



FAST-TRACK  
**CITIES**  
LONDON



# **Evolving the Care of People Living with HIV in London**

October 2021

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# Report oversight and governance

## Fast-Track Cities Initiative Leadership Group Membership

Name	Constituency / Stakeholder
Jane Anderson (Co-chair)	International Association of Providers of AIDS Care
Kevin Fenton (Co-chair)	Public Health England
Garry Brough	Community leadership
Jemma Gilbert	Healthy London Partnership
Clive Grimshaw	London Councils
Simon Hall	Integrated Care Systems/Clinical Commissioning Groups
Farrah Hart/Vicky Hobart	Greater London Authority
Ian Jackson	NHS England
Marilena Korkodilos/ Helen Corkin	Public Health England London
Aneesha Noonan	Primary Care
Melanie Smith	Association of Directors of Public Health
Kat Smithson	Voluntary sector
Laura Waters/ Nicky Mackie	HIV clinicians
Steve Worrall	Voluntary sector

### Authorship

Ruth Lowbury

# Contributors

## Evolving the Care of People Living with HIV in London Community Advisory Group (CAG)

Members	External Related Title/s and Organisation/s
Meriel Rattue (Chair)	UKCAB Rep BHIVA Guidelines HIV Psychosocial Network
Jamie Bennett	/
Juliet Bosa	/
Craig Hardaker	/
John Jaquiss	Executive Chairman TalkHealthTalk / HIV Activist
Revd Jide Macaulay	Founder/CEO, House of Rainbow CIC; Chair, INERELA Europe; Vice Chair, One Voice Network; Volunteer Chaplain, Mildmay Mission Hospital
Dr Vincent Manning	Exec. Director/Catholics for AIDS Prevention & Support
Rebecca Mbewe	GROWS Training & Policy Coordinator, Positively UK Co Director, 4M Mentor Mothers Network CIC
José Carlos Mejia Asserias	Project Manager, Researcher and Facilitator METRO Charity
Micael Milsten	HIV/AIDS advocate
Juddy Otti	Research and Peer Support Project Coordinator (Sophia Forum ) & HIV Services and Prevention Lead (Africa Advocacy Foundation)
Sophie Strachan	Director Sophia Forum
Chris Williams	Service Lead Plushealth
Derek	/
And other community members	/

# Contributors

## Evolving the Care of People Living with HIV in London Task and Finish Group

Individual	Title	Organisation
Jane Anderson (Chair)	Co-chair London's Fast-Track Cities Initiative/HIV Consultant Physician	Homerton University Hospital Foundation Trust
Valérie Delpech	Head of National HIV Surveillance	Public Health England
Jess Drummond	Senior Programme Manager	Healthy London Partnership
Jemma Gilbert	Director of Transformation	Healthy London Partnership
Cheryl Gowar	Policy and Campaigns Manager	National AIDS Trust
Simon Hall	Director of Transformation	North East London Health and Care Partnership (on behalf of all London CCGs/ ICSs)
Elizabeth Hamlyn	SEL sector representative/ HIV Consultant	King's College Hospital NHS Foundation Trust
Amanda Heeralall	Regional Programme of Care Manager Blood and Infection (London)	NHS England and NHS Improvement
Ian Jackson	Director	NHS England and NHS Improvement
Bernard Kelly	SWL sector representative/ Team Lead	St George's University Hospitals NHS Foundation Trust
Jacqueline Lindo	Public Health Consultant	NHS England and NHV Improvement, and Public Health England
Nicola Mackie	NWL sector representative/Co-chair London HIV Clinical forum/ HIV Consultant	Imperial College Healthcare Trust
Nashaba Matin	NEL sector representative/HIV Physician	Barts Health NHS Trust
Rebecca Mbewe	Community representative and Policy Coordinator / Co-Director	Positively UK/ 4M Mentor Mothers Network
Aneesha Noonan	GP & Deputy Medical Director	NHS England and NHS Improvement
Meriel Rattue	Community representative and Chair of the Community Advisory Group	Community Advisory Group
Iain Reeves	HIV Consultant	Homerton University Hospital Foundation Trust
Laura Waters	NCL sector representative/Co-chair London HIV Clinical forum/ HIV Consultant	Central and North West London NHS Foundation Trust and British HIV Association
Shaun Watson	Clinical Nurse Specialist	Chelsea and Westminster Hospital NHS Foundation Trust
Steve Worrall	Deputy Director	Positive East

# Foreword

## London HIV Clinical Forum Chairs

Whilst the evolution of HIV to a manageable, long-term condition for most individuals is one of modern medicine's notable successes, significant challenges remain. The national and regional commitment to achieving ZERO new infections, preventable HIV-related deaths and HIV stigma, while improving health and well-being for people with HIV, needs a new level of collaboration across health and social care.

As the NHS undergoes its biggest restructure since the 2012 Health and Social Care Act, we can use the new, joined up, regional working promised by Integrated Care Systems to eliminate new HIV transmissions and improve the health and quality of life of people with HIV as they age.

Whilst London is rightfully proud of its achievements in HIV care, inequalities persist across the region. Agreeing the right outcome measures and monitoring systems and levers to create change, will be crucial to ensure that the devolution of HIV services from national to regional commissioning narrows, not widens, existing gaps and inequalities.

As chairs of the London HIV Clinical Forum, we commit to:

- ensuring implementation of national standards and robust data collection
- minimising variation between services
- protecting the right of people with HIV to seek care at a centre of their choice in a more localised care structure
- reinvigorating programmes to maximise prescribing efficiency
- using the lessons learned from COVID to rationalise routine monitoring

By working more closely with Integrated Care Systems, by working with the HIV community to shape care and by maximising efficiency so there can be investment in any gaps in services, we hope to build on London's excellence to reach optimal outcomes for all.

The priorities for action developed by everyone outlined in this report, form an aspirational foundation for the next generation of HIV care in London. We very much look forward to working with the HIV community, and health and social care professionals to deliver these plans.

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**Dr Laura Waters**  
Consultant Physician HIV & Sexual Health  
Central & North West London NHS Trust  
Co-chair London HIV Clinical Forum

**Dr Nicky Mackie**  
Consultant Physician HIV & Sexual Health  
Imperial College NHS Trust  
Co-chair London HIV Clinical Forum

# Foreword

## Integrated Care Systems representative, London Fast Track Cities Initiative

Forty percent of people living with HIV in the UK live in London, so care and support for people with this long-term condition is important for the health and wellbeing of our communities.

As the representative on behalf of Integrated Care Systems on the Fast-Track Cities London Leadership Group, I am delighted to have been part of this report. The report provides clear short, medium and long term priorities for the future of HIV services as Integrated Care Systems develop and health and care systems recover from the COVID-19 pandemic.

The priorities laid out in this report were co-developed with a full and representative HIV community advisory group, to make sure the voice of people living with HIV was front and centre.

This report has only been made possible by the support from the HIV community and key partners. We are so grateful to those who contributed their time during a particularly difficult year, including the wide range of stakeholders across the HIV sector who submitted feedback to the early drafts.

The formation of the Integrated Care Systems is a new opportunity to coordinate commissioning in a way that has never been done before, joining up all partners responsible for the care of people with HIV in London. We look forward to bringing together councils, the NHS, the voluntary sector and representatives from the HIV community, to streamline, connect and improve the experience and outcomes for people living with HIV. This will not be an easy task. It will require strong relationship building and a willingness from all partners to work differently.

On behalf of the five Integrated Care Systems in London we look forward to continuing to work closely with all these partners in shaping the future of HIV services in London.

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**Simon Hall**  
Director of Transformation East London Health and Care Partnership  
Integrated Care Systems Representative, London Fast Track Cities Initiative

# Foreword

## Community Advisory Group Chair

The Community Advisory Group have contributed in a meaningful way throughout the process of creating this report and it has been an inspiration to Chair such a diverse and disruptive group of voices. The involvement of people living with HIV means the priorities put forward are reflective of our ideas and experiences and ensures that we are shaping the future of HIV services in London.

We have been valued as contributors and the report is a rich source of guidance because of this. Inequality, stigma and mental health are all highlighted here, as are the recommendations to build bridges to create a holistic and accessible model of care.

If you do not engage with the population of people living with HIV, how do you know the best way to support us? How are you going to help us sort out our problems, and how are you going to replicate our successes? It is vital that Integrated Care System's listen and link up across London to offer services that serve us all.

We have a collective knowledge and expertise from our lived experience in London and will continue to meet with Fast-Track Cities to influence and direct their strategies. We can support the Integrated Care System's to connect with people living with HIV in their areas and develop community input so that our involvement is meaningful and influential.

I am optimistic about the opportunities presented by this collaborative approach, which supports a way forward that places our community at the heart of our care.

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**Mel Rattue**  
Chair of the Fast-Track Cities Initiative  
Community Advisory Group

# Executive summary

HIV is a significant and evolving health concern for London and Londoners. Almost 40% of all those accessing care for HIV in the UK do so in the capital. As the health and care system in London embarks on major change with the formation of Integrated Care Systems (ICSs), this document sets out key priorities that aim to support them in delivering the best HIV-related outcomes for people, populations, and places across London.

*Evolving the Care of People Living with HIV in London* has been co-developed by a Task and Finish Group of professional stakeholders and a community advisory group of people living with HIV, facilitated and overseen by London's Fast-Track Cities Initiative Leadership Group (FTCI-LG). This NHS change document is designed to support all partners in ICSs to grasp the opportunity to build on existing successes to make HIV an exemplar of a how a place-based integrated model can best serve a complex long-term condition.

*Evolving the Care of People Living with HIV in London* identifies structural priorities for commissioning and partnership working, and key priorities for action to optimise outcomes. It sits in the context of the four HIV-specific strategic aims which the Mayor of London, NHS England, Public Health England (PHE) and London Councils have made a commitment to achieve in the capital by 2030:

- zero new HIV infections,
- zero preventable HIV-related deaths,
- zero HIV stigma, and
- the best health and quality of life for people living with HIV.<sup>12</sup>

Coinciding with the development of the Government's HIV Action Plan, expected in late 2021, and aligning with the aims of the health and care White Paper<sup>3</sup>, this document supports London's vision for becoming the healthiest global city.<sup>4</sup> London has already achieved world-leading success in tackling HIV: it was one of the first cities to exceed the UN's 90-90-90 targets<sup>5</sup> and the aim of eliminating new infections is in sight.

But there is still much to be done before London can achieve the four aims. More people are living with HIV in London than ever before, and their health and care needs are becoming more complex as they age. Ensuring integrated and personalised care to address these needs and achieve optimal outcomes, as well as stopping the transmission of the virus, requires sustained engagement at all levels, from neighbourhood to national, and from all partners in the system. Without this, today's gains could be reversed.

Furthermore, while clinical outcomes of HIV treatment in London are among the best in the world, they are subject to significant inequalities according to place, ethnicity, gender and other socio-economic factors.<sup>6</sup> Compounding this, people living with HIV are subject to HIV-related stigma which can hinder their access to testing and care, provoke discrimination against them and exacerbate other inequalities.

It is critically important that structural changes within the health and care system and post-COVID recovery interventions, are used to tackle these inequalities, contributing to the goals of the Mayor's health inequalities strategy.<sup>7</sup>

Key to this is the potential for HIV care to be an exemplar model for population health management, improving the health of those living with HIV by data-driven planning and delivery of proactive care to achieve maximum impact. The vision for *Evolving the Care of People Living with HIV in London* includes realigning leadership and governance, segmentation, stratification and impact modelling to design and target interventions to prevent ill-health, improve care and support for people with HIV and reduce unwarranted variations in outcomes.

Care for people living with HIV has suffered from variation, particularly in recent years following the division of HIV commissioning responsibilities established by the 2013 reforms,<sup>8</sup> and there have been inequalities in access to some, particularly community-based, services. London's ICSs, bringing together all parts of the system, have a unique opportunity to review the challenges across the whole HIV care pathway and jointly design services to make sure that, wherever people may live, they are able to access care of the highest standard.

People living with HIV have been integrally involved in the shaping of London's HIV services and key partners in the development of this document. They look forward to seeing action by ICSs on their recommendations, and ICSs can only benefit from maintaining their meaningful involvement as they take the next steps towards implementation.

<sup>1</sup> About us - Fast-Track Cities London ([fasttrackcities.london](https://fasttrackcities.london))

<sup>2</sup> Our Vision for London: The next steps on our journey to becoming the healthiest global city

<sup>3</sup> Integration and Innovation: working together to improve health and social care for all

<sup>4</sup> Our Vision for London: The next steps on our journey to becoming the healthiest global city

<sup>5</sup> By 2020, 90% of people living with HIV to be diagnosed, 90% of those diagnosed to be on treatment and 90% of those to be virally suppressed

<sup>6</sup> Up-to-date data on key HIV indicators in London, including local and regional comparisons, can be found at [Sexual & Reproductive Health profiles](#) and graphical representations at [HIV Lens](#)

<sup>7</sup> The London Health Inequalities Strategy

<sup>8</sup> Health and Social Care Act 2012

# Summary of key priorities

It is recognised that in the context of recovery and transition, constraints on capability and capacity will make it necessary to find levers available progressively to put all these actions in place.

The ask is therefore to take a phased approach that reflects what is possible now and what can be worked towards over time, with the suggested priorities grouped for action in the short, medium and longer term accordingly (Figure 1). The phasing reflects potential feasibility over time, not degree of importance.

Figure 1: Summary of priorities for high-level action

Priorities for high-level action	
<b>Ways of working</b>	
	Priority 1: Coordinate HIV commissioning across London
	Priority 2: Strengthen partnerships and community engagement
<b>Improving HIV care</b>	
<b>Short term</b>	Priority 3: Implement opt-out testing in emergency departments
	Priority 4: Meet people's service needs, regardless of where they live
<b>Medium term</b>	Priority 5: Collaborate to provide integrated primary and secondary care
	Priority 6: Make coordination an integral part of HIV care
	Priority 7: Eliminate stigma in care settings, starting with healthcare
	Priority 8: Embed peer support in the HIV pathway
	Priority 9: Ensure the right mental healthcare for everyone who needs it
	Priority 10: Meet psychosocial support needs of the most vulnerable and disadvantaged
	Priority 11: Ensure the workforce is fit for purpose
<b>Longer term</b>	Priority 12: Give confidence to people living with HIV about data sharing
	Priority 13: Develop and support the use of digital services

## Ways of working

### Priority 1: Coordinate HIV commissioning across London

A joint approach to commissioning HIV services is recommended to ensure equitable provision of care across the capital, including the maintenance of open access HIV clinics.

This city-wide approach is important because open access (whereby people can self-refer to the clinic of their choice without geographical restrictions) is a cornerstone of the UK's HIV service model and one of the reasons for its high rates of patient satisfaction and retention in care. ICS partners have the opportunity to bring together the best of place-based design that harnesses the asset base of local communities with more collective action that recognises the nature of the HIV-specific communities spread across the city.

City-wide action involving all parts of the system is also important for enabling existing workstreams to tackle stigma.

The single national service specification<sup>9</sup> for HIV clinical services has fostered high and consistent care quality throughout the country, supported by nationally determined care standards. The intention to maintain this at national level is welcome, as is the recent move to national procurement of HIV medication to further enhance cost savings achieved at regional level.

<sup>9</sup> B06/S/a. 2013/14 NHS Standard Contract for Specialised Human Immunodeficiency Virus Services (Adults) Section B Part 1 - Service specifications

## Priority 2: Strengthen partnerships and community engagement

HIV is uniquely characterised by the synergy and interaction of its treatment and prevention, with early diagnosis being the lynchpin of both.

Yet the division of HIV commissioning responsibilities between the NHS and local government since the 2013 reforms has created challenges for seamless care, particularly where pathways cross commissioning demarcations.

Within each ICS, partners from the NHS and local government, along with providers and people living with HIV, can work together to take a joined-up approach to commissioning the whole HIV care pathway, including prevention and diagnosis, identifying how place-based care that is best for local communities can be complemented by services that can achieve better outcomes or value on a wider geographical footprint.

**Voluntary sector organisations** providing HIV support services have an in-depth understanding of the populations they serve but have faced a tension between collaboration and competition for scarce funding, as well as precariousness arising from budget constraints and short-term contracts. ICSs can benefit from their expertise by recognising them as equal partners in service delivery and engaging them in future commissioning with a focus on collaboration to meet identified needs, designing together ways to engage those communities that continue to be most marginalised and have unequal access to testing, treatment and care.

Funding on a three to five-year basis would allow programmes to develop, build and be sustained.

**People living with HIV** should be meaningfully involved in the commissioning of HIV services and their involvement should be supported through investment in their induction, training and remuneration.

Similarly, the key role of cross-London and ICS-level HIV clinical leaders could be strengthened through leadership training and inclusion of the leadership role in their job plans.

**Clinical networks** can play a key role in supporting the coordination of service provision across a 'place', helping to ensure equitable standards and optimal use of resources. This could be enhanced by the further development of provider collaboratives. London has five HIV clinical networks whose value ICSs can further realise by strengthening and supporting their functioning.

HIV management can involve a range of non-HIV specialist and community-based services, particularly to meet the needs of those most subject to health inequalities. HIV-related needs may not always be recognised or understood by commissioners or providers and HIV-related stigma may affect perceptions. In this context, it is suggested that each ICS would benefit from appointing an HIV champion to keep a focus on HIV across all specialties and services and to ensure the needs of the population living with HIV are fully and appropriately addressed.

*"It's vital that people living with HIV are consulted because we are the service users. Our voice needs to be heard. When I was diagnosed, I went through the full cycle of 'grief, anger, shame' and felt very alone, even though I thought I was pretty clued up about HIV. Our views need to be heard to ensure services are effective, caring and compassionate."*

**Person living with HIV**



# Improving HIV care

## Short term

### Priority 3:

## Implement opt-out testing in emergency departments

Implement Sustainability and Transformation Partnership (STP) plan commitments to establish and maintain opt-out HIV testing in all emergency departments across London.

All five London ICSs are committed, through their STP plans, to implementing opt-out HIV testing in emergency departments as recommended by the National Institute for Health and Care Excellence (NICE).<sup>10</sup>

This is one of the most impactful actions ICSs can take towards the goals of zero new HIV transmissions and zero preventable HIV-related deaths, as late diagnosis is the leading cause of premature death and disease among people with HIV, whereas people who are diagnosed early and start treatment have a similar life expectancy to that of the general population and also become unable to transmit the virus.<sup>11</sup>

Testing in emergency departments can also identify people previously diagnosed with HIV who are at risk of ill health and transmitting HIV to others because not currently in care and receiving treatment.

Experience in NHS trusts within London has shown that near 100% rates of testing can be achieved in emergency departments, revealing a higher rate of HIV than the diagnosed prevalence in the local population, detecting more new infections than in other medical settings and identifying similar numbers of people previously diagnosed with HIV but lost to care as those who have never previously been diagnosed.<sup>12</sup>

*“Opt-out testing across the whole of London will lead to improvements in clinical outcomes and allow for earlier detection, treatment and support for people living with HIV. This early detection has been calculated to save significant sums for future treatment to each ICS.”*

**Director of Specialised Commissioning, NHS England**

<sup>10</sup> NICE. HIV testing: increasing uptake among people who may have undiagnosed HIV. 2016.

<sup>11</sup> HIV treatment suppresses the virus to an undetectable level which prevents transmission (Undetectable=Untransmissible, U=U)

<sup>12</sup> Vaccari LC, Parry S, Kirkham D et al. Sustained 97% HIV testing rate in the Emergency Department: the new gold standard. Conference abstract O001. BHIVA BASHH 2021



## Priority 4: Meet people's service needs, regardless of where they live

### Work together to resolve inequalities in access to services and to address the unmet needs of people living with HIV.

People living with HIV report significant levels of unmet need, particularly for non-HIV specialist healthcare, psychological support, social care and welfare services.<sup>13</sup> They express concern that access to such services can differ according to postcode.

Services provided for people with, or at risk of, HIV vary by type and scope, depending on local population needs and priorities. Local authorities (public health and social care), clinical commissioning groups (CCGs) and NHS England (specialised, health and justice and public health) each commission different aspects of care, sometimes from the same providers.<sup>14</sup>

As part of NHS specialised commissioning, the specification for HIV clinical services is nationally determined, while specifications for other services are developed locally, including those for which there is a legal mandate.

The development of more integrated commissioning arrangements through ICSS offers an opportunity to bring the whole system together to identify and address inequalities in access to certain services<sup>15</sup> which may have been compounded by the diversity in commissioning arrangements and budget pressures. A review of HIV-related population needs for services at all stages of the pathway would enable joint planning for their future provision across the system, so as to reduce inequalities in access to care while ensuring appropriately tailored responses to place-based need.

The following services require particular attention in an overview of needs and service provision. More detailed work on the first two is suggested in Priorities 9 and 10 below.

- **Mental healthcare**, for which people with HIV have a higher level of need than the general population, but for which referral pathways can be complex, appropriate care is often difficult to access and non-HIV specialist providers may be unclear about their role in relation to people with HIV.
- **Community-based HIV support services**, which provide a range of psychosocial support, particularly to the most vulnerable and disadvantaged, but have no shared core service specification and are often residence-based, even when provided in partnership with an open access HIV clinic.
- **Community-based HIV clinical nurse specialists (CNS)**, who provide multi-faceted support for self-management to patients with complex needs, including adherence to medication and care coordination, but for whose service there are varied funding models, access criteria and capacity, with no provision at all in some areas.
- **HIV testing**, the provision of which is variable leading to inequitable access to early identification and treatment for Londoners.
- **HIV pre-exposure prophylaxis (PrEP) provision**, for which there is currently no allocated responsibility for provision beyond sexual health services.

*"The people we serve in the community are often those who 'slip through the cracks' of other generic services, often isolated, vulnerable (physically or mentally) who find modern healthcare difficult to navigate without help, help that other health and social care services rarely offer."*

**HIV Community Clinical Nurse Specialist**

<sup>13</sup> Positive Voices: The National Survey of People Living with HIV. Findings from the 2017 survey

<sup>14</sup> Making it work: a guide to whole-system commissioning for sexual health, reproductive health and HIV. Public Health England, 2014

<sup>15</sup> The HIV Puzzle. All Party Parliamentary Group on HIV & AIDS, 2015

## Medium term

### Priority 5:

## Collaborate to provide integrated primary and secondary care

Establish mechanisms for more collaborative working between general practice and HIV clinics to provide integrated management of HIV and other long-term conditions.

While HIV specialists manage HIV, general practitioners (GPs) are experts in the management of other long-term conditions, such as cardiovascular disease (CVD) or diabetes, and they also provide access to some locally based mental healthcare, support for self-management of common conditions and intervention on risk factors.

As such, the roles of primary and secondary care are complementary. To achieve the best outcomes for people living with HIV, a more integrated and holistic approach to each patient's care is needed, with GPs, the HIV multidisciplinary team and people with HIV working in partnership. There is also scope to move towards a model of shared HIV care for people who are stable on treatment.

Many GPs have had little previous involvement with HIV. They have not always been informed of their patients' HIV status or kept up to date on their HIV care and may lack confidence in their knowledge of HIV.

Meanwhile, people with HIV may have concerns about whether their GPs understand their HIV and its treatment or the challenges of HIV-related stigma. A proportion still do not consent to their GP being informed of their HIV status.

Taking a more active role in relation to HIV and better integrating the management of HIV and other long-term conditions will enable GPs, working with HIV specialists, to improve the outcomes of a (usually) small group of their existing patients.

Measures need to be put in place for direct, two-way communication and coordination between GPs and the HIV multidisciplinary team such as a shared care plan, easy access to specialist advice, rapid referral to more specialised support when needed through an agreed care pathway, and access to support from HIV specialist pharmacists and community HIV clinical nurse specialists.

Digital technology can be an enabler for much of this. Primary care networks might facilitate the provision of high-level primary care services across a neighbourhood or place, linked into and supported by local HIV specialist services and with leadership from local 'GP champions'.

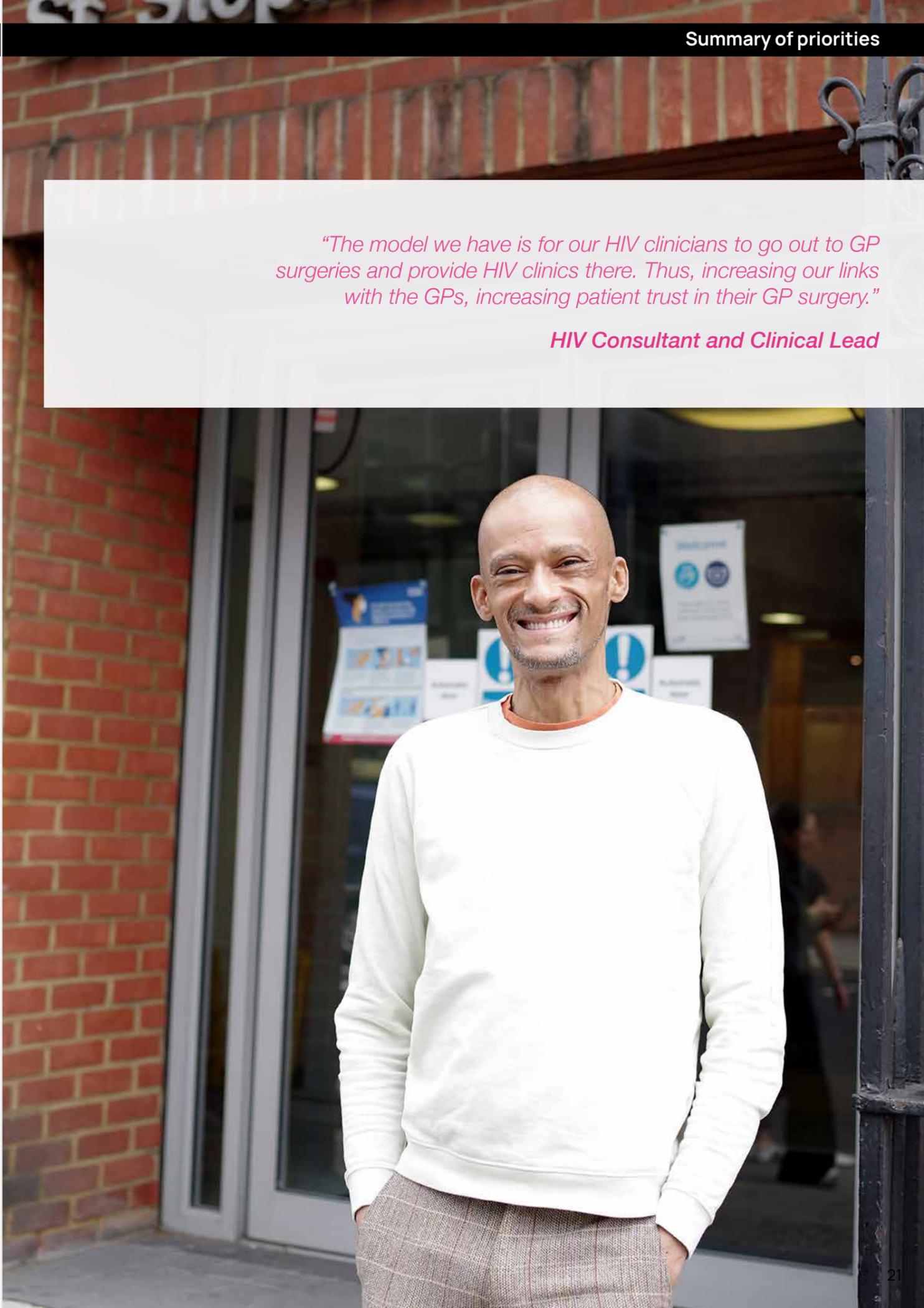
GPs need to build the trust of their patients with HIV by ensuring their practices offer them a welcoming, safe and confidential environment, becoming well-informed about local HIV support services and working with them to understand their needs and concerns.

