actually relevant and meaningful ways to support each other.

Secondly, we know that with support, Christian PLWH become active and visible members of the wider church. Our members give talks and disclose their HIV status to others in their church. This affects attitudes and encourages behaviour change at a local level, increasing awareness and reducing HIV stigma.

Resourcing HIV training for faith communities in the language of faith

The Health agencies failure to engage meaningfully within faith settings results from an approach which relies upon arguments made from a medical perspective. HIV agencies are speaking 'health outcomes language' rather than the language of faith.

Christian communities and individuals are motivated by Christian faith. Persuasive arguments made with the language of faith are more likely to effect lasting change. Why should churches or pastors be persuaded by arguments or proposals that are framed in scientific, medical or at best sociological language? Why should they prioritise HIV over less threatening and more understandable social needs?

CAPS' PHE funded 'Positive Faith' training resource comprises short films and training guides to facilitate conversations about HIV within churches. Made by PLWH, it is the first resource of its type anywhere in the world. Christian PLWH address HIV issues, in the language of faith. Their sharing serves as a kind of inter-personal encounter for other Christians. Our members have delivered introductory workshops in churches. Feedback indicates they are effective in raising awareness, challenging HIV religiously-generated stigma, and affecting some change within churches.

- **Rec: The Positive Faith resource should be trialled within churches and other faith-settings.**

Specialist advice and support services for PLWH

CAPS has witnessed a serious increase in PLWH who are in severe crisis with fewer available sources of HIV specialist help. Although our members often 'go the extra mile' providing immense social and actual support, peer support and Christian fellowship are not a substitute for the case-work advisers who used to be accessible through THT. Mainstream services cannot fill the gap in provision. We are acutely aware of the numbers of PLWH who need more HIV specialist support, especially at times of crisis

- **Rec: Specific support and guidance services should be recommissioned**

Conclusion

Thank you for taking the time to read through this paper. We encourage you in your work.

On behalf of CAPS Trustees and members

Dr Vincent Manning – Chair

NOTES

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[i] The MIPA principle is internationally agreed and considered 'best practice'. Sometimes colloquially understood as 'nothing about us without us'. It is not always applied meaningfully, as it can be challenging in practice.

[ii] For example in 2008 we inquired with the Health Protection Agency as to the religious affiliation of people diagnosed with HIV. In correspondence we were told that it was not data that was collected as it was not considered epidemiologically relevant.

[iii] PHE. Changing Perceptions – Talking about HIV and attitudes report, 2018. (4400 participants)

[iv] FPA, 2015. *HIV in the UK: Changes and Challenges; Actions and Answers. The People Living With HIV Stigma Survey UK 2015 National findings.* London: The Family Planning Association. (1576 participants)

[v] Fakoya, I., et al., 2012. Religion and HIV diagnosis among Africans living in London. *HIV Medicine*. Nov 2012, Vol. 13 Issue 10, p617-622

[vi] The proportion of the British population identifying as Christian has fallen from two-thirds (66%) to just over one-third (38%) since 1983. 52% now say they do not regard themselves as belonging to any religion. Curtice, J., et al. 2019. British Social Attitudes: The 36th Report, London: The National Centre for Social Research

[vii] Baylis, A. et al., 2017. The future of HIV services in England**:** Shaping the response to changing needs. London: The Kings Fund.

[viii] Burns, F. M., et al. 2007. Why the(y) wait? Key informant understandings of factors contributing to late presentation and poor utilization of HIV health and social care services by African migrants in Britain. *AIDS Care*, vol. 19, no. 1

[ix] Chinouya. M and E. O'Keefe, 2005. God will look after us: Africans, HIV and religion in Milton Keynes. *Diversity in Health and Social Care*.

[x] For example: Foy, S. L. and C. W. Mueller, 2018. Nourish the soul or damage the body? Belief in the connection between Christian moral failure and diminished health. *Social Compass*, vol. 65(2). Manning, V., 2019. *Encountering Christ Through the Passion of HIV: an Inquiry into the Theological Meaning of HIV in the Church.* PhD thesis, St Mary's University / University of Surrey.

[xi] Ironson, G., et al. 2011. View of God as benevolent and forgiving or punishing and judgmental predicts HIV disease progression. *Journal of Behavioural Medicine*, 34.

[xii] Doolittle, B. R., et al., 2018. Religion, spirituality, and HIV clinical outcomes: A systematic review of the literature. *AIDS and Behavior*, *22*(6)

[xiii] Ironson, G, et al., 2016. Relationship Between Spiritual Coping and Survival in Patients with HIV. *Journal of General Internal Medicine*, vol 31, issue 9. Ironson, G, et al., 2018. Compassionate love predicts long-term survival among people living with HIV followed for up to 17 years. *The Journal of Positive Psychology,* vol. 13, no. 6

[xiv] Van Wagoner, N., et al., 2016. Reported Church Attendance at the Time of Entry into HIV Care is Associated with Viral Load Suppression at 12 Months. *AIDS Behaviour.* Emlet, C. A., et al. 2018. "The Journey I Have Been Through": The Role of Religion and Spirituality in Aging Well Among HIV-Positive Older Adults. *Research on Aging, v*ol. 40 no. 3. Ironson, G. et al., 2011, 2016, 2018 above.

[xv] See for example: Barnes, S. L., 2013. *Live Long and Prosper: How Black Megachurches address HIV/AIDS and Poverty in the age of Prosperity Theology.* New York: Fordham University Press.

positive FAITH

HIV Action Plan for England- SURVEY – CALL for Views Sept. 2024.

1. Overall, what has worked well under the current Action Plan for England since 2022?

The opt-out A&E testing is identifying previously undiagnosed people & treating them.

2. What actions should be taken to best respond to the inequalities and unmet need experienced by people living with HIV?

In my comments I emphasise the empowerment of PLWH (Others will comment on other aspects of the past & future plans).
Empowering PLWH must be part of any effective long-term strategy. The empowerment of PLWH is an essential and as yet under-resourced and under-valued aspect of any strategy that will achieve change in society over the long-term. Stigma remains a major issue. The greater visibility of PLWH in communities, work-places etc... will contribute to the 'normalisation' of HIV & serve to de-stigmatize HIV - especially in those communities where HIV stigma acts to prevent HIV testing & contributes to late diagnoses. Overall, I think that a radical commitment to empower PLWH - especially those who are most marginalised - can contribute meaningfully to ending new transmissions. In practical terms this means supporting PLWH more effectively with those aspects of life (psychological, spiritual & emotional, social and practical) that they say they need more support with.

3. What new initiatives or interventions must the next Action Plan deliver?

PLWH in crisis are more likely to disengage in clinical care and/or have poor ARV adherence as previous plan acknowledges.

1. The lack of easily accessible specialist HIV advice services (previously provided by THT) that competently undertake case-work re: housing, immigration, welfare benefits etc... are needed, especially to support those PLWH who are most disadvantaged.

2. There is also a great need for Mental health Support for gay men LWH esp. regarding addiction & for support addressing Trauma for refugee PLWH.

3. Research shows that faith is an important aspect of life for many PLWH. We also know that religious beliefs and culture can create psychological problems for PLWH. At the same time research shows that faith & spirituality if integrated with HIV can be beneficial for overall well-being & clinical outcomes. Historically in this country the HIV sector has not been very good at addressing issues at the intersection of HIV & Faith. However, examples of best practice do exist - specifically CAPS Charity Positive Faith Peer Support groups have proven

relevant & demonstrated actual success in supporting PLWH, especially addressing internalised stigma. CAPS has also had some success in education & prevention within Christian communities. However, Churches are still not, generally able to provide HIV competent support for PLWH and religiously-generated stigma may be a contributory factor to poor adherence and late diagnosis. A commitment to providing Faith-sensitive support more adequately should be considered e.g. greater resourcing of existing faith-sensitive & HIV competent support groups; training for clinical staff & in-clinic peer support workers; properly conducted research into effectiveness of existing faith-sensitive support for PLWH.

4. More generally we perceive a 'de-valuing' of and disinvestment in peer support groups. Well-adjusted PLWH properly, may not need communities of peer support - although we know that many older PLWH continue to engage with peer support and find it helpful. PLWH with networks of family or friendship support may rely on peer support communities less. However, those PLWH who face multiple disadvantages or are isolated, who are poor or suffer most with internalised stigma (including those PLWH troubled because of religious belief or the rejection of their religious family or community) do need and value peer support groups. the importance and value of peer support groups generally ought to be emphasised and resourced in any new plan.

Objectives of the Action Plan

4. Prevention (including condoms and PrEP) - what's working, and what should be prioritised?

Access to PrEP appears to be effective in Gay community.
Educational initiatives to reduce Stigma in faith communities (and therefore increase access to HIV testing) should be considered afresh. Not only for the needs of adults in faith communities but to promote better sexual health amongst young people. In the same way that LGBTQ welcoming churches now exist (unthinkable in 1960) - consideration should be given to new initiatives that competently address HIV issues in the language that these communities may understand and find persuasive e.g. 'the language of faith'. The effectiveness of 'traditional' approaches taken to HIV Education & prevention amongst faith communities in the past is questionable. The approach that relies on ‘faith-leaders' has failed to significantly change attitudes or reduce stigma and probably contributes to denial within faith communities & correlates with late presentation.

The empowerment of PLWH of faith is an alternative approach that can work. If PLWH are enabled to provide workshops, training etc... within their own communities of faith this has been shown to effect attitudes, increase awareness, reduce stigma etc... again, to reach some of the poorest and most marginalised people, who may be undiagnosed, consideration might be given to resourcing HIV education & prevention initiatives that have met with some success in this country. Again, proper academic research might be considered to measure effectiveness.

5. HIV testing - (including Opt-Out in A&E departments, Sexual health services, postal testing, other settings) - what's working and what should be prioritised?

We understand that those people who are diagnosed in A&E may feel particularly shocked by diagnosis. we imagine that greater attention may be needed to support newly diagnosed people who may not have expected an HIV diagnosis and/or are not traditionally engaged with sexual health services. not sure what the research evidence shows but imagine some of these people may disengage with clinical care if not provided with adequate psychological and social support to adjust. consideration should be given to follow-up not just in terms of clinical care but also in terms of social and peer support, including faith-sensitive peer support for those for whom religious identity is important.

6. Access to treatment and retention in care (peer support, U=U, local commissioning) - what's working and what should be prioritised?

The Positive Voices surveys (2017 & 2022) both showed a significantly higher proportion, compared with general population, of PLWH who identify as Christian. For Christian PLWH the issues of faith and belief must be addressed adequately, in a faith-competent & HIV-competent way, if they are to overcome internalised stigma, share HIV status with family members and learn to live well with HIV. We know that for some PLWH religious faith interferes with adherence for example. The HIV sector needs to think more carefully about PLWH with faith needs and respond with more effective programs of support more widely available. Again, we know that our positive Faith model actually works. Consideration might be given to learning from the experience of Positive Faith community members and duplicating this model in partnership with HIV sector agencies.

7. Empowerment and Wellbeing (stigma, knowledge and awareness, quality of life, unmet need) - what's working and what should be prioritised?

See previous answers

Final thoughts - and top priority
Here's your chance to tell us anything else about how you think the ending of new HIV transmissions can be achieved

8. Final thoughts on the next Action Plan

As a Christian Charity we support PLWH of all faiths and none. We specialise in support for those most marginalised and we specialise in meeting the needs of PLWH with Christian faith & effectively supporting them to overcome religiously generated stigma in all it's aspects - adhering to treatment, addressing personal, interpersonal and communal issues etc... importantly, our model of support has been developed and led by PLWH with faith themselves.

We also specialise in education within faith communities. Again, programs are developed and led by PLWH. our top priority is therefore, to address and resource more adequately and undertake research more effectively, into issues at the intersection of Christian faith and HIV. As so many of the poorest and most marginalised members of society living with and affected by HIV are also religious, we consider our mission to support PLWH where the churches have failed and educate faith communities in the language of faith. And, our mission is carried out by PLWH who provide an example for others of what it means to live well with HIV as people of faith. We would welcome greater involvement and more meaningful engagement with the wider HIV sector.

9. If you could tell the Government one thing it MUST make sure is delivered in the new Action Plan what would it be?

PLWH say that faith matters. We should listen to them. Adequate peer support for PLWH is a must and this includes Faith-sensitive peer support. Faith should be named explicitly as a culturally important aspect of both HIV care & support and HIV prevention.

People living with HIV are the very actors of an ongoing epidemic that challenges their bodies, their faith, their personal development and social integration, and ultimately their survival. To sustain those who fight the disease, we need to heed their experience. To better accompany them in the complex challenges, we have to meet them on the ground and to trust them in the first place. Locally, they are the “experts,” the first-hand witnesses and the most direct actors of this epidemic.

The most vulnerable PLWH are not only part of the problem. If they were empowered enough by us, they would become the solution.

Dr Vincent Manning – exec. Director CAPS Charity.

Catholics for AIDS Prevention and Support (CAPS) is a Registered Charity no. 1196193
CAPS supports ‘Positive Faith’ and ‘South West London Fellowship’ Peer Support Ministries
https://www.positivefaith.org.uk/
CAPS provides video resources for Christian Faith and HIV
http://www.positivefaith.net/index.html

Chelsea and Westminster Hospital NHS Foundation Trust

Call for evidence: HIV in London

Many thanks for undertaking a review of HIV in London and London's progress towards zero-HIV targets by 2030. We write on behalf of Chelsea and Westminster Hospital NHS Foundation Trust (C+W), one of the largest providers of HIV, genitourinary medicine (GUM) and sexual and reproductive health (SRH) care in the UK.

London is the region most affected by HIV in the country, with 40% of all people seeking HIV care in the UK living in London, and new diagnoses rates and prevalence more than double the average outside London [1]. In addition, London has the greatest proportion of people living with undiagnosed HIV and there are estimated thousands who are diagnosed but not in care, who remain at risk of developing serious morbidity or mortality, with the added risk of transmission to others and increased burden on the healthcare system [1].

At C+W, we provide care for over 14 000 people with HIV (PWH). We have a diverse multidisciplinary team (MDT) and have embraced role diversification in order to meet the needs of a growing cohort, developing nurse and pharmacist-led services. HIV outcomes are excellent having achieved the UNAIDS 90:90:90 goals for years, reaching beyond 95:95:95. We work closely with our wider Trust and have established routine HIV testing in emergency departments, termination of pregnancy services and dermatology.

Although the HIV Action Plan for England sets out welcome goals to reach an 80% reduction in new HIV transmissions by 2030, London remains a critical geographical area in which to focus efforts in achieving these targets. We welcome this investigation by the London Assembly Health Committee and their commitment to supporting London 'Getting to Zero'.

What specific challenges to achieving the targets of ending new HIV infections, stopping preventable HIV deaths and eliminating stigma associated with HIV by 2030 is London facing?

HIV testing, reaching the undiagnosed and access to care

An estimated 1600 people are living with HIV in London and remain unaware of their diagnosis. Although overall testing in London has increased by 8% between 2022 and 2023, rates are still not as high as pre-pandemic testing rates and coverage remains lower in key target groups. There has been a decline in testing in heterosexual men and women of 10% and 22% respectively and a decline in testing in young individuals age 15 to 24 years from 2022 to 2023 [2] highlighting the widening gap in inequity for these groups and in particular women.

Sexual health services continue to provide the majority of HIV testing in London, however significant challenges are being faced by these services which deleteriously impact access and testing. The public health grant to local councils used to fund sexual health services was reduced by almost £1bn (24%) between 2015/16 and 2020/21. Across England, spending on STI testing, contraception and treatment decreased by almost 17% between 2015/16 and 2020/21, as local councils responded to the reduced funding. C+W GUM services are now paid based on activity at the rates set by the historical London Integrated Sexual Health Tariff (ISHT) and therefore, have seen a real terms reduction in income. As tariffs have not changed since inception, we have experienced income deflation, particularly once demographic and non-demographic growth is accounted for.

In 2022-23, there were just under 175 000 consultations across our GU clinic sites at C&W. Our data show that we offer care to a wide demographic, reflecting London's diversity. With the support of the local authority, in order to reach more vulnerable, minoritised cohorts, we have maintained outreach services despite the fact that this is a challenge from a workforce and income perspective.

The significant and ongoing disruption over the last 5-10 years from tendering of GU services and subsequent fragmentation from HIV services and declines in funding have destabilised many services. In order to safeguard the overarching principles of sexual healthcare i.e. we should be a free, open access service, and thus maintaining high levels of HIV testing and rapid linkage to care, a renewed appropriate funding policy for GU/HIV services is urgently needed.

HIV prevention

Prior to routine HIV PrEP commissioning, at C&W we facilitated private PrEP access and led the IMPACT trial. We now provide PrEP to > 40 000 PrEP users and run a national complex PrEP MDT in order to improve PrEP access and reduce inequity by ensuring that those with medical conditions who cannot access standard PrEP are able to access other forms of PrEP and HIV prevention tools. Our Dean St service created and led "PrEP Awareness week", a national campaign involving healthcare providers, public health authorities and third sector organisations driving increased PrEP knowledge and uptake in the population.

Even for those who know about PrEP and seek access, as detailed previously, fragmentation and cuts to funding due to reduced public health expenditure in local councils impacts the ability of sexual health services to cater for this need. The Not PrEPared report highlighted these stark issues and note almost half of clinicians in sexual health services stated there was insufficient workforce levels to meet patient demand, 23% of people were being turned away for lack of appointments and 57% on a waiting list for PrEP had waited more than 12 weeks to access care [3].

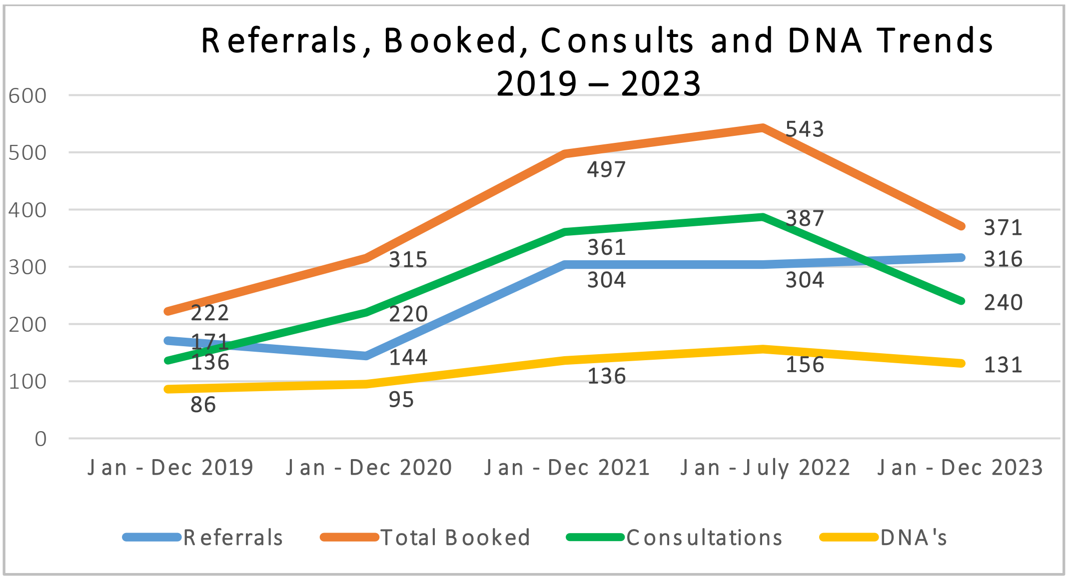
Caring for PWH who have complex health needs

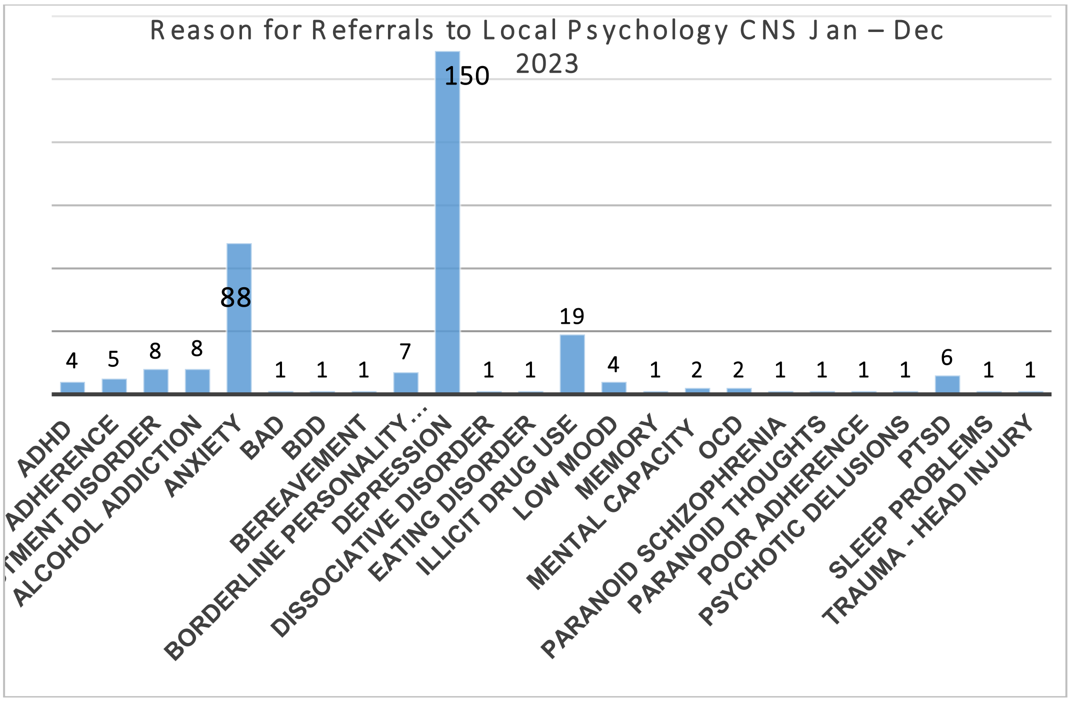
As with sexual health services, PWH are increasingly complex. The advances in care and antiretroviral therapy mean more people are living and ageing with HIV. This means we are delivering more specialist services in order to address increasing co-morbidities and polypharmacy. Isolation and loneliness in older people living with HIV is associated with poorer mental and physical health, with subsequent reduced cognitive function. Stigma, isolation, pain, fatigue and not working/volunteering all contribute to loneliness which in turn has been linked to cognitive difficulties, physical inactivity, increasing opioid use and mental health decline.

