

# Improving and integrating HIV care in South East London<sup>1</sup>



## 1 Key issues

Thirty percent of people who access HIV treatment and care in London live within the South East London (SEL) Integrated Care System (ICS) footprint. Lambeth's HIV prevalence rate of 14.6 per 1,000 people is the highest rate for a local authority in the UK, and the rate across the SEL footprint is 8 per 1,000 – the highest in the country. HIV in SEL constitutes a **health inequality** that affects Black, Asian and minority ethnic communities. In 2018, 5,395 of the 10,731 people accessing HIV care in SEL and 42% of new diagnoses were among people from BAME communities.<sup>2</sup>

There is variation of experience across the boroughs within SEL. For example, testing coverage among women is especially low in Southwark, and the late diagnoses rate among the heterosexual population is particularly high in Bexley. **The ICS needs to deploy a range of strategies to respond to variable needs across diverse communities living with or at risk of HIV in SEL.**

### SUMMARY

- Testing must be increased in emergency departments and primary care to reduce the numbers of late HIV diagnoses and people living with undiagnosed HIV. (See 2.1)
- Protocols must be agreed for shared care and communications between specialists and primary care. (See 2.2)
- GPs across the ICS footprint must be equipped to provide primary care and long-term condition management appropriate for people living with HIV. (See 2.3)
- A flexible referral system should be in place that presumes GP management of long-term conditions but supports direct communication and referral between specialists where appropriate. (See 2.4)
- Good quality social care must be integrated with healthcare provision. (See 2.5)
- More flexible prescribing and dispensing practices that support ARV adherence should be established. (See 2.6)
- Services must be available to meet mental health and drug and alcohol related needs. (See 2.7)
- Support must be made available for people living with HIV to manage their own care. (See 2.8)

*See page 3 for the full list of recommendations.*

People living with HIV in SEL experience significant **fragmentation of care**. SEL's GPs report that their patients living with other long-term conditions as well as HIV can be cared for in up to eight specialist clinics, scattered across London. Unmitigated fragmentation builds potential gaps, duplication and other inefficiencies into the system, and NAT's research shows that the consequences for fragmented, poorly coordinated care range from an excessive appointment, testing and treatment burden to avoidable death.<sup>3</sup>

Coordination needs can be complicated by wider complexity deriving from factors such as social care need or insecure housing status. It is difficult for clinicians working in isolation to respond to fragmentation, and even where individuals develop effective responses this leads to patchy and inconsistent practice across the ICS.

**High level strategic intervention is required to resolve the problem of fragmented care.**

1 This project has been supported by an educational grant from Gilead Sciences Ltd., a charitable donation from Pfizer Limited, and additional financial support from Janssen.

2 Public Health England, 2019, *PHE Centre and London Sector HIV data tables*. <https://www.gov.uk/government/statistics/hiv-annual-data-tables>

3 NAT (National AIDS Trust), 2020, *Providing coordinated care for people living with HIV* [https://www.nat.org.uk/sites/default/files/Providing%20coordinated%20care%20briefing\\_0.pdf](https://www.nat.org.uk/sites/default/files/Providing%20coordinated%20care%20briefing_0.pdf)

The appropriate response to fragmented care is improved communication and arrangements for shared care.<sup>4</sup> However, **pervasive HIV exceptionalism** – within the NHS as well as among the general public and some people living with HIV – shapes expectations of how GPs and HIV specialists should work together to deliver care to people living with HIV. Compared with other long-term conditions, communication between primary and secondary care is insufficient and varies between clinicians, and there is no consistently used GP model of care for HIV. This lack of clarity around responsibility affects the quality and safety of care. **Protocols around communication and shared care, and a GP model of HIV care must be agreed and consistently applied.**

UK-wide, one in nine people living with HIV report having been refused healthcare or delayed treatment because of their HIV status.<sup>5</sup> Many people living with HIV receive their medical care in the context of experienced and/or perceived stigma. Some have concerns around their GP's HIV-related knowledge and capacity; some are not prepared to disclose their HIV status to their GP.<sup>6</sup> As well as supporting efforts to challenge HIV stigma, **HIV care delivery must take into account preferences of people living with HIV to avoid them falling out of care.**

A Greenwich resident who is living with HIV described to us her difficulties in accessing annual cervical screening. The GP's receptionist told her she wasn't eligible for a screening, even after she had explained her HIV status, and she had to fight to get the appointment. At the appointment the nurse told her it was likely that the results would get rejected by the system because it wasn't geared to accept annual testing. The person's concern was primarily with the level of self-advocacy required to get a service that, historically, she would get automatically at the HIV clinic.

SEL is not alone in experiencing these difficulties, but as a leader in the integration process it can be among the first in the UK to respond to them. The formation of a single Clinical Commissioning Group (CCG) sitting across the ICS is an opportune moment for ensuring HIV prevention, treatment and care is appropriate and consistent across the footprint, while still responding to neighbourhood and place-level specificity.