*"When I saw my GP for the first time, what should have been a 10-minute appointment turned into a 45-minute coaching session where I educated him about HIV and hepatitis C. But it was valuable time spent and was the start of a great GP/patient relationship."*

**Person living with HIV, aged 61**

*"The model we have is for our HIV clinicians to go out to GP surgeries and provide HIV clinics there. Thus, increasing our links with the GPs, increasing patient trust in their GP surgery."*

**HIV Consultant and Clinical Lead**



## Priority 6: Make coordination an integral part of HIV care

Embed the concept of coordinated care into the HIV pathway, including identifying a member of the multidisciplinary team to make sure this is in place for each person living with HIV.

As people age, they have increasingly complex healthcare needs, to which HIV adds a further layer of complexity. In addition, they may have complex social care and support needs. An integrated management model is needed, similar to that for other long-term conditions but adapted to the particularities of HIV.

Yet many people with HIV report a fragmented experience of poorly integrated care and struggle to navigate the system, especially when they need services additional to what is provided by their HIV clinic. It is vital that such challenges do not lead people to disengage from care. While some feel empowered to self-manage but would benefit from the removal of administrative hurdles, others need support with the practicalities of care coordination.

The people most likely to need such support tend to be those with the most complex care needs and vulnerabilities such as mental ill-health, cognitive decline, drug and alcohol use or problems linked to social exclusion.

A shared care plan, agreed by the person with HIV and all their providers, should guide the coordination of their care. A named member of the multidisciplinary team needs to be responsible for ensuring that care is coordinated accordingly, including regular review of the individual's need for support and, when required, active coordination on their behalf, such as liaison with different providers. This role could be provided by a community HIV clinical nurse specialist, a social worker or a clinic-based peer navigator, or by other appropriately skilled roles, according to the individual's preference and predominant needs.

*“By integrating primary and secondary HIV care both GPs and HIV clinics will be better able to work together to provide the best care, at the right time and in the right place for their patients. In taking a more coordinated approach we can work with patients to offer care that treats them as whole people rather than disparate diagnoses and symptoms.”*

**London GP**



## Priority 7: Eliminate stigma in care settings, starting with healthcare

Put in place measures to eliminate HIV stigma and discrimination in care settings, including staff training, reporting and monitoring HIV-related discrimination and holding people responsible to account.

HIV-related stigma can blight the experience of service users in any care setting and discourage service use. It needs to be eliminated in all services providing care for people living with HIV. For ICSs, healthcare settings should be the first focus for intervention to tackle stigma, followed by other key services which affect the wider determinants of health, such as housing offices and job centres.

The NHS as both an employer and provider of healthcare has a duty to eliminate discriminatory behaviour against people with HIV in accordance with equalities legislation (HIV is classed as a disability under the Equality Act).

It also has a responsibility to ensure its staff are well-informed about HIV and do not inadvertently stigmatise or discriminate through fear or ignorance.

It can work towards this by ensuring HIV is included in relevant policies and mandatory staff training on equality and diversity and providing basic, up-to-date information and education on HIV for staff.

Where relevant, this should be tailored to their work contexts, including settings providing routine opt-out HIV testing such as emergency departments.

Internalised stigma and fear of discrimination have led one in thirteen Londoners living with HIV to report having avoided seeking healthcare when they needed it within the previous year, while one in 25 say they feel their HIV status has actually led to a refusal or delay in healthcare over the same period.<sup>16</sup>

These concerns are not unfounded, with recent research showing surprisingly high levels of misinformation, fear and stigmatising attitudes regarding HIV among staff in three London hospitals.<sup>17</sup>

Systems need to be in place for reporting and monitoring instances of HIV-related discrimination and stigmatising behaviour and holding those responsible to account, including mechanisms to empower patients, their carers and advocates, as well as employees, to report such instances.

The London FTCL has secured NHS England funding to support organisations to tackle stigma and become HIV-friendly, using an 'HIV Friendly charter' and kitemark.

A pilot to test this in NHS trusts and primary care will be launched in 2021 as the first phase. If successful, the second phase will be to adapt and test the same approach in other public-facing services.

*"Stigma continues to be one of the biggest challenges for most people living with HIV. Stigma can come from family, partners and wider communities. But it also, unexpectedly and devastatingly comes from those in healthcare professionals, from whom we greater knowledge and understanding."*

*Person living with HIV*

### Stigma in healthcare

A survey of staff at three London hospitals found that:

- 80% were unaware of U=U (that people on treatment with an undetectable viral load cannot transmit HIV).
- 38% said they would feel at risk of acquiring HIV if treating an HIV patient,
- 25% would consider isolating HIV-positive patients in side-rooms due to their HIV status
- 76% would not be confident discussing HIV with patients.
- 82% requested further information and training on HIV

Shongwe M et al. Measuring healthcare HIV knowledge within our NHS Trust. British HIV Association conference, abstract O06, November 2020.

<sup>16</sup> Public Health England. Positive Voices (2017 survey), London Regional Report

<sup>17</sup> Shongwe M et al. Measuring healthcare HIV knowledge within our NHS Trust. British HIV Association conference, abstract O06, November 2020.



## Priority 8: Embed peer support in the HIV pathway

Define peer support as a critical and essential part of the HIV care pathway and fund it accordingly, embedding the role in clinic multidisciplinary teams as well as in community settings.

Peer support leads to significant improvements in health and wellbeing outcomes for people with long-term physical and mental health conditions and also reduces pressure on health and social care services and therefore costs.<sup>18</sup>

People with HIV stress the value of peer support in addressing their needs, helping them to self-manage, deal with HIV-related stigma and improve their wellbeing. HIV clinicians often rely on peer support to supplement and enhance the care they can provide. When peer support workers are included as part of the clinic's multidisciplinary team, they are able to bring to it their knowledge of concerns that people with HIV may not share with clinical staff.

HIV clinical services are required to provide access to peer support<sup>19</sup> but, in practice, the extent and nature of this service varies across London. There is no universal model and it is provided by a range of organisations and groups, more or less informally, paid or unpaid, in clinic or community settings. In some HIV services it is an integral part of patient care, while in others referral may be inconsistent and arbitrary. Innovative peer support initiatives often rely on time-limited funding from non-statutory sources.

Such variability and precariousness is not satisfactory for a service which has been described by both HIV clinicians and people living with HIV as "mission critical". The essential role and value of peer support need to be recognised, and inequalities in access to it ironed out, by commissioning it as an integral part of the HIV care pathway.

*"Stigma is an issue because HIV is still not talked about enough. People can have the impression they are alone and not worthy of love. There are still many people who (because of their community or background) don't disclose their status to friends, loved ones and family."*

**Person living with HIV**

*"By talking to another person living with HIV, people share coping strategies and also a better understanding of the health system and other specialist services and how to better engage with them with confidence."*

**Deputy Director,  
HIV voluntary sector organisation**

<sup>18</sup> Realising the Value | Nesta

<sup>19</sup> B06/S/a. 2013/14 NHS Standard Contract for Specialised Human Immunodeficiency Virus Services (Adults) Section B Part 1 - Service specifications

## Priority 9: Ensure the right mental healthcare for everyone who needs it

Commission mental healthcare in partnership across London, in order to ensure that the right service is available for each individual at every level of need, provided by professionals with appropriate expertise.

People living with HIV are more likely than the general population to have mental health problems and these can lead, in turn, to problems with adherence to HIV medication and worse health outcomes.

Despite the requirement for HIV clinical services to provide access to HIV-related emotional and psychological support and pathways for psychological support to meet non-HIV-related needs,<sup>20</sup> the provision of such support at all levels is variable and subject to stresses in mental health provision across the health and social care system. People with HIV sometimes find mainstream mental health services reluctant to accept them for care in the belief that their problems need HIV-specialist support, and as a result find themselves 'ping-ponged' between services.

Long waits for mental healthcare, or referral to an inappropriate service due to capacity or budget constraints, may not only further exacerbate mental health problems but risk jeopardising patients' ability to adhere to HIV treatment, endangering their physical health, increasing risks of HIV transmission and ultimately increasing costs to the system. To avoid such outcomes, it is important to improve pathways and access, and to ensure that mental health professionals caring for people with HIV have an expert understanding of how HIV interacts with mental health and the effectiveness of different interventions for this patient group.

To these ends, the mental health of people living with HIV can only benefit from the improvements that a more integrated approach to commissioning by ICSs can provide, including measures to ensure optimal and equitable use of available mental health resources with HIV expertise, HIV specialist psychology input to HIV multidisciplinary teams, and seamless referral pathways for appropriate mental healthcare outside local boundaries.

*"Emotional and mental health challenges in people living with HIV are diverse and often related to the acceptance or lack of acceptance of our multiple identities. Bias narratives around our race, gender identity and sexual orientation, faith and immigration status, become a burden to our wellbeing and collide with our often-stigmatised HIV status."*

**Person living with HIV**

<sup>20</sup> B06/S/a. 2013/14 NHS Standard Contract for Specialised Human Immunodeficiency Virus Services (Adults) Section B Part 1 - Service specifications

## Priority 10:

### Meet psychosocial support needs of the most vulnerable and disadvantaged

#### Undertake a needs assessment and service mapping, and develop a strategy and core minimum service specification, for community-based HIV support services

Community-based HIV support services provide a range of psychosocial support in the community and sometimes within HIV clinics. Around one in six people with HIV report using such services over a one-year period.<sup>21</sup> However, among people with HIV reporting social and welfare needs, two-thirds said in 2017 that those needs had been unmet.<sup>22</sup> People in need of such services are often vulnerable and from disadvantaged communities, seeking help on a range of issues that are among the wider determinants of health such as loneliness and isolation, poverty, housing, immigration or domestic violence. Such factors can impact on adherence to HIV treatment and retention in care, on which good health outcomes depend.

There has been a substantial decline in the availability of community-based HIV support services in recent years, due largely to funding pressures.

Their role is synergistic with that of clinical services, which are commissioned on a wider geographical footprint, but while there are some collaborative arrangements between small groups of local commissioners, there is no London-wide register or joint commissioning arrangement for support services.

Given the alarming scale of unmet support needs reported by people with HIV and the negative impact of COVID-19 since then on wellbeing and social inequality, it is important to gain an up-to-date understanding of needs and how they are matched against the availability of support services across the capital. This would support ICSs, bringing together commissioners and providers across the system, to coordinate the planning of HIV support service provision as part of integrated HIV care pathways with the aim of reducing inequalities in access and optimising outcomes. A measure to facilitate this would be to agree a core minimum service specification at London or ICS level, to complement place-based commissioning tailored to locally specific needs.

*“Emotional and mental health challenges in people living with HIV are diverse and often related to the acceptance or lack of acceptance of our multiple identities. Bias narratives around our race, gender identity and sexual orientation, faith and immigration status, become a burden to our wellbeing and collide with our often-stigmatised HIV status.”*

*Person living with HIV*

<sup>21</sup> Public Health England. Positive Voices (2017 survey), London Regional Report

<sup>22</sup> Public Health England. Positive Voices (2017 survey), London Regional Report

## Priority 11:

### Ensure the workforce is fit for purpose

#### Review and develop the HIV specialist and non-HIV specialist workforce to ensure all people living with HIV receive care from professionals and staff with appropriate expertise

High quality care for people living with HIV requires providers to have appropriate levels of skills and expertise, and this includes an understanding of HIV relevant to their role.

There is currently no central oversight of the HIV multidisciplinary workforce. Access to HIV clinical nurse specialists and HIV-specialist allied healthcare professionals, such as psychologists and dieticians, is highly variable. HIV-specialist pharmacists play a key role but resourcing pressures create barriers to optimal use of their clinical skills and turnover is high. A London-wide survey of staffing and skills could usefully inform workforce development and planning for HIV care provision as the epidemic evolves.

While the new dual accreditation in general medicine for GUM trainees will provide greater flexibility for new HIV consultants, a core of specialist clinical expertise will still be needed to manage highly complex HIV care, including:

- opportunistic condition management
- antenatal HIV care
- care of children and adolescents living with HIV
- complex HIV resistance
- complex drug-drug interaction management.

Maintaining a workforce skilled to manage such care for a diminishing number of patients may require cross-ICS arrangements and regular review as the needs of people living with HIV evolve.

Non-HIV specialist health and social care staff across all organisations that provide services for people living with HIV require sufficient HIV-related knowledge and skills to offer personalised, holistic and culturally sensitive care. In addition to widespread dissemination of HIV information to dispel misinformation and reduce HIV stigma, appropriate education on HIV tailored to the context and functions of different professional and staff groups is needed. Workforce planning should recognise the important role (and time needed) of HIV specialists in training and supporting non-HIV specialist colleagues, and consideration could be given to educating a small core of GPs to become 'HIV champions' in primary care. HIV educational interventions will benefit hugely from the involvement of people living with HIV in their development and, where appropriate, delivery.

## Longer term

### Priority 12:

## Give confidence to people living with HIV about data sharing

In partnership with the HIV community and service providers, put in place measures to ensure people with HIV can be confident of confidentiality across the system and feel comfortable with sharing their data to support integrated care.

HIV stigma remains a barrier to further improvement and better integration of HIV care. Because of stigma, concern among people living with HIV about confidentiality is exceptionally high and HIV services have made it a priority to provide an environment where patients feel safe and confident of privacy. For some clinics this still means using separate clinic numbers and records, although others have managed to retain trust while moving to the use of shared hospital records. Beyond this perceived safety, people can be reluctant for their HIV status to be shared with other healthcare and non-NHS providers, fearing judgemental attitudes, discriminatory behaviour and onward sharing of their personal information without consent, or even just inadvertent sharing through lack of awareness. Experiences of such behaviour are often reported by people living with HIV.<sup>23</sup>

Stigma and discrimination must clearly be challenged and eradicated (see Priority 7 above) including where they lead to unauthorised sharing of information. But the issue of confidentiality per se is more nuanced. While rules for confidentiality apply in all settings, there are differences in how it is defined within different institutions.

So, although it is important to reassure people living with HIV that confidentiality is maintained when their information is shared for the purpose of providing their care, it is equally important to ensure that all services across the system offer a level of safety and security that will retain their confidence.

Recognising the importance of sharing patient information for safe, personalised and integrated care, it is suggested that putting HIV patient records on shared NHS systems needs to become the norm. For a minority of people living with HIV this would remain unacceptable, but the option of creating a system that routinely allows an 'opt-out' is neither feasible nor clinically safe.<sup>24</sup> Moreover, separate records systems are not 'watertight', as a shared record of HIV status may be created by default when investigations are requested from another hospital department.<sup>25</sup> It is therefore crucial to work in partnership with people living with HIV and their trusted organisations to provide education for the HIV community about the benefits of sharing medical information, the safeguards for confidentiality and what this means for them.

In view of the strength of concern expressed by HIV patient representatives, there is no simple solution to this delicate issue. But ICSs are in a position to bring the NHS, local government and the community together to clarify the measures needed, explore the potential for common rules of confidentiality for all, and develop mechanisms to assure safe, confidential, stigma-free environments across the system.

<sup>23</sup> HIV Patient Information and NHS Confidentiality | NAT 2014

<sup>24</sup> Confidentiality - GMC (gmc-uk.org)

<sup>25</sup> HIV Patient Information and NHS Confidentiality | NAT 2014



## Confidentiality

"Hospital outpatient for elective treatment to my back. There was a post-it attached to the front of my medical records folder on the bed that I was sent to saying, 'surely there is somewhere to record this patient is HIV+'. Another patient saw the post-it on my medical notes and made a loud comment about it in the outpatients' treatment room and again later at a follow-up appointment in the waiting room."

National AIDS Trust. HIV Patient Information and NHS Confidentiality in England. 2014

## Priority 13:

### Develop and support the use of digital services

Develop the use of digital service provision, while ensuring that access to in-person services, to an equal standard, remains available and support is provided to tackle digital poverty among people living with HIV.

Digital services have the potential to empower patients, increase the integration of care and reduce costs, especially for the routine care of those who are stable on treatment. The experience of COVID-19 has shown that there is clearly potential for moving HIV services towards more digital provision, while also highlighting the importance of maintaining some face-to-face interaction. Hybrid models for consultation (such as alternating appointments in person and by telephone) are likely to be useful in future.

With the ageing population of people needing more integrated care for multiple conditions, digital solutions can also enhance communication and coordination centred around the patient, such as real-time access for GPs to HIV specialist advice during consultations, joint e-consultations for patients with their HIV and other specialist clinicians, and 'apps' that allow patients to access and share their records and communicate with clinicians in advance of consultations.

*“Digital services are a good innovation especially where people are otherwise healthy and have busy lives. It’s useful for routine things like requesting meds, making and changing appointments. It could also enhance face-to-face appointments where there is a need to contact a specialist for example.”*

**Person living with HIV**

*“HIV as a health condition is much more complex, particularly in terms of mental health challenges. It would be wrong to assume that digital service can take over from traditional as has been confirmed during COVID times.”*

**Person living with HIV**

It will be important to apply NHS digital systems and software to HIV services as they become relevant and as far as HIV patient record systems allow, ensuring data protection safeguards adequately address the particularly acute confidentiality concerns of people living with HIV.

#### HIV sector support for implementation

This document is written to serve as a starting point for engagement between London ICSs and the HIV sector, which is eager to work alongside ICS colleagues and maximise the support it can offer towards achieving the priorities set out above. The sector already has several existing assets in place which could support ICSs to accelerate the implementation of key improvements.

As one of these, the Fast-Track Cities Initiative (FTCI), which has coordinated the development of this document, could serve as a useful contact point and convenor of HIV stakeholders that ICSs may wish to utilise as they develop.

# Evolving the Care of People Living with HIV in London

# 1

## Introduction

# Introduction

The evolving HIV epidemic in London in 2021 presents an exciting opportunity for developing integrated and personalised care and working towards London's vision for becoming the healthiest global city.<sup>26</sup>

London already delivers world-class clinical care for HIV with the potential to be the first city in the world to eliminate new HIV infections and HIV-related deaths by 2030 or sooner. The challenges facing London in moving towards these goals are the exact ones that Integrated Care Systems (ICSs) aim to address:

1. Designing joined-up pathways of integrated care which ensure that opportunities for diagnosis are not missed, and that people's holistic needs are met
2. Assuring equitable access to services
3. Serving a population disproportionately affected by health inequalities.

## What is this document?

*Evolving the Care of People Living with HIV* in London aims to assist all the partners in London ICSs, including commissioners and providers, NHS and local government, in their planning of HIV services. It identifies key challenges and priorities for commissioning and partnership working, along with feasible short and longer-term priorities for action to optimise outcomes.

It sits in the context of the four HIV-specific strategic aims which the Mayor of London, NHS England, Public Health England (PHE) and

London Councils have made a commitment to achieve in the capital by 2030:

- zero new HIV infections
- zero preventable HIV-related deaths
- zero HIV stigma
- the best health and quality of life for people living with HIV.<sup>27 28</sup>

The HIV sector is committed to supporting ICSs to build on the world-leading success of London on its path towards these four aims and to make HIV an exemplar of how a place-based integrated model can best serve a complex long-term condition. This document is a first step.

A number of further documents can provide additional support, including:

- *Standards of care for people living with HIV*<sup>29</sup>: evidence-based and covering the range of care needed from testing and diagnosis to end of life, embracing overall health and well-being as well as clinical care. The standards were developed in partnership with care providers, professional associations, commissioners and people living with HIV and offer outcomes that can be measured and audited.
- *Making it work: a guide to whole system commissioning for sexual and reproductive health and HIV*,<sup>30</sup> which offers practical advice on how commissioning bodies can work together to ensure that individuals experience seamless service delivery and to address the wider determinants of health.

## Why is this document needed?

HIV treatment is one of the most outstanding medical achievements of the last 25 years, shifting HIV from a terminal disease to a long-term condition. London HIV services have led the way in developing patient involvement and personalised care. Their excellent clinical outcomes, along with innovative public health and community-based approaches to prevention and testing, mean that nine out of ten of all Londoners living with HIV are now on effective treatment and unable to transmit the virus – a success of which the city can rightly be proud.

Yet as the average age of people with HIV continues to rise, other long-term conditions are impacting their health and social care needs. In response, HIV services will need to evolve and better coordinate with other, non-HIV specific, services, adopting a model influenced by Long-Term Condition Management.

Furthermore, HIV is a condition driven by and, in turn, exacerbating social and health inequalities. Multiple social and economic factors expose some people more than others to the risks of acquiring HIV and to experiencing worse health outcomes and quality of life when living with HIV.

In turn, HIV can reinforce other inequalities for people living with the virus, notably through the impact of HIV-related stigma which can act as a barrier to accessing HIV testing and other healthcare.

A system-wide approach is needed which prioritises better integration of care, personalised to individual needs, and equity in access to services. Without this, inequalities will persist, putting the most disadvantaged at highest risk of negative outcomes, and new infections will continue to occur, leading to preventable ill-health and deaths and generating avoidable costs to the system.

HIV care in London remains an exemplar model for population health management - improving the health of those living with HIV by data driven planning and delivery of proactive care to achieve maximum impact. The vision for *Evolving the Care of People Living with HIV in London* includes realigning leadership and governance, segmentation, stratification and impact modelling to design and target interventions to prevent ill-health, improve care and support for people with HIV and reducing unwarranted variations in outcomes.

People living with HIV experience high rates of stigma and as result in any given year up to 1 in 13 of those living in London avoided seeking healthcare.

Public Health England. Positive Voices (2017 survey), London Regional Report

<sup>26</sup> Our Vision for London: The next steps on our journey to becoming the healthiest global city

<sup>27</sup> About us - Fast-Track Cities London (fasttrackcities.london)

<sup>28</sup> Our Vision for London: The next steps on our journey to becoming the healthiest global city

<sup>29</sup> British HIV Association Standards of care for people living with HIV 2018 (bhiva.org)

<sup>30</sup> Making it work: a guide to whole system commissioning for sexual health, reproductive health and HIV. Public Health England, 2014

Figure 2: The NHS Population Health Management maturity matrix

The PHM Maturity Matrix: “four Is” capability overview

Infrastructure	Intelligence	Interventions	Incentives
Organisational and human factors	Advanced and analytical tools	Care model design and delivery through proactive and anticipatory care models	Incentives alignment - value and population health based contracting and blended payment models
Digitised health and care providers and common integrated health and care record	Analyses and actionable insight – to understand health and wellbeing needs of the population	Community wellbeing – asset based approach	Workforce development and modelling
Linked health and care data architecture and single version of the truth	Alignment of multi-disciplinary analytical and improvement teams	Citizen co-production	Enabling governance to empower more agile decision making
Information governance	Development of a cross system ICS intelligence function	Monitoring and evaluation of patient outcomes and impact of interventions	

Source : Imperial College Health Partners

The Population Health Management Maturity Matrix provides a framework for guiding work to reframe HIV care across the region, ensuring that as care evolves, infrastructure, intelligence, interventions and incentives for high quality HIV care are better aligned.

Defining the scope

The impetus for this document came from the expectation that NHS England’s responsibility for commissioning specialised adult HIV services would soon be passing to ICSs. Recognising the synergy between HIV treatment and prevention, it focuses on how ICS partners can improve outcomes for people living with HIV at all stages of the care pathway (testing, treatment, care and prevention), highlighting the need for coordination and integration between medical specialties, primary and secondary care, social care and community-based services.

It takes account of the impact of COVID-19 on service provision and how the learning from this can be taken forward for the longer-term modernisation of HIV care.

The term ‘care’ is used in this document to encompass all types of service commissioned to meet the needs of people living with HIV, including testing and diagnosis, community-based support and social care, as well as clinical services. The creation of ICS Health and Care Partnerships presents an ideal opportunity to identify priorities for HIV commissioning across the whole system, making optimal use of available resources to achieve jointly agreed goals. It is critically important that structural changes within the health and care system and post-COVID recovery interventions are used to reduce inequalities, and to maintain and enhance best practice.

Their focus on place-based care enables ICS partners to set priorities to meet the needs of their specific populations and communities at the most local level. This document aims to complement this focus by outlining London-wide priorities which should help ICSs improve outcomes and reduce inequalities across the capital.

How was Evolving the Care of People Living with HIV in London developed?