In addition, we continue to see high rate of late diagnoses; 41% of new HIV diagnoses in London are diagnosed late with a CD4 cell count <350 cells/uL which demonstrates a significantly impaired immune system. These individuals have a tenfold increased risk of dying in the first year after diagnosis compared to an individual with a fully functioning immune system and require greater resource and clinical input to support them. In addition, the recent increase in new diagnoses, both in those previously diagnosed abroad and newly diagnosed in the UK increase pressure on already stretched services. Within our Hertfordshire and Harlow services, for e.g., new joiner rates have doubled over the last 12 months. Despite these increases, there has been no increment in the block funding allocation or workforce.

At C&W HIV in-patient numbers have decreased, however, late presentation and advanced HIV-related illness remain too common despite being entirely preventable through early diagnosis, linkage to care and treatment. Concurrent co-morbidity, mental health, safeguarding and social care issues are a major challenge given the lack of rehabilitation facilities leading to discharge delays. This leads to issues with admitting PWH transferring from other units who are in need of specialist HIV care. Care of PWH in the community is increasingly demanding, requiring an increase in community specialist nurses.

Psychological ill health remains a significant issue. A previous APPG inquiry 'Mental Health Services Failing Patients with HIV' outlined the challenges clearly. Sadly-these prevail. Demand for services is at an all-time high and waiting lists are extensive. Our experience has demonstrated a lack of HIV awareness within many mental health units. Within our cohort, drug and alcohol use have become more prevalent, impacting on physical and mental health. Access to support is often limited, with geographical logistics causing health inequity.





Preventing lost to follow up and re-engaging those not in care

The UK Health Security Agency (UKHSA) now estimate the number of those not in care and aware of their HIV diagnosis to be between 15,000 and 24,000 individuals across England. Reasons for difficulty in engagement in care include HIV-related stigma, mental health issues, difficulties with immigration, housing, welfare and chemsex use. Without significant resource and in particular, embedded peer support within services and outreach HIV community based clinical nurse specialist to support people back into care, these individuals remain at risk of life-threatening infections and potential transmission to partners and children.

At C&W, we have a clear ‘lost-to-follow-up’ policy to ensure engagement in care. Subsequent high rates of viral suppression are of benefit to the individual and public health. This, in tandem with growth in HIV pre-exposure prophylaxis (PrEP) provision, has led to a marked reduction in new HIV diagnoses. In our 56 Dean St clinic, there were 341 new HIV diagnoses in 2016, this had dropped to 104 in 2023.

The benefits of peer support are well-evidenced demonstrating reduced stigma, loss-to-follow-up and engagement. Rates of viral suppression (VL<50) increased from 71% at referral, to 90% following peer support. HIV peer support at C&W is an essential service that, through temporary non-NHS funding streams, we have been able to embed in our clinics. Trained peer supporters, usually people with lived HIV experience, offer guidance, share coping strategies, and help foster a sense of community. This support is unique and vital to many of our patients’ journeys and helps support many to stay engaged in care as well as improving well-being. The lack of reliable and sustainable peer support funding presents a real risk to achieving the 2030 targets.

Stigma

Stigma remains a major barrier and underpins nearly all challenges in getting to zero; it impacts the physical and mental well-being of people with HIV and has been clearly linked to poor health outcomes [4] and is a barriers to HIV testing and accessing HIV prevention [5]. Coordinated efforts are needed to normalise HIV testing as routine, to reach those living with HIV but who do not self-identify as at risk and reach those in marginalised, under-served and vulnerable communities.

Within London, the Positive Voices survey described high levels of stigma, including internalised stigma. 9% of respondents had never told anyone about their HIV status outside a healthcare setting, 70% found it difficult to tell people about their HIV status, 18% had felt isolated and lonely in the previous year, 40% felt ashamed of their HIV status and 29% reported having low self-esteem due to their status.

Within C+W, we have embedded peer support workers throughout the unit having been awarded Fast Track Cities and other non-NHS, temporary funding streams. More secure funding is required to ensure peer support is delivered as part of the integrated care package, rather than a ‘luxury’

The HIV Confident Charter ran surveys at key pilot sites across London in 2024 in primary and secondary care among health care staff and the initial results demonstrated a worrying lack of knowledge around HIV transmission, inappropriate and unnecessary use of infection control measures and higher than expected levels of witnessed discrimination towards people with HIV.

Delegation of HIV service to Integrated Care Systems

HIV is due for delegation from NHS England to local Integrated Care Systems in April 2025 and concerns regarding vulnerability and uncertainty exist. While some regions have already transitioned to the Integrated Care System (ICS), for C+W (and London) there is a lack of clarity regarding future plans and organisation.

Currently, we are paid on a block contract which fails to reflect the complexity of the HIV services we offer, or the rise in cohort size. Our specialist clinics are paid within this block rather than attracting a separate tariff which would reflect the enhanced care delivered.

A large proportion of PWH who choose to use C+W services (67%) do not reside in NW London and we have grave concerns that ICSs may refuse to support PWH who opt to attend HIV units outside of their local ICS. There may be important reasons why PWH opt not to attend a local clinic where stigma, confidentiality and disclosure are concerns. Furthermore, the HIV service specification states PWH should be free to decide where to access care [6]. As HIV is a lifelong condition, clinicians and PWH often have long established therapeutic relationships which are a cornerstone of high quality care.

ICS priorities do not align with HIV; HIV is not mentioned as a long-term condition or a priority for the ICS, despite many people living with HIV meeting the core20PLUS5 criteria [7] and in the Women’s Health strategy, HIV and sexual health do not feature. Being low in priority in terms of workplan and strategy creates significant barriers for funding ICS applications for services in HIV.

What actions are being taken by local authorities, the NHS and the voluntary sector to meet the zero-HIV targets, and what impact are these having?

To meet the zero-HIV targets in London, coordinated action amongst all sectors and stakeholders is needed.

NHS services

At C&W >95%% of those in care are receiving antiretroviral treatment and >95% of these have an undetectable viral load (<200 copies/ml). These excellent outcomes are testament to the patient centred, holistic and high-quality care provided at C&W. Critically, and as for all HIV clinics, we offer open access services allowing individuals to self-refer to any clinic of their choice without geographical restriction or need for GP referral. This must be protected as it allows those living in rural areas to access large urban centres if they wish, with access to research opportunities and enables them to maintain confidentiality around their diagnosis by seeking care away from their area of residence.

NHS England

The Emergency Department blood borne virus (ED BBV) testing project, initiated and rolled out across London by NHSE in 2022 has been incredibly successful in both diagnosing the undiagnosed but also re-engaging people who have fallen out of care. Linkage to care rates are high (>90%) and this work has provided a blueprint for the rest of the UK and internationally. The project's rapid roll-out at scale was co-ordinated across multiple care groups within secondary care and third sector providers. In the first year the programme, 1.5 million HIV tests were performed, with 772 new diagnoses (638 linked to care) and 488 with known HIV but not in care identified (207 now linked to care). Initial evaluation also shows that, when compared to people diagnosed in other settings, new diagnoses are more likely to be in those who are older, female, of Black ethnicity and heterosexual.

NHSE mandated that a proportion of the funding for the ED opt out testing project should be spent on peer support. This unique approach has been successful in ensuring those newly diagnosed through ED testing were guaranteed access to peer support within NHS Trusts. Peer support at the time of diagnosis has been incredibly impactful and the funding has additionally allowed HIV clinics with no prior peer support in-house to have access to this valuable resource to reduce stigma and support re-engagement and advocacy.

Fast Track Cities

London has demonstrated excellent collaboration across all sectors and Fast Track Cities London have led the way to form many of these invaluable partnerships.

In 2020 C&W, entered a multi-organisation, third sector partnership with POS UK, Plus Health, Naz and Sophia Forum and were successfully awarded Fast Track Cities London grants to help establish vital peer support in all our clinics in. A further grant was awarded in 2024 to further embed this essential work.

Fast Track Cities have piloted GP champions in HIV, working across London to increase education and awareness and to promote HIV testing in GP surgeries. At C&W we have linked with named GPs working in the scheme to build better relationships with primary care to achieve better health outcomes for people with HIV.

The HIV Charter Mark, an anti-stigma accreditation for organisations, is now completing the first year with founder organisations surveying staff and contributing to the development of a powerful education tool to tackle stigma and discrimination. We recognise the value of this accreditation and the anti-stigma work it involves and as a Trust were one of the first in London to sign the HIV Charter Mark in October 2024. With support and resource from Fast Track Cities London, we are committing to become an HIV Confident NHS Trust by increasing employees' knowledge about HIV, improving employees' attitudes towards people living with HIV and providing anyone living with HIV a way to report stigma.

What role should the Mayor of London have in helping to meet these targets, and is there any further action he could take?

The Mayor of London has already provided considerable support for HIV, through championing of the HIV Action Plan and Fast Tract Cities. London is now seen as a global leader in getting to zero with the London experience and with opt out HIV testing in Emergency Departments being used to inform projects nationally and internationally.

The Mayor's ongoing leadership and support of public health policies that prioritise HIV prevention and care will help to empower local councils and integrated care systems to ensure that sexual health services remain adequately funded and prioritised in order to meet the zero-HIV targets. Holding these bodies to account will be pivotal in influencing change at a societal and institutional level.

We support the mayor's advocacy role leading London wide campaigns aimed at reducing stigma and promoting awareness of HIV. Previous campaigns leveraging social media, the use of public transport advertisements and community events have been shown to help disseminate information about testing and treatment and to help normalise conversations about HIV.

The Mayor can play a symbolic role in reducing stigma by publicly supporting people living with HIV and participating in events that promote inclusivity. Public support of initiatives like World AIDS Day sends a strong message about the importance of solidarity and compassion. By taking these actions, the Mayor of London can significantly contribute to the effort to end new HIV infections, reduce preventable deaths, and eliminate stigma, ultimately improving the health and well-being of Londoners.

How can London's health system address HIV health inequalities amongst minority groups?

Addressing HIV health inequalities among minority groups in London requires a multifaceted approach tailored to the specific needs and challenges faced by these communities.

People living with HIV remain among some of the most marginalised in our society. The majority live in the most deprived areas of the UK, suffer financial, housing, immigration and food insecurity, with higher levels of depression, anxiety and discrimination due to the intersectionality between HIV stigma, gender and race-based discrimination and violence. Addressing HIV health inequalities among minority groups in London requires a multifaceted approach tailored to the specific needs and challenges faced by these communities.

While in many centres, 90% of Emergency Department attendees receive an HIV test, only 50% of attendees are tested within specialised sexual health services. Emergency Department opt out BBV testing has been demonstrated to reach those individuals who do not appear to be attending traditional testing services such as sexual health services. Expansion of testing in other areas such as GP services (new patient registrations or for cancer screening) will be critical to close this gap. Equitable access to HIV prevention services, and tools such as PrEP must be ensured with a particular focus on those groups who are being left behind, for example, women. Women's services are historically and currently the most underfunded yet vital in supporting a disproportionate number of women and increasing numbers of new infections. Significant work needs to take place to understand a new model of delivery to support them.

Resources are needed for targeted outreach and education**,** robust peer support programs and data collection and research to fully understand barriers to testing, treatment and adherence within minority groups. We need advocates for policies that address social determinants of health, such as housing, education, and employment and full engagement from stakeholders in their commitment to addressing this issue.

By adopting these strategies, London's health system can better address HIV health inequalities among minority groups, ultimately leading to improved health outcomes and a reduction in new infections.

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London Assembly scrutiny on progress to 2030 HIV goals

Jonathan O’Sullivan

Director of Public Health, Islington, and Chair, London HIV Prevention Programme, for London Association of Directors of Public Health (London ADPH)

1. What are the main challenges that exist in London in reaching the target of ending new HIV cases by 2030?

Reaching the target of ending new HIV cases by 2030 in London presents several challenges across social, structural, and healthcare domains. An updated HIV action plan nationally, which is a commitment by the new government, would present the opportunity to stocktake and update London’s roadmap and underpinning actions. Some of the main challenges include:

Testing: Coming out of Covid, there have been reductions in testing among heterosexuals, which may yet be recovering. London provides the highest level of sexual health service access (attendances) in the country, far higher than any other region. Within sexual health services, there may be opportunities to increase testing among women attending for contraception (although I would caution on the direct comparison with ‘opt out’ testing in ED which uses leftover bloods, whereas blood would not usually be taken in a contraception appointment). Testing in pathways outside sexual health services may identify HIV infection, especially for conditions where HIV may be a contributory factor.

Reaching Undiagnosed Populations: 40% of people are diagnosed late, increasing complications and transmission, and new infections also continue. Among the groups affected, undocumented migrants and marginalised groups face additional barriers, which may include fear of deportation, poor experience of the state and lack of trust, and stigma which reduce engagement with healthcare services.

Tackling Stigma and Discrimination: Stigma remains strong in some groups, including some ethnic minority groups, religious communities, and among older people. Internalised Stigma affects mental health and engagement with care, and is one factor leading to lower treatment adherence.

Health Inequalities: Disparities in access to care reflect socio-economic factors and structural inequalities which represent significant barriers for Black African and Caribbean communities, GBMSM, and transgender individuals. Intersectional issues can compound multiple layers of disadvantage and make navigating the healthcare system challenging. While HIV brings its own very specific issues and considerations, there are many similarities with inequalities seen in other areas of health and care, and finding ways to align with wider programmes of action that address health and social inequalities and promote equality.

Sustaining Political and Financial Commitment: Pressures on public health budgets, following significant real terms cuts, risk impacting HIV prevention and HIV community and psycho-social services.

Barriers to PrEP Access and Use: Uptake of PrEP among GBMSM at risk seen by sexual health services is relatively high, although data suggests that just over 1 in 5 are not on PrEP. Uptake among heterosexual groups at risk seen in sexual health clinics is much lower, and there is much lower awareness and access among women, Black African communities, and transgender people, with less uptake and use. Further, since PrEP is available through Level 3 sexual health clinics, opportunities for direct access via other routes or services are lost.

Engagement with Key Populations, to better meet needs and respond to changing trends in needs, including:

- GBMSM community engagement to sustaining progress requires continued engagement and addressing evolving risk behaviours, such as rising rates of STIs and chemsex-related risks. GBMSM of colour and migrant GBMSM are disproportionately impacted and have lower access to HIV prevention.
- Racially minoritised community engagement including with Black African and Caribbean communities presents challenges like cultural stigma, distrust and negative experiences of healthcare systems, and barriers to accessing services. Intersectionality and compounded stigma further impact engagement, particularly for Black MSM and Black women.
- Shifting demographics of HIV infections: with the profile of those presenting with HIV changing, with increasing representation among GBMSM of colour, migrants, heterosexual Black Africans, and older individuals. Prevention efforts need to continue to adapt with tailored strategies for these populations.

Addressing Mental Health Needs: Mental health issues like depression and anxiety are higher among people living with HIV compared to the general population. Groups at higher risk of HIV infection also include groups who have higher levels of some mental health conditions. Integrated mental health services are not always accessible, especially for marginalised communities.

In considering the above, it may be worth reflecting that the challenges we have now are in the context of the substantial progress which has been made to date. It is difficult to think of other long term public health challenges which have seen such significant progress over the past decade, particularly with such a large reduction in the numbers of new diagnoses in London each year, around 68% since 2015.

Most of this dramatic reduction was seen in the period up to 2020, and particularly in GBMSM. Many health needs and indicators were adversely affected during the Covid period, and in terms of sexual health services, London's clinics were then subsequently significantly affected by the international Mpox outbreak in 2022. During this pandemic period, London importantly managed to maintain more access to HIV testing and sexual health services compared to most other parts of the country, through a mix of the online service offer and prioritisation within clinics for high risk, symptomatic needs and interventions which could only be delivered in-person. Against the backdrop of impacts on services through Covid, the introduction of PrEP as a routinely commissioned intervention was rolled out at scale and rapidly over this period. Where there have been small recent increases in HIV diagnoses, this is attributable to enhancements in the HIV testing offer across the capital through 'opt out' HIV tests in Emergency Departments. So, although the underlying reduction in HIV diagnoses has slowed in the most recent period to 2023, neither does it appear to have reversed through Covid, which might have been a risk, and important new interventions (PrEP and testing in EDs) have been introduced.

Reductions in diagnoses have been seen in most major groups over time, although there are different factors at work. The striking reduction in new diagnoses among GBMSM groups in the period to 2020 has been especially seen among White groups. So, while there is overall reduction, the inequalities have increased since other groups have not seen the same significant level of reduction.

The London HIV Prevention Programme identifies the four main personal strategies which essentially comprise the main population interventions for HIv prevention: using condoms; testing so you know your status; starting anti-HIV treatment if you are positive, which means you can't pass on the virus to anyone else (U=U); and using anti-HIV pre-exposure prophylaxis (PrEP) to reduce the risk of HIV infection. Underpinning these four ways, the programme's work seeks to address stigma via improved understanding of HIV and in particular draws on the U=U aspect in terms of improving understanding about how treatment means people cannot pass on the virus.

Getting towards the zero goals by 2030 therefore needs to sustain the above, and make further progress in offering the relevant interventions across the community and to targeted groups, underpinned by action to improve knowledge and address social attitudes, particularly in groups where stigma persists. From a practical point of view, this is really about action to continue to reduce the 'pool' of people who may be potentially infectious – so, people with new or undiagnosed infection, people who are in treatment but are not currently virally suppressed, and people who have been diagnosed but not in ongoing treatment and care. If we can get there, the goals around new infections, effective treatment and preventable deaths should broadly be realised.

2. What steps can be taken to address rising HIV diagnosis amongst ethnic minorities in London?

Addressing the increasing share of HIV diagnoses and late diagnosis among people from ethnic minorities in London requires community-focused, culturally sensitive interventions that tackle systemic barriers and social determinants of health. Building trust, reducing stigma, and ensuring equitable access to prevention tools are essential. Whilst HIV does bring its own specific considerations, there are some clear similarities with other areas of health and care for people from ethnic minority groups in terms of wider health and social needs, patterns of later diagnosis and experience of and access to services, underpinned by higher levels of socio-economic deprivation. For example, the contribution that the introduction of 'opt out' testing in Emergency Departments in terms of identifying previously undiagnosed HIV or people who may have dropped out of regular treatment and care is probably, at least in part, of these broader patterns.

There are a number of steps that could be considered to help reduce new HIV infections and late diagnoses in ethnic minority communities in London. While some of these would be open to London-level delivery or development, others may be more effective at more local or targeted levels. Steps might include:

Improve Access to Culturally Tailored Prevention Services:

- Partner with community leaders and organisations to deliver culturally sensitive HIV prevention campaigns, and as part of community engagement on HIV and related issues.
- Partner with faith-based organisations to work with faith leaders to raise awareness and reduce stigma.
- Develop resources in multiple languages to increase awareness, with formats and content that resonate with different groups and needs. Offer health promotion and outreach testing in high-need areas, which might include targeted engagement and planning with relevant community events and venues.

Increase Awareness and Education:

- High quality, inclusive sexual and reproductive health education for children and young people is an absolute cornerstone.
- Improve targeting and segment campaigns for different audiences and demographics, ensuring they are culturally relevant. The focus to address misconceptions, improve understanding and awareness, and tackle stigma in ways which most resonate with different groups. There is generally less awareness of U=U across all groups, and PrEP awareness is highly variable. Building awareness and knowledge of PrEP, and promote the effectiveness of treatment and preventive options.

- Targeted information and outreach for PrEP to increase promotion among groups with lower uptake, and provide support for understanding and accessing PrEP.

Address Stigma and Misinformation: Using multiple approaches, such as community-led conversations, which can provide safe spaces for dialogue; positive role models, highlighting stories of people living with HIV; and tackling gender dynamics, which can address cultural and gender norms.

Strengthen Health and care System Integration: Provide cultural competency training for health and care professionals, and offering HIV testing with other health services or as part of care pathways, particularly where HIV may be (an unrecognised) contributory factor.

Data Analysis and Insight: Collect and analyse data by ethnicity, gender, and geography to identify inequalities and missed opportunities. 'Feedback' loops with sexual health services and commissioners about uptake of testing and of PrEP to identify where/how to target actions to increase.

Social Determinants of Health: Addressing important determinants like housing instability and immigration status, which promote general health and wellbeing and are important in HIV prevention and care. Recognise the role of psycho-social support in living well with HIV and the role in wider care and treatment. Recognise and respond to higher levels of mental health and substance use needs and link or offer services.

Leverage Policy and Funding

- **Increase Public Health Funding**: Which helps to secure long-term funding for HIV prevention.
- **Advocate for Policy Changes**: Push for policies that improve healthcare access and address health inequalities.

London HIV Prevention Programme

From 2024/2025, the **London HIV Prevention Programme (LHPP)** is seeking to incorporate a new arm to the programme, which will sit alongside the communications and GBMSM outreach and engagement service, to address the **HIV prevention needs of Black heritage/heterosexual communities in London**.

The GBMSM arm of the programme is being procured with an increased focus on targeting GBMSM with intersectional characteristics, including race and ethnicity.

The LHPP will ensure the three arms of the programme to work collaboratively together to provide a cohesive strategy to address the HIV prevention needs of Londoners, via communication strategies and prioritising GBMSM and Black heritage communities.

A cornerstone of the programme is the promotion of the four proven methods of HIV prevention: condoms, HIV testing, Pre-Exposure Prophylaxis (PrEP) and being undetectable and therefore unable to transmit HIV (known as U=U).