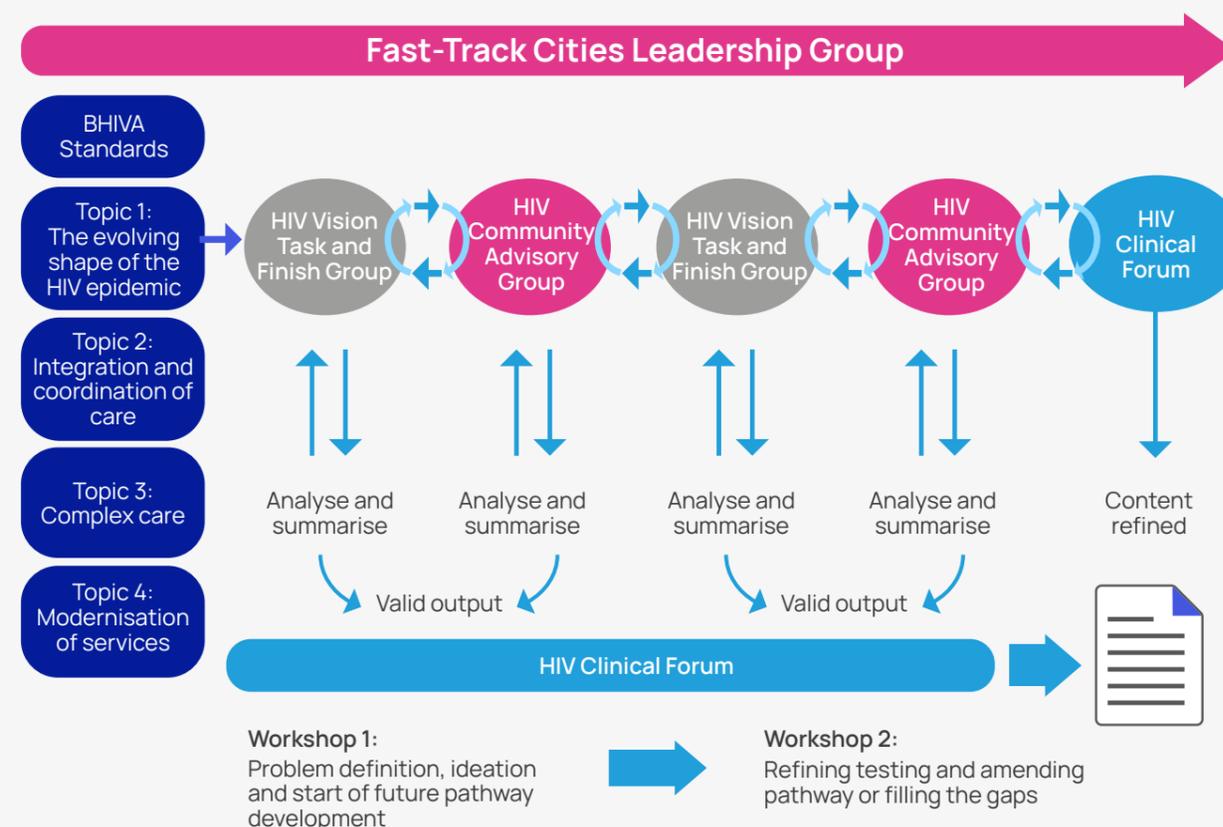
A Task and Finish Group was convened by the London FTCL at the request of NHS England’s London HIV Clinical Forum. This brought together the co-chairs of the Forum and HIV clinical leads representing each of the five areas of London with senior representatives from NHS England (specialised commissioning, transformation and public health), PHE epidemiologists, voluntary sector providers and the community of people living with HIV.

The group held workshops, informed by the available evidence, to identify the key challenges and agree priorities for action. In parallel, a Community Advisory Group consisting of 16 people living with HIV from a range of backgrounds was recruited and held a series of workshops using case studies to clarify key issues and priorities for improvement.

The draft paper synthesising recommendations from both groups was refined based on feedback from key public health representatives and ICS Directors of Strategy before wider circulation for comment to the HIV sector and beyond.

Where statements in this document are not referenced with published evidence, they represent the knowledge and expert opinion of the members of the Task and Finish Group and Community Advisory Group.

Figure 3: Development of Evolving the Care of People Living with HIV in London



## Alignment with wider policy

The priorities set out in this document align with key strategies and policies guiding NHS and public health commissioning, including the [NHS Long Term Plan](#), with its focus on joined-up, personalised care, support for people to manage their own health and increasing use of digital solutions, and the Government's White Paper [Integration and Innovation: working together to improve health and social care for all](#), which stresses integration across the NHS and greater collaboration between NHS, local government and wider delivery partners to improve the health and wellbeing of local populations.

A key cross-cutting priority of this document, in line with policies at regional as well as national and international<sup>31</sup> levels, is a commitment to narrowing health inequalities. [The London Health Inequalities Strategy](#) focuses on HIV and tuberculosis as particularly pressing health inequality issues in London and highlights the Mayor's commitment to support collaborative work on HIV prevention and treatment. In their health [Vision for London](#),<sup>32</sup> the Mayor, NHS England, PHE and London Councils identify improving services and prevention for HIV and other sexually transmitted infections (STIs) as one of ten issues requiring specific citywide action. Referencing the partners' joint commitment to, and financial support for, the London Fast-Track Cities Initiative (see below), the Vision aims to reduce HIV-related stigma, with a specific objective of stigma-free status for London health, care and government organisations by 2022.

In 2018, London<sup>33</sup> signed the Paris Declaration, [Fast-Track Cities: Ending the AIDS epidemic](#). Launched by UNAIDS, the Declaration states that cities are uniquely positioned to lead action towards achieving targets (including '90 90 90'<sup>34</sup>) on a trajectory towards getting to zero new HIV infections and zero HIV-related deaths by 2030. The [Fast-Track Cities London roadmap 2019-2030](#) shows the steps London must take on the journey to zero.

All five London Sustainability and Transformation Partnerships (STPs), which have now become ICSs, included a commitment in the 2019 refresh of their STP plans to implement opt-out HIV testing in all emergency departments. COVID-19 delayed its implementation, originally planned for April 2021, but this remains one of the most impactful actions ICSs could take collectively to accelerate London towards getting to zero.

During 2019-2020, an independent HIV Commission<sup>35</sup> led by Terrence Higgins Trust, National AIDS Trust and Elton John AIDS Foundation, gathered evidence and expertise from new and existing cross-sector partners. At the launch of its report, [How England will end new cases of HIV](#), on World AIDS Day<sup>36</sup> 2020, the Government announced the development of an HIV Action Plan for publication in 2021 based on the Commission's recommendations as part of its commitment to ending transmission of HIV in England by 2030.

<sup>31</sup> The [UNAIDS Global AIDS Strategy 2021-2026](#) lays out a framework for transformative action to reduce the intersecting inequalities that are preventing progress towards the goal of ending AIDS as a public health threat by 2030.

<sup>32</sup> [Our Vision for London: The next steps on our journey to becoming the healthiest global city](#)

<sup>33</sup> London Councils, NHS England, Public Health England and the Mayor of London

<sup>34</sup> By 2020, 90% of people living with HIV knowing their HIV status, 90% of people who know their HIV-positive status on treatment, 90% of those with undetectable virus, of people on treatment with suppressed viral loads

<sup>35</sup> [Final report and recommendations – HIV Commission](#)

<sup>36</sup> World AIDS Day is marked annually on 1 December

## Moving forward in partnership with the HIV community

The meaningful involvement of people living with HIV, as set out in the multi-governmental 1994 Paris Declaration on the Greater Involvement of People living with HIV (GIPA), is a principle that aims to realise the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives. GIPA seeks to ensure that people living with HIV are equal partners and breaks down simplistic (and false) assumptions of "service providers" (as those living without HIV) and "service receivers" (as those living with HIV).<sup>37</sup>

The involvement of people living with HIV has been integral to London's response to HIV and the shaping of its HIV services since the earliest days of the epidemic and could serve as an exemplar to support the management of other long-term conditions where patient involvement is not already embedded. GIPA principles have guided the involvement of HIV community representatives as key partners in the development of this document. They look forward to seeing action by ICSs on the recommendations they have put forward, and ICSs can only benefit from maintaining their meaningful involvement as they take the next steps towards implementation.

<sup>37</sup> [The Greater Involvement of People Living with HIV \(GIPA\): UNAIDS Policy Brief \(2007\)](#)

## 2

# Setting the Scene

## HIV in summary

Since the identification in 1981 of the first cases of AIDS (the syndrome, now rare in the UK, caused by HIV, the human immunodeficiency virus), the UK has seen a rapid evolution of HIV from its initial status as a fatal condition mostly affecting gay and bisexual men and people who injected drugs, characterised by fear and stigma across society and by trauma for the communities affected who saw thousands of premature deaths. This public health crisis prompted innovative and powerful community activism, ground-breaking public education and prevention, and new models of patient-centred healthcare. As it grew into a pandemic affecting the general population, particularly in sub-Saharan Africa, this was mirrored in the UK, with Black African communities increasingly affected. By the mid-1990s, inspiring achievements in medical research and treatment saw the introduction of combination antiretroviral therapy (ART), bringing with it hope for survival among people living with HIV.

Forty years on, with continued improvement and innovation, most people with HIV in the UK are able to lead healthy, active lives, to enjoy the same life expectancy as people who do not have HIV and to be confident that they will not transmit the virus.

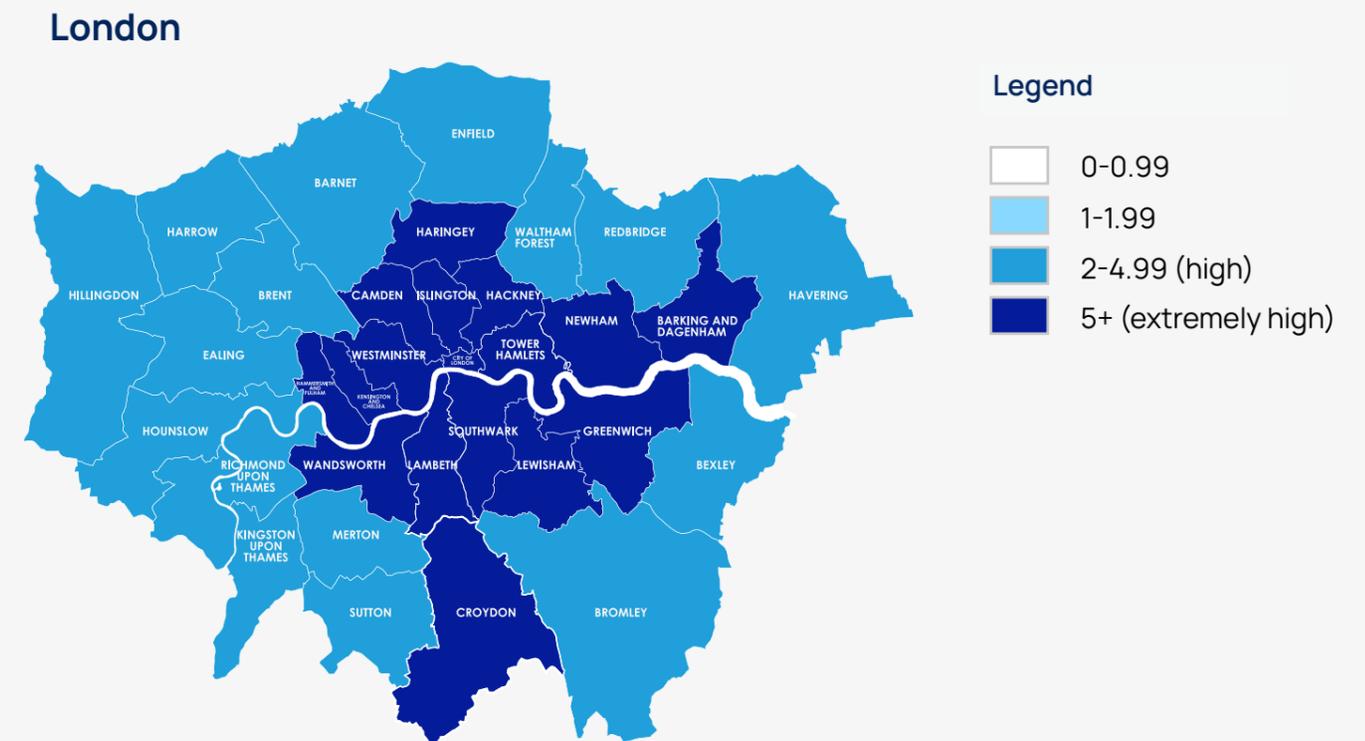
Yet this success story masks a parallel tale of ongoing inequalities in the experience of people living with HIV. Despite progress since the 1980s, the population groups most affected – principally gay and bisexual men and Black Africans (although a number of other communities also have higher-than-average rates of HIV) – still face prejudice and marginalisation. In addition, multiple social and economic factors expose some people more than others to the risks of HIV acquisition and having acquired it, to experiencing unnecessary illness or premature death due to late diagnosis. Once diagnosed, they may also have greater difficulties in accessing the care and support they need to remain healthy with HIV.

In turn, HIV can exacerbate other inequalities for people living with the virus, notably through the impact of HIV-related stigma. Although public knowledge and attitudes have improved since the earliest days of HIV, alarming levels of misinformation persist and this stigma remains pervasive,<sup>38</sup> and often intersects with the stigma associated with sexuality, ethnicity, migration status, substance use and misuse, mental ill-health, poverty and homelessness. Stigma can be internalised by people living with HIV and also be prevalent within communities, institutions and wider society, sometimes resulting in discrimination against people living with, or believed to have, HIV.

## HIV in London<sup>39</sup>

London is the region most affected by HIV in England. It is home to around two-fifths of all people seen for HIV care in the UK.<sup>40</sup> The 14 English local authorities with the highest rates of new HIV diagnoses are all in London, as are 17 of the 20 with the highest rates of diagnosed prevalence.<sup>41</sup> However, across the city there is significant local variation, with a fourteen-fold difference in the rates of new HIV diagnoses and a seven-fold difference in rates of diagnosed HIV prevalence among the 33 local authorities in 2019.

Figure 4: Prevalence of diagnosed HIV infection per 100,000 population, 2019



<sup>38</sup> National AIDS Trust. HIV: Public knowledge and attitudes. July 2021.

<sup>39</sup> Except where stated otherwise, the data, graphs and charts in this document are for 2019, from existing Public Health England publications and tables, or provided directly by Public Health England

<sup>40</sup> HIV: annual data tables - GOV.UK ([www.gov.uk](http://www.gov.uk))

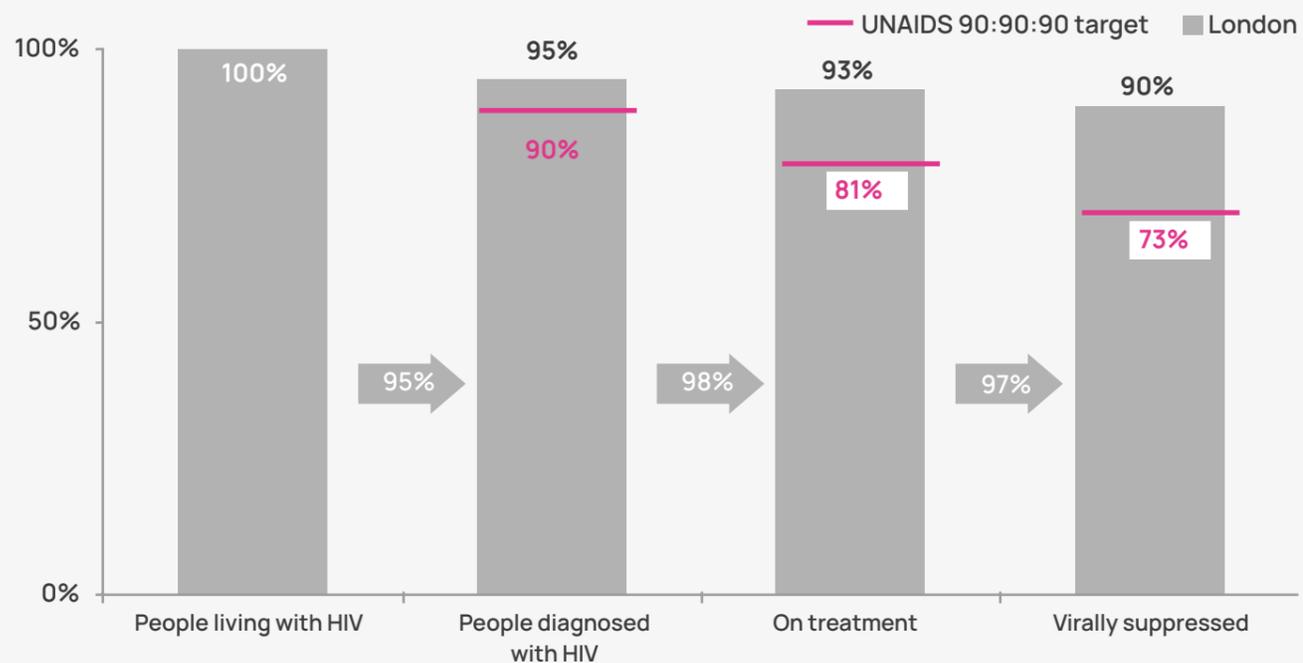
<sup>41</sup> Sexual and Reproductive Health Profiles - PHE

The capital has also been at the forefront of the UK's response to HIV, through its innovative prevention efforts and universally accessible treatment and care. London was among the first cities in the world to achieve the UN's 2020 "90 90 90" targets towards the elimination of HIV and was the first to exceed the "95 95 95" targets set for 2025: 95% of people living with HIV are aware of their status; of those, 98% are on treatment; and, of those, 97% are virally suppressed. This means that 90% of Londoners living with HIV are now on effective treatment and unable to transmit the virus.

Achieving these targets means London is well on the way to eliminating transmission of HIV in the city by 2030. A remaining challenge is to better serve the 10%<sup>44</sup> of Londoners living with HIV who are still at risk of sub-optimal health outcomes through not being on effective treatment or being unaware that they have HIV.

Moreover, while the UN targets provide a broad framework, they do not reflect the complexities of individuals' lives, their struggles to maintain social and psychological wellbeing, and the stigma they may experience, all of which affect their quality of life and broader health outcomes. To maintain and intensify the momentum towards elimination of new HIV infections, avoidable HIV-related deaths and HIV-related stigma, and to improve quality of life for people living with HIV, it is critical to recognise and address the challenges in the way the HIV epidemic is evolving, as well as to grasp new opportunities to improve how the system responds to these.

Figure 5: Continuum of care in London, 2019

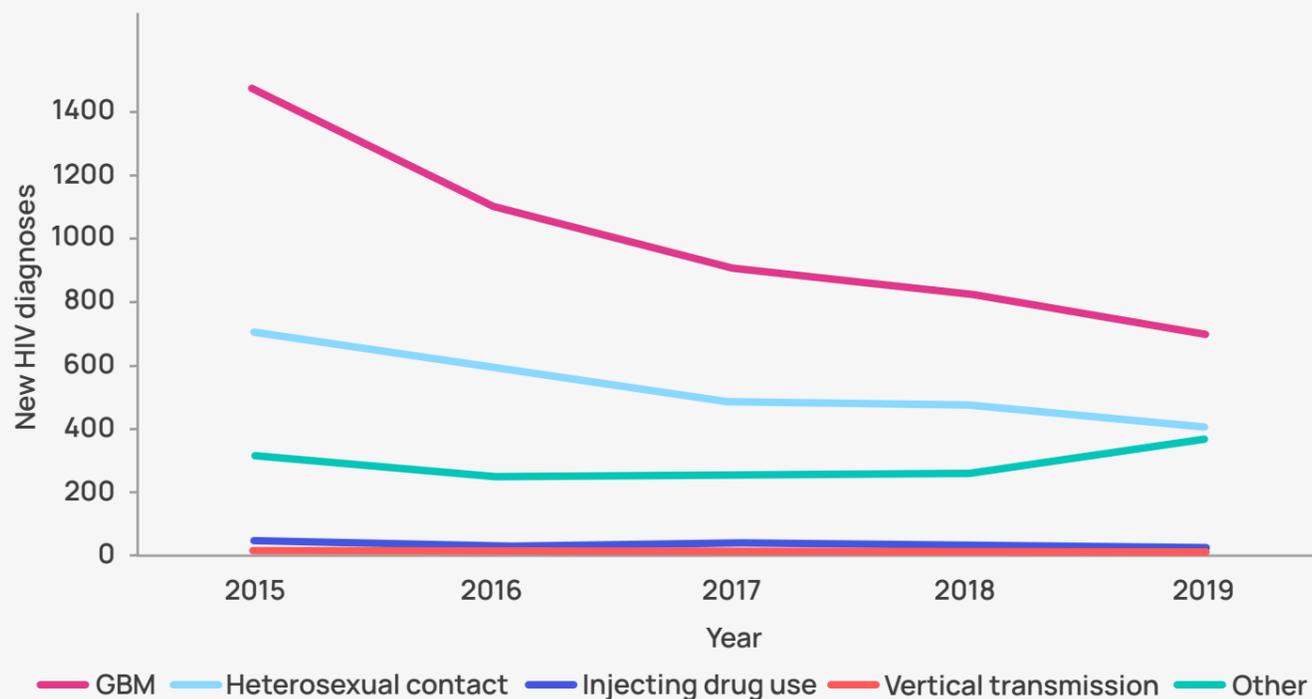


<sup>42</sup> By 2020, 90% of people living with HIV to be diagnosed, 90% of those diagnosed to be on treatment and 90% of those to be virally suppressed

<sup>43</sup> By 2025, 95% of people living with HIV to be diagnosed, 95% of those diagnosed to be on treatment and 95% of those to be virally suppressed

<sup>44</sup> This proportion may be slightly higher if people are included for whom up-to-date date information on treatment and viral load status is not available

Figure 6: New HIV diagnoses in London by probable exposure category, 2015 to 2019



### The evolving HIV epidemic

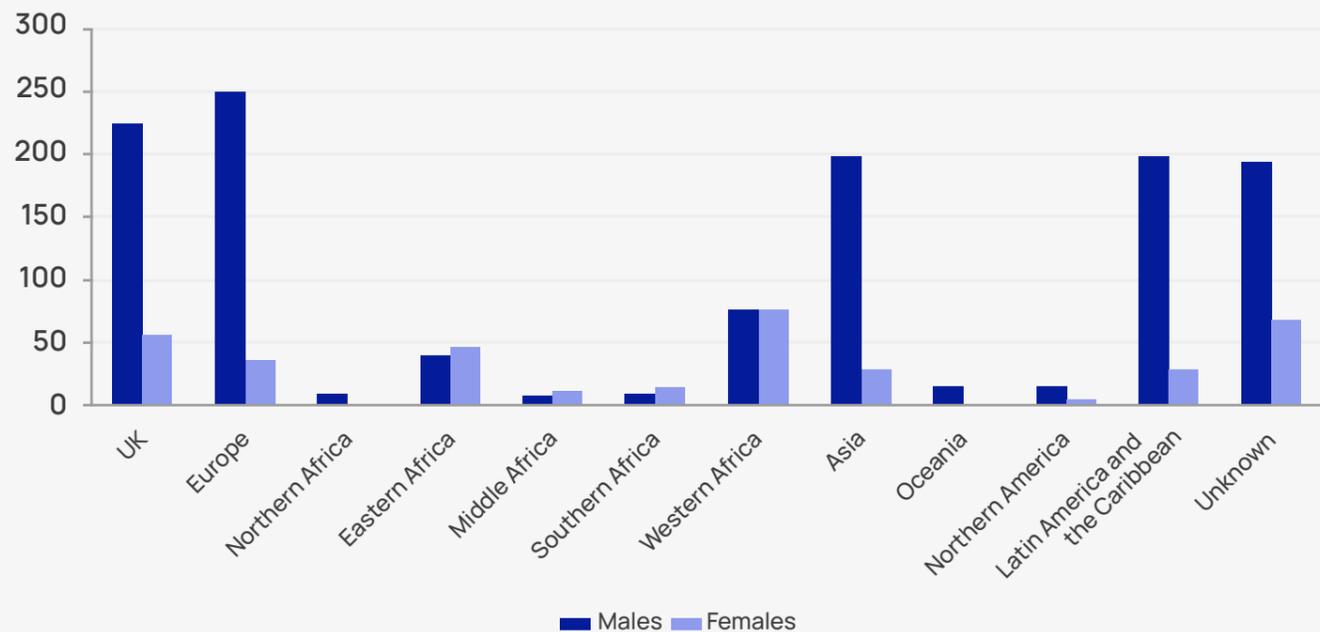
Up-to-date data on key HIV indicators in London, including local and regional comparisons, can be found at [Sexual & Reproductive Health profiles](#) and graphical representations at [HIV Lens](#).

### New HIV diagnoses

The number of people receiving a new HIV diagnosis has been declining rapidly in recent years, especially in London, where it fell by 40% between 2015 and 2019.

Despite this, 1510 people were newly diagnosed with HIV in London in 2019. The downward trend has been steepest among gay and bisexual men, who account for just under half of new diagnoses, and more so among those who are white than those of other ethnicities. Among heterosexuals, there has been a steeper decline in men than in women (who represent almost a quarter of people newly diagnosed).

Figure 7: New HIV diagnoses in London by region of birth and gender, 2019



There are now roughly equal numbers of new diagnoses among people born in the UK, the rest of Europe and Africa respectively, with the remainder mostly born in Latin America, the Caribbean and Asia.

About a quarter of people newly diagnosed in London in 2019 (370) had been previously diagnosed abroad, of whom two-fifths were gay or bisexual men. Like those first diagnosed in London, the number of people first diagnosed abroad has also declined.

Because of the significant proportions first diagnosed abroad, caution is required when using new diagnoses as a proxy for new infections. However, PHE analysis indicates that far fewer people in London are actually now acquiring HIV, a mark of the success of combination HIV prevention (including condom use, expanded HIV testing, prompt antiretroviral therapy (ART) and the availability of pre-exposure prophylaxis (PrEP)).

### Late diagnosis and undiagnosed HIV

People diagnosed with HIV at a late stage of infection are more likely than those diagnosed early to suffer ill-health and premature death. Since people diagnosed late are likely to have been living with undiagnosed HIV for at least three to five years,<sup>45</sup> there is a risk of transmission to other people while unaware of their status. The number of people unaware that they have HIV has been declining and is now estimated to be around 5% of all people living with HIV in London (versus 6% across England). Reducing late diagnosis not only improves the health of individuals living with HIV and prevents new infections, it also reduces the significant health and social care costs associated with severe disease, emergency hospital admissions, inpatient care and rehabilitation. Following concerted and ongoing efforts to reduce late HIV diagnosis by expanding HIV testing, the proportion of new

HIV diagnoses in London that were made late gradually decreased over several years to 34% in 2015. The numbers have continued to drop since then.

London has succeeded in reducing late diagnosis and undiagnosed HIV to below the national rates, but they remain higher among certain population groups, notably Black Africans and people of some other minority ethnicities, reflecting wider social inequalities.

### People living with diagnosed HIV

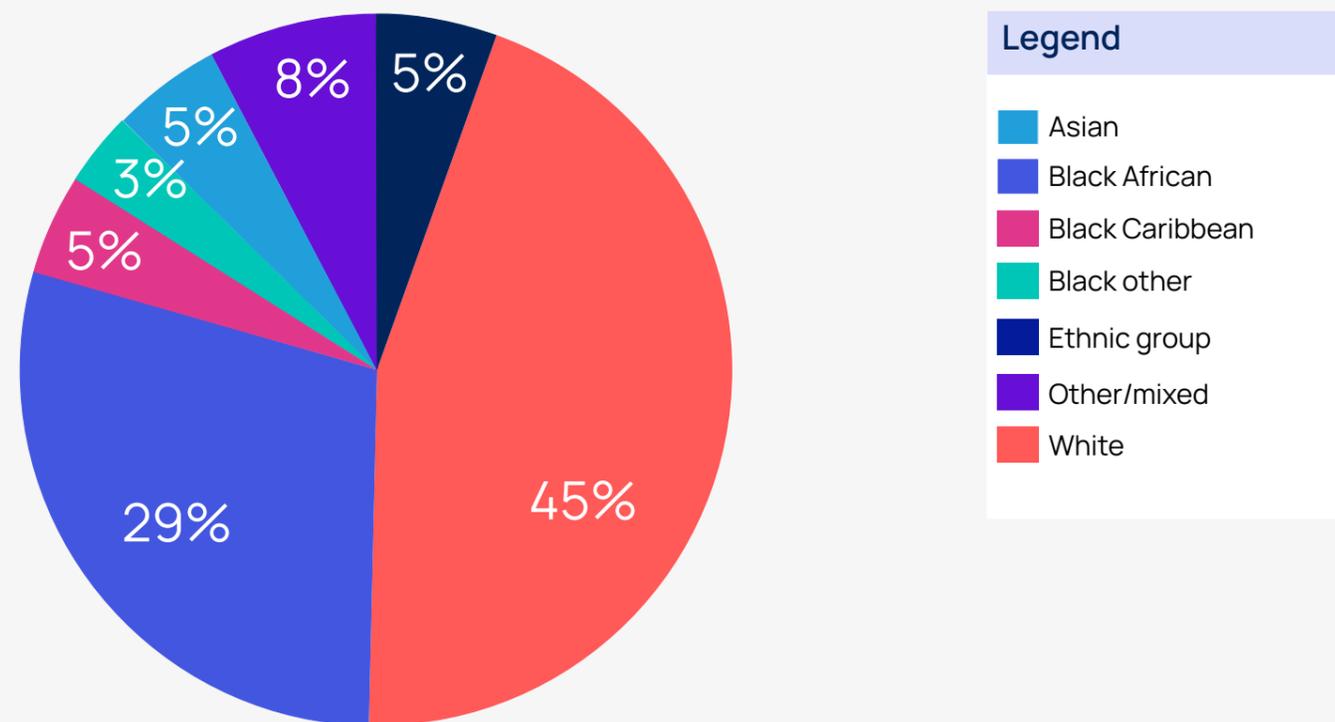
As people continue to acquire HIV and antiretroviral therapy prevents HIV-related deaths, the number of people living with HIV continues to increase. In London, 36,884 people living with HIV were seen for care in 2019. Almost a third were women and around a half were gay or bisexual men.

Just under half were white and a third Black African, with the rest from a range of other ethnicities.

The population living with HIV is ageing. The numbers in London aged 50 or over almost tripled in the last ten years and now make up almost half of the total. Most of these are aged between 50 and 64 but one in seven of them is 65 or older.

At the other end of the age spectrum, although antenatal screening and treatment of mothers diagnosed with HIV has almost eliminated vertical transmission of HIV in the UK, there remain around 200 children and young people who have been living with HIV since birth, cared for by specialist HIV paediatric services in London.<sup>46</sup>

Figure 8: People seen for HIV care in London by ethnicity, 2019



<sup>45</sup> Lodi S, Phillips A, Touloumi G, Geskus R, Meyer L, Thiebaut R, et al. Time from human immunodeficiency virus seroconversion to reaching CD4+ cell count thresholds <200, <350, and <500 Cells/mm (3): assessment of need following changes in treatment guidelines. Clin Infect Dis. 2011;53(8):817-25

<sup>46</sup> Summary Data I CHIPS (chipscohort.ac.uk)

Figure 9: Number of people seen for HIV care by age group, London 2010-2019



## Inequalities and vulnerability

Social and economic factors drive HIV transmission and HIV in turn can exacerbate social exclusion. Twenty-eight percent of London's population is living in poverty and the impact of COVID-19 is likely to have increased that number. For many people living with HIV, multiple marginalised identities and factors of disadvantage intersect. Marginalised and minority communities face systemic discrimination, and social exclusion and the stresses in their lives can lead to trauma, as can experiences specifically associated with their HIV.

There are high rates of intimate partner violence among women living with HIV.<sup>47</sup> Studies of HIV in homeless populations have found high rates of HIV as well as hepatitis B and C and tuberculosis.<sup>48</sup> Trans people living with HIV in the UK report poorer mental health and higher levels of stigma and discrimination, including in healthcare settings, than cisgender people with HIV.<sup>49 50</sup>

<sup>47</sup> Intimate partner violence in women living with HIV attending an inner-city clinic in the UK: prevalence and associated factors - Dhairyawan - 2013 - HIV Medicine - Wiley Online Library

<sup>48</sup> Sultan B et al. High prevalence of HIV among people who experience homelessness in London: results of an innovative peer-centred outreach bloodborne virus testing service initiated, at the start of the COVID-19 pandemic. Conference abstract O010. BHIVA BASHH 2021

<sup>49</sup> Kirwan, P., Hibbert, M., Kall, M., Nambiar, K., Ross, M., Croxford, S., Nash, S., Webb, L., Wolton, A. and Delpech, V. (2021), HIV prevalence and HIV clinical outcomes of transgender and gender-diverse people in England. *HIV Med*, 22: 131-139. <https://doi.org/10.1111/hiv.12987>

<sup>50</sup> M. Hibbert, A. Wolton, W. Crenna-Jennings, L. Benton, P. Kirwan, I. Lut, S. Okala, M. Ross, M. Furegato, K. Nambiar, N. Douglas, J. Roche, J. Jeffries, I. Reeves, M. Nelson, C. Weerawardhana, Z. Jamal, A. Hudson & V. Delpech (2018) Experiences of stigma and discrimination in social and healthcare settings among trans people living with HIV in the UK, *AIDS Care*, 30:7, 836-843, DOI: [10.1080/09540121.2018.1436687](https://doi.org/10.1080/09540121.2018.1436687)

## HIV-related deaths

207 people with HIV in London died in 2019, of whom almost four in five were men (reflecting the composition of the diagnosed population). A fifth of deaths were from AIDS, largely because of late diagnosis or lack of engagement in HIV care, and so should have been preventable.

## How and where are HIV services provided?

London is home to a rich tapestry of HIV services, from world-leading clinical services serving thousands of patients to small, informal grassroots community groups providing peer support. A more integrated environment for commissioning and provision of HIV services through ICSs provides opportunities to harness this diversity and reduce inequalities in access to service provision across the capital.

In doing this, there are some key aspects of HIV service provision, as set out below, which are highly valued and need to be preserved or strengthened.

A list and interactive map of 250 London HIV-related services, including treatment centres and community-based support organisations, can be found at [HIV services | HIV Lens \(hiv-lens.org\)](https://hiv-lens.org).

## HIV clinical services

Today's HIV service model is informed by its history. In the early days of HIV, clinics developed organically in response to need and, because the disease had many different clinical manifestations, a range of medical specialties took the lead. HIV is now most frequently managed in genitourinary medicine (GUM) but there are some HIV clinics within infectious diseases (ID) departments. There are 28 HIV clinics across London (including two for children).

As HIV was initially a novel, highly stigmatised and fatal disease with no effective treatment, concern for confidentiality was high, so clinic records were kept separately from other hospital records. GPs were not routinely informed when their patients had HIV and the clinics tended to manage all their patients' medical problems, many of which were due to their HIV or affected by it. Most GPs thus did not gain experience of caring for people with HIV and were not expected to.

Now that HIV has become a long-term condition and its clinical management in people who are stable on treatment can be quite routine, the old model has been largely superseded. While the expertise of HIV specialists is still needed to oversee the management of HIV, especially in more complex cases, general practice has the skills and is best placed to provide primary healthcare including the management of conditions common in people with HIV such as cardiovascular disease and diabetes. People with HIV also sometimes need to access mental health and other services in the community, and GPs can be a useful or necessary link to these. To a large degree the shift towards GP management of primary care and onward referral has already happened, partly driven by funding structures, but concerns remain among people living with HIV about encountering stigma and discrimination outside the HIV specialist setting, and about the level of knowledge and understanding of HIV among non-HIV specialists.<sup>51</sup>

## Open access

Like GUM services, which need to minimise access barriers from both an individual and a public health perspective, HIV clinical services are provided on an open access basis. This means that people can self-refer to the clinic of their choice, without geographical restrictions or requirement for a GP referral, and can change clinics on the same basis. Open access is a cornerstone of the HIV service model in the UK and is one of the reasons for its high rates of patient satisfaction and retention in care.

<sup>51</sup> Positive Voices: The National Survey of People Living with HIV. Findings from the 2017 survey

London clinics are the HIV service of choice for some people who work in London but live outside and for others who appreciate particular, specialised aspects of care they provide, such as dedicated clinics for gay men or for women. As a result, 12% of people accessing HIV care in 2019 lived outside the capital (ranging from 6% to 32% by clinic). Many more travel across ICS boundaries to different parts of the city for their care.

Ultimately, HIV clinical services are not 'place'-based; they may serve patient populations from outside their local area and, conversely, their local residents may choose to use services elsewhere. In addition, particular low volume but highly specialist services may only be provided in a small number of centres. In this context, while there are still specific local population needs that certain HIV clinics gear their services to meet, it makes sense to look at London HIV service provision from a city-wide perspective. This is one reason why pan-London commissioning of HIV clinical services has proved so beneficial.

### Multidisciplinary care

London's HIV services have multidisciplinary teams including clinical nurse specialists, HIV-specialist pharmacists, and sometimes members of other allied professions, such as dieticians and occupational therapists, with HIV-specialist expertise, all of whom play important roles. Some services have health advisers and there remain some dedicated HIV-specialist mental health professionals, especially clinical psychologists, although funding pressures have led many of these posts to be abolished or access to them reduced, with an expectation that HIV patients will use mainstream mental health services.

Many services run clinics for particular groups, such as women, older people with HIV or young people transitioning from paediatric care, or joint clinics with other specialties.

### Inpatient, highly complex and rehabilitation care

The effectiveness of antiretroviral therapy has resulted in a significant decline in the number of people who require admission to hospital with an HIV-related problem. This has led to reconfiguration of inpatient units across a smaller number of sites in order to maintain skills and expertise. Even as new infections and late diagnoses (with the associated clinical challenges) continue to decrease, any reconfiguration of HIV care pathways must still include provision for highly complex HIV care including, but not limited to, opportunistic condition management; antenatal HIV care; care of children and adolescents living with HIV; complex HIV resistance and complex drug-drug interaction management. This may require networked or cross-ICS arrangements.

The demographic profile suggests that admissions from age-related illness among people who also have HIV will increase in the longer term and this means that HIV specialist in-reach support (when HIV specialists support inpatient care led by other specialists) will be in greater demand.

Several clinics offer dedicated pathways for people with neurological issues, particularly cognitive impairment, and one service offers inpatient care for people with complex cognitive or rehabilitation needs. Commissioning arrangements for this HIV-specialist rehabilitation service vary between CCGs but generic rehabilitation services do not always recognise HIV-specific needs and complexities. HIV-specialist community rehabilitation services can be particularly beneficial for marginalised people living with HIV. ICSs may wish to review the role and potential fit of a such a service in the context of their broader strategies for step-down care and rehabilitation.

### Residential, nursing home and end of life care

As people with HIV age, most will face a death with, rather than from, HIV. Services crucial for any ageing population, including residential and nursing home care and end of life care pathways, will need to develop to meet their needs.<sup>52</sup> Service evaluation and data collection can help determine the merits of HIV-specific services against generic care and equip generic services to offer appropriate interventions for people living with HIV.

### Community-based HIV support services

The AIDS crisis of the 1980s led to a groundswell of community activism on prevention, and advocacy for services to treat people with HIV with respect and compassion. At a time when medication could not provide solutions, clinicians, activists and patients learnt together how to manage HIV. From these roots community engagement was rightly embedded in HIV care, with a focus on the empowerment of people with HIV, numerous community-based organisations offering support, and a strong patient voice within clinical services. As the needs of people with HIV have changed over the years, the role of HIV support organisations has evolved to meet them. Community and voluntary sector organisations are still an integral and vital part of the HIV sector and are depended on by many people living with HIV. Over a one-year period, around one in six use their services in London.

These organisations provide psychosocial support in the community and sometimes within HIV clinics. The services offered differ between organisations, as do their client groups, which may be drawn from their local populations and/or from particular communities based on ethnicity, sexuality, gender or other characteristics such as faith group.

Those in need of such services are often the most disadvantaged, seeking help on issues among the wider determinants of health such as poverty, housing, migration status, social exclusion, trauma, domestic violence or problematic drug use.

There is no one dominant provider of support services across London, and while some larger organisations have a national presence and work across the capital, others are most active within one geographical sector. A number of small, grassroots organisations also operate, sometimes unfunded, informal and relying on unpaid volunteers. Services provided include counselling, support groups, welfare rights and housing advice, immigration support, small financial grants, holistic therapies, 'buddying' and assistance with basic needs such as food. Most organisations provide some form of peer support, which may be offered in person, one-to-one or in groups, by phone or online.

It should be noted that the 'HIV community' binds people together through their common experience of HIV regardless of where they live and, because of stigma, people with HIV may not share their HIV status and are not visible within their local communities. Thus 'community-based' HIV services cannot be exclusively place-based, and some may achieve best outcomes and value when commissioned to deliver care across a wider geographical footprint. Alongside these, place-based services serve particular local communities, often in relation to prevention, testing and the wider determinants of health.

HIV support organisations face a tension between collaboration to meet local population needs and competition for scarce funding, which can hinder partnership working. However, a number of successful alliances have been forged, mainly focused on service delivery and sometimes in partnership with the NHS.

<sup>52</sup> Palliative care as an essential component of the HIV care continuum - The Lancet HIV

In addition, some organisations are providing local leadership through HIV training and guidance for non-HIV services (such as mental health, substance misuse, or housing) which have an important role to play in the complex care of some of the most vulnerable and socially disadvantaged people living with HIV.

### HIV testing services

The bulk of HIV testing in London (over 80%) is carried out either as part of antenatal screening or in sexual health services (SHS), mostly GUM or integrated GUM/sexual and reproductive health (SRH), but the proportion carried out in non-SHS settings including primary care and other secondary care services has increased progressively. Testing is also offered through outreach with groups at higher risk, such as sex workers or homeless people, and in a range of voluntary sector and community settings to reach populations where HIV prevalence is higher, such as among Black Africans.

Home testing options (both self-sampling and self-testing<sup>53</sup>) have increased in recent years, particularly with the launch of Sexual Health London, the online testing service jointly commissioned by 31 London local authorities. COVID-19 has led to a rapid expansion in online testing and a reduction in face-to-face provision: Sexual Health London reports over 50% more online HIV tests performed in 2020/21 than 2019/20, with the increase highest among people from some key minority ethnic populations, gay and bisexual men, trans people and teenagers.<sup>54</sup> (See also Section 5 on the impact of COVID-19.)

Some routine HIV testing takes place on an opt-out basis<sup>55</sup> in general medical settings, such as emergency departments, as recommended by NICE<sup>56</sup> and the British HIV Association (BHIVA),<sup>57</sup> to reduce rates of undiagnosed HIV. Implementation of this is currently variable across the city.

Most people with HIV are still diagnosed in sexual health services, which tested around 300,000 people in London in 2019, but the proportion varies by gender (see Figure 10) and ethnic group. Black Africans are less likely than people of white ethnicity to be diagnosed in sexual health services (58% versus 73% respectively in 2019), but more likely to be diagnosed in general practice (15% versus 3%). Women are more likely than men to be diagnosed in non-sexual health medical settings.

### HIV prevention

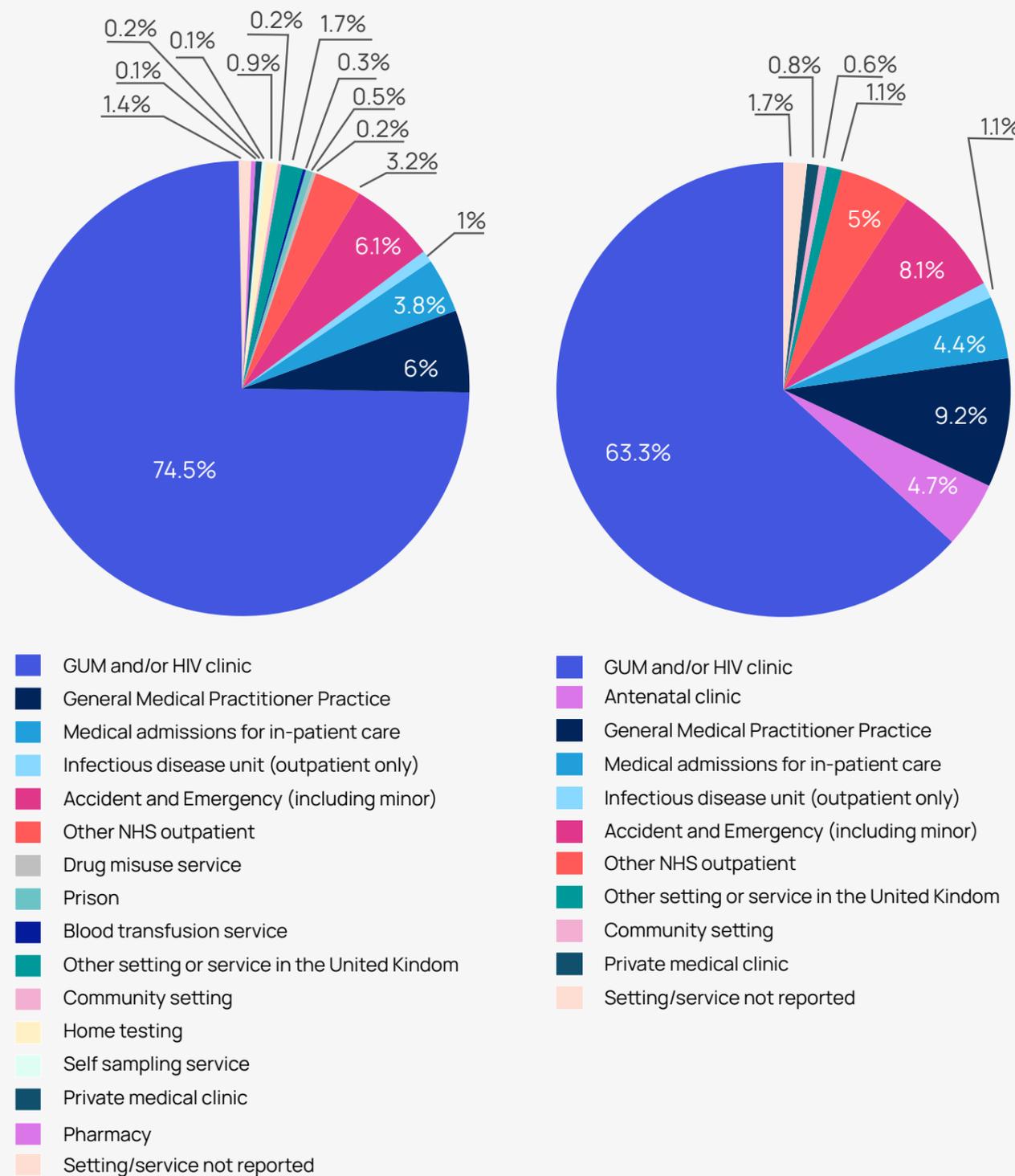
Citywide HIV prevention services are delivered through the London HIV Prevention Programme (LHPP), which runs the Do It London campaign on behalf of 32 London councils. In addition to disseminating public education messages promoting HIV testing and combination prevention, the LHPP has worked with the GMI partnership to deliver sexual health promotion outreach to men who have sex with men, and a free condom distribution scheme across more than sixty venues in the capital.

In addition to the LHPP, a range of other community-based HIV prevention initiatives for populations at higher risk of HIV are in place at local level.

Figure 10: Setting of HIV diagnosis in London, men and women (aged 15 and over), 2019<sup>58</sup>

New diagnoses among adult men, by setting of first positive test: London 2019 (n=1,146)

New diagnoses among adult women by setting of first positive test: London 2019 (n=360)



<sup>53</sup> Self-sampling = the individual orders a test kit and returns the sample for analysis, with linkage to care facilitated when positive results are provided. Self-testing = the individual orders a test kit and performs the test themselves.

<sup>54</sup> Luke Byron-Davies, Commissioning Manager, London Sexual Health Programme – personal communication.

<sup>55</sup> Opt-out testing means that attendees are informed that they will be automatically tested unless they actively decline.

<sup>56</sup> NICE. HIV testing: increasing uptake among people who may have undiagnosed HIV. 2016.

<sup>57</sup> British HIV Association/British Association for Sexual Health and HIV/British Infection Association Adult HIV Testing Guidelines 2020.

<sup>58</sup> HIV diagnoses are often reported by sexual health services following confirmatory testing, so the graphs probably underestimate the relative contribution of non-sexual health settings where initial tests were performed.

## How are HIV services commissioned?

The current commissioning arrangements for HIV have been in place since 2013, following the implementation of the Health and Social Care Act 2012. Responsibilities for commissioning services across the HIV pathway are divided between the NHS and local government as set out below.<sup>59</sup>

### Allocated responsibilities for commissioning HIV services

NHS England:

- Specialised HIV treatment and care services for adults and children
- HIV antiretroviral medication for treatment and prevention, including PrEP
- All healthcare, including HIV care, in secure and detained settings
- HIV screening in pregnancy as part of the Infectious Diseases in Pregnancy Screening Programme
- HIV testing when clinically indicated in general practice, as part of 'essential services' under the GP contract
- HIV testing when clinically indicated in other NHS England-commissioned services

CCGs :

- HIV testing as part of the abortion pathway
- HIV testing when clinically indicated in CCG-commissioned services (including emergency departments and other medical specialties)

Local authorities:

- HIV testing as part of sexual health services in specialist, primary care and community settings, HIV partner notification and provision of PrEP
- Population HIV screening in primary care and general medical settings
- Local HIV prevention
- HIV social care

The assignment of HIV treatment and care services to NHS England specialised commissioning has brought major benefits. Having a single national service specification<sup>60</sup> has fostered a high and consistent quality of clinical care throughout the country, and the commitment to maintain this at national level is welcome.

Regional drug procurement has enabled significant cost savings and the recent move to national procurement is expected to enhance this further, while it will be important to ensure that this enables people with HIV to have access to newly emerging therapies that can optimise outcomes.

At regional level NHS England specialised commissioning has supported a London-wide approach to minimise duplication or unwarranted variation across the city. It has also eliminated the bureaucracy and expense associated with cross-charging between local commissioners, as was required under the pre-2013 primary care trust (PCT)-based commissioning arrangements.

The assignment of public health commissioning to local government has enabled councils to use their unique understanding of their residents to develop and improve services such as HIV prevention and testing, tailored to local needs and priorities. The London Sexual Health Programme is structured to agree collaborative positions between councils where this is beneficial whilst maintaining a local focus.

## Standards of care for people living with HIV

The most recent evidence-based *Standards of care for people living with HIV* were published by the BHIVA in 2018. Co-developed with care providers, professional associations, commissioners, and people living with HIV, they set out the care that any adult living with HIV in the UK should expect to receive from testing and diagnosis to the end of life, taking a holistic approach that embraces overall health and well-being, as well as clinical care.

The standards call for improved coordination and integration of care to enable people with HIV to live well. They provide a framework for high quality care against which any new HIV service model should be tested.

While HIV clinical care has largely been found to meet the standards, there are gaps and inequalities in the provision of broader, holistic care (described in Section 4).

This document identifies transformational changes that ICSs and their Health and Care Partnerships may wish to prioritise in order to ensure the care standards are met.

<sup>59</sup> Adapted from: Making it work: a guide to whole system commissioning for sexual health, reproductive health and HIV. Public Health England, 2014

<sup>60</sup> B06/S/a. 2013/14 NHS Standard Contract for Specialised Human Immunodeficiency Virus Services (Adults) Section B Part 1 - Service specifications

## 3

# Challenges in meeting London's HIV aims

## London's aims for HIV

The Mayor of London, NHS England, PHE and London Councils are committed to achieving four strategic aims by 2030:

- zero new HIV infections
- zero preventable deaths
- zero HIV stigma
- the best health and quality of life for people living with HIV.<sup>61 62</sup>

These goals are closely intertwined, as many of the same actions work towards achieving them all. Although not a cure, successful antiretroviral therapy reduces the amount of virus in the blood (viral load) to a level which is undetectable (viral suppression).

People with HIV who are not diagnosed late and have stable viral suppression can expect good health outcomes and a near-normal lifespan, and they are also unable to transmit the virus to other people. Thus, effectively managing the 'continuum of care' - from early diagnosis, through prompt treatment initiation, to the achievement and maintenance of viral suppression - is crucial in enabling people living with HIV to lead healthy lives, eliminating HIV-related deaths and reducing new infections. Helping people to understand this process, particularly the effectiveness of HIV treatment in preventing transmission (U=U),<sup>63</sup> also combats stigma.

## Ending new HIV infections

### Combination HIV prevention

The success of combination HIV prevention is the principal explanation for the fall in new infections among gay and bisexual men.<sup>64</sup>

Getting to zero new HIV infections requires the maintenance and expansion of the 'combination prevention' approach, comprising:

- the promotion and provision of condoms, still a highly effective means of preventing transmission of both HIV and other STIs
- availability of pre-exposure prophylaxis (PrEP), HIV antiretroviral drugs usually taken daily and found to be xx% effective at preventing acquisition of HIV among people at risk
- frequent and expanded HIV testing, which enables people with HIV to be diagnosed and access treatment early, and those who are HIV-negative to be informed about prevention options and assessed for suitability for PrEP
- treatment as prevention (TasP), whereby viral suppression in people with HIV who are stable on antiretroviral therapy means they cannot transmit the virus (U=U)
- post-exposure prophylaxis (PEP), a short course of antiretroviral drugs prescribed as an emergency measure following possible exposure to HIV
- public education to raise awareness and knowledge of HIV and how to prevent it.