To inform the design of the new service Black heritage communities, LHPP has commissioned a needs assessment to better understand the HIV prevention needs of this key population.

The needs assessment aims:

- To optimise the delivery of evidence based Black heritage HIV prevention services in London including the type of HIV prevention services and the preferred locations they will be delivered from.
- To understand/assess gaps, barriers and opportunities in HIV prevention efforts with the focus on Black heritage communities to inform the development of the new LHPP arm
- To identify the types of communications including social media that people of Black Heritage would use to be signposted to HIV prevention services including understanding the necessary resources, and the support required to develop the new arm

A residents' survey is currently running until 9th February 2025. The link to the survey is here: surveymonkey.com/r/ResidentHIVPreventionSurvey

3. How effective are HIV prevention services commissioned by local authorities in London, and how is this work joined up with HIV services delivered by other parts of London's health system?

The citywide **London HIV Prevention Programme (LHPP)** commissioned collectively by London's local authorities, and hosted by Lambeth Council, promotes HIV prevention through communications to all Londoners and targets key populations (GBMSM and Black heritage communities) via outreach and engagement. It's *Do It London* campaign raise awareness about the four ways to help prevent HIV, such as PrEP, condoms, and U=U, contributing to behaviour change and aims to improve understanding and knowledge of HIV and to destigmatise HIV. The campaigns run on London-wide footprints, helping to engage with key populations that move around the city, or can be accessed via key locations, and via London-wide communications, such as campaigns which have been run on the underground or radio stations. The communication channels used are kept under review, and change over time as trends change: examples include digital promotion, campaigns which have been run on the underground, articles in printed media, and broadcast adverts on radio stations. I say more about *Do It London* in my response on Q5.

Other HIV prevention services may be commissioned by local authorities individually or among neighbouring authorities, and provide more localised focus. They may be provided by community and voluntary sector services or by NHS services. Activities may include community-based testing, outreach, and more targeted public awareness campaigns with larger groups at higher risk; they may also focus on local health inclusion groups. Such initiatives can help reach individuals who might not access traditional healthcare settings and can help increase testing in key groups.

There is a general challenge with how best to evaluate the impact of population level interventions of this type, i.e. one which is primarily about providing health promotion information across population groups, particularly via routine measures and outside of fuller studies and evaluations. Available approaches include measuring changes in knowledge and/or attitudes (e.g. before/after how much did people know about how to prevent HIV), whether people went on to adopt interventions (e.g. was there an increase in testing during a campaign), 'click' type measurements which assess use and access of online materials (e.g. how many people viewed an advert or video or clicked through on a link for more information) and surveys (e.g. do people recollect campaigns, views on how informative resources are, etc). Testing out messages for relevance and impact, and insight into which sources are most likely to reach target audiences, inform the content of the Programme's materials and how they are promoted. All of these measures have been used at various times by the London HIV Prevention Programme, together with needs assessments and other evaluations, e.g. including views of stakeholders.

Integration with Other Parts of London's Health System

HIV prevention services in London require collaboration between local authorities, the NHS, and community organisations to address the complex needs of people at risk of HIV. While there are strong examples of London-wide and local collaboration, the varying responsibilities of different bodies, periods of organisational change, and challenges in reaching cooperation around shared gaols across different sectors and administrative boundaries means that partnership needs to be a continued focus for attention. Examples of joined-up working, from a London-wide perspective, include:

Sexual Health London (SHL): The city-wide service commissioned by the large majority of local authorities in London, SHL provides free home STI and HIV testing. It integrates with NHS services for follow-up and treatment, ensuring seamless care.

PrEP Delivery: NHS England funds PrEP medication, but local authorities commission sexual health clinics that provide the testing, adherence support, and follow-up required for people on PrEP.

Fast-Track Cities Initiative: London's status as a Fast-Track City has fostered partnerships between local authorities, NHS bodies, and voluntary organisations, ensuring coordinated prevention and care efforts aligned with the 2030 target.

London Sexual Health Programme Equality, Diversity, Inclusion Advisory Group (EDIAG): EDIAG purpose is to ensure that service users' voices are heard and represented on all matters related to the pan London Sexual Health Programme. This includes areas including but not limited to new guidelines into patient pathways, reviewing the LSHP Need Assessment.

London HIV Prevention Programme: The LHPP collaborates extensively with Fast Track Cities, Sexual Health London, and the EDIAG. This partnership ensures a coordinated and comprehensive response to HIV prevention. The LHPP also coordinates with national campaigns and resources, such as for national HIV testing week and It Starts With Me, which the Terrence Higgins Trust produce, funded nationally by OHID. By sharing best practices and pooling resources, these organisations work together to enhance the effectiveness of their initiatives, optimise resource utilisation, and deliver improved health outcomes for the Londoners and specifically key populations impacted by HIV.

London and local collaboration with **community-based organisations** can help tackle disparities in access and outcomes, particularly among marginalised groups.

4. What is the long-term impact of reductions to the public health grant on HIV prevention services?

HIV prevention services in the community commissioned by local authorities are funded through the Public Health Grant funds. Prevention services typically include condom distribution, sexual health education, and outreach efforts which may include taking clinical interventions out into more excluded or marginalised groups or settings less likely to be seen in clinic or to use online services. This may include health inclusion groups such as sex workers, people who are homeless, people with problem drug or alcohol use and refugee and undocumented migrant groups.

The Public Health Grant also funds integrated sexual health clinics which provide contraception and the testing and treatment of Sexually Transmitted Infections, including testing for HIV, and online sexual health services. The NHS funds the drug costs of PrEP, but the clinical pathways to offer and monitor PrEP, together with regular HIV and STI testing, are funded through the Public Health Grant. Psycho-social and other community and voluntary sector services for HIV may also be funded through the Public Health Grant.

There has been long term erosion in the value of public health grants to local government, as well as in the funding of regional and national public health bodies which also play vital roles in HIV prevention, such as UKHSA which provided the evidence and insight seen by the Panel in November, and OHID. It is estimated that the value of the public health grant to local government fell in real terms by 28% per capita since 2015/16; in terms of financial value, in 2022/23, the LGA estimated this represented a real terms reduction of £858 million in the value of the Public Health Grant in England.

There has been significant transformation and innovation in HIV prevention and sexual health services, including through service re-design, workforce development, changing mixes of in-person and digital service offers, among other initiatives, in order to continue to be able to deliver population health improvement interventions and the vital public health services for which local government is directly responsible. These measures have been important in helping to ensure sustained investment in HIV prevention and allied public health interventions which are crucial to achieving public health goals and ensuring equitable access to essential services for all residents.

The long-term reduction in the value of the Public Health Grant means there is very little room for investment in new activities or initiatives, and indeed there are pressures on maintaining existing levels of provision, particularly given increasing cost pressures in recent years in many services. The cumulative pressures resulting from real terms grant reductions mean that further action at scale and/or projects for additional more granular or targeted activity that may be indicated in achievement of the 2030 goals need to be carefully considered and planned in the light of the resources available, consider how actions can be achieved in as cost-effective a way as possible, and the case needs to be made in the context of many other important health needs and priorities, and system-wide pressures.

Having reviewed the panel's discussion fully, the scope appeared to be limited for anything we could perhaps now do less of (which might free up resources to be re-directed) and there is acknowledgement that the system is under pressure (and so cannot readily do more within resources available). There are also concerns that time-limited funding may not be renewed, such as the current programme of 'opt out' testing in EDs. I would probably also note that while digital innovation has been highly important in helping to manage or reduce costs, and importantly modernising how we best reach many people, we are seeing that use of the online sexual health service is now plateauing, with more people heading back into clinic, and increasing use of digital platforms in order to reach people around HIV prevention is highlighting concerns about how to best reach groups with less or no digital access within constrained resources. There were some interesting and specific options discussed by the Panel that could alleviate some pressures and potentially further enhance progress towards the zero goals – the uptake and numbers of people on PrEP is still growing, and an online PrEP service may be an option in the future; there may be other ways to follow up people who are believed to have left active treatment and care and who could be re-engaged, as more specific examples – but these may also bring extra cost implications, even though they may be more efficient than alternatives and support longer term cost-effectiveness.

Reductions to the public health grant therefore have significant long-term implications for HIV prevention services in London, and while local government and services will continue to innovate and find new ways to deliver outcomes and reach out across the community as cost-effectively as possible, the cumulative reduction limits the ability to invest in or expand activities if needed towards the zero goals.

5. What has the impact been of HIV awareness campaigns led by Do It London, and how could these be improved?

I've partly answered this in my response to Question 3. *Do It London* campaigns evaluate well, have been grounded in key personal strategies for HIV prevention, have helped to maintain and raise awareness about HIV prevention, especially among high-risk groups like GBMSM, and helps to improve knowledge about HIV and tackle stigma.

The Programme's core messaging and information is based around the four main ways to prevent HIV. While the core HIV prevention messaging has remained a steady and effective focus for the Programme over several years, there is a continuous need to review and adapt how the Programme communicates with and reaches Londoners, given the context of changes in population, trends in HIV infection and diagnoses, communication channels, developments in interventions and other trends. The Programme continues to need to consider how it can most effectively maintain awareness of HIV prevention in the context of the huge amount of media and information flows that most people experience on a daily basis, and how it best provides or signposts people to reliable health advice and information concerning HIV. It continues to develop partnerships with other services, programmes and events, and to use insight and intelligence to best target outreach activities, in order to better reach key groups.

In particular:

- The campaigns have successfully promoted the combination prevention approach—testing, condom use, PrEP, and U=U (Undetectable = Untransmissible)—helping to raise awareness, build knowledge and normalise conversations about HIV prevention.
- Campaigns have used diverse platforms, including social media, billboards, and public transport, to target different demographics. These have helped to ensure visibility across the city and all boroughs.
- The campaigns' focus on four ways that Londoners can help prevent HIV contributes to the broader strategy of reducing new HIV cases and reducing late diagnoses, aligning with London's status as a Fast-Track City committed to ending HIV by 2030.
- A continuing emphasis within HIV prevention messaging that people living with HIV on effective treatment cannot transmit the virus (U=U), *Do It London* has helped combat stigma, encouraging people to test and seek treatment.
- Surveys and evaluations indicate that the campaigns have been effective in raising awareness among men who have sex with men (MSM) and other high-prevalence groups. These also provide feedback around levels of understanding of the four ways, so, for example, we know that although U=U is reasonably well understood, it is notably less understood than the three others.

To meet the 2030 target of ending new HIV transmissions, the campaigns need to broaden their reach to underserved populations, address persistent stigma, and develop how they link more closely with community-based services or events. The Programme is currently developing approaches to black heritage heterosexual groups (described in the answer to Q2). Enhanced evaluation and inclusive, culturally sensitive messaging is intended to ensure that the content of the Programme continues to be relevent and to impact in London's diverse population.

Areas of focus or improvement under consideration for future Do It London Campaigns, include:

- Awareness campaigns have to date been less effective at reaching some communities and groups, such as Black African heterosexual men and women, older adults, and people whose first language isn't English. The Programme intends to develop more culturally tailored campaigns with input from affected communities, particularly Black African and other minority groups. The current needs analysis will help the Programme to develop how it addresses specific barriers and areas of concern for groups underrepresented in HIV prevention efforts, such as women and heterosexual men. The Programme intends to incorporate multilingual materials to engage London's diverse population.

- U=U messaging has been and will remain a central part of campaigns. As well as its direct role in helping to prevent new HIV infections, it is one important element in helping to address stigma and misunderstanding that is still associated with HIV. However, feedback and insight around the Programme's messaging continues to show that this element has lower awareness than other HIV prevention measures, and stigma or lack of understanding surrounding HIV remains pervasive in some communities and groups. This indicates that more work is needed to raise awareness around this, increasing the prominence of U=U messaging and educating the public on the realities of HIV transmission and treatment, which will help also to tackle other deeply rooted misconceptions.

- The communication campaigns and related information resources increasingly rely on digital platforms. To an important extent, this reflects trends in the use of digital and social media, and the decline of other formats. It also, in part, reflects the context of increasing costs of other forms of media and advertisement, and that digital routes can reach populations at scale or in targeted ways in a cost-effective way. However, it risks excluding those without regular internet access or digital literacy. Therefore, the Programme is considering which non-digital methods (e.g., radio, community events, posters in non-traditional settings like faith organisations or workplaces, etc) will help to best reach groups who may be less able to engage with online campaigns and digital information resources.

- There are further opportunities to develop in working with other services and initiatives. The Programme is looking at further opportunities to link campaigns more explicitly to services like community testing events, home testing kits, and PrEP clinics, ensuring that awareness translates into action; and to partner with local sexual health clinics and community organisations to distribute campaign materials and host educational sessions.

- The Programme has a long track record of using insights from evaluation, surveys and feedback to refine and target campaigns more effectively. This is more straightforward in terms of changes in knowledge, intentions, awareness and attitudes, but it is inherently difficult with health information-based campaigns to routinely track direct links with changes in behaviours or service use, such as with testing rates, PrEP uptake, or risk behaviours. Therefore, the Programme continues to look at how it develops data collection and analysis to assess the campaigns' impact on behaviour change, testing rates, and prevention tool uptake.

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25 October 2024

London Assembly Health Committee call for evidence: HIV in London

This evidence is provided on behalf of the HIV London Clinical Forum, which has representation from HIV clinical leads from each NHS HIV service across London, NHS England commissioners, London HIV and NHSE specialist pharmacists and community representatives who provide a clinical perspective on evidence on HIV in London for the London Assembly Health Committee.

1. **What specific challenges to achieving the targets of ending new HIV infections, stopping preventable HIV deaths and eliminating stigma associated with HIV by 2030 is London facing?**

London is the region most affected by HIV in the country, with 40% of all people seeking HIV care in the UK living in London, and new diagnoses rates and prevalence more than double the average outside London (1). London remains a critical geographical area in which to focus efforts to achieve the HIV Action Plan goal of Getting to Zero. Any threats to services such as uncertainty around delegation leave London at great risk of fragmentation of services.

Although the HIV Action Plan for England sets out welcome goals to reach an 80% reduction in new HIV transmissions by 2030 and there has been international acclaim for innovations such as Opt-out testing in Emergency departments for blood borne viruses including HIV, many challenges remain. London has the greatest proportion of people living with undiagnosed HIV and there are estimated thousands who are diagnosed but not in care, who remain at risk of developing serious morbidity or mortality, with the added risk of transmission to others and increased burden on the healthcare system (1). This must remain an important focus of any strategy to achieve zero new transmissions or deaths from HIV by 2030.

HIV testing and reaching the undiagnosed

An estimated 1600 people are living with HIV in London and remain unaware of their diagnosis. Although overall testing in London has increased by 8% between 2022 and 2023, rates are still not as high as pre-pandemic testing rates and coverage remains lower in key target groups. There has been a decline in testing in heterosexual men and women of 10% and 22% respectively and a decline in testing in young individuals age 15 to 24 years from 2022 to 2023 (2) highlighting the widening gap in inequity for these groups and in particular women. As the total number of undiagnosed declines, reaching these individuals will become increasingly challenging and will require sustained commitment from all stakeholders to reach zero.

Sexual health services continue to provide the majority of HIV testing in London, however significant challenges are being faced by these services which deleteriously impact access and testing. These services have experienced significant and ongoing disruption over the last 5-10 years from tendering with subsequent fragmentation from HIV services and declines in funding. There have also been additional pressures with the recent Mpox outbreak and need to deliver care and provide vaccines alongside routine sexual health management. Despite 4.5 million sexual health consultations being carried out in 2022 (a third more than 2013), public health and sexual health funding has been cut by £880 million between 2015 and 2024 (3). The HIV testing paradigm needs to change, for example taking the Emergency department into primary care and introducing testing strategies into mainstream health care settings.

Other barriers to testing include stigma, consistently identified as a barrier to testing and normalisation of testing as routine to reach those living with HIV but who do not self-identify as at risk and reaching those in marginalised, under-served and vulnerable communities. Stigma needs to be targeted outside the HIV and sexual health sector and work such as the HIV Confident Charter needs to have commitment from ICBs and Trusts.

HIV prevention

New HIV diagnoses data published in 2024 demonstrate we are not on track to meet the HIV Action plan targets. Unacceptable disparity exist with new HIV diagnoses continuing to increase among heterosexual men and women and gay and bisexual men of other ethnicities, and action must be taken to end this inequity (2). Pre-exposure prophylaxis has been available free of charge from the NHS in England since 2020 and is currently provided through Level 3 sexual health services (dealing with complex sexual health) yet there remains inequity of access with women and marginalised groups such as ethnic minorities and trans and non-binary people and men who have sex with men who do not identify as gay under-utilising services and leaving themselves at risk of HIV acquisition.

Even for those who know about PrEP and seek access, as detailed previously, fragmentation and cuts to funding due to reduced public health expenditure in local councils impacts the ability of sexual health services to cater for this need. The Not PrEPared report highlighted these stark issues and note almost half of clinicians in sexual health services stated there was insufficient workforce levels to meet patient demand, 23% of people were being turned away for lack of appointments and 57% on a waiting list for PrEP had waited more than 12 weeks to access care (4).

We welcome the change in commissioning of PrEP in November 2024 and new national guidelines in draft consultation to expand provision of PrEP, however challenges remain. Any service outside of secondary (hospital based) care, for example sexual health services run by private companies following tendering or primary care/local pharmacies, are unable to access the drug tenofovir alafenamide for PrEP. This is used if there are unacceptable risks to using standard PrEP due to bone or kidney health but is a high-cost drug and only commissioned via secondary care. Sustained and co-ordinated approaches to roll out community-based PrEP will be required with the support of sexual health services for complex referrals.

Managing complex care for people with HIV

41% of new HIV diagnoses in London are diagnosed late with a CD4 cell count <350 cells/uL which demonstrates a significantly impaired immune system. These individuals have a tenfold increased risk of dying in the first year after diagnosis compared to an individual with a fully functioning immune system and require greater resource and clinical input to support them. In addition, the recent increase in new diagnoses, both in those previously diagnosed abroad and newly diagnosed in the UK increase pressure on already stretched services.

For those stable on treatment, people with HIV have a disproportionate burden of co-morbidities, and some become frail decades earlier than the general population. Over half of all people living with HIV are age over 50 years and 20% are aged over 60 years and these proportions increase year on year. Care for these individuals has added complexity due to drug interactions with HIV treatment and polypharmacy and the perceived and experienced stigma from other healthcare workers when accessing other services (5). There are difficulties across all London with access to primary care services and within secondary care, and the lack of integration of services leads to poor health outcomes and inadequately addresses people's needs.

In addition, there remain a high level of burden of poor social determinants of health. The 2022 Positive Voices survey in London demonstrate that a high proportion of individuals live in food or financial poverty, in need of immigration housing or employment support and a high level of need for psychology services and substance misuse, including chemsex support which is currently unmet (5). Those with high levels of competing needs struggle to attend appointments and take regular medication and significant input is required to support these individuals to remain in care and undetectable on treatment.

Re-engaging those not in care

Although London appears to exceed 95:95:95 targets (95% of all those with HIV diagnosed, 95% of all those diagnosed on treatment and 95% of all those on treatment having an undetectable viral load), this data only represents those in care for the previous year. The UK Health Security Agency (UKHSA) now estimate the number of those not in care and aware of their HIV diagnosis to be between 15,000 and 24,000 individuals across England. Reasons for difficulty in engagement in care include HIV-related stigma, mental health issues, difficulties with immigration, housing, welfare and substance misuse. Without significant resource and in particular, embedded peer support within services and outreach HIV community based clinical nurse specialist to support people back into care, these individuals remain at risk of life-threatening infections and potential transmission to partners and children.

Equitable access to HIV community-based clinical nurse specialists has been highlighted by HIV services as a particular challenge. They are recommended in the Standards of care for people living with HIV (6) and the HIV specialised commissioning service specification but there is no legal mandate to commission them . These services, where available, provide invaluable support for the most vulnerable of people living with HIV, including adherence support, hospital at home, early detection and management of physical and mental health crises and care co-ordination across community, primary and secondary health and social services. Despite clear financial risk in terms of costs for increased secondary or tertiary inpatient care if these services are cut, they have been decommissioned in several areas across London and the coverage is now limited with none for example in South-West London. There is no centrally allocated commissioning responsibility for these roles and where these roles exist remains, they remain dependent on historic funding provision, through a variety of sources including Local Authorities, ICBs and individual Trusts. Support for these roles is critical as our population ages, with more complex care needs, a high burden of poor social determinants of health and stigma, and more people struggling to engage in care.

Stigma

Stigma remains a major barrier and underpins nearly all challenges in getting to zero; it impacts the physical and mental well-being of people with HIV and has been clearly linked to poor health outcomes (7) and is a barriers to HIV testing and accessing HIV prevention (8).

The HIV Confident Charter ran surveys at key pilot sites across London in 2024 in primary and secondary care among health care staff and the initial results demonstrated a worrying lack of knowledge around HIV transmission, inappropriate and unnecessary use of infection control measures and higher than expected levels of witnessed discrimination towards people with HIV.

Within London, the Positive Voices survey described high levels of stigma, including internalised stigma. 9% of respondents had never told anyone about their HIV status outside a healthcare setting, 70% found it difficult to tell people about their HIV status, 18% had felt isolated and lonely in the previous year, 40% felt ashamed of their HIV status and 29% reported having low self-esteem due to their status. In the previous year in London, 5% of respondents avoided accessing healthcare services when they needed to and 12% were worried that they would be treated differently to other patients by healthcare staff. Additionally, 3% reported that they had been refused healthcare or delayed a treatment or a medical procedure in the previous year.

Challenges to tackling stigma include the need to change both knowledge as well as behaviour, overcoming internalised stigma and enabling a wide reach across the general population. Variation in care exists across London where simple but powerful interventions such as peer support are only funded by some integrated care systems but not others and the provision of in-house peer support, which has clearly been demonstrated to be the most effective method of providing this service [personal communication, Garry Brough] has been variably implemented.