While in general people living with HIV are well-informed about, and reassured by, U=U, knowledge of this is disappointingly low among the general population.<sup>65 66</sup>

Experience of PrEP uptake in the UK shows disparity between population groups, with awareness and use of PrEP highest among gay and bisexual men who are white, well-educated, employed, and young.<sup>67</sup>

Measures to strengthen prevention, echoing the HIV Commission's recommendations,<sup>68</sup> include:

- Continuing to fund and implement a multi-year coordinated health promotion programme aiming to increase access for all to the full set of combination HIV prevention options available. This should include promotion and access to PrEP, condom use, HIV testing and the role of treatment as prevention (U=U).
- Clarifying financial accountability and responsibility for PrEP provision beyond sexual health clinics (for example, in GP surgeries, maternity units, abortion services, gender clinics and pharmacies). This should include promotion to improve awareness and uptake for all communities who will benefit from PrEP.
- Continuing to provide campaigns aiming to enable people in London to know how to find out their HIV status and increase their awareness of combination HIV prevention and change behaviours.

<sup>61</sup> HIV diagnoses are often reported by sexual health services following confirmatory testing, so the graphs probably underestimate the relative contribution of non-sexual health settings where initial tests were performed.

<sup>62</sup> Our Vision for London: The next steps on our journey to becoming the healthiest global city

<sup>63</sup> Undetectable = Untransmittable, i.e., that being on HIV treatment with an undetectable viral load means people cannot pass on HIV to their sexual partners.

<sup>64</sup> Final report and recommendations – HIV Commission

<sup>65</sup> Terrence Higgins Trust press release, 4 July 2019. Almost half of Brits would feel uncomfortable kissing someone with HIV

<sup>66</sup> Women and HIV: Invisible no longer. Sophia Forum and Terrence Higgins Trust. 2018

<sup>67</sup> Final report and recommendations – HIV Commission

<sup>68</sup> Final report and recommendations – HIV Commission

## HIV testing guidelines

Complementary approaches to HIV testing are needed to detect infections which remain undiagnosed and to diagnose new infections as early as possible. Recent national guidelines,<sup>69</sup> broadly reflecting 2016 NICE guidance,<sup>70</sup> recommend that HIV testing should be routinely offered to:

- people in groups at increased risk of HIV
- people attending certain defined healthcare settings where HIV may be more prevalent
- people with symptoms and/or signs of an HIV indicator condition<sup>71</sup>
- all patients accessing primary and secondary healthcare, including emergency departments, in areas of high and extremely high HIV prevalence (categories which apply to the whole of London).

## Frequent testing and early treatment initiation

Frequent HIV testing for people at higher risk of HIV and early treatment initiation for those testing positive play a key role in reducing new infections. A few central London sexual health clinics have taken a particularly innovative and pro-active approach to this which, along with access to pre-exposure prophylaxis (PrEP), has been credited with responsibility for much of the steep fall in new infections in the capital.<sup>72</sup>

More broadly across London, there is scope for improvement. 84% of gay and bisexual men newly diagnosed with HIV in London in 2019 had not had a test at the same clinic in the previous year<sup>73</sup> but the proportion of people initiating treatment early (within 91 days of diagnosis) has been increasing (from 60% in 2015 to 76% in 2019).

Further analysis is needed of variation in these measures between clinics across London and by population groups to pinpoint whether there are inequalities as regards rapid treatment initiation.

In services caring for people at higher risk of HIV, significant opportunities to test are still being missed. Testing coverage in London specialist sexual health clinics is only 69% despite guidelines recommending that all attenders (except those already diagnosed with HIV) be offered and recommended a test. Of those not tested, about half are not offered a test and the remainder decline. Of particular concern is the third of women born in a country with high HIV prevalence who are not offered testing.

Online testing can offer cost savings as well as convenience, but it is not equally accessible or appropriate for all population groups. Older people and Black Africans are less likely to use the national HIV self-sampling scheme than community testing services, as are first-time testers.<sup>74</sup>

The following measures to increase rates of testing are suggested:

- Explore how the learning from the clinics that achieved a steep fall in new infections can be applied to those with different characteristics and in other parts of the city and use this learning to develop new service models for other communities at higher risk of HIV.<sup>75</sup>
- Explore the factors leading to low rates of testing offer and acceptance in sexual health clinics and put in place measures to increase uptake.
- Ensure that COVID recovery includes re-establishing or expanding provision of face-to-face HIV testing in non-traditional and community settings, particularly for underserved communities at higher risk of HIV and those for whom digital options are a barrier to testing access.

## Routine opt-out testing in healthcare settings

The HIV Commission judged that widespread, routine opt-out HIV testing across the NHS is the single most important intervention for eliminating new HIV infections.<sup>76</sup>

HIV testing guidelines<sup>77</sup> recommend a universal opt-out approach in a broad range of healthcare settings when the local prevalence of undiagnosed HIV means that testing is cost-effective or where 100% testing coverage is desirable.

A number of such initiatives in London emergency departments are proving successful and cost-effective at detecting infections reaching a higher proportion than other testing services of people at an advanced stage of HIV and from some disadvantaged minority communities.<sup>78</sup> Testing in this setting is also effective at identifying people previously diagnosed who have dropped out of HIV care.<sup>79</sup> High-level action is needed to roll this out across the city and ensure it is sustainably funded. London ICSs have committed to implementing emergency department testing universally across London.

Implementation of the NICE recommendations in general practice has been mixed, although there have been some encouraging local initiatives.<sup>80,81</sup> In addition to emergency department testing, measures to increase routine testing could include:

- Commissioning HIV testing in primary and secondary care according to NICE guidance
- Establishing performance-based incentives to improve rates of HIV testing or diagnosis in primary and secondary care
- Integrating HIV testing with hepatitis C testing programmes

## HIV contact tracing

HIV contact tracing (or 'partner notification') is a process by which sexual contacts of people newly diagnosed with HIV, or living with a transmissible level of virus, are identified and offered HIV testing.<sup>82</sup>

<sup>69</sup> British HIV Association/British Association for Sexual Health and HIV/British Infection Association Adult HIV Testing Guidelines 2020

<sup>70</sup> NICE. HIV testing: increasing uptake among people who may have undiagnosed HIV. 2016.

<sup>71</sup> An indicator condition is any medical condition associated with an undiagnosed HIV seroprevalence  $\geq 1$  per 1000. This may be due to either shared transmission routes with HIV (e.g. hepatitis B and C) or dysregulated immunity.

<sup>72</sup> Brown AE, Mohammed H, Ogaz D, Kirwan PD, Yung M, Nash SG et al. Fall in new HIV diagnoses among men who have sex with men (MSM) at selected London sexual health clinics since early 2015: testing or treatment or preexposure prophylaxis (PrEP)? *Euro Surveill* 2017;22(25):pii=30553. <https://doi.org/10.2807/15607917.ES.2017.22.25.30553>

<sup>73</sup> Trends in HIV testing, new diagnoses and people receiving HIV-related care in the United Kingdom: data to the end of December 2019. *Health Protection Report, Volume 14 Number 20, 3 November 2020*

<sup>74</sup> Trends in HIV testing, new diagnoses and people receiving HIV-related care in the United Kingdom: data to the end of December 2019. *Health Protection Report, Volume 14 Number 20, 3 November 2020*

<sup>75</sup> Lowbury R. A roadmap for eliminating late diagnosis of HIV in England. Halve It position paper. Halve It, 2018

<sup>76</sup> Final report and recommendations – HIV Commission

<sup>77</sup> British HIV Association/British Association for Sexual Health and HIV/British Infection Association Adult HIV Testing Guidelines 2020

<sup>78</sup> Evidence on HIV Testing and Reengagement from the Elton John AIDS Foundation Zero HIV Social Impact Bond. Steve Hindle and Jennifer Warner, June 2021.

<sup>79</sup> Vaccari LC, Parry S, Kirkham D et al. Sustained 97% HIV testing rate in the Emergency Department: the new gold standard. *Conference abstract O001. BHIVA BASHH 2021*

<sup>80</sup> Leber W, McMullen H, Anderson J, Marlin N, Santos AC, Bremner S et al. Promotion of rapid testing for HIV in primary care (RHIVA2): a cluster randomised controlled trial. *Lancet HIV* 2015;2(6):e229–e235. Available at: [https://doi.org/10.1016/S2352-3018\(15\)00059-4](https://doi.org/10.1016/S2352-3018(15)00059-4)

<sup>81</sup> Evidence on HIV Testing and Reengagement from the Elton John AIDS Foundation Zero HIV Social Impact Bond. Steve Hindle and Jennifer Warner, June 2021

<sup>82</sup> Sullivan AK et al. HIV partner notification for adults: definitions, outcomes and standards. National AIDS Trust, British Association for Sexual Health and HIV, Society of Sexual Health Advisors and British HIV Association, 2015

Because so closely targeted at those at high risk, it is a highly effective way of finding people with undiagnosed HIV, achieving the highest positivity rate of all testing interventions (4.6%) – 30 times higher than for testing in specialist sexual health services overall.<sup>83</sup>

Usually carried out by sexual health advisers or nurses, the complexity and labour-intensive nature of partner notification can act as barriers to its implementation in busy sexual health services, especially where health adviser posts have been reduced or abolished. Furthermore, rapid referral of people with HIV from sexual health services to HIV treatment centres can actually reduce the opportunity for the necessary interaction with a sexual health adviser. A 2018 national audit against standards for HIV partner notification<sup>84</sup> found scope for improvement with informing and testing contactable contacts.<sup>85</sup>

The HIV Commission concluded that partner notification is often not prioritised by sexual health commissioners, despite its probable cost effectiveness. Yet as new infections move closer to zero, the highly targeted nature of contact tracing will increase its value as a tool to find the remaining people living with undiagnosed HIV.

Public awareness of contact tracing as a concept has increased during the COVID-19 pandemic, potentially providing an opportunity to normalise and de-stigmatise it along with more routine HIV testing.

To maximise the impact of contact tracing, the following measures are suggested:

- Prioritise and resource contact tracing in the commissioning of HIV testing pathway
- Use community engagement to develop contact tracing methods appropriate for marginalised communities
- Explore how digital technology can be further exploited to improve contact tracing for HIV

## Stopping preventable HIV-related deaths

### Reducing late diagnosis of HIV

Late diagnosis is the leading cause of premature death and disease among people living with HIV.<sup>86</sup> It frequently occurs after diagnostic opportunities have been missed in primary or secondary care, where non-HIV specialist clinicians have failed to offer a test when clinically indicated.<sup>87</sup> Medical specialties mentioned for improvement on this count in an audit of late HIV diagnoses include emergency departments, medical admissions, haematology, gastroenterology, respiratory medicine, internal medicine, dermatology and general practice.<sup>88</sup> According to NICE guidance,<sup>89</sup> everyone admitted to hospital or seen in general practice with symptoms that may indicate HIV, or an HIV risk factor, should be offered and recommended an HIV test.

This requires non-HIV specialist clinicians to have sufficient awareness and understanding of HIV, especially HIV-indicator conditions<sup>90</sup> and the reasons for, and acceptability of, HIV testing.

By bringing together commissioning and providers across the system, ICSs are well-placed to galvanise action to reduce missed and late diagnoses in all healthcare settings.<sup>91</sup> Measures could include:

- In partnership with HIV specialists, providing appropriate education about HIV, indicator conditions and HIV testing to clinicians in primary and secondary care
- Integrating HIV testing into standard protocols within medical services whose patients are more likely to present with HIV indicator conditions
- Investigating all late HIV diagnoses as serious incidents and using the findings to inform commissioning of testing and health professional training

## Supporting adherence, and retaining and re-engaging people in care

An estimated 1800 people in London are living with diagnosed HIV which is detectable, increasing their risk of illness and death, and of transmitting the virus. Reasons for this can be not attending an HIV service after diagnosis, dropping out of care at a later date, not initiating HIV treatment or not adhering to treatment.

Stigma has a negative impact on attendance for care and disengagement is associated with a range of psychological, social and economic issues. People who are younger, who have been diagnosed for longer, who have children or have drug issues experience greater difficulties with attendance,<sup>92</sup> and those of Black African, Black Caribbean and mixed/other ethnicity are more likely than those of White ethnicity to disengage from care.<sup>93</sup> A London teaching hospital audit found the biggest psychosocial risk factor for disengagement from care was homelessness.<sup>94</sup>

Improving retention in care and adherence to medication brings benefits for individual and public health and avoids unnecessary costs to the NHS. The above-mentioned audit concluded that patients poorly engaged in HIV care are now the biggest driver of HIV-related hospital admissions and are more likely to have longer hospital stays than those admitted who are engaged in care.

People at risk of disengaging need to be identified and supported to remain in care. Systematic efforts to trace and re-engage people who have already been lost to care require the allocation of dedicated clinical time but can be successful and are cost-effective.<sup>95</sup>

Some people who appear to have dropped out of care may actually have started attending a clinic elsewhere, without informing their earlier provider, while others may have moved overseas. Finding out which patients are not actually lost to care is important to enable appropriate targeting of re-engagement efforts.

<sup>83</sup> Trends in HIV testing, new diagnoses and people receiving HIV-related care in the United Kingdom: data to the end of December 2019. Health Protection Report, Volume 14 Number 20, 3 November 2020

<sup>84</sup> Sullivan AK et al. HIV partner notification for adults: definitions, outcomes and standards. National AIDS Trust, British Association for Sexual Health and HIV, Society of Sexual Health Advisors and British HIV Association, 2015

<sup>85</sup> Bull L, Apea V, Wiggins H, et al. BASHH 2018 UK national audit of HIV partner notification. International Journal of STD & AIDS. 2021;32(9):872-877. doi:10.1177/0956462421990281

<sup>86</sup> Brown AE, Kirwan PD, Chau C, Khawam J, Gill ON, Delpech VC. Towards elimination of HIV transmission, AIDS and HIV-related deaths in the UK – 2017 report. November 2017. Public Health England, London.

<sup>87</sup> Harris J, Khatri R. Late diagnosis of HIV in the United Kingdom: An evidence review. December 2015. Centre for Public Health, Liverpool John Moores University.

<sup>88</sup> British HIV Association. National audit report, 2016. Review of late diagnoses: Audit of individuals diagnosed with advanced HIV.

<sup>89</sup> NICE. HIV testing: increasing uptake among people who may have undiagnosed HIV. 2016.

<sup>90</sup> An indicator condition is any medical condition associated with an undiagnosed HIV seroprevalence  $\geq 1$  per 1000. This may be due to either shared transmission routes with HIV (e.g. hepatitis B and C) or dysregulated immunity.

<sup>91</sup> Many more recommendations for reducing late HIV diagnosis are included in: Lowbury R, A roadmap for eliminating late diagnosis of HIV in England. Halve It position paper. Halve It, 2018

<sup>92</sup> REACH: a mixed-methods study to investigate the measurement, prediction and improvement of retention and engagement in outpatient HIV care (nhr.ac.uk)

<sup>93</sup> Dhairyawan R et al. Antiretroviral treatment uptake and outcomes in heterosexual people living with HIV in the United Kingdom according to ethnic group. British HIV Association conference, abstract O1, November 2020.

<sup>94</sup> Bilinska J., Coleman H., Craven M., Alexander H. Disengagement from HIV care is driving morbidity and expenditure: Interventions are needed to retain at-risk groups in care. Poster P135. 2020 British HIV Association, HIV Medicine, 21 (Suppl. 4), 16–57 <https://doi.org/10.1111/hiv.12860>

<sup>95</sup> Evidence on HIV Testing and Reengagement from the Elton John AIDS Foundation Zero HIV Social Impact Bond. Steve Hindle and Jennifer Warner, June 2021

Some measures showing promise include the following:

- Commissioning support for linkage to care as an explicit part of community-based testing provision
- Ensuring the provision of community-based support for people who have difficulties attending an HIV clinic, for example through community HIV nurse specialists and peer support
- Investing in adherence support services, using appropriately trained professionals (such as HIV clinical psychologists)
- Ensuring antiretroviral drug formulations best meet each patient's needs, to optimise adherence, including provision of long-term injectables when these become available
- Using the results of research with people living with HIV to address the reasons why some people disengage from care. Based on such research, the REACH study proposed interventions that support a holistic approach to care including peer support, addressing stigma by holding clinics in alternative locations and training staff to encourage attendance<sup>96</sup>
- Undertaking dedicated work to trace patients lost to care, re-engage and subsequently retain them in care, including the involvement of local GPs and HIV community nurses<sup>97</sup>

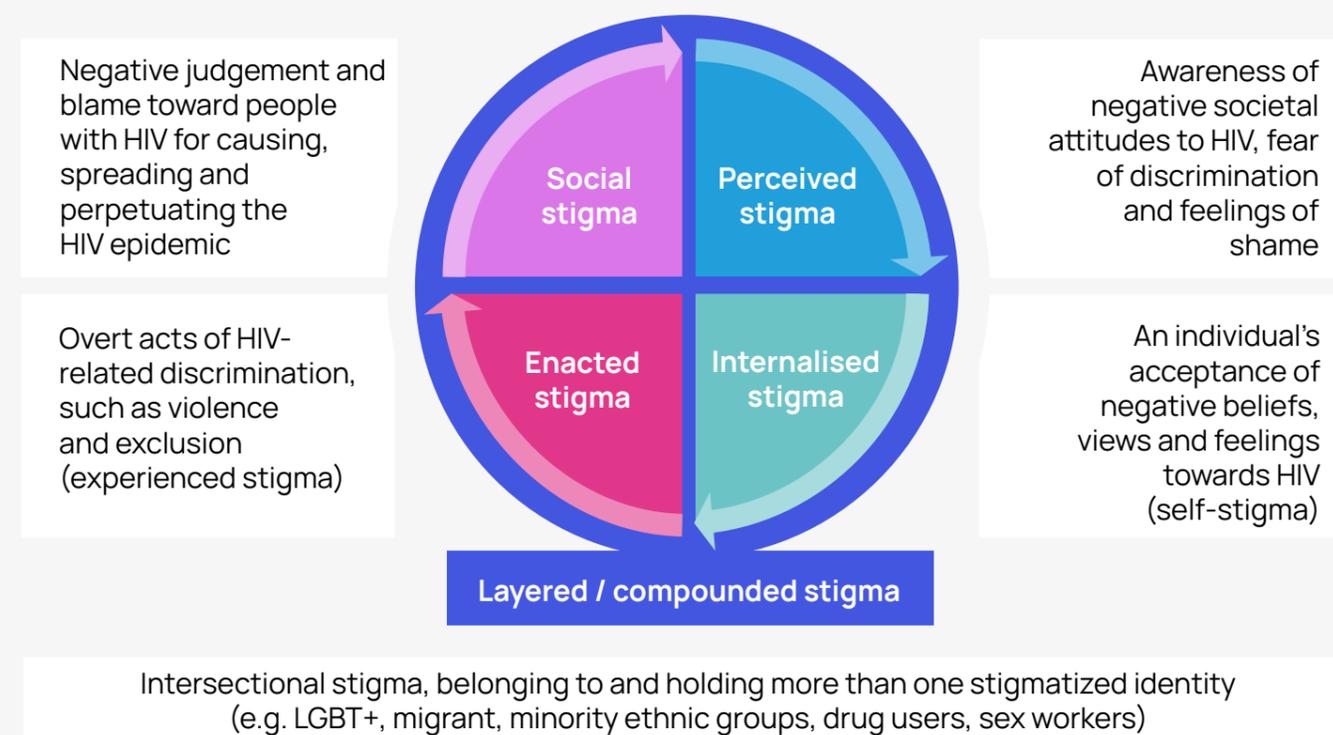
- Working with PHE to cross-reference patients apparently lost to care against the HIV & AIDS Reporting System (HARS) dataset,<sup>98</sup> to find out if in fact they are attending for care elsewhere<sup>99</sup>
- Identifying people who have disengaged from care through opt-out testing in general medical settings. Emergency department testing in London has identified similar numbers of people previously diagnosed with HIV but lost to care as those who have never previously been diagnosed.<sup>100</sup> These are often people with severely damaged immune systems who are likely to need extensive inpatient care if not re-engaged on HIV treatment.

## Stopping HIV-related stigma and discrimination

### HIV-related stigma

Probably the most important way in which HIV differs from other long-term conditions is the stigma that surrounds it. UNAIDS<sup>101</sup> defines HIV-related stigma as: "...a 'process of devaluation' of people either living with or associated with HIV and AIDS",<sup>102</sup> stating that it builds upon, and reinforces, existing prejudices and also plays into, and strengthens, existing social inequalities. Stigma may arise from misconceptions about HIV transmission and judgemental attitudes towards those social groups that are disproportionately affected by HIV.<sup>103</sup>

Figure 11: Types of HIV stigma



Source: Meaghan Kall, PHE

HIV-related stigma functions at different levels. At the individual level, a person with HIV may experience internalised stigma (or 'self-stigma'), whereby they accept negative beliefs about HIV and devalue themselves, and 'perceived stigma' whereby their awareness of negative societal attitudes to HIV leads them to feel shame or fear being discriminated against. At the societal level, 'social stigma' involves negative judgements and blame among the general population or in certain communities towards people with HIV, and 'enacted stigma' occurs when negative attitudes lead to overt acts of HIV-related discrimination. Stigma can cause people to be rejected by, or even face violence from, partners, family or community or lead to differential treatment in the workplace, in healthcare or other settings. Most people living with HIV in the UK hold at least one other stigmatised identity relating to sexuality, ethnicity or gender.

HIV-related stigma has a detrimental impact on a variety of health-related outcomes in people living with HIV. It is associated with higher rates of depression, lower levels of adherence to antiretroviral medications and lower access to and usage of health and social services. It has also been found to be associated with lower levels of social support, and research on how to moderate stigma at the individual level points to focusing on strategies that improve coping and strengthen social support networks among people living with HIV.<sup>104</sup> This is important, as internalised stigma and fear of discrimination are common among Londoners living with HIV, leading one in thirteen to report having avoided seeking healthcare when they needed it within the previous year.

<sup>96</sup> REACH: a mixed-methods study to investigate the measurement, prediction and improvement of retention and engagement in outpatient HIV care (nih.ac.uk)

<sup>97</sup> Evidence on HIV Testing and Reengagement from the Elton John AIDS Foundation Zero HIV Social Impact Bond.

Steve Hindle and Jennifer Warner, June 2021

<sup>98</sup> The HIV and AIDS Reporting System, a consultation based, disaggregate dataset which is submitted on a quarterly basis and reported by all outpatient HIV service providers.

<sup>99</sup> Ottaway Z et al. Going backwards on the treatment cascade? Identifying and reengaging people living with HIV (PLWH) who are lost to follow up (LTFU). Conference abstract PO25. BHIVA BASHH 2021

<sup>100</sup> Vaccari LC, Parry S, Kirkham D et al. Sustained 97% HIV testing rate in the Emergency Department: the new gold standard. Conference abstract O001. BHIVA BASHH 2021

<sup>101</sup> Joint United Nations Programme on HIV/AIDS

<sup>102</sup> Stigma and Discrimination. UNAIDS Fact sheet, 2003

<sup>103</sup> Rueda S, Mitra S, Chen S, et al. Examining the associations between HIV related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses. BMJ Open 2016;6:e011453. <http://dx.doi.org/10.1136/bmjopen-2016-011453>

<sup>104</sup> Rueda S, Mitra S, Chen S, et al. Examining the associations between HIV related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses. BMJ Open 2016;6:e011453 <http://dx.doi.org/10.1136/bmjopen-2016-011453>

Eliminating HIV-related stigma must be a priority. The U=U message<sup>105</sup> needs to be widely disseminated and understood among people living with HIV, the professionals who care for them and wider society, to counter inaccurate and outdated information which can still fuel fear and stigma. U=U is one of the key messages of the London HIV Prevention Programme, Do it London. The Fast-Track Cities Initiative (FTCI) has launched a programme of action in London to meet its target of zero HIV-related stigma.

### HIV-related stigma and discrimination in healthcare settings

For ICSs, healthcare settings should be the first focus for intervention to tackle stigma, as health professionals and employees should lead the way in their knowledge and attitudes to people living with HIV.

Londoners with HIV are less likely to report stigma or discrimination in healthcare settings than people with HIV in other parts of the country; nevertheless, over the course of a year, one in seven have worried about being treated differently from other patients because of their HIV status,<sup>106</sup> one in 16 have felt this has actually happened<sup>107</sup> and one in 25 say they feel their HIV status has actually led to a refusal or delay in the provision of care.<sup>108</sup>

The NHS as both an employer and provider of healthcare has a duty tackle this, in accordance with equalities legislation (HIV is classed as a disability under the Equality Act), and to ensure the human rights of its staff and patients are upheld. It also has a responsibility to ensure its staff are well-informed about HIV and do not inadvertently stigmatise or discriminate against people with HIV through fear or ignorance.

While much good practice exists, there are still surprisingly high levels of misinformation and fear of HIV among healthcare staff, and the concerns of people living with HIV about HIV stigma are not unfounded. One recent survey of staff at three London hospitals found that 80% were unaware of U=U. Two in five said they would feel at risk of acquiring HIV if treating an HIV patient, and a quarter would consider isolating HIV-positive patients in side-rooms due to their HIV status alone – a totally unnecessary and discriminatory practice. Three-quarters said they would not be confident discussing HIV with patients. Healthcare staff would be unlikely to express attitudes such as these if they had received up-to-date education about HIV. Most of the staff surveyed said they would like more information and training about HIV.<sup>109</sup>

As part of its work to combat stigma, the London FTCI has secured NHS England funding to support organisations to tackle stigma and become HIV-friendly, using an 'HIV Friendly charter' and kitemark. A pilot to test this in NHS trusts and primary care will be launched in 2021. If successful, this will be rolled out to all NHS organisations in London. The second phase of this work will be to adapt and test the same approach in other public-facing services.