Workforce issues

Workforce issues continue to have a considerable and concerning impact on services; trainee numbers in sexual health and HIV have declined significantly, reducing new consultant numbers, and there are fewer highly specialised pharmacists and nurses in HIV as many skilled and experienced clinicians retire, leaving a reduction in the number of clinicians skilled in managing complex HIV. Changes to training and uncertainty over the future of the speciality secondary to uncertainty around commissioning are thought to have driven this shortage.

There exist significant barriers to working between organisations, with honorary contracts allowing individuals to work across multiple Trusts and for community partners to work within the NHS taking months or years to complete. Short term funding for projects such as peer support often translate into limited contracts within clinical services once the lead time for honorary contracts is included.

Delegation of HIV service to Integrated Care Systems

HIV is due for delegation from NHS England to local Integrated Care Systems in April 2025 and concerns regarding vulnerability and uncertainty exist. ICS re-structuring has meant some services are unable to identify the relevant people responsible for delegation due to restructuring, and HIV services are concerned that our voices will not be heard.

There exists unacceptable variation in provision of HIV care across London. The South East London ICS funds critical support for engagement in care work allowing providers to actively case find and engage those not in care and also funds community HIV clinical nurse specialist teams who provide invaluable outreach work for vulnerable people with HIV. Conversely, similar funding requests were rejected in South West London, driving unacceptable variation in care across London. In North West London there is a very active HIV & sexual and reproductive health Clinical Reference Group but with limited administrative and project management to ensure advocacy for HIV within the ICS.

ICS priorities do not align with HIV; HIV is not mentioned as a long-term condition or a priority for the ICS, despite many people living with HIV meeting the core20PLUS5 criteria (9) and in the Women's health strategy, HIV and sexual health do not feature. Being low in priority in terms of workplan and strategy creates significant barriers for funding ICS applications for services in HIV.

The Evolving Care Report produced in October 2021 (10) in collaboration with the London HIV Forum and Fast Track Cities aimed to support Integrated Care Boards (ICBs) to help achieve integrated and person-centred care for people with HIV. 13 priorities were identified and while good progress has been made in some areas such as strengthening partnerships and community engagement, there remains much to achieve. These priorities remain valid and we need to engage ICBs and advocate for support for these aims.

Although assurances have been given that people attending an HIV service outside of their ICS of residence will still be able to access their service of choice, this has not been confirmed. Often individuals will travel outside of their area of residence or work to HIV services due to confidentiality issues and this must be protected. Antiretroviral therapy costs will remain with NHS England but again, this has not been confirmed, nor details provided about how this will work in practice; this contributes further to anxiety around funding for HIV care.

2. **What actions are being taken by local authorities, the NHS and the voluntary sector to meet the zero-HIV targets, and what impact are these having?**

<u>NHS services</u>

Despite the challenges within the healthcare system overall, treatment outcomes for people with HIV in London and across the UK remain excellent, with 98% of those in care receiving antiretroviral treatment and 99% of these having an undetectable viral load (<200 copies/ml) (1). This is striking given that people with HIV must engage in lifelong relationships with their HIV care providers, with six monthly follow up in order to maintain viral suppression and good health outcomes. Life expectancy for those in care now exceed UK estimates.

These excellent outcomes are driven by HIV services commitment to patient centred, holistic and high-quality care and critically, open access services allowing individuals to self-refer to any clinic of their choice without geographical restriction or need for GP referral. This allows those living in rural areas to access large urban centres, with access to research opportunities and enables them to maintain confidentiality around their diagnosis by seeking care away from their area of residence. This is reflected in the most recent Positive Voices Survey in 2022, where people with HIV in London report overall extremely high levels of clinic satisfaction (9.4/10) (5).

NHS England

The Emergency Department blood borne virus (ED BBV) testing project, initiated and rolled out across London by NHSE in 2022 has been incredibly successful in both diagnosing the undiagnosed but also re-engaging people who have fallen out of care. Linkage to care rates are high (>90%) and this work has provided a blueprint for the rest of the UK and internationally. The project's rapid roll-out at scale was co-ordinated across multiple care groups within secondary care and third sector providers. In the first year the programme, 1.5 million HIV tests were performed, with 772 new diagnoses (638 linked to care) and 488 with known HIV but not in care identified (207 now linked to care). Initial evaluation also shows that, when compared to people diagnosed in other settings, new diagnoses are more likely to be in those who are older, female, of Black ethnicity and heterosexual.

NHSE mandated that a proportion of the funding for the ED opt out testing project should be spent on peer support. This unique approach has been successful in ensuring those newly diagnosed through ED testing were guaranteed access to peer support within NHS Trusts. Peer support at the time of diagnosis has been incredibly impactful and the funding has additionally allowed HIV clinics with no prior peer support in-house to have access to this valuable resource to reduce stigma and support re-engagement and advocacy.

Fast Track Cities

London has demonstrated excellent collaboration across all sectors, not just to roll out the ambitious ED BBV testing at pace, but also London-wide and local level collaboration with voluntary organisations, community and partnerships such as Fast Track Cities.

Fast Track Cities London have led the way to form these invaluable partnerships. Their collaboration between clinical partners, the third sector, primary care and key stakeholders for HIV prevention is unique and has enabled the successful roll out of a number of key strategies to tackle some of the challenges facing people with HIV.

Fast Track Cities have piloted GP champions in HIV, working across London to increase education and awareness, promote HIV testing in GP surgeries, and develop links with primary care to achieve better health outcomes for people with HIV. Innovative federation level pilots of opt-out HIV testing in GP services for people over 40 years of age having health checks in the borough of Hackney have been incredibly successful and demonstrate meaningful collaboration between public health, primary and secondary care to close the HIV testing gap and reach the undiagnosed. GP champions are now embedded in clinical networks across London, providing a primary care perspective on critical HIV issues and bridging the gap between primary and secondary care.

The HIV Charter Mark, an anti-stigma accreditation for organisations, is now completing the first year with founder organisations surveying staff and contributing to the development of a powerful education tool to tackle stigma and discrimination. The HIV ambassador programme has supported this work and other important projects, including education within primary care, secondary care, medical schools and other non-NHS organisations.

Fast Track Cities have brought together clinicians and professional stakeholders to determine key priorities to support the best HIV outcomes for people with HIV and developed reports such as Evolving the Care of People Living with HIV in London (10) and the HIV Clinical Round Table report which have been invaluable as frameworks for services to utilise.

3. What role should the Mayor of London have in helping to meet these targets, and is there any further action he could take?

The Mayor of London has already provided considerable support for HIV, through championing of the HIV Action Plan and Fast Tract Cities. London is now seen as a global leader in getting to zero with the London experience with opt out HIV testing in Emergency Departments being used to inform projects nationally and internationally. The mayor's ongoing leadership and support to empower local councils, integrated care systems and wider organisations such as education and the police to tackle stigma and to hold these bodies to account will be pivotal in influencing change at a societal and institutional level.

4. How can London's health system address HIV health inequalities amongst minority groups?

People living with HIV remain among some of the most marginalised in our society. The majority live in the most deprived areas of the UK, suffer financial, housing, immigration and food insecurity, with higher levels of depression, anxiety and discrimination due to the intersectionality between HIV stigma, gender and race-based discrimination and violence. Levels of addiction, mental health and vulnerability among people with HIV remains higher than in the general population and the challenge to meet these complex needs remains high. Many of these issues are experienced by the general population in London, however people with HIV often have multiple, intersecting inequalities with the added complexity of stigma.

While in many centres, 90% of Emergency Department attendees receive an HIV test, only 50% of attendees are tested within specialised sexual health services. Emergency Department opt out BBV testing has been demonstrated to reach those individuals who do not appear to be attending traditional testing services such as sexual health services. Expansion of testing in other areas such as GP services (new patient registrations or for cancer screening) will be critical to close this gap. Equitable access to HIV prevention services, and tools such as PrEP must be ensured with a particular focus on those groups who are being left behind, for example, women.

Yours sincerely,

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Ref No.005, London HIV Prevention Programme (LHPP)

London Assembly – Call for submission October 2024

Submitted by the London HIV Prevention Programme (LHPP)

Q.1 What specific challenges to achieving the targets of ending new HIV infections, stopping preventable HIV deaths and eliminating stigma associated with HIV by 2030 is London facing?

1. Reaching Undiagnosed Populations

Late Diagnoses: A significant proportion of people in London (40%) are diagnosed late in the course of their infection, increasing the likelihood of HIV-related complications and transmission. Although testing rates are generally high, some groups (especially older adults and racially minoritised) are less likely to get tested regularly, leading to late diagnoses.

Undocumented Migrants and Marginalised Groups: Migrants, especially those with precarious immigration statuses, face barriers to accessing healthcare, including fear of deportation, stigma, and misinformation. This reduces their engagement with testing and treatment services, and they are less likely to benefit from preventive interventions such as PrEP (Pre-exposure prophylaxis).

2. Tackling Stigma and Discrimination

Persistent Stigma: Despite improvements in awareness, stigma around HIV remains entrenched. This is particularly true among some ethnic minority groups, some religious communities, and older people. Stigma discourages individuals from getting tested, seeking treatment, or openly discussing their HIV status, which hinders public health efforts.

Internalised Stigma: Many people living with HIV experience internalised stigma, which affects mental health and engagement with care. This can lead to lower adherence to treatment and reluctance to disclose their status, impacting their well-being and increasing the risk of transmission.

3. Health Inequalities

Disparities in Access to Care: London is home to a highly diverse population, and significant health inequalities exist across different groups. Black African and Caribbean communities, gay, bi and other men who have sex with men (GBMSM), and transgender individuals face disproportionate barriers to accessing HIV prevention and treatment services. Social determinants like poverty, housing insecurity, and language barriers exacerbate these inequalities.

Intersectional Issues: For those facing multiple layers of disadvantage (e.g., race, sexuality, gender identity, immigration status), navigating the healthcare system can be particularly challenging. This may lead to lower engagement in care and prevention services, which hinders progress toward the 2030 goals.

4. Sustaining Political and Financial Commitment

Funding Cuts: HIV services in London have been affected by cuts to local authority public health budgets. This has impacted outreach programs, sexual health services, and community-based organizations that provide essential support for HIV prevention and treatment. Sustaining the current level of care and prevention efforts requires continuous political will and financial investment.

Impact of COVID-19: The COVID-19 pandemic disrupted healthcare services, including HIV testing and outreach efforts. Many sexual health services were repurposed for COVID-19 response, leading to reduced capacity for routine HIV testing and prevention interventions. London is still recovering from the impact of this disruption.

5. Barriers to PrEP Access and Use

Awareness and Uptake of PrEP: While PrEP is widely available in London, there are still barriers to access, especially among certain groups like women, Black African communities, and transgender people. Awareness of PrEP's benefits remains lower in these communities, and there are ongoing challenges with ensuring equitable access and adherence.

PrEP Delivery Systems: Access to PrEP through sexual health clinics is sometimes constrained by waiting times, limited availability of appointments, and inadequate geographic coverage. More accessible, community-based options are needed to ensure widespread uptake.

6. Engagement with Key Populations

GBMSM Community Engagement: While some groups of GBMSM have benefitted from high levels of HIV prevention and treatment, sustaining this progress requires continued engagement and addressing evolving risk behaviours, such as rising rates of STIs (sexually transmitted infections) and chemsex-related risks.

Whilst there has been a significant decrease in prevalence in this key population, GBMSM of colour and migrant GBMSM continue to be disproportionately impacted by HIV. These sub-populations of the GBMSM community and have lower levels of access to and engagement with HIV prevention message and tool and treatment.

Racially Minoritised Community Engagement: Engaging with racial minorities, particularly those from Black African and Caribbean communities, presents several specific challenges for HIV prevention efforts. These communities are disproportionately affected by HIV in London and the UK but often face unique barriers that hinder their participation in HIV prevention and care. The challenges include Cultural stigma and misinformation, distrust of healthcare systems, barriers to accessing HIV services (language barriers, financial and social barriers, immigration status and legal fears), underrepresentation in public health campaigns, ack of culturally competent healthcare, structural inequalities, religious and spiritual barriers. Intersectionality and compounded stigma impact on engagement. Many individuals from racial minority groups face intersecting challenges based on their race, immigration status, socioeconomic background, and sexual orientation. For example, Black MSM (men who have sex with men) face both racial and homophobic discrimination, which may exacerbate their experiences of HIV-related stigma and reduce their engagement with HIV services.

Black women, particularly heterosexual women, may not see themselves as at risk for HIV due to the way HIV prevention efforts have historically focused on MSM. This lack of tailored messaging leaves them vulnerable to underutilizing services like HIV testing or PrEP.

7. Addressing Mental Health Needs

Mental Health and HIV: Mental health issues, including depression and anxiety, are prevalent among people living with HIV, particularly due to stigma, trauma, and the ongoing burden of managing a chronic condition. Mental health services that are integrated into HIV care are not always readily accessible, particularly for those from marginalized communities.

8. Adapting to New Challenges

Changing Demographics of HIV Infections: The profile of those affected by HIV in London is changing. While new infections among some groups of GBMSM have decreased significantly, other groups, such as GBMSM of colour and migrants, heterosexual Black Africans and older individuals, are increasingly represented among new diagnoses. Public health efforts must adapt to this shift by developing tailored strategies for these populations.

Q2. Local authorities, the NHS, and the voluntary sector in London are working collaboratively to meet the zero-HIV targets of ending new HIV infections, stopping preventable HIV-related deaths, and eliminating stigma by 2030. Below are key actions being taken and their impact:

1. HIV Testing Expansion

Routine and Opt-Out Testing in Healthcare Settings:

NHS hospitals in high-prevalence areas, including many parts of London, are offering routine HIV testing to all patients in emergency departments, as part of opt-out screening programs. This has been extended to GP practices and other healthcare settings.

Impact: This approach has significantly increased the identification of people living with undiagnosed HIV. By normalising HIV testing in routine medical care, stigma is reduced, and earlier diagnoses are made, reducing the likelihood of HIV-related deaths. In some areas, testing rates have doubled, leading to earlier linkage to care and improved health outcomes.

Community-Based and Home Testing:

Local authorities and voluntary organisations, like Positive East, Spectra and the Love Tank, offer free home testing kits and pop-up community testing events. This is often targeted at hard-to-reach populations, including Black African and Caribbean communities, gay bisexual and other men who have sex with men (GBMSM), and those with insecure immigration status.

Impact: These initiatives have been crucial in reaching populations who might not engage with traditional healthcare systems. Community-led testing increases access to at-risk groups, reduces barriers to care, and helps lower the number of people living with undiagnosed HIV. Home testing has also made testing more discreet and convenient, which has proven effective in overcoming stigma-related barriers.

2. Widespread Access to PrEP (Pre-exposure Prophylaxis)

NHS PrEP Programme:

PrEP is now widely available through the NHS in London, with efforts to increase access through sexual health clinics and online services. NHS England has committed to expanding PrEP delivery, especially to underrepresented groups, such as women, transgender individuals, and people from Black African and Caribbean communities.

Impact: PrEP has been a game-changer in reducing new HIV infections, especially among GBMSM. The expansion of PrEP has led to a steady decline in new diagnoses among groups at high risk, including a significant reduction in HIV transmission among

GBMSM. However, there are still challenges in ensuring equitable access across all communities.

3. Public Health Campaigns and Stigma Reduction Efforts

Campaigns Led by Local Authorities and Voluntary Sector:

Local health authorities, in partnership with the voluntary sector, run public health campaigns aimed at raising awareness of HIV, and promoting the four proven methods of HIV prevention (HIV testing, condoms, PrEP and U=U: Undetectable = Untransmittable.

Impact: These campaigns have contributed to increased public awareness, improved knowledge of HIV prevention, and have played a key role in normalising conversations about HIV. The U=U message has been particularly powerful in reducing the stigma attached to living with HIV, leading to better mental health and quality of life for people living with HIV.

Community Engagement and Education:

Local community groups, often led by people from affected populations, work to provide culturally sensitive education and support around HIV. This is particularly crucial for engaging racially marginalised communities. Peer-led support groups and workshops in schools and faith-based organisations aim to change perceptions about HIV within communities where stigma is prevalent.

Impact: These community-led initiatives have had a positive impact on reducing stigma, encouraging open discussions about sexual health, and supporting individuals in getting tested and starting treatment. Increased community engagement has helped address specific cultural barriers to HIV prevention.

4. Integrated HIV Care and Support Services

One-Stop Sexual Health Clinics:

NHS services are increasingly integrating HIV prevention, treatment, and sexual health services in “one-stop” clinics. These clinics provide comprehensive care, including testing, PrEP, treatment, and mental health support, all in one place. They aim to reduce the fragmentation of services that can deter people from seeking care.

Impact: This model has improved access to HIV services, particularly for marginalised groups who may face multiple barriers to care. Integration also ensures that people living with HIV can receive holistic care, including treatment for other sexually transmitted infections (STIs), mental health support, and social services, which helps to improve adherence to treatment and overall well-being.

Support for People Living with HIV:

Voluntary organisations like Positively UK and THT offer peer support, counselling, and advocacy services for people living with HIV. These services focus on helping individuals manage their health, reduce isolation, and address issues related to HIV stigma and discrimination.

Impact: Peer-led support has been shown to improve mental health, treatment adherence, and quality of life for people living with HIV. It also provides a space for people to share experiences and receive support from those with lived experience, further reducing the stigma around HIV.

5. Addressing Health Inequalities and Targeting High-Risk Populations

Tailored Services for Marginalised Groups:

Local authorities and NHS services are working with the voluntary sector to provide targeted outreach for groups disproportionately affected by HIV, such as Black African and Caribbean communities, GBMSM, transgender individuals, and migrants. This includes mobile testing units, culturally competent healthcare, and specific programs addressing the needs of women, young people, and those with insecure immigration status.

Impact: These targeted efforts have begun to address the disproportionate burden of HIV in these communities. There has been an increase in testing rates and early diagnosis among racially marginalised groups, although there is still more work to be done in ensuring equitable access to services like PrEP and treatment.

Mental Health and Social Support:

Integrated mental health services are increasingly being offered alongside HIV care, recognising the high levels of depression, anxiety, and trauma among people living with HIV. Services that address social determinants of health, such as housing and employment support, are also part of this approach.

Impact: Addressing mental health alongside HIV care improves treatment outcomes and quality of life, leading to better engagement with services and a higher likelihood of maintaining viral suppression. Social support services also help to mitigate the broader challenges faced by people living with HIV, particularly among marginalized populations.

6. Advocacy and Policy Development

Policy Initiatives and Government Commitments:

The UK government, in collaboration with local authorities and organisations such as THT and NAT and the Elton John AIDS Foundation, has committed to achieving the zero-HIV targets by 2030. This includes substantial investment in HIV prevention, research, and scaling up services like PrEP and routine testing.

Impact: Government support has been crucial in driving the expansion of services and ensuring that resources are allocated to areas with the greatest need. However, achieving the 2030 targets will require continued and sustained political will, particularly in the face of ongoing challenges like budget cuts to local public health services.

Q3. What role should the Mayor of London have in helping to meet these targets, and is there any further action he could take?

The Mayor of London should continue to London's response to HIV alongside other health partners in London. A commitment to work towards a joint ambition of 'Getting London to Zero' is seen as a purposeful role for the Mayor of London to continue to advocate and support.

The London Health Inequalities Strategy (published in 2018) and subsequent Action Plan (2018 -2030) promotes London's partnership working and sets out a commitment where the Mayor of London agreed to support pan-London work led by partners and that London's boroughs will continue to fund the London-wide HIV Prevention Programme to increase HIV testing and promote prevention choices, particularly through the Do It London campaign. This sends a strong message in his role as an ambassador that reducing HIV remains a priority in the fight to reduce health inequalities and reduce HIV.

The Mayor of London signed the Paris declaration in 2018, when London became members of the Fast Track Cities initiative with signatory partners including the NHS England and London Councils. This collaborative work, which includes voluntary sector partners continues to influence progress to get towards London's HIV ambition through its an effective partnership working approach.

An essential part of the Mayor's role, should be to advocate and support an increase in the public health grant. This income is allocated to local authorities from the Department of Health and Social Care to provide health public services aimed at reducing health inequalities. In the last decade since the transfer of public health responsibilities from the NHS to local government in 2014, there has been a real decrease in real terms, in London. The public health grant allocation for 2024/2025 is £3.6 billion for England, with London receiving £730m compared, and £715 million in 2023/2024. Whilst there is an increase this year (in part to the Agenda for Change pay awards), in real terms over the past decade, there has been a 28% cut in the value of the grant, between the initial allocations for 2015/2016 and 2024/2025. Fundamentally, the increase fall to consider the rate of inflation and London's growing population. Spending on sexual health services has suffered a 40% cut in 2023/2024 severely undermining efforts to improve sexually transmitted infections and improving HIV outcomes.

Q4. How can London's health system address HIV health inequalities amongst minority groups?

Continue to work in partnership. London has an excellent record of working collaboratively, especially evidenced during the health challenges faced during the Covid-19 pandemic. The Health and Care Partnership consisting of the Mayor of London, London Councils, NHSE and ICSs worked effectively together in partnership reporting regularly to the London Health Board chaired by the Mayor of London. The partnership must continue to work together and to support London's efforts to keep HIV as priority and of relevance.

London's health system partnership success is evidenced in the roll out of HIV, HCV, and HBV (Hepatitis BV) testing to every Emergency Department across all 28 departments at the end of August 2022. This approach has seen impressive results with peer support offered for those people newly diagnosed. This innovative approach is an illustration of how partners can effectively work together, and seeking new ways to innovate through pan-London activity should be encouraged, if London is to successfully tackle the more complex approaches required to meet the needs of minority groups.

Learn to engage with and understand the needs of ethnic communities. There is an acknowledgement that Black African and heterosexual communities are disproportionately overrepresented compared to other ethnic groups. This includes disparities in the way HIV prevention is accessed, including a lower take up of treatment such as Pre-exposure prophylaxis (PrEP), a higher number of late diagnoses, demonstrates an urgent need to improve access to testing and the full implementation of HIV testing guidelines.

London has a history of effectively engaging with its communities during Covid-19 pandemic through the vaccination programme. It is essential that lessons from this experience are embedded in future approaches about how we listen and empower our communities at a place level. Co-designing and ensuring that communities must remain at the heart of decision making. London's health system must continue to work together to better understand our communities, specifically minority communities to ensure equitable access to services, improve late diagnosis and ensure preventative measures are consistent and maintained.

Currently, the London HIV Prevention Programme is responding to the lack of information by conducting a needs assessment of the Black heritage community, which will reflect the intersectional characteristics of the community, including race and ethnicity. This new aspect of the programme recognises the need to better understand the distinct cultural, intersectional, and structural factors influencing HIV transmission. Also being intentional about the methods to improve communication, language, stigma and discrimination and the socio-economic factors that exist with our Black communities. The findings will inform how the programme should evolve, with tailored interventions designed to advance HIV prevention efforts with Black heritage communities.

Ref No.006, London Sexual Health Provider Group

London Sexual Health Provider Group

Many thanks for undertaking a review of HIV in London and London's progress towards zero-HIV targets by 2030. This submission is on behalf of the London Sexual Health Providers Group: a forum of Lead Clinicians from the Local Authority (LA) commissioned Sexual Health Services of London Boroughs.

We wish to flag our concern that London will not reach the aims of the HIV Action Plan given the state of sexual health service funding in the capital. As stated by the Local Government Association, sexual health clinics are at breaking point.

https://www.local.gov.uk/publications/breaking-point-securing-future-sexual-health-services

HIV and sexual health services are intertwined in the UK. Lack of investment in terrestrial sexual health clinics is likely to result in reduced HIV testing, increased late presentation of HIV, a fall in HIV Post-exposure Exposure Prophylaxis (PEP) and Pre-exposure prophylaxis (PrEP) uptake, and a rise in health inequalities. Neglecting sexual health is a false economy.

Despite a Sexual Health London online STI testing service, demand for sexual health services has continued to grow, with nearly 4.5 million consultations carried out in 2022, up by a third since 2013. Those presenting to terrestrial services are now more complex. Online testing has been shown to be unacceptable for some individuals, including those who are most at risk of adverse health outcomes. The main burden of STIs is borne by those who already experience health inequalities and people experiencing health inequalities are less digitally and health literate.

https://sti.bmj.com/content/97/Suppl_1/A2.4

We welcome the UKHSA STI Prioritisation Framework which provides guidance on areas of focus when resources are constrained. The aim is to prioritise reductions in adverse health outcomes and reductions in inequalities. Guiding principles include focussing on under-served populations; addressing safeguarding concerns; complex cases; health promotion; treating those with diagnosed infection; partner notification. Some activities need to be de-prioritised, and this includes asymptomatic testing of lower risk individuals. This makes pragmatic sense, and we agree with principles outlined, but it will be difficult or impossible to reach zero-HIV transmissions if asymptomatic testing is limited.

Why is London special?

- London has the highest prevalence of sexual ill health in the UK. This has a disproportionate impact on inequalities, public health and the financial burden to local authorities.
- The last census revealed London to be the most diverse city in England. The greatest burden of sexual ill health is born within young people, gay and bisexual men, people of colour and other minoritised communities, leading to stark health inequalities.
- The boroughs with the ten highest rates of gonorrhoea in England were all in inner London.
- London has highest rates of syphilis.

- London's abortion rate is above the national average, the third highest in England.
- London has been affected by recent STI outbreaks e.g. syphilis, LGV, Hepatitis A, shigella and other enteric infections. The majority of the country's mpox infections were diagnosed and managed in London.
- Sexual health clinics within London are mostly provided by NHS Trusts, with many sexual health services running at a significant financial deficit. Current contract negotiations across London involve risk of reductions in clinic sites, opening hours and staffing over the next 12-24 months.

What happened to London's funding?

The public health grant to local councils used to fund sexual health services was reduced by over £1bn (24 per cent) between 2015/16 and 2020/21. Across England, spending on STI testing, contraception and treatment decreased by almost 17 per cent between 2015/16 and 2020/21, as local councils were forced to respond to the reduced funding.

The majority of London providers are paid on activity through the London Integrated Sexual Health Tariff (ISHT) tariffs, first developed in 2011/2012. All providers have seen a real terms reduction in income due to the following factors:

- Tariff prices have not increased in line with inflation or staff wages.
- Increase complexity of case mix due to shift of asymptomatic individuals to online providers. Tariffs were not designed to reflect this level of complexity.
- New clinical presentations and testing technologies, for which tariffs have not been created. This includes mpox testing, diagnosis and management, which remain unfunded, for example.
- Contracts hold providers to previous activity levels, with lower "marginal rates" payable for activity over historical baselines, even if demand increases.
- Increased funding is required to develop IT facilities to support more efficient working
- The short term nature of the contract awards stifles the ability to develop services and plan for the future.

Future evidence-based developments may include injectable PrEP, doxycycline PEP and Men-B vaccines, in the absence of any agreed funding.

Why are London sexual health clinics so busy?

- Demand for our services continues to outstrip supply, with activity increasing year-on-year. Challenges in accessing primary care are causing further demands on our service given our open access structure. We are well equipped to manage many of the individuals diverted from primary care and other disciplines, however, there is no suitable tariff to reflect the complex care they require.
- Addition of HIV PrEP services into pre-existing local authority contracts with no review of the staffing establishment required to deliver these services or the impact on other sexual health clinical outcomes.
- Increasing antimicrobial resistance have led to more costly and complex treatment pathways e.g. IM ceftriaxone for gonorrhoea treatment, pristinomycin for *Mycoplasma genitalium*

- Covid-19, austerity and the cost-of-living crisis have resulted in an increase in social and psychological need, felt disproportionately by the most vulnerable young people and adults. Open access sexual health services assess and signpost, refer and appropriately safeguard all children, young people and adults with vulnerabilities attending services. A recent audit from one sexual health provider demonstrated:
    - 9% of individuals presented with significant psychosocial complexity which required detailed discussion during the consultation.
    - The most common problems were mental health related (36%), alcohol, drugs or other harm minimisation (20%), intimate partner violence (20%) and sexual assault (16%).
    - Complexity also included disclosure of domestic violence in childhood, sex addiction, adult safeguarding and health anxiety.
    - Of the patients with psychosocial complexity, 48% were signposted and 16% referred to the relevant services.

HIV

HIV testing rates in London have reached pre-pandemic levels. There has been excellent progress in supporting BBV screening in Emergency Departments which have normalised testing in non-traditional settings and diagnosed those who may not otherwise have presented.

PrEP has had a significant impact on HIV rates in England. Available via level 3 sexual health services, access to PrEP has been increasing on an annual basis since 2020. However, as detailed in the recent UKHSA report, inequalities in access remain ongoing with unmet needs by specific exposure groups.

https://www.gov.uk/government/statistics/hiv-annual-data-tables/

Without improved funding in our sexual health services, these inequalities will worsen, leaving the most vulnerable behind.

Workforce

In line with the majority of UK care providers, services are facing profound workforce issues. Managing the complexity observed within clinics requires an experienced workforce. The cost-of-living crisis has forced a significant proportion of the workforce to relocate, frequently leaving London for non-NHS jobs outside the capital (please see NHS exit data).

Underinvestment and uncertainty regarding the future of the specialty has had a year on year impact on doctors choosing to enter specialty training in GUM. This means that there are multiple vacant training posts across the capital and very soon the rate of substantive GUM consultant posts being advertised will exceed the number of trainees completing their training in GUM.

2024 Genitourinary Medicine (GUM) ST4 Competition Ratios (specialty-applications.co.uk)

In conclusion, the zero-HIV targets will only be met through adequately funded sexual health services, and we call for a London-specific Sexual Health strategy. We would greatly welcome the Mayor’s input into both.

Yours sincerely,

The London Sexual Health Provider Group

Croydon Health Services NHS Trust
Dr David Phillips, Clinical Lead Sexual Health

Kings College Hospital NHS Foundation Trust
Dr Larissa Mulka, Clinical Lead

Central North West London Trust
Dr Rita Browne, Clinical Lead for Sexual Health

Homerton Healthcare NHS Foundation Trust
Dr Katherine Coyne, Clinical Lead

Barts Health NHS Trust
Dr Andy Williams, Clinical Lead

Chelsea and Westminster Hospital NHS Foundation Trust/SHL
Dr Diarmuid Nugent, Service Director
Dr Rachael Jones, Service Director, 10 Hammersmith Broadway

Falcon Road, CLCH, Wandsworth
Dr Rebecca Marchant, Clinical Lead

London North West Healthcare NHS Trust
John McSorley, Clinical Lead

October 2024

Evidence provided on the impact of the Fast Track Cities London HIV Ambassador Programme, managed by Terrence Higgins Trust

Background

In organisations across the public and private sector, we have identified there is a significant need for up-to-date education on HIV. The Fast Track Cities London HIV Ambassador Programme, delivered by Terrence Higgins Trust, aims to tackle societal stigma and support London's ambition of reaching zero HIV stigma by 2030 through education and the sharing of lived experience testament.

Over the last year and a half, we have been re-educating organisations primarily in the health and care sector to tackle stigma and worked closely with people living with HIV to build their confidence and internalised stigma.

The below outlines the impact of our work. We have been collecting pre and post session to measure the impact of education as part of our attempt to reach the 2030 target of zero HIV-related stigma.

Achievements to date

In its first 18 months, the programme has:

- **Recruited and trained 27 HIV Ambassadors** who share their personal stories to highlight and tackle HIV stigma.
- Delivered **75 hours of education** (50 talks) to **2,500 people** working in the health, care, and public sectors across London. Since April, we have reached 1885 people directly and over 12,000 more through social media posts. This includes over 20 talks delivered to Metropolitan Police Officers and PCSOs in the Safer Transport team between May-June 2024.
- **Impact –** evaluation data shows our training improved healthcare professionals' knowledge of HIV, reduced HIV-related stigma, and increased confidence in working with people living with HIV. Feedback has been overwhelmingly positive on the Ambassadors' personal stories, many feeling very moved by their courage to share their lived experiences in public.

Feedback

While feedback is currently being evaluated, initial review of the programme is incredibly positive, and we can already see attitudes towards HIV changing from those who have attended sessions. Notable quotes include:

- "I found the real-life experiences extremely interesting, valuable, and touching. It made it not 'scary' or a 'taboo' subject" – **Healthcare worker**

- "As a police officer I can forget that things I say as a throwaway or thoughtless comment can have a lasting effect on people. I have a terrible habit of saying silly things when I am nervous or want to fill a silence and I could have easily said something similar to the nurse. Thank you all again for your time and I promise that what you have said will stay with me and I will make sure everyone that I come into contact with will get a better service from me because of it" - **Police Officer**

October 2024

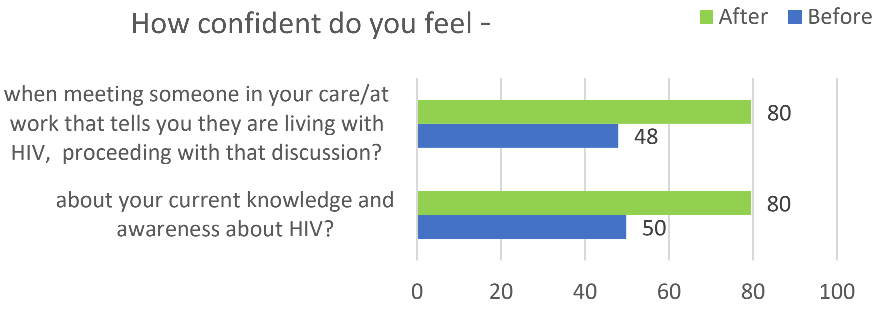
Summary of Data

Below is a summary of the pre-and post-training surveys from our sessions with health and care teams. They assess understanding of, and attitudes towards, HIV, and demonstrate the impact of the programme.

A note on the data: we have received a significant disparity in the number of responses to pre and post training surveys so data should be interpreted with caution.

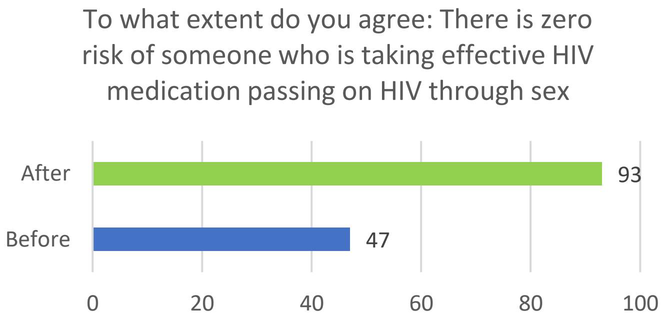
	Before training	**After training**	**Period**	**Total Audience**
Responses	220 (6.4%)	49 (1.4%)	6 Sep 23 – 16 Oct 24	3456

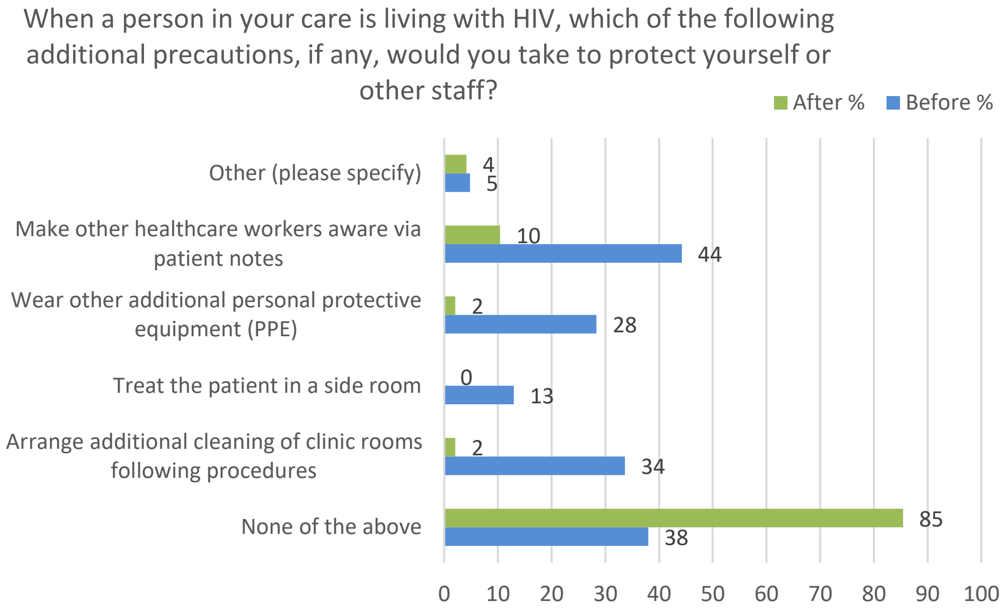
The specialties most represented were primary care (accounting for 31% of pre-training respondents and 70% post) and pharmacy (53% pre, 8%post). Respondents were most likely to be working as doctors, pharmacists, nurses or in non-medical people-facing roles.



Our training increased attendees' confidence in their knowledge and ability to have conversations about HIV, which is essential to supporting patients and tackling stigma.

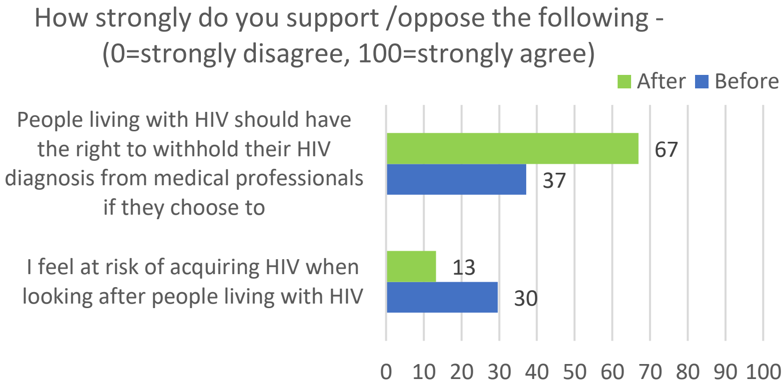
They also came away with a better understanding of U=U (undetectable=untransmissible). showing higher scores than the National Aids Trust Knowledge and Attitudes and Positive Voices surveys.

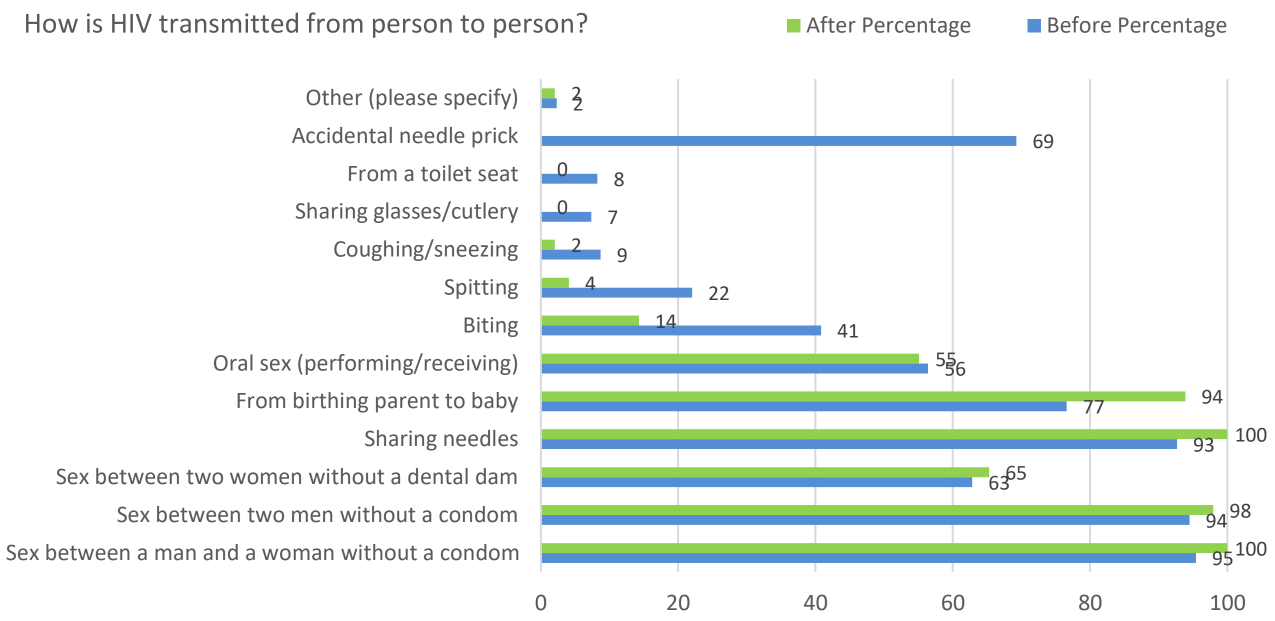




Ambassadors have shared many stigmatising experiences in healthcare such as unnecessary use of additional PPE so we're very pleased that most attendees now understand this isn't necessary.

Training reduced attendee's feelings of risk when looking after people living with HIV and showed greater understanding of transmission routes. As so much of HIV stigma is rooted in misinformation, improved understanding of transmission routes is a key indicator in measuring a change in both knowledge and attitudes.





When asked what particular insights people gained from training they told us

- ‘It was reinforced to me just how much of an impact I can have on patients and how important my role and my knowledge are’

- ‘It was interesting seeing how it could make someone feel that their world collapses with the diagnosis of HIV due to the stigma about it, but then realising that with treatment, there are no limitations in life with HIV.’

- ‘Found them very moving and really thought they added value to the session, helping us remember that despite U=U the work is not done.’

- ‘Very impactful personal account of lived experience and also very clear explanation of HIV transmission risks’

- ‘All of the talks were extremely powerful and very informative. Thank you to everyone who shared their experiences. This will stay with me forever’

- “Their stories were really beautiful, heartbreaking at some points but also inspiring.”

- “It’s unbelievable how people with HIV are treated within society.”

- “Really interesting to get patient perspective and his journey and experience with doctors important to learn from.”

- “It was shocking to hear the discrimination he received from his healthcare team in primary care.”

- “Thank you very much to everyone for sharing their stories. They were very powerful and will stay with me as a clinician when I see patients”.

NHS
Mildmay Hospital

HIV in London:
Evidence to the London Assembly

Scrutiny and Investigations
LONDON ASSEMBLY
Health Committee

The last decade has seen an erosion of HIV rehabilitation capacity across London as a response to less available funding and a misunderstanding of the needs of people living with HIV in a fractured commissioning environment.

Executive Summary

HIV Services Financial Constraints

For over a decade, increasingly stringent health commissioning budgets have negatively impacted specialist HIV rehabilitation centres like Mildmay Hospital, as well as long-term community care facilities.

Cost-effectiveness and rehabilitation outcomes:

Mildmay Hospital was designed to deliver high-quality, specialised, and cost-effective rehabilitation for HIV patients with complex health needs. National data show that it generates significant savings for the UK economy over the medium term.

Block-booking beds under a Pan-London contract would provide a more efficient and cost-effective solution compared to alternative methods. However, NHS commissioners have prioritised other immediate demands, reducing the availability of HIV-specific rehabilitation beds.

Along with broader cuts to HIV services across the capital, this threatens London’s ability to meet the Fast-Track Cities 2030 target. Mildmay contributes data to the UK Rehabilitation Outcomes Collaborative (UK ROC), allowing us to demonstrate the clinical effectiveness of our interventions and the cost-efficiency of our services.

Research has shown that specialist inpatient rehabilitation is one of the most cost-effective healthcare interventions, with estimated lifetime savings in ongoing care costs ranging between £670,000 and £1 million per patient.