Measure to deliver on NHS responsibilities could include:

- Ensuring HIV is included in relevant policies and mandatory staff training programmes on equality and diversity
- Providing basic, up-to-date information and education for staff on HIV, including U=U (see also Workforce in Section 5)
- Working with FTCI to develop and adopt its HIV-friendly charter and kitemark for NHS organisations

- Putting in place systems for reporting and monitoring instances of HIV-related discrimination and stigmatising behaviour and holding those responsible to account. This should include mechanisms to empower patients, their carers and advocates, as well as members of staff, to report such instances
- Working with partners providing social care and support services, to inform and educate their workforce about HIV and tackle HIV-related stigma in all settings
- Ensuring all people living with HIV have access to, and are encouraged to take up, peer support when newly diagnosed, and thereafter at times when they choose based on their self-assessed need
- Continue to provide public education to ensure the general population and communities most affected have up-to-date information about HIV

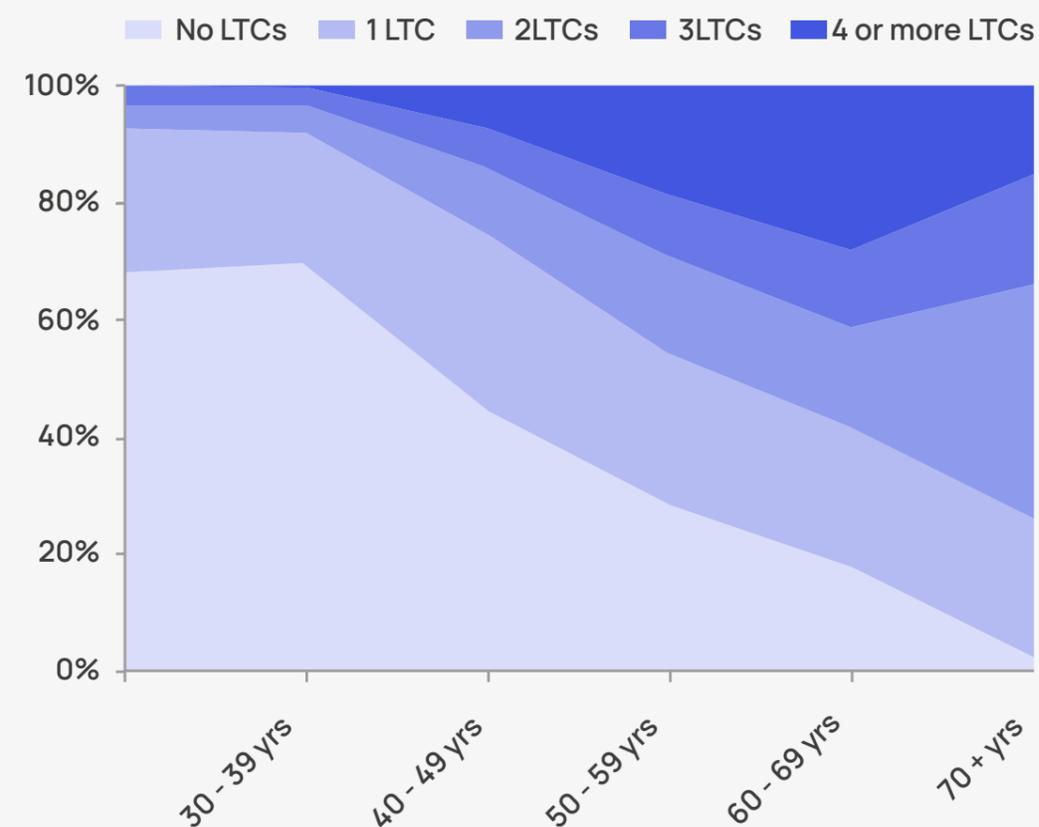
## Improving health, quality of life and wellbeing

### Ageing with HIV

#### Growing older

People seen for HIV care are growing older. As such, their needs are becoming more complex, often requiring the coordinated management of other long-term conditions and increased dependency on social care and support services. These needs will intensify and evolve over time, as their numbers continue to grow and more people experience age-related conditions, such as dementia. This is a key challenge for the planning of future integrated health and social care services for the population living with HIV in London.

Figure 12: Burden of self-reported diagnosed long-term conditions (LTCs) in people with HIV in London by age group



<sup>105</sup> Undetectable = untransmittable, i.e. that being on HIV treatment with an undetectable viral load means people cannot pass on HIV to their sexual partners.

<sup>106</sup> Public Health England. Positive Voices (2017 survey), London Regional Report

<sup>107</sup> Positive Voices: The National Survey of People Living with HIV. Findings from the 2017 survey

<sup>108</sup> Public Health England. Positive Voices (2017 survey), London Regional Report

<sup>109</sup> Shongwe M et al. Measuring healthcare HIV knowledge within our NHS Trust. British HIV Association conference, abstract O06, November 2020.

## Menopause

Increasing numbers of women living with HIV are reaching the age where they face the challenges of managing menopause in the context of their HIV. These include distinguishing menopausal from HIV-related symptoms, difficulties accessing appropriate HIV-sensitive menopause care, and the impact of menopausal symptoms on HIV management, including adherence to antiretroviral therapy.<sup>110</sup> Women living with HIV should be educated early about menopause and HIV, and then supported with specialist menopausal care when needed. Menopause increases the risk of certain co-morbidities to which women living with HIV are already predisposed, such as CVD and osteoporosis, and these should be proactively managed.

## Pregnancy

Thanks to the success of antiretroviral therapy in preventing vertical transmission, women with HIV can become pregnant in the expectation that their child will not have HIV. For many, pregnancy and early motherhood is a joyful time, but some may experience psychosocial challenges during and/or after pregnancy, including barriers to accessing HIV care such as HIV-related stigma, unemployment and lack of financial resources. Pregnancy and the postpartum period may precipitate new psychosocial issues, or exacerbate existing issues, among women living with HIV, and between a third and a half may experience post-natal depression.<sup>111</sup>

In this context, the continuation of specialist antenatal services with peer support is important to maintain the extremely low rates of vertical transmission through support for adherence and breastfeeding where appropriate.

Opt-out HIV testing is well embedded in antenatal care and coverage remains high, at over 99%. Maintaining this high rate is critical, to ensure that all pregnant women with HIV are diagnosed and can prevent vertical transmission.

## Young people

The HIV-positive children born to mothers with HIV are now growing up and most are transitioning from paediatric to adult HIV care. This is a particularly vulnerable period for young people with HIV, when risk behaviours increase and there is a greater likelihood of them not adhering to treatment or not attending the HIV clinic,<sup>112</sup> and vulnerability can continue into young adulthood. Young adults who were born with HIV also have a higher risk of mental ill-health, cancer and premature death than their HIV-negative peers.<sup>113 114 115</sup>

Healthcare transition should be a planned process addressing not only medical but also psychosocial and educational/vocational needs.<sup>116</sup> Young people with HIV have to achieve autonomy and learn to manage their own healthcare, while also grappling with HIV-specific issues such as how to safely negotiate disclosure of their HIV status and avoid HIV transmission when they become sexually active.

As such, transitional services require a planned and coordinated multidisciplinary approach sensitive to the multifaceted needs of this first generation to have lived all their lives with HIV. This can be provided by dedicated young people's clinics offering youth peer support and flexible access arrangements, serving young people up to the age of 30.

## Managing multiple health conditions

Most people living with HIV rate their own health as good or very good, only slightly below the general population; however, three in five report having been diagnosed with at least one other long-term condition. Although many are common in an ageing population, HIV can make their management more complex, highlighting the need for an integrated and holistic approach.

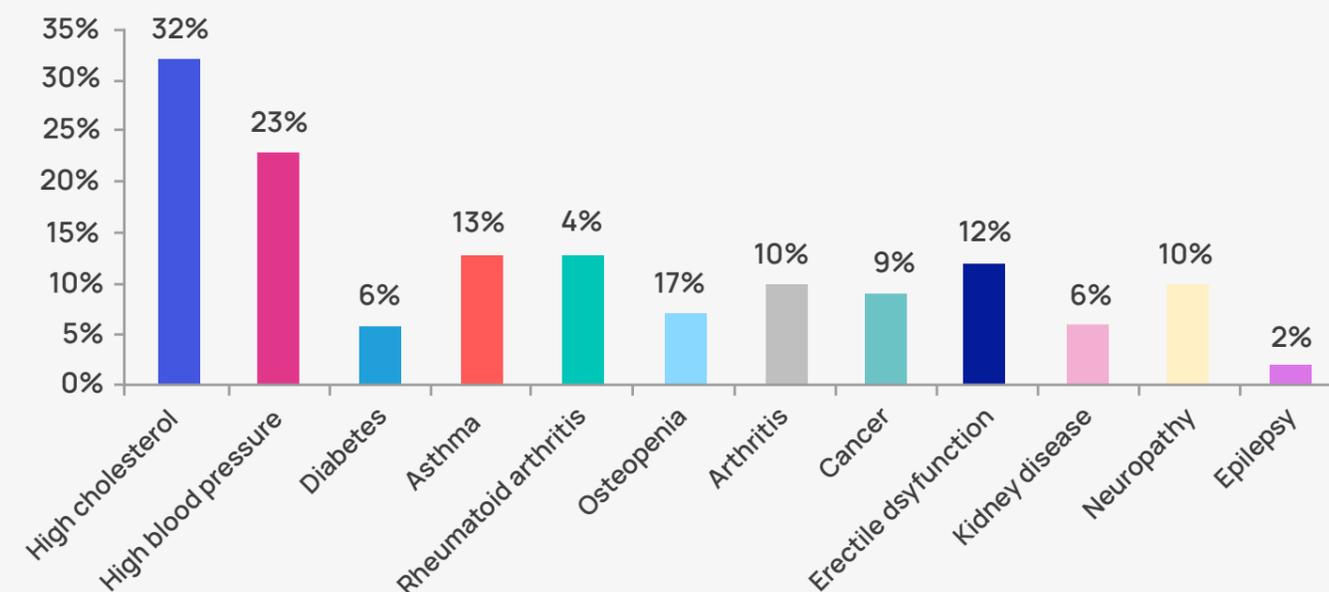
The risk of cardiovascular disease for people living with HIV is twice that of the general population.

High cholesterol and high blood pressure are each diagnosed in around a quarter of all people with HIV, rising to a half of those aged 65 and over, with rates varying according to gender and ethnicity.

Other long-term conditions common among people living with HIV include bone conditions such as osteoarthritis and a range of cancers (both related and unrelated to HIV infection). Other conditions are shown in Figure 13 on the next page.

The NHS Long-Term Condition Management model, such as that developed for diabetes, contains much of value that should be adopted to improve coordination of the care of people living with HIV, for example integration between primary and secondary care. It needs to be complemented by the provision of care informed by a specialist understanding of the particular challenges facing people living with HIV, particularly the impact of stigma and, for some, earlier experiences of trauma.

Figure 13: Prevalence of self-reported diagnosed long-term conditions in people with HIV in London, 2019



<sup>110</sup> Menopause in women living with HIV in England: findings from the PRIME Study

<sup>111</sup> BHIVA guidelines for the management of HIV in pregnancy and postpartum 2018 (2020 third interim update)

<sup>112</sup> Foster C, Ayers S, Fidler S. Antiretroviral adherence for adolescents growing up with HIV: understanding real life, drug delivery and forgiveness. *Ther Adv Infect Dis.* 2020 May 7;7:2049936120920177. <https://doi.org/10.1177/2049936120920177>. PMID: 32523693; PMCID: PMC7236389

<sup>113</sup> Mallik I, Pasvol T, Frize G, Ayres S, Barrera A, Fidler S, Foster C. Psychotic disorders in young adults with perinatally acquired HIV: a UK case series. *Psychol Med.* 2020 Nov 13:1-7. DOI: <https://doi.org/10.1017/S0033291720004134>

<sup>114</sup> Chhabra S, Fidler S, Bower M, Ayers S, Lyall H, Foster C. Malignancy and all-cause mortality: incidence in adolescents and young adults living with perinatally acquired HIV. *JVE* 2020; 6(1):30-33. [https://doi.org/10.1016/S2055-6640\(20\)30008-X](https://doi.org/10.1016/S2055-6640(20)30008-X)

<sup>115</sup> Foster C, Ayers S, McDonald S, Frize G, Chhabra S, Pasvol S, Fidler S. Clinical outcomes post transition to adult services in young adults with perinatally acquired HIV infection: mortality, retention in care and viral suppression. *AIDS* 2020 1;34(2):261-266.

<sup>116</sup> Foster C, Fidler S. Optimizing HIV transition services for young adults. *Curr Opin Infect Dis.* 2018 Feb;31(1):33-38. doi: 10.1097/QCO.0000000000000424. PMID: 29210712.

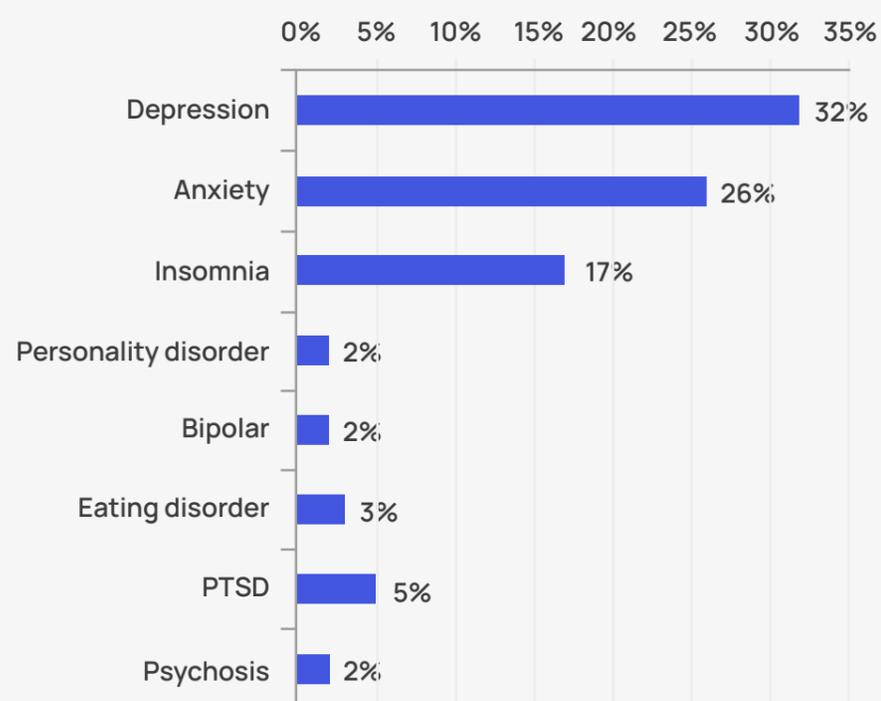
## Multiple medications

Over a third of all people with HIV, and more than half of those over 55, say they take at least one prescribed non-HIV medication for long-term conditions.<sup>118</sup> As almost everyone living with HIV is already on daily antiretroviral medication (usually itself a combination), when they need medication for other conditions they face the challenge of taking numerous drugs (polypharmacy) often prescribed by different clinicians. Some commonly prescribed medications can interact adversely with HIV antiretrovirals so good communication and coordination between clinicians is crucial, as is review by HIV specialist pharmacists.<sup>119</sup> Practical support is also needed for those patients who struggle to organise their multiple pill-taking.

## Quality of life, wellbeing and mental health

The success of HIV antiretroviral therapy means that HIV is often now described by doctors, clinically, as a 'manageable condition'. Yet for people living with HIV, antiretroviral success is not the only measure of their health and wellbeing and they do not always experience their HIV in all its dimensions as 'manageable'. They rate their health-related quality of life<sup>120</sup> slightly lower than do the general population, particularly in relation to anxiety and depression, of which over half report current symptoms,<sup>121</sup> compared to under a third of the general population.<sup>122</sup> Trans people, men and people of white ethnicity are most likely to report mental health symptoms.<sup>123</sup>

**Figure 14: Prevalence of diagnosed mental health conditions reported by people with HIV in London, 2019<sup>125</sup>**



<sup>118</sup> Public Health England. Positive Voices (2017 survey), unpublished London data

<sup>119</sup> A Katiyar, L Swaden, TJ Barber. HIV Specialist Pharmacists –An essential role in managing complexity in HIV related frailty and ageing services. Poster.

<sup>120</sup> Using the standard (non-HIV specific) EuroQol tool to measure health-related quality of life

<sup>121</sup> Public Health England. Positive Voices (2017 survey), London Regional Report

<sup>122</sup> Public Health England. Positive Voices (2017 survey), unpublished London data

<sup>123</sup> Public Health England. Positive Voices (2017 survey), unpublished London data

More than one in three people living with HIV report having at some point been diagnosed with a mental health condition, significantly more than in the general population, most commonly depression or anxiety. Other conditions (see Figure 14) are much rarer but still at least twice as common in people with HIV. The rate of suicide among men within a year of an HIV diagnosis is five times higher than among the general population.<sup>124</sup>

The stigma associated with HIV affects the wellbeing of people living with HIV and can make them reluctant to tell people that they have the virus. One in eight has told no-one outside a healthcare setting<sup>126</sup> and few tell people not close to them, such as co-workers or neighbours. The People Living with HIV Stigma Survey in 2015 found that more than three times as many people of Black or other minority ethnicity (one in six) had not told anyone about their HIV compared to other people living with HIV.<sup>127</sup> This secrecy can compound the social isolation and loneliness that people with HIV often experience.<sup>128</sup>

## Poverty

When surveyed in 2017 (notably before COVID-19) people with HIV had a rate of unemployment over three times as high as that of the general population, just under half reported not always having enough money for their basic needs, and one in four were receiving at least one form of means-tested welfare benefit. Women, Black Africans and people of other minority ethnicities were most likely to have low income, to experience financial difficulties and to be unemployed.<sup>129</sup>

Financial precarity and dependence on benefits increase with age among people living with HIV, and are particularly common among those diagnosed before effective HIV treatment became available.

Statistics available suggest that levels of poverty seen in people living with HIV aged 55 and over are double those seen in the general population.<sup>130</sup> A survey of over-50s living with HIV<sup>131</sup> found that almost nine in ten had not made financial plans to fund future care needs.

Poverty is generally an important predictor of poor health and people with HIV rate their health much worse when they do not have enough money to meet their basic needs. Lower income has been found to be associated with higher levels of self-stigma in older people living with HIV.<sup>132</sup> For people with HIV to achieve good health and wellbeing, advice and support for those who are struggling financially is a necessary complement to the provision of medical care.

## Lifestyle risks and drug use

Like the general population, people with HIV may need support to maintain healthy lifestyles or deal with problem risk behaviours. Overall, they are less likely to be overweight or obese than the general population, and they have fairly similar smoking rates, but there is very significant disparity by gender and ethnicity, with some groups at much higher risk. One in five (19%) people with HIV in London report recent binge drinking, higher than the national average rate among people with HIV or the general population (both 15%).<sup>133</sup>

<sup>124</sup> Croxford S et al. Suicide among people diagnosed with HIV in England and Wales compared to the general population. British HIV Association conference, abstract O16, Liverpool, April 2017

<sup>125</sup> Public Health England. Positive Voices (2017 survey), London Regional Report

<sup>126</sup> Public Health England. Positive Voices (2017 survey), London Regional Report

<sup>127</sup> The People Living With HIV Stigma Survey UK 2015 London

<sup>128</sup> Uncharted Territory. A report into the first generation growing older with HIV. Terrence Higgins Trust, 2017

<sup>129</sup> Public Health England. Positive Voices (2017 survey), unpublished London data

<sup>130</sup> Uncharted Territory. A report into the first generation growing older with HIV. Terrence Higgins Trust, 2017

<sup>131</sup> Uncharted Territory. A report into the first generation growing older with HIV. Terrence Higgins Trust, 2017

<sup>132</sup> Uncharted Territory. A report into the first generation growing older with HIV. Terrence Higgins Trust, 2017

<sup>133</sup> Public Health England. Positive Voices (2017 survey), unpublished London data

The majority of people with HIV do not use recreational drugs, but one in three in London report recent use, most commonly cannabis, nitrates and cocaine (versus one in four outside London).<sup>134</sup> Almost a fifth of sexually active gay and bisexual men with HIV report recent chemsex (the use of specific drugs to enhance sex) including, for over a quarter of them, injecting during sex.<sup>135</sup>

Thanks to needle exchange and opioid substitution therapy, the UK has avoided the high rates of HIV infection seen in many countries among people who inject drugs. Just over one in ten people living with HIV in London report ever having injected drugs, and the majority of these have not done so recently.<sup>136</sup> However, those who do may experience other social and health inequalities and are more likely to have difficulties adhering to HIV medication or attending HIV services.<sup>137</sup> One in five people with HIV who reports having ever injected drugs has also had hepatitis B and almost two in five have had hepatitis C.<sup>138</sup>

There need to be clear pathways and coordination of care between drug and alcohol, mental health, HIV and viral hepatitis services, to meet the needs of the particularly vulnerable population of people living with HIV who experience problem substance use and ensure they do not disengage from care. Ensuring, and offering reassurance about, the confidentiality maintained along these pathways is critical, to retain the trust of this population for whom stigma may be particularly acute.

### Sexual and reproductive health<sup>139</sup>

Almost two-thirds of people living with HIV

report being recently sexually active. People living with HIV, like the general population, have reproductive health needs and can experience sexual ill-health.

Gay and bisexual men with HIV are much more likely than heterosexual men or women to have had a recent sexually transmitted infection (STI). Among sexually active women with HIV of reproductive age, more than a quarter report using no form of contraception, although those who say they are trying to conceive, or are currently or have recently been pregnant account for fewer than one in ten. For women with HIV who use contraception, the most common method is condoms.

When surveyed in 2017, people with HIV-negative partners were more likely to use condoms and to be sexually abstinent than those with HIV-positive partners, suggesting that they were not all aware of, or did not believe, that being on HIV treatment with an undetectable viral load means they cannot pass on HIV (U=U).

### Experience of services

The *Positive Voices* survey<sup>140</sup> asked people living with HIV, recruited through HIV clinics, about their experience of different services. The findings, as follows, are from 2017, before the impact of COVID-19.

#### HIV clinical services

On average, people using London HIV specialist services give them a satisfaction rating of 9.2/10. This high level of satisfaction holds true regardless of age, ethnicity, gender or socio-economic status. People say they have enough

information, are supported to self-manage their HIV, are involved in decisions about their care, have enough time at their appointments and are listened to by the staff.<sup>141</sup>

#### General practice

Nearly all people with HIV are registered with a GP and 92% in London report having shared their HIV status with their GP. Over a 3-month period, 43% of people with HIV visited their GP at least once. People with HIV report lower satisfaction with GPs than with HIV services, although the average rating of 6.8/10 is similar to the rating given to GPs by the general population in the 2017 British Social Attitudes survey. Young people are less likely than older people to have told their GP that they have HIV and less likely to be satisfied with their GP.<sup>142</sup>

#### Other healthcare services

Over half of people living with HIV say they have attended a sexual health service or been to the dentist in the last three months. One in five has attended an emergency department and one in ten has been an inpatient.<sup>143</sup>

#### HIV support services

Over a one-year period, around one in six people with HIV use voluntary sector HIV support services, and the proportion is higher (one in five) among women, trans people and Black Africans. People who use these services value them highly, almost all of them saying that they have been important for their health and wellbeing, and nearly two-thirds saying they have been 'very' important. However, over a third have found these services becoming more difficult to access (a national finding but highest in London).<sup>144</sup>

### Need and unmet need for health and care services

The *Positive Voices* survey also undertook a comprehensive needs assessment among people living with HIV. In 2017, it asked people to identify specific services they had needed over the past year and whether they had received each of these services. (Where needs were categorised as unmet, this was because either people could not get a service they needed or they did not try to get it.)

The survey revealed significant levels of unmet need for a range of services. Needs for HIV-related services were largely met, but nearly half of other health-related service needs were not, while alarmingly almost two-thirds of social and welfare needs were unmet.

The greatest unmet need was for services dealing with loneliness and isolation (see Figure 15).

Given the scale of this unmet need and its likely impact on people's health and wellbeing, expanding the availability of support services and especially making them equally available to all must be a priority.

### Inequalities in service access/ provision

Londoners with HIV face inequalities in access to services and this can exacerbate existing health inequalities. Some groups who are particularly marginalised may have the most difficulty accessing services or feel that the services available do not meet their needs. These include migrant; trans people; people held in prisons and other closed settings; people who are homeless or in unstable housing; sex workers; and people who inject drugs.<sup>145</sup> People in these groups may have multiple health and care needs.

<sup>134</sup> Public Health England. *Positive Voices* (2017 survey), London Regional Report

<sup>135</sup> Public Health England. *Positive Voices* (2017 survey), unpublished London data

<sup>136</sup> Public Health England. *Positive Voices* (2017 survey), unpublished London data

<sup>137</sup> REACH: a mixed-methods study to investigate the measurement, prediction and improvement of retention and engagement in outpatient HIV care ([nhr.ac.uk](http://nhr.ac.uk))

<sup>138</sup> Public Health England. *Positive Voices* (2017 survey), unpublished London data

<sup>139</sup> Public Health England. *Positive Voices* (2017 survey), unpublished London data

<sup>140</sup> *Positive Voices: The National Survey of People Living with HIV. Findings from the 2017 survey*

<sup>141</sup> Public Health England. *Positive Voices* (2017 survey), London Regional Report

<sup>142</sup> Public Health England. *Positive Voices* (2017 survey), London Regional Report

<sup>143</sup> Public Health England. *Positive Voices* (2017 survey), unpublished London data

<sup>144</sup> Public Health England. *Positive Voices* (2017 survey), London Regional Report

<sup>145</sup> *Providing coordinated care for people living with HIV. National AIDS Trust, 2020*

Access to non-HIV specialist healthcare, social care and community-based support services is variable across the city, with entitlement often determined by postcode of residence. This can be a particular problem for those who are homeless with no postcode, especially the street homeless who often also have other health conditions. It may also impede access for those who, for reasons of stigma, are unwilling to share their HIV status with their GP who may be the gatekeeper for referral. Variation and inequality in access to services across London is particularly acute in relation to community-based HIV support services and community mental health services.

Drug and alcohol services, traditionally serving opiate users, sometimes do not provide support around the use of club drugs and chemsex.

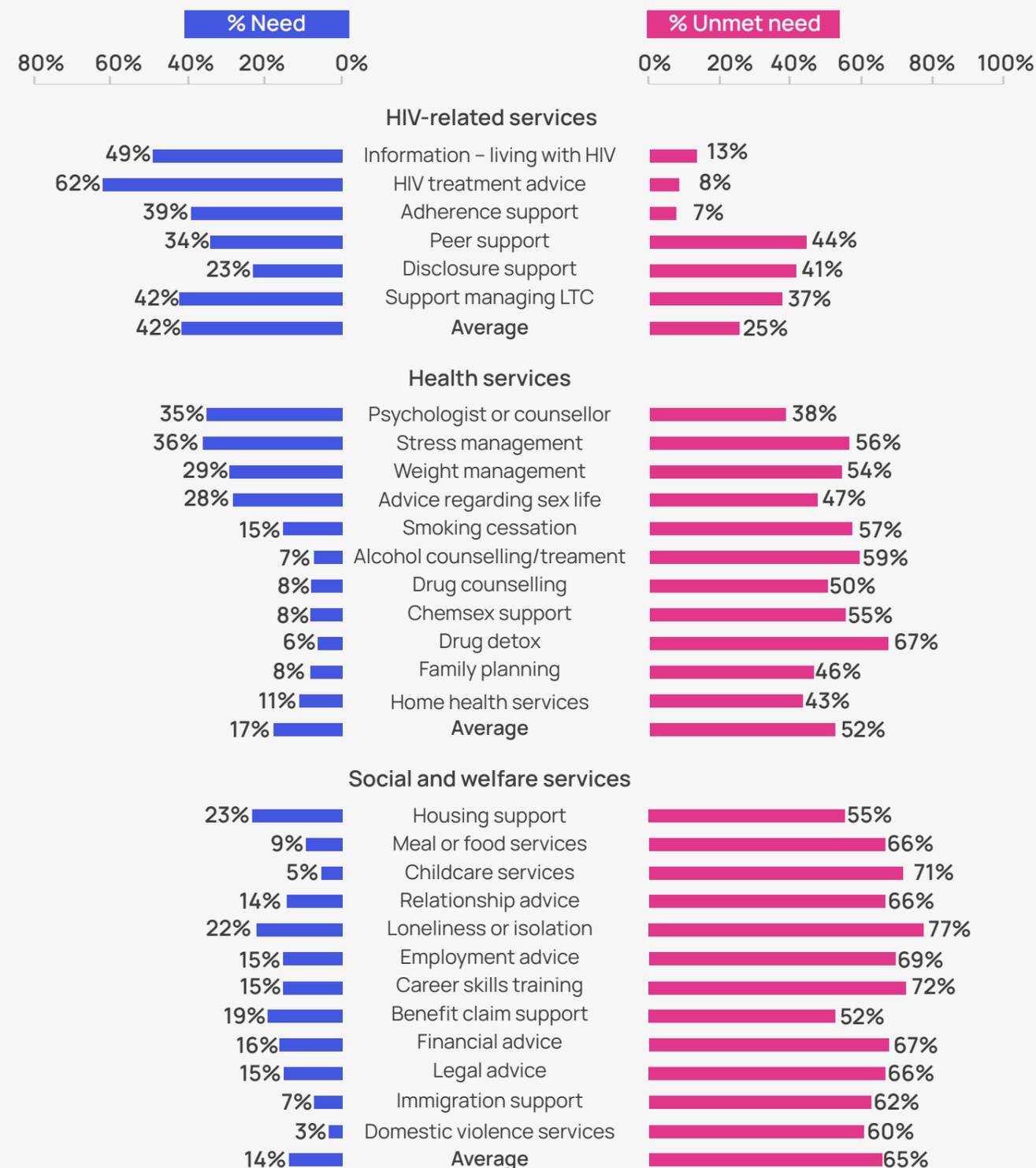
In addition, people with HIV may be reluctant to discuss drug and alcohol use with their GP because of stigmatising factors such as disclosure of sexuality, or the hidden nature of their drinking, depriving them of the opportunity for referral to such services.

Undocumented migrants may not only be at elevated risk of acquiring HIV, for example if subject to sexual exploitation or working as sex workers, but also are not entitled to healthcare beyond testing and treatment for certain communicable diseases which include HIV, rendering them particularly vulnerable to negative health outcomes.

They may be fearful of engaging with healthcare services because of concerns about their data being shared, especially with the Home Office,<sup>146</sup> and more likely to drop out of HIV care, not only endangering their own health but increasing the risk of transmitting HIV to other people.

With health information and healthcare provision relying increasingly on digital solutions, people who do not have access to the internet, equipment such as smart phones, or the skills to use new technology can become excluded from service provision.

Figure 15: Needs and unmet needs identified by people living with HIV<sup>147</sup>



Key: % need = proportion of people who said they had this need  
 % Unmet need = proportion of the people saying they had a need who said this need was unmet

<sup>146</sup> HIV and migration: Understanding the barriers faced by people born abroad living with HIV in the UK (nat.org.uk) National AIDS Trust, 2021

<sup>147</sup> Public Health England. Positive Voices (2017 survey), London Regional Report

## 4

# Overcoming the barriers to integration

## Fragmented commissioning

The division of responsibilities between NHS, local government and CCGs (see Section 2) has created a number of challenges, particularly where pathways cross commissioning demarcations. These are described in PHE's *Making it work: a guide to whole system commissioning for sexual health, reproductive health and HIV*<sup>148</sup> which articulates how commissioning bodies can work together to ensure seamless delivery of services.

Making it work highlights that there is no centrally determined allocation of commissioning responsibility for two key aspects of HIV service provision - community-based HIV support services and community-based HIV clinical nurse specialists.

As a result, responsibility for these is locally determined and may vary from place to place.

This is discussed in more detail below.

The HIV Commission concluded that the fragmentation of commissioning remains a significant obstacle to more effective joined-up HIV services, noting that cuts and changes to one body have knock-on impacts for others and highlighting the successive cuts to the ring-fenced public health grant between 2013/14 and 2017/18 which resulted in sizeable reductions in local authority funding.

The development of more integrated commissioning arrangements through ICSs presents an ideal opportunity to review population needs for these services, and to plan jointly for their future provision so as to reduce inequalities in access to care and ensure the best outcomes for people living with HIV across London.

Risk-share arrangements could be considered to reduce the impact of fragmented funding streams, potentially mitigating the risk of further cuts to prevention and support services.

## Commissioning of community-based HIV support services

Community-based HIV support services sit at the interface of healthcare, social care and public health and there is no single model for their funding. Their provision is recommended in the Standards of care for people living with HIV<sup>149</sup> and the HIV specialised commissioning service specification but, unlike HIV prevention and sexual health services, there is no legal mandate to commission them. Local authorities have often taken the lead in funding these services but austerity and cuts to public health budgets have left many struggling to fund non-mandated services. As a result, recent years have seen reductions in contracts for HIV support services and a significant decline in the number and size of organisations that provide them.

With commissioning determined by local needs and priorities, support services vary geographically. Although their role is synergistic with that of clinical services, which are commissioned on a wider geographical footprint, there is currently no London-wide core service specification or joint commissioning arrangement (except some local arrangements between small groups of commissioners). This means that an organisation serving an ICS area, for example, may offer services to some users which they cannot offer to others who have a different postcode. Services which benefit some of the most vulnerable people living with HIV, such as welfare rights, housing advice or provision of food, are among those more subject to this variation in provision.

The supplementary charitable funding that some organisations manage to obtain rarely provides a sustainable basis for longer-term service planning, and the same applies to short-term, sometimes one-year, NHS and public health contracts.

Bidding for and reporting on contracts with multiple individual commissioners, who may have different reporting requirements, particularly disadvantages small grassroots organisations with little infrastructure or contracting expertise.

## Commissioning of community-based HIV clinical nurse specialists

Community-based HIV clinical nurse specialists (CNS) provide multi-faceted support for self-management to patients who have complex needs, particularly adherence to medication, early detection and management of health crises and care coordination. The potential for escalating costs if the role were to be decommissioned is clear.<sup>150</sup> Commissioning arrangements for this role vary.

Funding for CNS posts currently comes from different sources, usually either NHS provider trusts or CCGs. Coverage is variable, some areas have none, and while some CNS work within specific CCG or local authority areas, others will work from an HIV clinic to serve their patients' needs wherever they live, across London and beyond. Consequently, access is unequal and some of the most vulnerable people with HIV are unable to benefit from the support of a CNS, increasing the risk of negative health outcomes, as well as the costs of avoidable crises.

<sup>148</sup> Making it work: a guide to whole system commissioning for sexual health, reproductive health and HIV. Public Health England, 2014

<sup>149</sup> British HIV Association Standards of care for people living with HIV 2018 (bhiva.org)

<sup>150</sup> Providing a model of HIV community nursing (nhivna.org)

Figure 16: The House of Care long-term condition management model



## Fragmented services

NHS England's specification for specialised HIV services, which the White Paper has committed to update to provide standards for care delivery at ICS level, acknowledges that specialised HIV services are part of a care pathway that includes other locally commissioned services. The service specification requires HIV services to collaborate with other health, social care and third sector organisations to meet the holistic needs of patients, to support the transition of young people with HIV from paediatric HIV to adult HIV services and to support care pathway simplification for vulnerable people with HIV, such as prisoners, migrants and people with learning difficulties.<sup>151</sup> In practice, such collaboration requires cross-system working that is not always supported by current structures and processes, and the experience of patients can be disjointed and confusing.

Many of the difficulties in coordinating care across the system, such as the lack of health and social care integration, are common to other areas of healthcare. Others are more specific to HIV.

People with HIV report their experience of poorly integrated care. Examples include multiple appointments with different providers; duplication of tests; inconsistent or contradictory advice; being bounced back and forth due to uncertainty of clinical responsibility; having to repeat complex histories; insufficient continuity of care; lack of communication between healthcare providers; inability to access necessary services following referral; and difficulty with administrative arrangements such as re-arranging appointments. Furthermore, people report inadequate support for managing their multiple long-term conditions and uncertainty about where to go for information and support.<sup>152</sup>

These experiences not only cause frustration but hinder patients' ability to self-manage and damage their confidence in their healthcare providers. Those whose needs are most complex or who are most disadvantaged struggle the most to navigate the system and coordinate their own care.

## Moving towards integration

### Management of HIV and other long-term conditions

It is striking how the experiences described above by people with HIV mirror the barriers to great care for people with long term conditions which NHS England lists and sums up as "failure to provide integrated care around the person", in its presentation of the rationale for a new long-term condition management model, the House of Care.<sup>153</sup>

Like other long-term conditions, HIV requires an integrated and holistic management model similar to that of other long-term conditions, based on person-centred, coordinated care, delivered by health and care professionals committed to partnership working, and informed people living with HIV. The model needs to accommodate the additional challenges that impact people with HIV, notably stigma, trauma they may have experienced as a result of their HIV or other life experiences (such as rejection by family, intimate partner violence, or migration), and the cultural sensitivities of different communities affected by HIV. In addition, HIV drugs, like all drugs, can be subject to drug-drug interactions but, unlike medications for other long-term conditions, suboptimal adherence or drug interactions can drive resistance, which can be challenging to manage. Teams with HIV expertise will remain crucial to optimal HIV management.

As HIV care moves to a more integrated model, clinical networks will need to work with their ICS partners to develop appropriate shared care models and collaborative care pathways in line with the needs of service users and local service capacity.

### Collaboration between primary and secondary care

GPs have responsibility for the management of other long-term conditions in people with HIV, such as CVD or diabetes, including onward referral to specialist care where necessary. Most have a relatively small number of patients with HIV, and many have had little previous involvement with its management. They may face concerns from their patients about whether they understand the condition or appreciate the impact of HIV-related stigma. To assist them in providing high quality, holistic care and to achieve the best outcomes for their patients with HIV, clarity about roles, better communication between primary and secondary care, and a more integrated approach are needed, with GPs, the HIV multidisciplinary team and people with HIV working in partnership. Over time there may be scope to move towards a model of shared HIV care for people who are stable on treatment.

Primary care networks employ a wide range of allied health care professionals to coordinate care, including care coordinators, social prescribers, mental health practitioners and clinical pharmacists. To facilitate integrated care, there could be potential to integrate HIV-related functions such as education and training or peer support with these network services.

Measures to improve coordination could include:

- Supporting and normalising routine two-way communication between HIV clinics, GPs and other care providers about investigations, medication and ongoing clinical care issues.
- Providing rapid, easy access for GPs to HIV-specialist medical and pharmacy advice.
- Developing closer working relationships between HIV services and primary care through the community HIV CNS who might, for example, attend the practice to see patients who have just had a positive HIV test.

<sup>151</sup> B06/S/a. 2013/14 NHS Standard Contract for Specialised Human Immunodeficiency Virus Services (Adults) Section B Part 1 - Service specifications

<sup>152</sup> Providing coordinated care for people living with HIV. National AIDS Trust, 2020

<sup>153</sup> <https://www.england.nhs.uk/ourwork/clinical-policy/ltc/house-of-care>

- Develop the role of practice-based pharmacists, working collaboratively with HIV specialist pharmacists and GPs, to undertake individual medication reviews in the primary care setting covering all prescriptions, including antiretrovirals, and offering support on safe prescribing to GPs.
- Creating a shared care plan for each person living with HIV, agreed by them with all their care providers, addressing their health, social care and support needs holistically.
- Piloting offsite HIV clinics provided by HIV specialist teams within primary care or community health centres.
- Working with primary care networks to develop the provision of high-level primary care services for people with HIV across a neighbourhood or place, linked into and supported by local HIV specialist services.
- Appointing local 'GP HIV champions' to take a lead role on increasing HIV testing and diagnosis in general practice and managing the primary care of people living with HIV.
- Creating a London-wide network of GP HIV champions/leads to share learning and support, with input from specialist HIV services and leadership from primary and secondary care.
- Exploring how ICSs could develop frameworks to offer people with HIV more flexible and equitable access to hospital-prescribed medications closer to home, building on experience during COVID-19 and examples of local practice.

## Interfaces and referrals between services

HIV specialists identify a number of barriers to integrated care in their interfaces with primary care, other specialist services, social care and community-based support services. The following measures could address these.

- Identify a named member of the multidisciplinary team responsible for ensuring that care coordination is in place for each person living with HIV, including regular review of the individual's need for support and, when required, active coordination on their behalf, such as liaison with different providers. This role may be most appropriately provided by a community HIV clinical nurse specialist, a social worker or a clinic-based peer navigator, according to the individual's preference and predominant needs, who can easily access key services on the patient's behalf, for example through direct phone numbers for GP practices or use of an NHS email address.
- Permit and facilitate consultant-to-consultant referrals when HIV specialists identify the need for their patients to see doctors in another medical specialty. Referral (when required) to the patient's GP in order for them to make a new specialist referral is inefficient for both GPs and specialists and leads to delays, frustration and potentially worse outcomes for people living with HIV.
- Develop better mechanisms for referral from HIV clinics to support services. This can currently be problematic, particularly for inpatients being discharged back to their local area from a central acute unit. Provision varies widely and liaising with out of area services – often required because HIV clinics are not always close to where patients live – is cumbersome. There is a risk that without effective management and coordination of this interface, people with HIV will lack the support they need and drop out of care.

## Sharing patient information

Because of HIV-related stigma, concern among people living with HIV about confidentiality is exceptionally high and HIV services have made it a priority to provide an environment where patients feel safe and confident of privacy. For some clinics this still means using separate clinic numbers and records, although others have managed to retain trust while moving to the use of shared hospital records. Beyond the HIV clinic, people can be reluctant for their HIV status to be shared with other healthcare and non-NHS providers, such as housing or social services, fearing judgemental attitudes, discriminatory behaviour and onward sharing of their personal information without consent, or even just inadvertent sharing through lack of awareness. Experiences of such behaviour are often reported by people living with HIV.<sup>154</sup>

Stigma and discrimination must clearly be challenged and eradicated including where they lead to unauthorised sharing of information (see Section 3). But the issue of confidentiality itself is more nuanced. While rules for confidentiality apply in all settings, there are differences in how it is defined within different institutions. So, although it is important to reassure people living with HIV that confidentiality is maintained when their information is shared for the purpose of providing their care, it is equally important to ensure that all services across the system offer a level of safety and security that will retain their confidence.

Recognising the importance of sharing patient information for safe, personalised and integrated care, it is suggested that putting HIV patient records on shared NHS systems needs to become the norm, in line with the introduction of the Local Health and Care Record currently under development.<sup>155</sup>

But although people with HIV, especially those recently diagnosed, have become increasingly willing for their HIV status to be shared with other healthcare professionals, for a minority of people living with HIV this would remain unacceptable. However, the option of creating a system that routinely allows an 'opt-out' is neither feasible nor clinically safe.<sup>156</sup> Moreover, separate records systems are not 'watertight', as a shared record of HIV status may be created by default when investigations are requested from another hospital department.<sup>157</sup> It is therefore crucial to work in partnership with people living with HIV and their trusted organisations to provide education for the HIV community about the benefits of sharing medical information, the safeguards for confidentiality and what this means for them.

In view of the strength of concern expressed by HIV patient representatives, there is no simple solution to this delicate issue. But ICSs are in a position to bring the NHS, local government, the voluntary sector and the community together to clarify the measures needed, explore the potential for common rules of confidentiality for all, and develop mechanisms to assure safe, confidential, stigma-free environments across the system.

<sup>154</sup> HIV Patient Information and NHS Confidentiality. National AIDS Trust, 2014

<sup>155</sup> NHS Long Term Plan

<sup>156</sup> General Medical Council. Confidentiality: good practice in handling patient information. 2017.

<sup>157</sup> HIV Patient Information and NHS Confidentiality. National AIDS Trust, 2014

A number of measures have been suggested to work towards normalising the sharing of HIV patient information in line with how medical records are managed for other conditions.

- In partnership with people living with HIV and organisations trusted by the community, develop and publicise guidance on sharing patient information
- Provide education for the HIV community, including through peer ambassadors, to explain the benefits of sharing medical information between their providers, the existing safeguards for confidentiality and what this means for people living with HIV
- Make it a routine part of HIV clinic practice to inform GPs of their patients' HIV diagnosis and ongoing care, on an 'opt-out' rather than 'opt-in' basis, ensuring the benefits are explained to patients
- Work to align electronic patient records over the medium term to make systems utilised within ICSs compatible, to help track patients if they move between clinics
- Ensure that clinical and non-clinical staff in primary care and other medical settings are aware of the particular sensitivity and concerns among people living with HIV about sharing their patient information, and that they work in a way that assures people living with HIV that their data is protected by the highest standards of confidentiality
- Consider how the findings and/or methodology of The OneLondon Citizens' Summit, a large scale and in-depth public deliberation on uses of health and care data commissioned by London's five Health and Care Partnerships, might be built on to reach a consensus on the sharing of HIV patient information.

## Managing crises

People living with HIV need to be proactively supported to prevent health crises. When crises arise, they can highlight the inadequacy of the currently fragmented and siloed system. To ensure smooth management of crises, a coordinated approach is needed:

- Agree clear and distinct pathways for managing health, mental health and social care crises in people living with HIV, as all can be critical but may require different approaches
- Provide support to prevent or deal with housing problems, immigration issues, welfare needs and food poverty which can lead to health crises
- Agree shared 'trigger' indicators and consider the adaptation of Patient Activation Measures (PAMs)<sup>158</sup> for people living with HIV, to alert clinicians and service users to early signs before a crisis stage is reached – these could include patterns of adherence to medication, serum drug levels, and mental health status.
- Support and empower people living with HIV to identify and monitor their own signs of an impending crisis and provide easy access to emergency help. However, the ability of each individual to self-monitor needs to be considered and more active ongoing monitoring and support provided for those who are less empowered.
- Ensure sufficient provision and equitable access to community-based HIV CNSs who can keep a 'watching brief' on people with complex care needs, for example by spotting signs in their home of non-adherence, mental health issues or risky use of drugs or alcohol, as well as providing rescue work and management for those who may not meet criteria for other services but who may need rapid referral at some point.<sup>159</sup>

## Psychological support and mental healthcare

People living with HIV are more likely than the general population to have mental health problems and, conversely, people with existing mental health problems are more likely to acquire HIV.<sup>160</sup> Poor mental health can lead to problems with adherence to HIV medication and worse health outcomes, while mental health support is proven to increase adherence.<sup>161</sup> The *Standards of care for people living with HIV*,<sup>162</sup> state that people with HIV should receive care and support that assesses, manages and promotes their emotional, mental and cognitive well-being and health, and is sensitive to the unique aspects of living with HIV.

Key to this is a stepped-care model in which the psychological support needs of people living with HIV should be considered and managed by all health and social care providers they encounter, with self-help and peer support throughout.

NHS England's specification for specialist HIV services requires them to provide access to a health advisor/counsellor and other forms of emotional and psychological support (including peer support) as required to address difficulties associated HIV, and to ensure that pathways are in place for psychological support to meet non-HIV-related needs.

Figure 17: Stepped care model for psychological support<sup>163</sup>



<sup>160</sup> The missing link: HIV and mental health. All Party Parliamentary Group on HIV and AIDS. 2017.

<sup>161</sup> The missing link: HIV and mental health. All Party Parliamentary Group on HIV and AIDS. 2017.

<sup>162</sup> BHIVA British HIV Association Standards of care for people living with HIV 2018 (bhiva.org)

<sup>163</sup> Standards for psychological support for adults living with HIV (bhiva.org)

<sup>158</sup> Kearns R, Harris Roxas B, McDonald J, et al. Implementing the Patient Activation Measure (PAM) in clinical settings for patients with chronic conditions: a scoping review. *Integrated Healthcare Journal* 2020;2:e000032. doi:10.1136/ihj-2019-000032

<sup>159</sup> Providing a model of HIV community nursing (nhivna.org)

In practice, the provision of psychological support at all levels is variable<sup>164</sup> and subject to stresses in mental health provision across the health and social care system as a whole. Some, usually larger, HIV clinics include HIV-specialist psychologists as part of their multi-disciplinary team, while others refer to generic mental health professionals. Community mental health services can be difficult for people with HIV to access, especially if they need urgent help when in crisis, or their HIV clinic is located in a different part of the city from their area of residence, or they do not wish to share their HIV status with their GP to get a referral.

HIV support organisations report that people with HIV who need clinical psychology or psychiatric services sometimes end up attending their services inappropriately for counselling because the waiting list for mental health services is too long.

People with HIV report that non-HIV specialist mental health services and GPs are sometimes reluctant to offer them mental health care in the belief that their problems need HIV-specialist support, and as a result they find themselves 'ping-ponged' between services without receiving the care they need. This highlights the need for greater clarity in commissioning expectations of mental health services and also for greater education of mental health professionals and GPs about HIV.

Many people living with HIV need psychological support at a level in the middle range of the stepped care model. Contracts for the provision of Improving Access to Psychological Therapies (IAPT) services usually allow six sessions with a possible extension to a maximum of 12, which providers say is not suitable for many people who present with HIV-related needs.

Post-traumatic stress disorder (PTSD) is more common in people living with HIV, especially women who have come from areas of conflict and people who have experienced intimate partner violence, and it is important to recognise that some models of psychological support may not work with some communities and a more culturally adapted approach to intervention may be required.

Providers and people with HIV also highlight the high level of unmet need for support 'below the level of IAPT' but more complex than informal or peer support. They also feel that a greater focus on wellbeing and quality of life is needed for all people living with HIV informed by an understanding of the impact of internalised HIV stigma, with peer support provided as an integral part of the care pathway and improved recognition of poor mental health when it occurs.

Better detection of cognitive changes is needed. These can occur as a result of HIV but may not be detected or be severe enough to be classified as needing a psychology intervention but can have an impact on people's ability to self-manage their care and adhere to medication.

Psychological support and mental health care are a crucial part of integrated care for people living with HIV and can only benefit from the improvements that a more integrated approach to commissioning by ICSs can provide. While achieving the goal of parity of esteem for mental health with physical health remains a challenge across the system, some measures are suggested for improvements in relation to the psychological support of people living with HIV:

- Where possible, ensure the involvement of a psychologist with HIV expertise in HIV service multidisciplinary teams or access to such expertise through a clinical network, as well as links to psychiatry services with expertise in HIV.

<sup>164</sup> The missing link: HIV and mental health. All Party Parliamentary Group on HIV and AIDS. 2017.

- Provide sufficiently in-depth training on the specific needs of people with HIV for mental health professionals who will be receiving referrals from HIV services.
- Enable referral for psychological support and community mental health services outside local boundaries.
- Clarify who is responsible for commissioning mental health support directly related to HIV and commission in partnership across the system at London-wide or ICS level.
- Assess whether wellbeing resources developed for NHS staff through COVID could be repurposed to support others.

### Peer support

Peer support leads to significant improvements for people with long-term physical and mental health conditions across a range of health and wellbeing outcomes as well as reducing pressure on health and social care services and therefore costs.<sup>165</sup> It is recognised in the *NHS Long-Term Plan* as a key pillar of supported self-management within models of personalised care.<sup>166</sup> In line with the *Standards of Care for people living with HIV*,<sup>167</sup> NHS England's service specification for commissioning specialised HIV services includes a requirement for patients to have access to peer support<sup>168</sup> and there are dedicated standards for its provision.<sup>169</sup> In practice, however, its provision is variable.

Peer support complements (but does not replace) other forms of psychological support for people living with HIV. In London is provided by a range of organisations and groups, more or less informally, paid or unpaid.

Sometimes it is provided by peers with HIV from the same community, such as country of origin or faith group, while other times people prefer to seek support outside their community.

<sup>165</sup> Realising the Value | Nesta

<sup>166</sup> NHS England » Supported self-management

<sup>167</sup> British HIV Association Standards of care for people living with HIV 2018 (bhiva.org)

<sup>168</sup> B06/S/a. 2013/14 NHS Standard Contract for Specialised Human Immunodeficiency Virus Services (Adults) Section B Part 1 - Service specifications

<sup>169</sup> Positively UK in partnership with BHIVA, NHIVNA, CHIVA, THT and UK-CAB. National Standards for Peer Support in HIV (hivpeersupport.com)

<sup>170</sup> Positively UK's 'Peer Navigators' Project for people living with HIV | National Voices

It can be offered in person, one-to-one or in groups, by phone or online. Peer support may involve accompanying people with HIV to clinic appointments or acting as their advocate with providers.

People living with HIV report particular difficulties with navigation through the system when they need services other than their HIV care. Some feel empowered to manage and coordinate their own care while others need support with identifying how to get help for their needs, managing the practicalities of care coordination, and integrating a range of clinical advice and treatment into their daily lives. The people who have the most need of such support tend to be those with complex care needs and vulnerabilities, such as problems with mental health, drugs or alcohol, homelessness, poverty, migration status or language difficulties.

People with HIV stress the value of peer support in helping them to self-manage, deal with HIV-related stigma and improve their wellbeing. The role of peer support can also be extended to provide peer navigation,<sup>170</sup> offering practical help with coordinating individuals' care across the system. Despite its potential to be highly cost-effective, this role currently only exists in a small minority of London clinics.

There is no universal model of peer support, whether integrated within clinical services or in community settings. People living with HIV stress that the recipient of peer support should have choice as to the type of peer support that is right for them. It may be worth considering central coordination of peer support across London or each ICS to reduce inequalities in access and share the learning from good practice.