Contribution to UK and London policy objectives

Mildmay Hospital plays a critical role in tackling the morbidity and mortality associated with HIV, homelessness, and substance misuse—three major public health challenges in the UK, especially in London. The hospital supports the Government's 2030 goals of ending AIDS, eliminating new HIV infections, reducing stigma, and addressing homelessness.

Recognised as the only specialist HIV rehabilitation facility in London, Mildmay was highlighted in the Fast-Track Cities London report for its unique contribution to HIV care and rehabilitation.

Strategic block-booking is the most cost-effective solution for HIV patient rehabilitation in London

Currently, fully funding Mildmay Hospital costs over £4 million annually. However, block-booking beds is a more cost-effective solution for commissioners compared to extra-contractual referrals. Given the increasing demand for rehabilitation beds for HIV patients in London, at least twenty of the hospital's twenty-eight beds should be block-booked.

Achieving this would require collaboration between the five London ICBs on a Pan-London contract to ensure this vital care is available to the most vulnerable. Alternatively, a higher authority, such as NHS England or a London-wide body, could step in to take over the direct commissioning of Mildmay's HIV services.

Contents

Introduction to Mildmay Hospital

Mildmay Hospital provides rehabilitation, treatment and care for people with complex and severe HIV-related health conditions, including HIV-associated brain impairment (also known as HIV-Associated Neurocognitive Disorder or HAND), in a modern hospital setting in London. It is the only specialist rehabilitation hospital of its kind in London and the entire United Kingdom.

The UK, and London, in particular, have a large burden of the morbidity caused by HIV infection and of the poor health associated with this group of patients.

Whilst a large proportion of patients living with HIV in the UK have their illness well controlled, there remains a substantial minority with complex physical and mental ill-health, which can be further complicated by substance misuse disorders and issues such as homelessness, which then limit their access to effective treatment.

Often patients may struggle with challenges of adherence to medication and experience difficulties in accessing healthcare and full participation in society due to expressed and internalised stigma.

Fast-Track Cities Objectives

The UK has made HIV policy objectives of ending new cases of AIDS and new HIV infections and of an end to stigma by 2030. London is already leading the way globally to reach zero HIV transmissions, with 96% of people living with HIV knowing their status: 98% on treatment and 99% virally supressed. The Fast-Track Cities partnership has supported the HIV Confident anti-stigma charter.

HIV Situation in London as of 2022:

- An estimated 38,680 people were living with HIV in London, which was 39% of all people living with HIV in England.
- The 37,267 people living with diagnosed HIV in London in 2022 was 1% higher than 2021 and 11% higher than 2013.
- In 2022, an estimated 1,363 London residents were newly diagnosed with HIV, accounting for 36% of new diagnoses in England. This represents a rise of 17% from 2021.
- The new diagnosis rate for London residents (15 per 100,000) was above that of England in 2022 (7 per 100,000).
- 48% of all new diagnoses in London residents were gay, bisexual, and other men who have sex with men.
- Heterosexual contact was the largest transmission route for new diagnoses in London residents in 2022 (49%).
- It is of particular concern that a large proportion of London residents with HIV are diagnosed late (39% from 2020 to 2022, compared to 43% in England).
- In 2022, it is estimated that 3.7% (CrI 2.8% to 5.0%) of people living with HIV in London were undiagnosed. This equates to an estimated 1,425 (CrI 1,073 to 1,957) undiagnosed people.
- A total of 156,355 people were tested for HIV in specialist sexual health services (SHSs) in London in 2022, a decrease of 46% since 2018, but opt-out testing in accident and emergency is now much more established and is detecting more HIV cases, including some of those lost to follow-up.

1. Annual epidemiological spotlight on HIV in London: 2022 data
2. UK HIV Statistics | National AIDS Trust
3. HIV statistics | Terrence Higgins Trust

Continuum of HIV care – the problem of falling out of care

England has already met its WHO 95-95-95 targets, with estimates of 95% of those living with HIV knowing their diagnosis, and 99% of those being in care and on treatment, and 98% of those being virally suppressed.

However, due to the way data is collected it is likely that this is an overestimation as it is a snapshot, and cumulative. It underestimates those patients who default from or are out of care. Recent estimates reveal that somewhere between 4 and 19% of patients may not be in care at any given time. These patients, often 'lost to follow-up,' typically present with advanced HIV and significant healthcare needs due to disease complications.

A significant portion of the patients admitted to Mildmay Hospital for rehabilitation have been those who were lost to follow-up and later presented with advanced disease, requiring prolonged periods of care.

1. Jose et al. A continuum of HIV care describing mortality and loss to follow-up: a longitudinal cohort study. Lancet HIV. 2018 Jun;5(6):e301-e308. doi: 10.1016/S2352-3018(18)30048-1.
2. Childs K e al. Addressing a significant health inequality: a project to re-engage patients lost to HIV follow-up. British HIV Association spring conference, 2022, Manchester. Abstract O08.
3. De Souza BC et al. Rebuilding the missing link to the fourth 90: addressing the mental health needs of an urban population of people living with HIV in a Greater London clinic. British HIV Association spring conference, 2022, Manchester. Abstract O20

Other Challenges faced by people living with HIV in London

1. **Stigma:** For many, HIV remains a stigmatising condition that negatively impacts quality of life. Much of the stigma exists because people do not realise it is impossible for patients with an undetectable viral load to pass on the virus. There also remains unacceptable levels of stigmatising behaviours demonstrated within the health and social care system itself towards those living with HIV which affects on their engagement in care.

2. **Mental Health:** People with HIV are twice as likely to experience mental health difficulties. Access to mental health services is particularly challenging with patients living with HIV, as there is often a lack of expertise in HIV specific determinants of mental illness. The lack of capacity in mental health services and of specialist mental health professionals in many HIV clinics could be significantly contributing to lack of engagement in care, and will potentially prevent the attainment of the Fast Track City goals by 2030.

3. **Psychosocial Support Services:** Funding cuts mean some people living with HIV are now longer able to access previous sources of psychosocial support, such as peer support and advice on benefits, work, immigation and housing .

4. **Addressing substance misuses problem:** Again easy access to support for thos living with substance misuse, and HIV can be difficult to access.

All of the above challenges can be lead to disengagement in care, but can also be addressed within the HIV rehabilitation environment.

1. NHS is 'failing' patients living with HIV - BBC News
2. Fast-Track Cities initiative - Transformation Partners in Health and Care
3. The future of HIV services in England | The King's Fund
4. HIV and Migration: Understanding the barriers faced by people born ...
5. End the domestic HIV epidemic in London by 2030

Commissioning

Following the introduction of the Health & Social Care Act 2012, the commissioning environment for small providers such as Mildmay has become ever more challenging. There were increasing barriers to arranging patient admissions, and the commissioners were increasingly reluctant to spend resources on rehabilitation services for patients with HIV infection.

It is clear that adequate rehabilitation provision for those living with HIV at the appropriate time clinically can aid adherence to care and antiretroviral therapy and increase quality of life among those living with HIV. Generic rehabilitation services do not always recognise HIV-specific needs and complexities The Fast Track Cities report "Evolving HIV care in London from 2021 recognises Mildmay as the only HIV specific HIV rehabilitation provider, and suggests that without adequate provision of this sort, then The Fast Track Cities goals will struggle to be met.

Sustainable Commissioning of Services

There are enough people living with HIV across London who require rehabilitation to justify block-booking at least twenty of Mildmay's twenty-eight beds. To ensure a sustainable, city-wide solution for these rehabilitation needs, collaboration between the five London ICBs would be essential to establish a pan-London contract, ensuring care for some of the most vulnerable in society. Alternatively, a central commissioning body, such as NHS England or the London Assembly, could intervene and take direct responsibility for commissioning Mildmay's HIV rehabilitation services, ensuring continued access to specialised care.

National AIDS Trust

Introduction:

National AIDS Trust is 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.

We welcome the opportunity to contribute to this call for evidence. London's HIV response plays a pivotal role in ending all new HIV transmissions in England by 2030: London accounted for over a quarter (26%) of new HIV diagnosis in England in 2023 and 38% of the people living with HIV in England lived in London.[1] Of the 1538 people in England who are not receiving antiretroviral treatment, 48% % of them were from London.[2] Furthermore, within the same year, the percentage of late diagnosis in London (30%) was higher than the UK average of 27%.[3]

Late diagnosis significantly increases the risk of comorbidities and of dying from HIV related complications. This inquiry has come at a time when London, and indeed England, need to reflect on what has worked and what has not. The recommendations and actions from this inquiry are essential for London to see further progress against the Government's 2030 goals.

Leadership:

As a city, London often leads in innovation and continues to set examples for what is possible. This was illustrated with initial pilot for opt-out blood borne virus testing in emergency departments – as one of the first cities to introduce it. The success of this pilot led to the expansion of this approach to all high prevalence areas in England. The work of Fast Track Cities London has also facilitated innovation and positive impact for people living with and at risk of HIV through its innovation, sector wide leadership and collaboration with key stakeholders.

Access to testing, pre-exposure prophylaxis (PrEP), sexual health outreach, treatment adherence, linkage and re-engagement to care should all be priorities if London is to continue to lead the UK in progress against the Government's 2030 targets to reach zero new HIV transmissions and to ensure people living with HIV live well.

These next 5 years will require targeted work, sustainable funding and further strengthening of partnerships with key stakeholders in the HIV response. There should also be further research into impact of existing and new approaches and technologies to reach these goals.

What specific challenges to achieving zero-HIV targets is London facing?

Access to PrEP

The UK Government's HIV Action Plan and PrEP roadmap highlights the pivotal role PrEP must play in ending new HIV cases by 2030 and the significant differences in PrEP need and uptake among marginalised communities.[4] There remain barriers to accessing PrEP in London which must be addressed.

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[1] UK Health Security Agency (2024), New diagnoses, AIDS, deaths and people in care in country and region data tables (https://www.gov.uk/government/statistics/hiv-annual-data-tables)

[2] Ibid.

[3] Ibid.

[4] Department of Health and Social Care (2021), 'Towards Zero - An action plan towards ending HIV transmission, AIDS and HIV-related deaths in England - 2022 to 2025' (https://www.gov.uk/government/

Our 2022 Not PrEPared report saw that no more than 5 women were reported to be on PrEP by any local authority in England including London which is deeply concerning.[5] From 2022 to 2023, in London, the rates of new HIV diagnoses in women increased by 27% in comparison to a 4% increase for men.[6] With reference to the point above, women in London were less likely than men to be initiated on PrEP after the need was identified, at 54% and 79% respectively.[7] Within the same period, Black African communities saw a 49% increase in rates of new diagnose compared to White British communities that saw a 13% decrease in rates of new diagnoses. [8]It is clear the need to successfully engage with women and Black communities about the benefits of PrEP is becoming more urgent.

Our 2022 report also identified that London was the region with the second highest amount of people turned away, so this suggests a need to diversify the routes for PrEP initiation and access. Of the people in London who responded to our survey, 18% reported being turned away by clinics. [9] These statistics show it is necessary to develop a London-wide strategy that diversifies the routes to PrEP initiation. This should include investing in PrEP pilots where PrEP is available online and working with the NHS to encourage expanding PrEP access to GP surgeries, community pharmacies, termination of pregnancy services and gender clinics.

Our research also highlights that there needs to be further investment into sexual health clinics, so they have the resources to reduce missed opportunities for PrEP initiation and to meet demand for PrEP need. In London, PrEP need has increased from 16.7% in 2022 to 17.7% in 2023 and the percentage of people initiated on PrEP has only increased from 78.1% to 78.2% he same period of time.[10] Progress on PrEP initiation could continue to stagnate where there is no evaluation of what work is currently being done.

Awareness of PrEP according to the 2021 Public Attitudes report was higher in London but more than two thirds of people in London were aware of PrEP.[11] For people who did not know someone living with HIV or who are cisgender and heterosexual, awareness dropped to 29% of people being aware of PrEP. In London-wide strategy, plans should be made to introduce a London-wide PrEP awareness campaign developed with the voluntary sector, clinicians and people living with HIV.

Tackle HIV stigma

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publications/towards-zero-the-hiv-action-plan-forengland-2022-to-2025/towards-zero-an-actionplan-towards-ending-hiv-transmission-aids-and-hivrelated-deaths-in-england-2022-to-2025)

[5] National AIDS Trust (2022) Not PrEPared: Barriers to accessing HIV prevention drugs in England. (https://www.nat.org.uk/sites/default/files/ publications/Not%20PrEPared.pdf)

[6] UK Health Security Agency (2024), New diagnoses, AIDS, deaths and people in care in country and region data tables (https://www.gov.uk/government/statistics/hiv-annual-data-tables)

[7] UK Health Security Agency (2024), HIV pre-exposure (PrEP) need and use data tables (https://www.gov.uk/government/statistics/hiv-annual-data-tables)

[8] Ibid.

[9] National AIDS Trust (2022) Not PrEPared: Barriers to accessing HIV prevention drugs in England. (https://www.nat.org.uk/sites/default/files/ publications/Not%20PrEPared.pdf)

[10] UK Health Security Agency (2024), HIV pre-exposure (PrEP) need and use data tables (https://www.gov.uk/government/statistics/hiv-annual-data-tables)

[11] National AIDS Trust & Fast-Track Cities London (2021), HIV: Public Knowledge and Attitudes (https://www.nat.org.uk/files/hiv-public-knowledge-and-attitudes-pdf)

Stigma in the healthcare system also prevents people in London from accessing HIV testing, treatment and care. Our charter mark, HIV Confident, addresses stigma in a range of settings such as healthcare and employment to challenge outdated myths and educate people on the needs of people living with HIV.[12] HIV Confident has conducted a survey identifying gaps in knowledge within clinical and non-clinical staff across three NHS Trusts and three GP Practices in London and one NHS Trust in the North of England. Almost 20% of respondents disagreed to some extent that having an undetectable viral load meant that a person living with HIV would not pass on HIV through sex and 17% answered that they did not know. Furthermore, at least 75% of respondents misidentified a transmission route – some people believing that HIV can be transmitted through biting, spitting, sneezing, coughing and through discarded needles.

Lack of accurate information and the presence of stigmatising beliefs from healthcare providers will make people reluctant to test, start PrEP, or seek HIV care when they are diagnosed.

Research shows that many people don't perceive themselves as at risk of acquiring HIV or they fear judgement and discrimination for asking about HIV, testing or asking about PrEP. A workforce that does not understand HIV or HIV stigma are not equipped to support people who are worried by stigma or lack knowledge of HIV themselves. For this reason, it's important to ensure healthcare providers are equipped with adequate knowledge and understand the impact stigma can have on people's healthcare decisions.

In the HIV Confident survey, 59% of respondents disagreed that people living with HIV should have the right to withhold their HIV diagnosis from medical professionals if they choose to. People living with HIV who fear stigma can be careful about who they share their status with so healthcare staff should be aware of consider how confidentiality protocols impact the wellbeing of people living with HIV.

Topics such as this are important to understanding how to support people living with HIV and how to improve uptake of testing and PrEP. HIV Confident has developed an e-learning module to address key areas of misinformation. The Mayor of London signed up City Hall as one of the founding members of the HIV Confident Charter Mark, we encourage that work be done by Greater London Authority to support uptake of the charter mark programme across London.

Primary Care plays a significant role in improving uptake of testing for people who are hesitant about attending a sexual health clinic. Therefore, it's important that Primary Care staff are equipped with accurate knowledge of stigma to ensure they can proactively encourage testing and continued engagement with treatment and care as needed.

In our 'Public Knowledge and Attitudes' report, only 33% of people in London reported that having a family member acquire HIV would not have a negative impact all on their relationship with them.[13] When further analysed, 46% of people with a better understanding of HIV transmission were more likely than average to say this would not impact their relationship. This fear that you might be treated differently if you were to acquire HIV can isolate people living with HIV and discourage people from getting tested.

These statistics show how improving HIV knowledge contributes to the reduction of HIV stigma in all parts of life. While knowledge of HIV transmission is higher in London than the UK average,

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[12] National AIDS Trust, aidsmap and Positively UK, HIV Confident website (https://www.hivconfident.org.uk/)

[13] National AIDS Trust & Fast-Track Cities London (2021), HIV: Public Knowledge and Attitudes (https://www.nat.org.uk/files/hiv-public-knowledge-and-attitudes-pdf)

only 20% of people in London believed that there is zero risk in a person living with HIV on effective HIV treatment passing on HIV through sex.[14] This suggests that sexual health messaging and educational resources are either not reaching enough people or the general public do not trust the information being given. In either case, misinformation causes fear and creates less incentive for people to test or attempt to initiate PrEP.

Provide culturally competent services

A lack of culturally competent services and care are barriers to reaching zero HIV transmissions by 2030 as health disparities faced by ethnic minority communities, especially Black communities, are widening. ONS census data from 2021 states 46.2% of London's population belong to an ethnic minority group, with 13.5% belonging to Black communities; a demographic that is disproportionately impacted by HIV.

In a survey NAT led on Black people living with HIV's experiences with primary care, more than a third (36%) responded 'Neutral' when asked if their GP understands their cultural and/or religious background and how it affects their healthcare; with more than a sixth (18%) of respondents clearly stating, 'Not Confident'. Worryingly, 81% of respondents did not know how to access interpretation services despite there being 27 first languages spoken by respondents (as well as English) . In addition, of respondents, 23% shared they had never been asked about their mental health and social wellbeing in appointments, which many expressed was worsened by cultural barriers, immigration issues and racism.

The Greater London Authority should work with NHS London and London ICBs to develop resources such as toolkits, guidance or minimum standards for culturally competent healthcare. This will ensure healthcare reflects the cultural experiences of ethnic minority communities impacted by HIV.

Find and re-engage people living with HIV who are not in care, and support everyone to live well with HIV

Approximately 14,393 people living with HIV in England are essentially *lost* to the health service, having not been to their HIV clinic for more than 15 months. They are at risk of passing on the virus, developing serious illness and dying.

Disengagement from care is the result of many factors, including experiencing complex medical and mental health needs, poverty, discrimination and fear of stigma. The Positive Voices survey shows that in 2023, people living with HIV experienced poorer levels of wellbeing and higher unmet needs than five years ago, with marked inequalities by race, age and gender.

Pilot work by the South East London Integrated Care Board has successfully returned people to care through case-finding, focused follow up and wrap-around support for people, which now must be rolled out across London.

Supporting people to live well with HIV not only improves individual health outcomes but also strengthens public health efforts by increasing retention in care, reduces transmission rates, and lowers the overall burden on healthcare services. Building on existing services and programming in London (as explored below), action must also be taken to make HIV support

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[14] Ibid.

services (including peer-support) and social services accessible to all, addressing the drivers of inequalities and supporting people with HIV to live and age will dignity.

Recommendations

- Introduce a national, year-round one-stop-shop for online PrEP service
- Local authorities and ICBs should invest in exploring barriers to postal self sampling kits and routes to increase uptake of at-home kits. They should also invest in community based testing initiatives.
- introduce a London-wide PrEP awareness campaign developed with the voluntary sector, clinicians and people living with HIV.
- Greater London Authority should work with other stakeholders to research missed opportunities for PrEP initiation and provide recommendations
- The UK Government and London stakeholders should advance work to implement PrEP access beyond sexual health services, to increase access to PrEP more widely amongst underrepresented, at-risk communities.
- The UK Government should provide a year-on-year, above-inflation increase in funding for the local authority public health grant, and increase funding to ICBs, to ensure that all ICSs can prevent HIV transmissions and better meet the health-related quality of life needs of people living with HIV. Urgently increasing resources to sexual health services will relieve capacity issues and circumvent existing staffing pressures.
- The UK Government and relevant London stakeholders should prioritise, support, and champion programmes that address HIV stigma including rolling-out the HIV Confident charter mark.
- London Integrated Care Systems should fund programmes to find and re-engage people living with HIV
- City Hall, London stakeholders and NHS should convene with voluntary sector organisation to provide distributable resources to establish standards for culturally competent care that adequately reflects London's diversity

What actions are being taken by local authorities, NHS England and the voluntary sector to meet the target of ending new HIV transmissions by 2030, and what impact are these having?

Impact of the HIV voluntary sector

The voluntary sector in London has a deep knowledge of the complex needs of the diverse community they are servicing. Although facing increasing pressure on services with new HIV diagnoses and cuts to resources, the HIV voluntary sector manage to deliver important community facing projects that are innovative in how they raise awareness and access to testing, PrEP and wider sexual health programmes.

For example, Positive East's project supported by Queen Mary University London, Women4Women is a community centred project that involved training Black African women to be PrEP champions within their local communities. The training that women in this programme received enabled them to engage with friends, family and their wider community about access to PrEP, to dispel myths and address concerns. The PrEP champions know their community, are trusted and have a shared language and cultural understanding that makes conversations on PrEP more accessible to the people around them. Projects such as this benefit from working with people with lived experience and community knowledge; however, they require long term sustainable funding to continue having positive impact.

Fast Track London

Fast Track London is a partnership of organisations which has driven many innovations and significant progress in London's HIV response.

This includes Fast Track Cities London's 'Getting to Zero' collaborative which consists of NHS and voluntary sector partnerships aiming to deliver holistic wraparound care that includes peer support in every London clinic. This project reflects the need to fund projects that address the social determinants of health and how they impact treatment adherence for people living with HIV.

Making socioeconomic and mental health support available can improve people's ability to prioritise their healthcare by working with them on developing healthy habits and addressing practical problems they face around immigration, housing and benefits. Investing in coordinated models of care such as this can drastically improve health outcomes and significantly reduce opportunities for onward transmission by helping people reach viral suppression.