The following approaches have been found to make a difference and could be implemented across London.

- Working in partnership with voluntary sector providers to embed peer support in the clinic as an integrated part of the care pathway. All clinicians in the service need to be aware of this and routinely refer, and peer support sessions should integrate with clinical appointment times.
- Including peer support workers as part of the clinic's multidisciplinary team, able to bring to case meetings their knowledge of concerns that people with HIV may not share with clinical staff.
- Employing peer navigators within the NHS or giving them NHS honorary contracts, thus enhancing their power to act on patients' behalf. Peer support workers are usually volunteers or voluntary sector organisation staff and, while in some contexts this status can be useful in providing a safe space which is clearly separate from the clinical sphere, it may limit the practical help they can offer, as their role may not be recognised across the system.
- Providing peer support services in the community as well as in clinical settings.
- Ensuring peer support workers receive appropriate training and support for their role, for example through a peer mentoring programme.
- Ensuring people have access to peer support which is appropriate for their needs and acceptable to them, including recognising the importance for some of factors such as ethnic and national origin, gender, sexuality, cultural traditions, faith and spirituality.
- Identifying peer support as 'mission critical' rather than an optional extra and funding it accordingly.

## Surveillance and data monitoring

A number of national databases provide high quality information to describe and understand the HIV epidemic in the UK and inform commissioning and service provision. Key data systems include the HIV & AIDS Reporting System (HARS), the HIV & AIDS New Diagnoses Database (HANDD), the Positive Voices Survey and the Genito-Urinary Medicine Clinic Activity Dataset.

Monitoring to assess performance against the key stages on the HIV continuum of care (see Figure 5) is key in London's drive to reach its strategic aims of zero new infections and zero HIV-related deaths. Key indicators are produced at clinic, trust and London-wide levels using the HARS submission and form part of the NHS England HIV Clinical Dashboard.

Data to assess progress against London's other two HIV-specific strategic aims - zero HIV-related stigma and discrimination, and improvement in the health, quality of life and wellbeing of people living with HIV - are less easily available and work is needed to progress these.

Beneficial developments would include:

- High quality data with completeness of new diagnoses fields including risk, country of birth and ethnicity, which are key for tracking the elimination of HIV transmission
- Routine use of HARS quarterly returns to inform service delivery and highlight inequalities in care attendance, treatment uptake and retention in care
- Review of current HIV Clinical Dashboard indicators to ensure they are still fit for purpose

- Development of a London-based quality of life and wellbeing dashboard, including mental health and unmet needs. This could be based on future *Positive Voices Survey* findings, encouraging all London sites to take part in the survey.
- Use of clinic-specific *Positive Voices Survey* results by clinics to engage with their patients, ensure services are appropriate and identify changes required to meet their needs.
- Use of local data on HIV testing uptake in different settings to better inform testing strategies.
- Development and use of Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) at every clinic attendance, including agreement on shared measures for use across London.

Figure 18: NHS England HIV Clinical Dashboard, London, data for 2019

HIV Clinical DASHBOARD			
LONDON, Data for 2019			
Description	%	Numerator	Denominator
HIV01: Late HIV diagnosis	37%	361	970
HIV01a: Very late HIV diagnosis	17%	167	970
HIV02b: Newly diagnosed adults seen for care within 1 month	94%	630	671
HIV03a: Virological success in people established on ART <sup>171</sup>	97%	29,298	30,115
HIV03b: Virological success in people newly starting ART	97%	1,092	1,131
HIV04a: ART coverage (all adults)	99%	40,949	41,216
HIV04b: ART coverage (adults with the last CD4 count < 350)	98%	2,906	2,951
HIV09a: Retention in care (newly diagnosed)	89%	1,195	1,343
HIV09b: Retention in care (all adults)	95%	38,436	40,643
HIV10: Time to treatment (initiating treatment within 91 days)	77%	943	1,229

<sup>171</sup> ART = antiretroviral therapy

## 5

# Recovery and modernisation

## Impact of COVID-19

### Health and wellbeing of people living with HIV

There is recent evidence that people with HIV have are more likely to die from COVID-19 than people who are HIV-negative<sup>172 173</sup> and some evidence that the risk is greater for younger people and those of Black or Asian ethnicity.<sup>174</sup> It is too soon to draw broader conclusions about the impact of the disease on the health and wellbeing of people living with HIV, but, as part of recovery planning, it will be important to ensure that services address the needs of people with, or at risk of, HIV for emotional and psychological support as well as physical healthcare.

<sup>172</sup> Croxford S et al. COVID-19 mortality among people with HIV compared to the general population during the first wave of the epidemic in England. Conference abstract O009. BHIVA BASHH 2021.

<sup>173</sup> K et al. HIV infection and COVID-19 death: a population-based cohort analysis of UK primary care data and linked national death registrations within the OpenSAFELY platform. *Lancet HIV*. 2021 Jan;8(1):e24-e32. [https://doi.org/10.1016/S2352-3018\(20\)30305-2](https://doi.org/10.1016/S2352-3018(20)30305-2)

<sup>174</sup> Croxford S et al. COVID-19 mortality among people with HIV compared to the general population during the first wave of the epidemic in England. Conference abstract O009. BHIVA BASHH 2021

<sup>175</sup> Hyndman I, Nugent D, Whitlock GG, et al COVID-19 restrictions and changing sexual behaviours in HIV-negative MSM at high risk of HIV infection in London, UK Sexually Transmitted Infections Published Online First: 18 January 2021. <http://dx.doi.org/10.1136/sextrans-2020-054768>

<sup>176</sup> Sex During COVID-19 Survey – GMI Partnership

<sup>177</sup> Sultan B et al. High prevalence of HIV among people who experience homelessness in London: results of an innovative peer-centred outreach bloodborne virus testing service initiated, at the start of the COVID-19 pandemic. Conference abstract O010. BHIVA BASHH 2021

### HIV risk, testing and outreach

COVID-19 restrictions had an impact on the sexual behaviour and mental well-being of people at risk of HIV, but high rates of sexual activity and STI diagnoses were reported during lockdown, as well as some difficulty accessing sexual health services.<sup>175 176</sup>

Not surprisingly, COVID-19 driven restrictions led to a decline in in-person HIV testing and increased use of online testing services. 'On the ground' outreach services were mostly discontinued, although there were innovative blood-borne virus (including HIV) testing initiatives with the homeless.<sup>177</sup>

COVID-19 actually improved HIV testing coverage in hospital settings as many trusts incorporated it into routine 'COVID panels'. The opportunity to offer HIV testing alongside community COVID testing is one that ICSs could explore, as is the option of incorporating HIV testing into other health screening initiatives such as a primary care wellness checks.

### HIV service provision

Nationally, fewer consultations took place in January-September 2020 compared to the same period in 2019, and lockdown-related fluctuations were particularly marked in London.<sup>178</sup> It may be too early to say whether the pandemic has resulted in significant numbers of people with HIV becoming lost to care, but even small numbers would lead to negative individual and public health outcomes as well as cost pressures from subsequent hospital admissions.

HIV services saw a dramatic shift from face-to-face to virtual (mostly phone) consultations in 2020. There was significant variation between clinics in the scale of this change, with decisions about shifting based on safety considerations and individual needs. An online patient survey at one London HIV clinic found the switch to phone consultations had been largely acceptable although not as a total replacement for face-to-face interaction.<sup>179</sup> Both clinicians and service users feel strongly that some face-to-face interaction is essential. In future, hybrid models (such as alternating appointments in person and by telephone) are likely to be useful.

<sup>178</sup> Shah A et al. Impact of the COVID-19 pandemic measures on HIV consultations in England. Conference abstract O011. BHIVA BASHH 2021

<sup>179</sup> Flanagan S et al. Planning a Post-Pandemic HIV Service – the Patients' Perspective. Conference abstract O012. BHIVA BASHH 2021

<sup>180</sup> Sultan B et al. High prevalence of HIV among people who experience homelessness in London: results of an innovative peer-centred outreach bloodborne virus testing service initiated, at the start of the COVID-19 pandemic. Presentation at BHIVA BASHH 2021 (video) 5th Joint Conference of BHIVA with BASHH (2021) - Oral Research Presentations Session 2 on Vimeo

<sup>181</sup> UK-CAB Survey, Alex Sparrowhawk, presented at HIV Glasgow 2020 <https://www.sciencedirect.com/science/article/pii/S2055664021000042?via%3Dihub>

Many people with HIV switched to home delivery of medication during the pandemic and were pleased with the service. Voluntary sector organisations managed to deliver peer support, group work and advice services online, although the willingness of service users to engage in this way has been variable, with some expressing concerns about confidentiality and some dropping out of using the services altogether.

Reduced in-person attendance at HIV specialist clinics as well as the need to obtain COVID-19 vaccination may have prompted more people with HIV than usual to consult their GP and to share their HIV status with them for the first time.

### Inequalities

COVID-19 has thrown into stark relief and exacerbated inequalities in the existing system for people living with HIV. Marginalised populations have been particularly vulnerable. Research among homeless people in London found that one in five of those with HIV and on antiretroviral therapy had experienced treatment interruption due to their inability to access medications during the pandemic.<sup>180</sup>

Digital poverty prevented some people from benefiting from virtual services, whether they lacked the necessary hardware (5% of UK households have no mobile phone), data or phone credits, the skills to use IT or the privacy at home for confidential phone calls.<sup>181</sup> In order to optimise outcomes, access to in-person services of an equal standard, as well as the option of support for increasing digital access and literacy, always need to be available to people unable or unwilling to use virtual services and those with complex needs.

## Service providers

While HIV clinical services experienced staff redeployment and exhaustion during the pandemic, HIV voluntary sector organisations faced major financial pressures and have described their infrastructure as decimated by COVID-19, with staffing levels reduced despite the rise in need for their services. Their scope to address this was limited as they were unable to fund raise during the pandemic. In addition, in some cases they were contracted to provide services that were not possible to provide during the pandemic, resulting in the need to renegotiate targets or refocus resources. More positively, alongside the shift to virtual care, COVID-19 triggered a move to virtual multidisciplinary meetings, training events and conferences. This has increased the capacity to deliver appropriate advice and training with less service disruption and has great potential to support HIV management in primary care.

## NHS communications

Flaws in NHS communications were exposed during the pandemic, for example when some people with HIV were not informed by their GP that they were on or off the shielding list or were given conflicting information about entitlement to early COVID-19 vaccination. BHIVA's interventions with the Department of Health and Social Care to clarify these issues and their guidance to clinicians on the implications of COVID-19 for the HIV sector were valued. Community forums such as the UK Community Advisory Board (UK-CAB) also played a useful role in disseminating this information, and correcting misinformation, to people living with HIV.

## Applying the learning from COVID-19 to future HIV service planning

As some of the specific circumstances of the pandemic period will not continue (for example telephone appointments worked well because most people were at home and able to take calls throughout the day), planning to integrate any of the new ways of working into future routine HIV service provision will need to pay close attention to such factors before implementing changes that may not work so well in other circumstances.

## Digital service provision

It will be important to apply NHS digital systems and software, such as those developed to support e-consultations or remote monitoring, to HIV services as they become relevant and as far as HIV patient record systems allow, ensure data protection safeguards adequately address the particularly acute confidentiality concerns of people living with HIV.

There are several more specific options which could facilitate the introduction of digital services and use of new technology to improve the care of people living with HIV.

- Expand the use of an 'app' for patients that acts as a single source of HIV information to support self-management. An example of this is 'Patients Know Best', currently used in some HIV clinics, which allows people to access, share and communicate their complete medical record wherever they are, and to communicate with their clinicians in advance of consultations, enhancing consultation value.
- Create a digital platform for a centralised list of HIV peer support and other support services around London. Such a resource could raise awareness amongst clinicians and, as suggested by the community, permit self-referral.

- Provide training and support for people with HIV who need it, for example those facing age, economic or migration-related barriers, to enable them to use and benefit from digital information and service provision.
- Develop the use of virtual dual consultations that have emerged during COVID, whereby one clinician (such as a GP) meets a patient face-to-face while a second (such as a consultant) joins the consultation by video. This system can be a useful part of multidisciplinary long-term condition management.
- Draw learning from the current pilot of Consultant Connect (which allows GPs to contact an 'on call' consultant during a consultation for expert advice) and, if successful, roll out its ongoing use across London.

## Workforce

### The HIV clinical workforce

There is currently no central oversight of the HIV multidisciplinary clinical workforce. Access to HIV clinical nurse specialists and HIV-specialist allied healthcare professionals, such as psychologists and dieticians, is highly variable. HIV-specialist pharmacists play a key role in the multidisciplinary team yet, despite the mainstream policy drive for pharmacists to spend more time on clinical services<sup>182</sup>, resourcing pressures and the conflicting priorities of inpatient care can create barriers to the full utilisation of their clinical skills in HIV outpatient services; HIV pharmacist turnover is high.

Most HIV medical care in London is provided by specialists in genitourinary medicine (GUM), a specialty that has faced trainee recruitment challenges in recent years.

Trainees entering GUM from 2021 will complete their training dual-accredited in general medicine which will result in a new generation of HIV specialist clinicians who also have the training to help manage other acute and chronic medical issues. A core of specialist clinical expertise will still be needed to manage highly complex HIV care including opportunistic condition management; antenatal HIV care; care of children and adolescents living with HIV; complex HIV resistance and complex drug-drug interaction management.

The following measures could help in planning and developing the HIV clinical workforce as the needs of people living with HIV evolve:

- Undertake a London-wide survey of staffing and skills to inform the development of the HIV multidisciplinary workforce.
- Ensure succession planning for HIV-specialist pharmacists and the retention of HIV-specialist pharmacy knowledge.
- Plan service provision to enable full utilisation of HIV pharmacists' clinical skills.
- Set up cross-ICS arrangements, and keep them under regular review, to maintain a workforce skilled to manage highly complex HIV clinical care for the diminishing number of patients across London who need it.

### The wider workforce

Health and social care professionals who are not HIV-specialists need sufficient knowledge, understanding and skills relating to HIV to provide personalised and holistic care. As well as an awareness of HIV stigma and its impact, this should include an ability to provide culturally sensitive care appropriate for people from different communities affected by HIV. Clinicians also need to understand how HIV and other conditions, or their medications, may interact and where to go for specialist advice when necessary.

<sup>182</sup> Operational productivity and performance in English NHS acute hospitals: Unwarranted variations: An independent report for the Department of Health by Lord Carter of Coles. February 2016.

In order to equip all health and social care professionals (broadly defined, from community pharmacists to housing officers to homecare workers) to provide optimal care for people with HIV, the following measures are suggested:

- Pro-actively disseminate up-to-date information on HIV to all staff to dispel misinformation and reduce HIV-related stigma.
- Review wider training programmes to incorporate basic information on HIV that all health and care staff should know.
- Additionally, ensure relevant context-based training is provided for staff whose role involves HIV-related functions, such as administering opt-out HIV testing in emergency departments and other secondary care settings.
- Review and address HIV-related workforce development needs among providers of specialist health and social care services for older people, to ensure they are equipped to meet the needs of the growing numbers of people living to an old age with HIV.
- Tailor more in-depth training on HIV for certain professionals, particularly those in mental health and social care, to enable them to provide appropriate, sensitive and well-informed care for people with HIV and complex needs.
- Provide training on HIV for primary care teams, including administrative staff, to ensure that general practice is welcoming and sensitive to the needs and concerns of people with HIV, including their fears about confidentiality.
- Work with professional educational bodies to provide and disseminate HIV updates for GPs and other secondary care specialties.
- Work with relevant bodies, such as Health Education England and British Association for HIV and Sexual Health (HIV), to create a qualification for a small core of GPs to enable them to become 'HIV champions' in primary care.
- Involve people living with HIV in the development and, where appropriate, delivery of HIV educational interventions.

# 6

## Priorities for high-level action

The ICS model offers an exciting opportunity to achieve integrated and personalised care for people living with HIV, a reduction in HIV-related health inequalities and zero HIV transmissions, and to ensure the *Standards of care for people living with HIV*<sup>183</sup> are met across London.

This section sets out recommendations to support ICSs in addressing these challenges. It identifies structural priorities for commissioning and partnership working, followed by key priorities for action to improve the provision of HIV care.

These priorities for improvement are categorised for action in the short, medium and longer term based on the potential speed at which they might be initiated but all are critical for enabling the HIV care standards to be fully implemented and improving the health and wellbeing of people living with HIV across London.

<sup>183</sup> British HIV Association Standards of care for people living with HIV 2018 (bhiva.org)

## Priority 1.

Coordinate HIV commissioning across London:

- Take a joint approach to the commissioning of HIV services to ensure equitable provision of care across the capital and complement place-based commissioning to address local diversity and needs
- Maintain open access to HIV services across London, including for patients from outside London
- Retain national-level determination of HIV care standards and the HIV clinical service specification and move to national drug procurement

## Priority 2.

Strengthen partnerships and community engagement:

- Address the whole HIV care pathway, including prevention and diagnosis, in future HIV commissioning, undertaken in partnership between the NHS and local government commissioners with providers and people living with HIV
- Engage the voluntary sector as a partner in commissioning, with a focus on collaboration across the sector to meet identified needs
- Ensure the meaningful involvement of people living with HIV in commissioning, including investment in induction and training and clear remuneration for community members who would like to become patient representatives on relevant forums
- Strengthen the role of cross-London and ICS-level HIV clinical leaders with leadership training and inclusion of the leadership role in job plans
- Realise the value of HIV clinical networks by strengthening and supporting them to foster joint working and optimum use of resources within each ICS
- Fund HIV support services on a three to five-year basis to allow programmes to develop, build and be sustained

- Appoint an HIV champion in each ICS to keep a focus on HIV across all specialties

## Key priorities for improvement

### Short-term

## Priority 3.

Implement STP plan commitments to establish and maintain opt-out HIV testing in all emergency departments across London.

## Priority 4.

Collaborate to resolve inequalities in service access and address unmet needs.

### Medium-term

## Priority 5.

Establish mechanisms for more collaborative working between general practice and HIV clinics to provide integrated management of HIV and other long-term conditions.

## Priority 6.

Embed the concept of coordinated care in the HIV pathway, including the identification of a named member of the multidisciplinary team responsible for ensuring that this is in place for each person living with HIV.

## Priority 7.

Put in place measures to eliminate HIV stigma and discrimination in settings in which people receive care and services, starting with healthcare, to include staff training, and systems for reporting and monitoring HIV-related discrimination and ensuring those responsible are held accountable.

## Priority 8.

Define peer support as a critical and essential part of the HIV care pathway and fund it accordingly, embedding the role in clinic multidisciplinary teams as well as in community settings.

## Priority 9.

Commission mental healthcare in partnership across London, in order to ensure that the right service is available for each individual at every level of need, provided by professionals with appropriate expertise.

## Priority 10.

Undertake a needs assessment, service mapping and develop a strategy and core minimum specification for community-based HIV support services.

## Priority 11.

Review and develop the HIV specialist and non-HIV specialist workforce to ensure all people living with HIV receive care from professionals and staff with appropriate expertise.

## Longer-term

## Priority 12.

In partnership with the HIV community and service providers, put in place measures to ensure people with HIV can be confident of confidentiality across the system and feel comfortable with sharing their data to support integrated care.

## Priority 13.

Develop the use of digital service provision, while ensuring that access to in-person services, to an equal standard, remains available and support is provided to tackle digital poverty among people living with HIV.

## 7

# How the HIV sector can help

This document is written to serve as a starting point for engagement between London ICSs and the HIV sector, which is eager to work alongside ICS colleagues and maximise the support it can offer towards achieving the priorities set out in Section 6. The sector already has several existing assets in place which could support ICSs to accelerate the implementation of key improvements.

As one of these, the FTCL, which has coordinated the development of this document, could serve as a useful contact point and convenor of the London HIV sector that ICSs may wish to utilise as they develop.

## The HIV sector

The HIV sector is made up of a diverse range of services and professionals providing specialist clinical care, psychosocial care and support, as well as many people living with HIV acting as patient representatives, community advocates, peer support workers and other roles. Their leaders in London wish to partner with ICSs as they take on the challenge of improving HIV care across the capital. Leadership in different parts of the sector is as described below.

## Clinical leadership

Advice on HIV specialised commissioning is provided at national level by NHS England's Clinical Reference Group for HIV, which reports to its Blood and Infections Programme of Care Board.

At regional level, the London HIV Clinical Forum brings together HIV specialist clinicians from across the capital. Its current membership includes the lead HIV clinician and lead HIV pharmacist from each trust providing specialised HIV services, along with representatives of people living with HIV. The Forum provides clinical leadership and ambassadorship, and expert clinical advice and support to NHS England on issues such as service design. Its co-chairs report to NHS England's Regional Director of Specialised Commissioning and are members of the FTCL London Leadership Group, along with a clinical lead from each ICS area. In response to the evolving shape of the HIV epidemic in London and the changing commissioning environment, the Clinical Forum has the potential to play a key role in supporting ICSs to shape future HIV services across London. To enhance its capability for this, its membership should be updated to include other key professions such as nursing, and the leadership function of its chair(s) and clinical leads would benefit from recognition and support of their role through its inclusion in their job plans and the provision of relevant training.

On a footprint roughly aligned to each ICS, London has five HIV clinical networks which mainly serve to share good practice, education and audit. In some cases, they also share highly specialist clinical expertise, but other workforce sharing is rare although this may have increased during COVID-19. Prior to implementation of the Health and Social Care Act 2012, five networks encompassing HIV and sexual health services played a more active collaborative role but, as funding for their facilitation ceased and the reforms led to a more competitive relationship between trusts, this level of activity could not be sustained.

However, the experience demonstrates the potential for such networks, if adequately resourced and encouraged, to play a valuable part in supporting the coordination of service provision across a 'place', helping to ensure equitable standards and optimal use of resources in partnership with commissioners and service users.

## Voluntary sector leadership

The HIV voluntary sector across London is diverse, encompassing a range of differently-sized organisations. It differs from the often long-established large voluntary sector organisations working on many other health conditions, where local branches are coordinated by one central body.

The London HIV Providers Forum brings together the chief officers of the larger organisations to discuss policy and delivery issues. With its members beset by funding and operational challenges as well as soaring levels of service need, the Forum has struggled to meet during COVID-19 but, with support for its development, could provide a valuable resource for voluntary sector engagement in service planning and development across London, driven by need and optimal use of shared resources. However, it does not represent the entirety of the HIV voluntary sector and smaller organisations may struggle to find a voice.

At national level, two voluntary sector organisations – National AIDS Trust (NAT) and Terrence Higgins Trust (THT) – are recognised for their lead on policy development and campaigning.

## Community leadership

A dedicated Community Advisory Group consisting of 16 people living with HIV was recruited to contribute to the development of this paper and remains active. The FTCL London leadership group includes community representatives, as does the London HIV Clinical Forum.

There is a large overlap between community organisations representing people living with HIV and HIV voluntary sector organisations. Many of the latter have their roots in community activism and a significant number of their employees and volunteers are themselves living with HIV so, in practice, voluntary sector organisations often provide a voice for people living with HIV. There is no single, London-specific locus of HIV community leadership.

The [UK Community Advisory Board \(UK-CAB\)](#) is a peer-led network which aims to empower people living with HIV and those supporting them to become effective HIV treatment advocates. Although a national body, many of its members are London-based, as is its host organisation (HIV iBase).

A number of London HIV clinics have patient groups and forums to provide support for service users and secure their input to the shaping of services. These have tended to be strongest when supported by paid facilitator posts.

While there is a core of community advocates with high levels of skill, knowledge and dedication, the number of people involved in HIV activism, speaking on behalf of the community of people living with HIV, has diminished in recent years. This may be partly because modern treatment has made HIV easier for many people to manage while living active and fully functional lives. But the stigma associated with the condition still presents a major barrier to participation and visibility, and this is particularly the case among some of the most vulnerable and disadvantaged, such as people from minority ethnic communities, those with substance misuse or mental health problems, trans people, and those disengaged from HIV care.

## Public health leadership

Responsible for commissioning HIV prevention and most HIV testing as part of its public health functions, local government works together across London, as well as commissioning prevention, testing and support services locally in response to local needs.

One local Director of Public Health serves as HIV Prevention Lead for the Association of Directors of Public Health (London). The joint London HIV Prevention Programme runs the Do It London campaign on behalf of 32 London councils. Governance of this programme is via the London HIV Prevention Programme Board, hosted by London Councils.

In parallel, the London Sexual Health Programme, hosted by the City of London Corporation, is led by a director of London Sexual Health (part-time role) to support local authorities to commission the online Sexual Health London service and clinic-based services. The Programme's governance structure includes a director level Strategic Board, Commissioner Boards and a Clinical Advisory Group.

Expert public health advice and leadership to specialised commissioning programmes comes from staff currently employed by PHE and embedded within NHSE, and for HIV in London this function is led by a Consultant in Public Health Medicine. PHE also has a regional Sexual and Reproductive Health Lead for London, one of its nationwide network of sexual health facilitators based at PHE Centres who support commissioning by providing data and evidence to improve local services. While further details about public health system changes are awaited later in 2021, the Government's consultation document<sup>184</sup> states that key functions which are currently delivered at regional level to support local systems will be maintained and proposes that the PHE staff currently embedded in NHS England will transfer to NHS England employment while continuing to work collaboratively across the system.

The PHE national HIV and STI team (which will move to the new UK Health Security Agency) plays a key role in surveillance, research and expert advice, including the maintenance of HIV databases.

## HIV System convener

Since its establishment in 2018, when the Mayor of London, NHS England, PHE and London Councils signed the *Paris Declaration on Fast-Track Cities Ending the AIDS Epidemic* (ref), the London Fast-Track Cities Initiative (London's FTCI) has brought a new element of system leadership to the HIV sector. It is committed to working with partners across the city to end new HIV infections in the capital by 2030, put a stop to HIV-related stigma and discrimination, stop preventable deaths from HIV-related causes, and work to improve the health, quality of life and well-being of people living with HIV across the capital.

London's FTCI acts as a system convener, bringing together all the key players already working to tackle HIV across the capital to work towards a common set of goals, share knowledge and experience and maximise efforts collectively. The [Fast-Track Cities Leadership Group](#) includes senior representatives from the city's four accountable health and care bodies, people living with HIV, clinicians, and community-based organisations. Programme management for London's FTCI is provided by Healthy London Partnership, London's city-wide transformation and delivery unit, bringing team capacity to support its activities.

London's Fast-Track Cities Leadership Group has overseen the work to develop the recommendations set out in this paper.



September 2021

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