Other projects facilitated by Fast Track Cities included London HIV GP Champions pilot which has played a key role in improving HIV awareness and tackling stigma in primary care, increased HIV testing, improved the health and wellbeing of for people living with HIV, and improved collaborative working between primary and secondary care, and HIV community organisations

NHS

The UK is fortunate to have access to free, high quality HIV treatment for all. Within London's HIV services, overall, there is effective linkage to care, prompt HIV treatment for those newly diagnosed and high levels of treatment coverage. Guidance, such as the NHS England (NHSE) Service Specification for adult HIV services, and BHIVA and BASHH guidelines, provide a useful framework for ensuring the provision of person-centred HIV services that meet the holistic needs of people living with HIV.

Data from the Positive Voices 2022 report highlights the very high average HIV clinic rating among people living with HIV of 9.4 out of 10, which clearly demonstrates a high level of satisfaction among people living with HIV on their HIV clinical services.[15] To help ensure effective support can be provided to people living with HIV and meet new challenges (including an ageing demographic of people living with the HIV), ICBs should work to ensure that all HIV services are equipped with the necessary resources, staffing and pathways to fully implement the BHIVA Standards of care, and the NHSE Service Specifications for specialised services for people living with HIV.

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[15] UK Health Security Agency (2024), Positive Voices 2022: survey reports (https://www.gov.uk/government/publications/hiv-positive-voices-survey/positive-voices-2022-survey-report)

The opt-out blood-borne virus programme in A&Es, first started in London, has been a remarkable success and is now being expanded across the country, with 81 emergency departments now benefitting from national funding in total. Thanks to the programme, hundreds of people living with HIV in London have been identified and initiated on treatment or re-engaged in care. The programme has highlighted the key role of the NHS and London ICBs in realising the ambitions of the 2030 goals, alongside delivering care. We are keen that this built on and that London NHS stakeholders continue play a key leadership role in reaching the next HIV Action Plan targets for London.

Local authorities

Some local authorities are managing to reach key populations often left behind by codesigning services. In the Unheard Voices report One London local authority responded in the survey for that they developed HIV services tailored towards the health and psychosocial needs of sex workers. The commissioner explained the service design and delivery required continuous engagement with local sex worker support organisations and sex workers to map and respond to their specific needs. As a result, they were able to deliver a comprehensive holistic support service that merged sexual health services such as HIV testing and resource provision with workshops on immigration, financial advice and peer mentoring.

Strengthened leadership of ICBs

The delegation of HIV services to Integrated Care Boards (ICBs) means they have become key stakeholders in the delivery of the HIV Action Plan. All London ICBs will be responsible for commissioning HIV treatment and care services from April 2025. Whilst devolving commissioning could introduce welcome changes, by helping to ensure that systems are more responsive to the health-related quality of life needs of local populations living with HIV, it is by no means a given and could result in a loss of momentum in the HIV response.

Several London ICBs have shown leadership for their HIV response with the roll-out of the opt-out BBV testing programme in emergency department, North East London ICS developing a Joint Sexual & Reproductive Health Strategy (which commits to the 2030 goals) and the South East London ICB is funding a project to find and re-engage people with their HIV care.

For the South East London ICB's project, three hospital trusts cross referenced their data on people living with HIV with UK Health Security Agency's data to identify people living with HIV who had not attended an appointment in at least a year. This project identifies people, checked if they changed clinics, passed away, or were just not engaged with care, and then contact them if they were not already in contact with a HIV clinic. Through this work, 824 patients who were disengaged from care were identified and through different means of contact, 18.5% were re-engaged in care with a third of them having a CD4 count less than 200.[16] A CD4 count less than 200 leaves many people living with HIV more susceptible to developing other serious illnesses.

Southeast London ICB was the only ICB to fund this work even though the need is apparent across all London; it is essential ICBs continue to invest in reengagement in care alongside testing, PrEP, and other sexual health outreach. London's approaches to re-engagement are

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[16] National AIDS Trust and HIV Outcomes UK (2023), 'Unlocking synergies
between Core20Plus5
and HIV response' (https://www.nat.org.uk/sites/default/files/publications/HIV%20Outcomes%20-%20Unlocking%20synergies%20between%20Core20Plus5%20and%20HIV%20response.pdf)

pivotal to ending new HIV transmissions as the risk of further transmission is reduced when more people are in care, virally suppressed and connected with adequate support.

To help ensure that London ICBs can respond to the local priorities of people living with HIV, they should appoint an accountable representative for their HIV response and work across the ICS (including with local authorities and the HIV voluntary sector) to develop local HIV Action Plans. These plans should outline how the ICS is delivering locally against the UK Government's HIV Action Plan, how it is responding to HIV inequalities in their system, how it is meeting the priorities of people living with HIV, and how the success of the response will be monitored. ICSs should also be required to report annually on their work implementing the next HIV Action Plan for England.

Recommendations:

- London local authorities and ICBs should adequately fund and expand access to wrap-around support services provided by HIV VCSEs. This should include ensuring provision of peer support for everyone, wherever they live in London. This should incorporate in-community, in-clinic and online methods to maximise engagement and support.
- London ICBs should continue funding the HIV GP Champion initiative after Fast Track London's pilot.
- Following the success of the opt-out testing programme in London A&E's, the UK Government and commissioners should expand opt-out testing in London so that everyone registering with a GP in high prevalence areas gets tested.
- London ICBs should appoint accountable representative for their HIV response and work across the ICS (including with local authorities and the HIV voluntary sector) to develop local HIV Action Plans. ICSs should also be required to report annually on their work implementing the next HIV Action Plan for England.

How can London address HIV health inequalities amongst minority groups?

In order to address health inequalities in London, people from underserved communities must be involved in the service design for tailored programmes of work and for key messaging in campaigns. To reach key populations from marginalised backgrounds, it requires understanding their concerns and what prevents them from accessing PrEP, getting tested and being retained in care. According to our Unheard Voices report, PrEP awareness and initiation and testing services were the most common services local authorities commissioned that were tailored to Black African and Caribbean communities. However, in 2023, Black African (62.1%) and Black Caribbean (62.4%) people were the least likely ethnicity to start PrEP in London after a need was identified.[17] Even though there is investment into PrEP access projects, the services are not effectively reaching the key demographics so should be co-designed with Black people living with HIV to make improvements.

Additionally, in our 'HIV and Migration' report, participants, who accessed London services, shared in interviews that their mental and physical health was impacted by their immigration status, so it is fundament to have services that factor in their experiences as migrants. ICBs

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[17] UK Health Security Agency (2024), HIV pre-exposure (PrEP) need and use data tables (https://www.gov.uk/government/statistics/hiv-annual-data-tables)

should evaluate what creates barriers to testing, PrEP, treatment and care so they can deliver targetted campaigns, in a range of languages, and services that reach communities of people who are new to the UK.

We cannot identify those concerns and answer the questions communities have until these communities are meaningfully involved in the decision-making process so that their lived experience can inform campaigns and services. The Unheard Voices report identified that 80% of London local authorities involved members of their local community to initial consultation periods before developing strategies, programmes of work and messaging. However, from responses it seemed that the involvement was confined to only initial consultation and not an ongoing process throughout the commissioning cycle.

Some councils, such as Camden and Islington, have centred community involvement in service design by creating opportunities for people living with HIV to shape services. They started a co-production group, so they have an established group to consult with regularly who also have control over the allocation of the Local Innovation Fund. This means people within the community have a deciding vote over the use of resources to support people living with HIV and to improve PrEP and testing access. ICBs and local authorities should be supported to embedding continuous meaningful involvement of Black and marginalised people living with HIV in all stages of service design.

Black-led voluntary sector organisations have highlighted in recent research the need to further involve them in research, policy and service design. Cuts to the voluntary sector as a whole are disproportionately felt by organisations that provide tailored HIV outreach and support to Black and ethnic minority communities.

For example, the French African Welfare Association previously were able to run and manage community-based peer support for French speaking Black African people living with HIV but did not have the funding to continue this programme that was positively impacting people’s lives. The peer support group reached a key demographic who are vulnerable and helped many people connect with and navigate the NHS and socioeconomic issues they faced.

To build contacts with local community leaders, community-based organisations and key demographics often left behind ICBs and local authorities must invest in programmes of work informed by the insight of the voluntary sector. ICBs should consider including HIV as part of system-level strategies and initiatives to tackle health inequalities. However, the Mayoral office must work with ICBs as they are facing a 30% cut in real terms by 2025-26 of their running cost allowance as they take responsibility over adult HIV services.

Recommendations:

- London ICBs and local authorities should integrate continuous meaningful involvement of underserved groups such as Black and minority ethnic communities. This may look like establishing lived experience groups or including lived experience representatives on steering groups, in tender assessment or other decision-making spaces.
- City Hall, Local councils, and ICBs should review or establish community engagement policies to embed diverse lived experience in service design and procurement processes. This should map out how to practically work with local communities including making involvement accessible, long term and reimbursed.

- Local authorities and ICBs should adopt best practice recommendations illustrated in National AIDS Trust and One Voice Network's report, 'Unheard Voices: Understanding the landscape of London HIV commissioning and community involvement of Black African and Caribbean communities.
- London ICBs should regularly communicate with voluntary sector organisations who provide tailored programmes of outreach, testing and support to better understand the needs of local communities.
- Greater London Authority and London ICBs should explore barriers to accessing healthcare for migrants.
- ICBs and local authorities should include in any health inequalities strategy actions to proactively engage with people born abroad who have recently entered the country with resources on healthcare entitlements including information on when migrants would have to pay for healthcare.
- Local authorities, NHS trusts and other London stakeholders should work to build referral pathways to between HIV services and other support services such as immigration support, housing, nutrition and financial support.

Would London benefit from a London-wide needs assessment in relation to HIV, and do the NHS and OHID have plans to introduce such an assessment?

A London-wide needs assessment is a crucial step in identifying the best allocation of resources and provide a roadmap on how London can achieve the targets of the UK Government's HIV Action Plan. This assessment could also serve to map and assess the impact of current programmes of work and different regional approaches. This should include audits of how clinics and voluntary sector are working to improve access to PrEP for communities who are not accessing it. This information can facilitate best practice across London on engagement with key populations and how different clinics respond to identified barriers for key demographics. It would also support mapping out where training and resources are useful to improve sexual health messaging, testing uptake and PrEP uptake outside sexual health clinics. For example, it will be easier to pinpoint a need to introduce training or resource sharing for healthcare staff around PrEP.

ICBs would significantly benefit from this research into HIV related needs across London. This assessment can support the development of local HIV strategies that would be the responsibility of individual ICBs so they can outline and execute actions to meet holistic needs of people living with HIV and strengthen prevention work such as stigma and PrEP campaigns, knowledge sharing between primary and secondary care. This would only be possible if ICBs create roles and assign leads for the delivery of this London assessment and subsequent regional Action Plans.

Recommendations:

- London City Hall should work with NHS and OHID to lead a London wide-needs assessment. They should ensure to engage with stakeholders across London including voluntary sector organisations, people living with HIV across various demographics, people who need PrEP, sexual clinics, HIV consultants, GPs, nurses and other healthcare providers.

PositiveEast
better futures for positive people

Positive East Submission

London Health Committee Call for evidence: HIV in London

Positive East is an HIV Charity rooted in the communities of East London affected by HIV where we have been operating for over 3 decades tackling health inequities and inequalities. The Charity supports people living with HIV to gain and sustain their independence through the provision of an holistic offer of HIV support services. Positive East also works towards ensuring that good sexual health is realised for all, ending new HIV transmissions, identifying undiagnosed and late HIV diagnosis through the provision of community based HIV testing and community insight driven approaches to HIV Prevention.

We are grateful for the opportunity to participate in the London Health Committee consideration of HIV in London. We have set out responses to questions below.

1.0 What Specific Challenges to achieving the targets…

1.1 The Voluntary Sector is a key player in achieving the shared London Fast Track City Goals of

- ending new HIV cases
- stopping preventable deaths
- eliminating HIV related Stigma
- Work to improve the health, quality of life and well-being of people living with HIV across the capital

1.2 Organisations, such as Positive East, are rooted in our local communities and have therefore developed relationships of trust with the communities and groups that carry the burden of HIV. Our staff and volunteers are mostly from the communities that we are working with and as such this builds in a cultural sensitivity and competence in our approach.

We are therefore best placed to reach and connect with communities, deliver interventions, build community capability and capacity, bring back community insight, articulate community need and contribute to strategic planning. All key qualities which take an even greater importance in the stage we are at with the pandemic.

1.3 However we do experience challenges that impact on our ability to contribute to the goals and these include:

1.3.1 Resourcing

Statutory funding is under pressure, which is passed onto Voluntary Sector Organisations, resulting in actual or effective real terms cuts in contract values . This means that statutory funding is rarely if ever full cost recovery. It also means voluntary organisations will be subsidising the cost of their statutory contracts through their voluntary income and that some services will either be more limited in their scope or completely cut if alternate sources of funding cannot be found.

This is particularly concerning as the cost of reaching and engaging the communities that we need to connect with is likely to be more expensive and often more intensive.

Statutory Funding for Voluntary Sector organisations such as Positive East is largely from Local Government and is funded mainly from the Public Health Grant. Local Government is under enormous financial pressure and this is exacerbated by the cuts to the Public Health Grant. The Health Foundation states that the Public Health Grant has been cut by '28% on a real terms per person basis since 2015/16'[1]

This situation naturally has an impact on funding for the voluntary sector and as a result the scope and extent of our service offer and places achieving the Fast Track Cities goals at risk.

1.3.2 De-prioritisation of HIV Support Services

We are concerned that voluntary sector services promoting the quality of life and health and wellbeing of people living with HIV are being deprioritised by Local Government Statutory Funders. This is a likely consequence of the financial pressures that they are experiencing.

This is however problematic. Promoting the quality of life of people living with HIV is of course a good in itself. It is particularly important as the majority of people living with HIV are over 50 and an aging population. The Positive Voices Survey[2] also highlighted that 64% of people living with HIV were living with one or more co-morbidities, 39% has a diagnosed mental health condition and just over 50% stated that they didn't have enough money to meet their needs (this rises to 74.4% when considering people living with HIV of Black African ethnicity).

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[1] Investing in the public health grant

[2] Positive Voices 2022: survey report - GOV.UK

Voluntary Sector services such as advice services, peer support, counselling, support groups, health and wellbeing workshops all play a significant role in addressing or at least mitigating the impact of these factors on people's lives preventing the escalation of need. It has been suggested to us that people can access generic service provision to address these needs. However this does not take into account the wider voluntary sector has been hollowed out as a result of austerity, covid and increasing demand. Perhaps more importantly it belies that role that HIV stigma still plays in the lives of people living with HIV and the impact that this will have on a persons ability to access services and support. Further HIV peer support cannot by definition be provided by a generic service.

We also now know that the disengagement from HIV medical care is significant factor in terms of the outcomes for people living with HIV. It is also a wider public health matter that will have an impact on enabling us to reach the goal of ending new HIV cases. The drivers of disengagement from care are not medical and are largely to do with complexity of need and social determinants of health. Positive East undertook with our partners Metro Charity and Spectra a literature review exploring the reasons for disengagement from HIV medical care[3] . It is clear that the specialist HIV Voluntary Sector has a key role to play in both sustaining people in care and enabling people to reengage with care. This is because of our relationships of trust with individuals, the greater frequency with which we see people (people may only attend HIV clinics once or twice a year), our holistic service offer and the fact we are integrated into HIV pathways of care.

We are therefore concerned to see Local Authority Commissioners reduce funding for this type of work because of the potential risks to individual health, public health and the Fast Track City Goals.

1.3.3 PrEP Equity

PrEP is an clearly a game changer and a key prevention tool that will enable us to achieve our goals. However we are concerned that some groups and communities are underserved. It is why we very much welcome the BHIVA/BASSH consultation on the new guidelines.

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[3] Literature review: what factors promote disengagement from, and re-engagement back into, care for London PLHIV?

In particular through our PrEP Equity project 'Women 4 Women' we gathered insights that illustrate some personal and institutional barriers to women accessing PrEP.

In particular we heard that women would like to access PrEP in community settings and outside of Sexual Health Clinics.

This was echoed in the qualitative study we undertook, with our partners Metro and Spectra, exploring access to PrEP with people of Black African Heritage, Trans people and people from Latinx communities (we presented findings at BHIVA spring conference 2024 and HPE conference 2024) .

We have seen good examples of Community PrEP clinics at the offices of Terrence Higgins Trust in Brighton and Yorkshire MESMAC in Leeds. We believe that these community based offers should be replicated in London alongside other alternate methods such as a digital PrEP offer to address the existing inequity in service to underserved groups (such as women) and communities

2.0 What Actions are being by Local Authorities, the NHS and the Voluntary Sector…

2.1 In general terms the voluntary sector is a key partner in delivering the required impact to achieve the Fast Track City Goals through:

a) Its relationships of trust with communities and groups that statutory services cannot reach and engage. These are communities that are being left behind in the good news about HIV and who we need to reach and engage to achieve our goals.

b) Delivering culturally competent effective HIV Support and Prevention Services to communities and groups that statutory services could not reach and engage. These services include those promoting the health and wellbeing of people living with HIV preventing the escalation of need, sustaining and mitigating the risk of people disengaging from care. Examples include peer support, advice services (with an HIV specialist knowledge and understanding), and Counselling Services.

They also include HIV Prevention and Testing services which address the barriers to undeserved communities through culturally competent service delivery, being driven by community insight, involving communities in service design and delivery. Examples include community based HIV testing and STI screening services (30% of our testers have never tested before and a significant number do not have a GP) delivered in our offices and in a range of community settings across North East London. At Positive East we also have successfully used digital technology to engage with minoritised communities through our Chat Bot Pat[4] that answers questions about HIV and Sexual Health and through which HIV testing and STI screening appointments can be booked. Pat is a 'people powered' Chat Bot as its script has been developed with people from minoritised communities which ensures its ability to effectively engage (Pat was the Centre of an NIHR study at the University of Westminster demonstrating its acceptability by racially minoritised groups[5]).

Our PrEP equity project Women 4 Women is an example of a community insight driven programme training up women from Black African and Black Caribbean communities to be HIV and Sexual Health Champions and Community Researchers taking information and raising awareness about PrEP to their communities using their own social networks and bringing back insights that inform service planning and development. The women in this programme co-created a PrEP information film[6] . This was the second co-produced PrEP awareness film we have produced the first being Mama Says[7].

Other projects that demonstrate our culturally competent approach and involvement of communities are the resources we developed for both Muslim and Christian communities. We recognised that many of the communities we work with are people of faith. We co-produced 2 resources HIV and Islam[8] (produced with imams, mulsim women and LGBT muslims) and HIV Christianity[9] (produced with Christian faith leaders and community members).

c) Our ability to engage with communities enables us to have an understanding of need We will often see that needs is changing and when new needs are emerging ahead of statutory services. We therefore play a critical role in contributing to strategic thinking, planning and supporting communities to effectively articulate their needs in service design and development.

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[4] Positive East

[5] The impact of chatbot-assisted self-assessment (CASA) on intentions for sexual health screening in people from minoritised ethnic groups at risk of sexually transmitted infections : WestminsterResearch

[6] What is PrEP?

[7] Mama Says

[8] Islam booklet for print 3mm upated 25 June

d) Increasing the financial investment in the work of the sector through raising funds for services. Charities raise funds for our work via Trusts and Foundations, Community Events, Corporate and Individual donations. At Positive East approximately 40% of our income is from voluntary sources and increasingly we would not be able to undertake our work without such funding. Fundraising can also provide opportunities for engagement with people who we may not otherwise be able to reach and share key messages

e) Mobilising volunteers increasing the scope and reach of the work that is being undertaken in London. We estimate, at Positive East, that in any one-year volunteers contribute approximately £100K in terms of their time (using the London Living Wage as an hourly rate). This will undoubtedly be replicated in voluntary organisations across London showing the real almost hidden energy that powers our work.

f) Building community capability and capacity around HIV both through our direct interventions and through training up volunteers who take their skills and new knowledge into their communities and social networks.

g) Being a constant and persistent challenge to HIV Stigma an example being the Red Run[10] (which the Mayor opened in 2018) that Positive East organises annually in Victoria Park. Over 28 different HIV organisations and 3000 people in a very public display of solidarity and challenge to HIV stigma.

2.2 Local Authorities Funding Innovation

2.2.1 We are very grateful to East London Local Authorities that have funded our 'Women 4 Women' Project described above. Similarly we are very grateful to the City of London and London Borough of Hackney for funding our 'Project Community' programme an HIV and Sexual Health Equity programme focused on people from Black African, Black Caribbean communities and other minoritised communities and groups. Being community insight driven projects they are not traditional approaches to statutory service commissioning. However they are the approaches needed to be able to reach and connect with the communities and groups that we need engage to achieve our goals.

They should be held as examples of positive approaches to statutory service delivery

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[10] The World AIDS Day RED RUN in London

3.0 What role should the Mayor of London have in helping to meet these targets and is there any further action he could take?

3.1 The Mayor has the opportunity through his various strategies, being a signatory to the London Fast Track City Initiative, general convening powers, and the London Health Board to:

a) Promote the Voluntary Sector as a key strategic partner in achieving the goals. The voluntary sector is often simply considered as a 'provider' and not strategic partners who are a bridge to underserved and minoritised communities and groups, able to articulate community need, deliver culturally competent services and bring resources to the conversation.

b) Ensure all stakeholders continue to live up to their commitment to deliver the Fast Track City Goals and continue to commit resources to ensure the job is done. The pressure on statutory sector commissioners to reduce funding because of financial pressures is immense. They should be supported to resist the pressure to reduce funding because of the significant risk this poses to achieving the goals. In particular, for the reasons highlighted above, we would ask the Mayor to support continued funding of HIV support services.

c) Raise awareness that 'We're not done Yet' and despite the good news that if we don't continue with investment and our focus we will not achieve the Fast Track City Goals. This is important to ensure continued momentum and the sense of urgency needed to achieve the goals.

d) Promote widening access and removing barriers to both oral and injectible PrEP through ensuring that there is a strong community offer and is not limited to being provided within sexual health clinics

e) Actively encourage the NHS through the devolvement of HIV specialised care from NHSE to Integrated Care Boards to not simply 'lift and shift'. The opportunity of this change is to look at how the changing needs of people living with HIV require a difference in approach. We believe that the NHS should get involved in funding the wider voluntary support services required to keep people well in the community, prevent the escalation of need, and sustain and mitigate the risk of people disengaging from care. We also believe that this is an opportunity to explore ideas about community based clinics with wrap around primary care and voluntary sector services support.

4.0 How can London's Health System address the HIV health inequalities amongst minority groups

There are a number of issues we believe that the London Health system could do and these include:

a) Continued funding of London Fast Track Cities Initiatives. London FTCI has been a positive force in creating a single vision and bringing together key stakeholders within the Capital's HIV Health and Social Care system. Funding has allowed investment in the voluntary sector to support achievement of goals addressing inequalities

b) Ensuring that there is not just a 'lift and shift' approach to the devolving of HIV specialised care and consideration is given to how the changing needs should now be addressed (as suggested above)

Mark A. Santos
Positive East
October 2024

POSITIVELY UK

Positively UK Response to the London Assembly Health Committee's Investigation into HIV in London

Thank you for the opportunity to contribute to the London Assembly's investigation on HIV.

Positively UK is a national charity dedicated to protecting the health and well-being of people living with HIV through tailored peer support, advocacy, and promoting equitable access to healthcare.

At the heart of our work is the belief that the lived experiences of people with HIV are key to finding solutions to end HIV. We are committed to the meaningful involvement of people living with HIV, with 90% of our staff and 60% of our board of trustees representing this lived experience.

Below are our responses to your questions

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1. What specific challenges to achieving zero-HIV targets is London facing?

To achieve zero-HIV targets, we must **focus on and invest in the quality of life and well-being** of people living with HIV. Currently, many people face significant challenges in staying engaged in care and maintaining undetectable viral loads.

According to UKHSA data (2020), over **6,000 people have disengaged from care** in England, with a large proportion likely residing in London.

The reasons for this are complex and include:

- **Stigma and Discrimination**
  Stigma persists in both community and healthcare settings, often preventing people from accessing care due to fear of being identified as HIV-positive. Stigma is a major barrier to quality of life for many of those we support.
- **Mental Health**
  High levels of stress and anxiety are prevalent among people with HIV, often leading to disengagement from care. Additionally, poor mental health can lead to coping mechanisms such as alcohol and drug use, with **chemsex** being particularly common among London's LGBTQ+ community.
- **Poverty and Financial Instability**
  Many individuals struggle to meet basic needs, and our **Welfare and Benefits advice service** is under heavy demand. Over half of the Londoners we support face homelessness or inappropriate housing.
- **Immigration**
  People with insecure immigration status or those who are asylum seekers with no recourse to public funds face significant barriers to healthcare and require help navigating complex health and social care systems.

- **Cultural and Language Barriers**
  Discussing taboo subjects like HIV and sex, coupled with limited English proficiency, makes it difficult for many individuals to understand vital healthcare information.
- **Healthcare System Challenges**
  Navigating fragmented or complex healthcare systems can be overwhelming for many. Scheduling appointments, coordinating care, and accessing referrals can become too difficult to manage.
- **Medication Side Effects**
  Long-term HIV medication can cause side effects, and many individuals struggle to manage these or communicate effectively with healthcare providers.
- **Geographical Barriers**
  Travel costs and distances to HIV clinics are challenging for people with mobility issues or those with limited funds.
- **Competing Health Priorities**
  Many people with HIV are aging and managing multiple chronic conditions, making it difficult to prioritize HIV care.
- **Gender Inequality, Racism, and Transphobia**
  Structural discrimination against women, ethnic minorities, and gender-diverse people is linked to poor health outcomes. There are clear connections between HIV and gender-based violence, maternal mortality among Black women, and the high prevalence of HIV among trans women.

The lack of focus and investment in improving the **quality of life** for people living with HIV is a significant challenge. Community-based services such as peer support, which we know are vital, are increasingly difficult to sustain due to financial constraints.

However, we have seen positive developments through the **Fast Track Cities Initiative**, which has helped integrate HIV services within clinical care.

Unfortunately, services like the **Gay Men Pan London Group**, which provides vital support to gay and bisexual men, especially those from minority backgrounds, continue to face funding challenges. This group is the only one of its kind and helps prevent severe isolation for many.

Additional services, such as programs for those engaged in **chemsex**, **trans women**, and **young adults born with HIV**, are critically needed but underfunded. These groups face intersectional issues that demand specialized support.

Focusing on Quality of Life for People with HIV is Crucial for Six Key Reasons:

1. It is a **basic human right** and valuable in itself.
2. It helps people stay engaged in healthcare, ensuring that people with HIV remain undetectable and unable to transmit the virus.
3. It equips individuals with the knowledge and skills needed to manage HIV and other co-morbidities, including mental health.
4. It reduces social isolation and fosters a sense of belonging for those who may have experienced exclusion.
5. It builds self-esteem and reduces internalized stigma.
6. It empowers individuals and communities to participate in decision-making, addressing one of the root causes of health inequalities—**lack of voice and influence**.

2. What actions are being taken by local authorities, NHS England, and the voluntary sector to meet the target of ending new HIV transmissions by 2030, and what impact are these having?

Ending HIV transmissions will not be possible unless **all people living with HIV have consistent access to healthcare** and remain engaged with their clinical teams. Peer support plays a critical role in improving engagement with healthcare, and evidence demonstrates its effectiveness in reducing HIV transmission.

Our data shows that **98%** of individuals who access peer support remain engaged in care and maintain undetectable viral loads. This engagement not only reduces transmission risk but also improves overall health outcomes.

Peer support also reduces isolation and fosters social connections, helping people overcome stigma and navigate the healthcare system.

The **voluntary sector** is vital in raising awareness about HIV and challenging institutional stigma. Positively UK, in collaboration with the **National AIDS Trust**, has developed the **HIV-Confident Charter**, funded by the Fast-Track Cities Initiative. This charter educates organizations, including NHS Trusts, about HIV and promotes stigma-free environments.

However, many voluntary organizations are facing financial challenges, making it increasingly difficult to continue this essential work. It is crucial that HIV remains a public health priority and that funding is allocated accordingly.

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3. How can London address HIV health inequalities amongst minority groups?

Addressing health inequalities among minority groups requires **systemic change**, investment, and collaboration.

London's strategy must ensure the **meaningful involvement** of minority communities, actively promoting community voices and empowerment. Direct funding should be allocated to initiatives led by individuals with lived experience, as these leaders are best positioned to address the unique challenges within their communities. Funding must be accessible to smaller grassroots organizations and available through multi-year programs to ensure sustainability.

Community-based, peer-led research and collaborations with academic institutions are crucial. Research on what works for minority groups must be co-produced with those communities to ensure their specific needs are met.

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4. Would London benefit from a London-wide needs assessment in relation to HIV, and do the NHS and OHID have plans to introduce such an assessment?

Positively UK would welcome a **London-wide needs assessment** related to HIV. We are aware of unmet community needs that are not currently being addressed, but robust evidence is required to respond effectively. To our knowledge, no plans for such an assessment have been announced by the NHS or OHID.

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Ref No.012, Terrence Higgins Trust

Submission to London Assembly Health Committee Inquiry: HIV in London and what progress has been made towards achieving zero-HIV targets by 2030

There is one Mayoral term left to end new cases of HIV in London by 2030. London could be the first city in the world to reach that goal.

The new government has committed to publishing a new HIV Action Plan for England by summer 2025, in pursuit of ending new HIV cases by 2030. That makes this a timely investigation from the committee.

We have all the tools we need to end new HIV cases in London and across the country:

1. Quick and easy HIV testing technologies
2. The prevention pill PrEP which prevents HIV acquisition
3. Effective medication that means people living with HIV can't pass it on and can have a normal life expectancy

However, latest data indicates that England is not on track to get to zero. There are significant inequalities in who is impacted by HIV, who is benefitting from PrEP and who is accessing care.

To reach the goal of ending new HIV cases by 2030, concerted action to improve access to testing, PrEP and HIV care in London – and across England - is crucial.

HIV in London in context

London has the very highest HIV prevalence in the country.

- 15 London boroughs are classed by UKHSA as having a 'very high' HIV prevalence. In Lambeth and Southwark, more than 1 / 100 residents are living with HIV.[1]
- More than 1 in 3 people (38,477 of the 100,063) who accessed HIV care in England do so in London.[2]
- More than 1 in 3 diagnoses of those first diagnosed in England last year were made in London (930 out of 2,810) – with 30% of those diagnoses made at a late stage.[3]
- Nearly half of PrEP users in England are in London: 46,345 of the 96,562 total[4]

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[1] UKHSA, Fingertips: Sexual and Reproductive Health Data, October 2024.
[2] UKHSA, HIV Annual Data Tables, October 2024.
[3] Ibid.
[4] Ibid.

Opt-out HIV and hepatitis testing in London's emergency departments

- A routine, opt-out approach to HIV testing was first trialled in A&Es in Lambeth, Southwark and Lewisham in 2018. The pilots, funded by the Elton John AIDS Foundation, demonstrated that an opt-out approach to testing everyone who had their blood tested for HIV was not just effective at diagnosing people, but also disproportionately found those more likely to be diagnosed late in other services: people of Black African ethnicity, women and older people.[5]

- In 2021, following a recommendation from the HIV Commission, the first HIV Action Plan for England included a £20 million investment in 3 years of opt-out HIV testing in emergency departments in areas classed by UKHSA as having a 'very high' HIV prevalence – parts of London, Brighton, Blackpool and Manchester.

- Thanks to additional funding from NHS England's Hepatitis C Elimination Fund, Hepatitis B and C testing was added and all of London benefited. Since April 2022, A&Es across London have been taking this 'opt-out' approach to BBV testing with remarkable results.

London results (April 2022-24)	**HIV**	**Hepatitis B**	**Hepatitis C**	**Total**
Number of people newly diagnosed	676	3,164	911	**4,751**
Number of people previously diagnosed but not in care	446	642	169	**1,257**
Total	**1,122**	**3,806**	**1,080**	**6,008**

- The programme is also relieving pressure on the NHS: At Croydon University Hospital, when they first started opt-out testing the average hospital stay for a newly diagnosed HIV patient was 34.9 days. After two years of opt-out, the average stay was just 2.4 days.

- As a result of the success of the programme and a concerted campaign, on World AIDS Day 2023 the government invested a further £20 million for opt-out testing in areas classed by UKHSA as having a 'high' HIV prevalence (a further 47 hospitals across 33 local authority areas).

- The first wave of hospitals in London, Brighton, Blackpool and Manchester currently face a funding cliff-edge in March 2025. With more Londoners being diagnosed with HIV, Hep B and Hep C every month – and therefore getting the care they need – it's crucial that this funding continues.

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[5] Fraser et al, Service Evaluation of the Elton John AIDS Foundation's Zero HIV Social Impact Bond intervention in South London: An investigation into the implementation and sustainability of activities and system changes designed to bring us closer to an AIDS free future, March 2022.

Recommendation 1: The Mayor of London should write to the Health Secretary to ask for a guarantee that the funding for opt-out HIV testing in London and all areas with a high/very high prevalence of HIV is extended.

People living with HIV but 'lost' to care

More than 1 / 3 of those found with HIV through opt-out HIV testing are people previously diagnosed with HIV 'lost to care' – haven't been seen by their HIV clinic for more than 15 months. UKHSA's lower estimate is that in total 3,000 people living with HIV in London are not accessing the life-saving treatment they need.[6]

First and foremost this poses a threat to the health of people living with HIV but not in care, who are at risk of getting seriously ill or dying. It also jeopardises the target of ending new HIV by 2030.

Work piloted in hospitals in South London, funded by the Elton John AIDS Foundation to return people to HIV care has demonstrated that it is possible to return people to care with dedicated case finding and wrap-around support. The project found this is possible for £3,000 per person.[7] This is significantly cheaper than the cost of in-patient care if someone develops serious HIV-related illness or of the care costs related to onward transmissions.

At Terrence Higgins Trust we are proud to be working on a project funded by Fast Track Cities London across 6 HIV clinics in London – Guys and St Thomas', Kings, Lewisham and Greenwich, St George's, North Middlesex and London North West University - to retain and re-engage people in HIV care. We are undertaking this work in partnership with a consortium of support organisations – The Food Chain, 4M Network, African Advocacy Foundation, Living Well, METRO Charity, Positive East and Positively UK.

As part of this project, our dedicated HIV care co-ordinator is working to establish barriers to individuals engaging with care and supporting them re-engage, including through referrals to these partner services. In the first quarter of the project, we have received 20 referrals from HIV clinics with 6 patients already successfully re-engaging with their clinic, and 17 engaged with our care co-ordinator.

In total UKHSA estimates that up to 14,393 people are lost to HIV care in England. We hope that this work in London provides further evidence of the value of dedicated voluntary support for people living with HIV to stay in HIV care. We would be pleased to keep the committee updated on the progress of the project. Ultimately, a national HIV retention and re-engagement programme is needed.

Recommendation 2: The Mayor of London should use examples of good work taking place in London to advocate for funding from NHS England for a national Retention and Re-engagement in care programme as part of the new HIV Action Plan for England.

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[6] Veronique Martin (UKHSA), Presentation at BHIVA Conference: Monitoring people not retained in care and subsequent re-engagement,
April 2024.

[7] Fraser et al, Service Evaluation of the Elton John AIDS Foundation's Zero HIV Social Impact Bond intervention in South London: An investigation into the implementation and sustainability of activities and system changes designed to bring us closer to an AIDS free future, March 2022.

Reporting against UNAIDS 95-95-95 targets

UNAIDS measures progress towards ending new cases of HIV against a cascade, with targets to initially reach 90% of each measure and then 95%. '90-90-90' and then '95-95-95' represents three measures:

1. % of people living with HIV knowing their HIV status
2. % of those people who are in HIV care who are on treatment *(people lost to HIV care, who we can assume are not in treatment, are not captured in this measure)*
3. % of people in HIV care and on treatment with an undetectable viral load

UKHSA reports that London has reached 96:98:97 against these measures.[8]

However, people who are lost to HIV care are not captured in this cascade, as the second '90' only represents treatment for people who are accessing care. For those lost, we don't know about their treatment or their viral suppression, and so that cascade misrepresents the reality of care and viral repression. A more accurate care cascade would be:

1. % of people living with HIV knowing their HIV status
2. % of people diagnosed who are in HIV care and on treatment *(people who are lost to HIV care would therefore be part of this measure)*
3. % of people in HIV care and on treatment with an undetectable viral load

Our HIV surveillance systems in England are world-leading. Epidemiologists at UKHSA flagged this discrepency in the reporting framework at the International AIDS Conference in Montreal in 2022.5 Since then, Scotland's Deputy Chief Medical Officer recently presented a version of this more accurate cascade for Scotland. Considering people lost to care, Dr Nicola Spencer calculated that the care cascade for Scotland could have been as low as 93-70-94 in 2021 (as opposed to the 93-97-94 that was officially reported).[9]

We cannot end new cases of HIV in London if we don't have a full representation of the epidemic. Current figures suggest to funders and decision makers that progress is on track. A simple change to reporting could lead to increased attention and action on people lost to HIV care in London and across the UK.

Recommendation 3: The Mayor of London should ask UKHSA, with Fast Track Cities London, to publish an HIV care cascade for London that includes people lost to HIV care and then write to UNAIDS to officially report a new 95-95-95 figure for the city.

Improving access to PrEP

PrEP has been game-changing for those accessing it –particularly for gay and bisexual men and other men who have sex with men (GBMSM) who make up more than 4/5 PrEP users in London. However, it is not reaching everyone who could benefit:

- Many seeking PrEP struggle to access it: our survey of PrEP access in 2022 (before the mpox outbreak added intense additional pressure to sexual health services) found that in 18% of cases, respondents in London seeking PrEP were

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[8] UKHSA, HIV Action Plan Monitoring and Evaluation Framework 2023 Report, December 2023.

[9] Professor Nicola Steadman, Presentation at BASHH Conference 2023, Countdown to Zero. HIV Transmission Elimination Plans for Scotland, June 2023.

turned away.[10]

- Others attending sexual health clinics who could benefit from PrEP do not have that need identified in the clinic. In 2023, 30% of people of Black African ethnicity in London (a group disproportionately affected by HIV) who attended a sexual health clinic and had a PrEP need, did not have that need identified in the course of an appointment.

Sexual health services must remain a key route of access for PrEP and must be properly resourced to deliver it. Currently services are under over-stretched and under-strain.[11] PrEP should also be accessible beyond sexual health services, in order to:

1. Improve access for people who want to take PrEP but currently face barriers to getting it.
2. Relieve pressure on sexual health services and free up clinical time for more complex patients and outreach work.

In Brighton, one of the few areas where there is no PrEP waiting list, pilot work is showing what's possible. The app PrEP Emerge has enabled existing PrEP users to manage their PrEP prescriptions digitally, freeing up over 1,000 clinical appointments.

This capacity is being used for a twice-weekly outreach community PrEP clinic at Terrence Higgins Trust in Brighton. The community clinic has proved an effective way of reaching groups currently less likely to benefit from PrEP, particularly women.

Recommendation 4: The Mayor of London should use his convening power to make the case for investment in PrEP access beyond sexual health services in London, including through a digital platform.

HIV testing in other services

Although HIV testing in sexual health services in London increased by 8% overall between 2022 and 2023, testing in heterosexual and bisexual women and heterosexual men remains at pre-COVID levels.[12]

The British HIV Association, British Association for Sexual Health and HIV and British Infection Association's HIV testing guidelines recommend 'opt-out' HIV testing for all patients attending a sexual health service.[13]

Despite this, more than 400,000 people who attended a sexual health service in England in 2022 left without having been even offered an HIV test.[14] This is 35% of attendees. A further 16% attendees declined the test, meaning only 48% of those eligible were tested. (Comparable numbers are not yet available for 2023).

This tells us that in practice HIV testing is not being offered on an opt-out basis in all sexual health services. Sexual health services must adopt this routine approach to HIV

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[10] Terrence Higgins Trust, National AIDS Trust, PrEPster, One Voice Network and the Sophia Forum, Not PrEPared: Barriers to accessing HIV prevention drugs in England, November 2022.

[11] Terrence Higgins Trust, Over-stretched and under strain: A mystery shopper approach to access to sexual health services in England, Scotland and Wales, July 2023.

[12] UKHSA, HIV testing, PrEP, new HIV diagnoses and care outcomes for people accessing HIV services: 2024 report, October 2024.

[13] BHIVA, BASHH and BIA, Adult HIV Testing Guidelines, September 2020.

[14] UKHSA, HIV Annual Data Tables, October 2023.

testing and at the very least, no one should be leaving a service without having been offered a test.

There are also inequalities in who is likely to be offered an HIV test when they attend a sexual health service and who is tested:

- Testing is highest in GBMSM, with 74% of attendees tested in 2022.
- Women of Black African ethnicity were less likely to be offered a test than GBMSM or heterosexual men of Black African ethnicity in 2022

The lessons from opt-out HIV testing in A&Es suggest that a non-targeted, routine approach can also significantly reduce the numbers of people who refuse a test.

National testing guidelines also recommend that everyone accessing healthcare settings in areas of very high HIV prevalence should be tested for HIV on an opt-out basis – not just in emergency departments, and whether or not they are undergoing venepuncture. This includes GP services, reproductive health services and termination of pregnancy services. There is currently no data on HIV testing offers or uptake in these services. More than half of London boroughs have a 'very high' prevalence of HIV.

Recommendation 5: The Mayor of London should use his convening power to work with health bodies in London to increase HIV testing rates across sexual health services, GP services, reproductive health services and termination of pregnancy services.

Tackling HIV stigma in London – the Fast Track Cities London HIV Ambassador Programme

We are proud to deliver the Fast Track Cities London HIV Ambassador Programme, which aims to tackle HIV stigma and support London's ambition of reaching zero HIV stigma by 2030 through education and the sharing of lived experience testimonies. Launched in April 2023, it is a three-year funded programme.

Achievements to date

In its first 18 months, the programme has:

- Recruited and **trained 27 HIV Ambassadors** who share their personal stories to highlight and tackle HIV stigma.
- Delivered **75 hours of education** (50 talks) to **2,500 people** working in the health, care and public sectors across London. This includes over 20 talks delivered to Metropolitan Police Officers and PCSOs in the Safer Transport team between May-June 2024.

Ambassadors have additionally: Filmed content for social media; Appeared on an HIV stigma podcast; Written a blog post on pregnancy and HIV stigma within healthcare settings; Undertaken outreach at Black Pride; and delivered a session to healthcare professionals at the British HIV Association Spring Conference.

Feedback

While feedback is currently being evaluated, initial review of the programme is incredibly positive, and we can already see attitudes towards HIV changing from those who have attended sessions. Notable quotes include:

- "I found the real life experiences extremely interesting, valuable and touching. It made it not 'scary' or a 'taboo' subject" – **Healthcare worker**

- "The insight into how unfair [*people living with HIV*] were treated and the language used helped me understand what I can do in order to prevent unfair treatment." – **Social care worker**

- "As a police officer I can forget that things I say as a throwaway or thoughtless comment can have a lasting effect on people. I have a terrible habit of saying silly things when I am nervous or want to fill a silence and I could have easily said something similar to the nurse. I have also not been brave enough to say the word 'rape' to a victim before. Thank you all again for your time and I promise that what you have said will stay with me and I will make sure everyone that I come into contact with will get a better service from me because of it" - **Police Officer**

Further, feedback from sessions with Metropolitan Police Officers and PCSOs in the Safer Transport team showed positive results. Respondents surveyed (111) said that because of the training received, they:

- Were more confident dealing with people living with HIV.
- Understand more about how HIV transmission can be prevented.
- Thought other in their role would benefit from this session.