The requirements for SEL's HIV response are established in the context of **obligations laid out in NHS England's Long-term Plan**. The plan prioritises responding to health inequalities and local prevention needs, providing personalised care (as set out in *Universal Personalised Care*), removing the divide between primary and community care, and utilising digital technologies. It also promises the shift to system level commissioning decision-making within ICSs, emphasising integration of primary and specialist care, physical and mental health services, and social care with health.<sup>7</sup> These top-line messages should be incorporated in plans developed by each ICS (or their predecessors, Sustainability and Transformation Partnerships), which are due to be published shortly. For HIV specifically, a range of national level guidance exists that can support planning for best practice but, **to ensure effective implementation, guidelines must be accompanied by proven approaches to education and implementation support.**

The recommendations in this document are mainly the result of engagement with people living with HIV and other stakeholders from across the SEL ICS footprint, but also draw on UK-wide research. Some of the measures discussed are already in place in parts of the ICS area, meaning that the change required is about identifying, evaluating and scaling up what is already in operation. Other proposals comprise either adjustments within the existing system or more fundamental systemic transformations, responding to specific problems identified by those receiving or delivering care in SEL.

4 BHIVA, 2017, *Shared Care: How can we do it? Findings from the BHIVA Primary Care Project* <https://www.bhiva.org/shared-care>

5 Public Health England, Positively UK, NAT (National AIDS Trust) and Watipa, 2018, *Changing Perceptions: Talking About HIV and Attitudes* [https://www.nat.org.uk/sites/default/files/publications/web\\_PV\\_Changing%20Perceptions-Stigma-report.pdf](https://www.nat.org.uk/sites/default/files/publications/web_PV_Changing%20Perceptions-Stigma-report.pdf)

6 NAT, 2020, *op. cit.*

7 NHS England, 2019, *The NHS Long-term Plan*; NHS England, 2019, *Implementing the NHS Long term plan*; NHS England, 2019, *Universal personalised care: Implementing the Comprehensive Model*

### SUMMARY OF RECOMMENDATIONS

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| <b>Testing</b>                                     | <ul style="list-style-type: none"><li>• The ICS must commit to provide a sustainable funding model for HIV testing in emergency departments and primary care across SEL.</li><li>• Training that has been proven to be effective must be funded and delivered to GPs and other primary healthcare professionals to ensure that HIV tests are offered appropriately.</li><li>• Testing requirements must be included in any re-evaluation of the role of GPs in delivering HIV prevention and care.</li></ul>   |
| <b>Shared care</b>                                 | <ul style="list-style-type: none"><li>• Agreement must be secured between secondary and primary care on responsibilities around delivery of HIV care and delivery of routine care to people living with HIV.</li><li>• An improved GP model of HIV care must be in place to facilitate effective and trusted shared care.</li><li>• Where care coordination is required, especially for those with multimorbidity and older people living with HIV, clarification over where that role should sit must be decided on a case by case basis.</li><li>• A protocol must be put in place for consistent communications between primary and secondary care.</li><li>• Protocols for shared care must be extended beyond immediately clinical need to incorporate wider social need. A care coordinator should be available for those that need one, especially older people living with HIV.</li><li>• Information systems that support effective communications must be in place. SEL should support the development of a model of communication and shared care for HIV, with IT innovation or existing means of record sharing, as appropriate.</li></ul>  |
| <b>GP model of care</b>                            | <ul style="list-style-type: none"><li>• GPs and other relevant primary healthcare workers should receive sufficient training to enable them to deliver primary care that complements specialist HIV care. Support must be made available for implementation as well as training.</li><li>• People living with HIV must be involved in the process of transitioning their primary care to their GP.</li><li>• HIV clinics and primary care practices must collaborate to find safe and effective ways of delivering vaccinations according to BHIVA guidelines.</li><li>• The ICS should support care providers, PCNs and commissioners to work together to determine where HIV leads and champions should be introduced across the system.</li><li>• GP practices (especially those with HIV leads) should engage in quality improvement activities including audits to identify people lost to follow up, late diagnosis review and annual reviews, in collaboration with HIV clinics where appropriate.</li><li>• HIV clinics, primary care providers and commissioners should explore ways to support delivery of primary care, including locating CNSs in primary care and GPs in HIV clinics.</li><li>• The ICS should consider a pilot for GP delivery of routine HIV care for people with stable HIV.</li><li>• The ICS must ensure that financial and time resource is available to invest in projects that will improve effective and efficient care delivery for people living with HIV.</li></ul> |
| <b>Referrals</b>                                   | <ul style="list-style-type: none"><li>• Clearer referral pathways should be established on where to refer patients who the HIV clinic have assessed.</li><li>• Referrals to specialists should be managed in primary care, except for in complex cases where communication and direct referrals between specialists would improve delivery of care.</li><li>• The CCG should facilitate funding models that allow HIV clinicians to make referrals into other secondary care (both within their own hospital and to other hospitals) where appropriate, without the need for referral from a GP practice.</li></ul>  |
| <b>Social care</b>                                 | <ul style="list-style-type: none"><li>• Integration of social care must be recognised as a priority for the individual, as well as for the system.</li><li>• Local authorities must ensure that social care providers train their staff appropriately.</li><li>• The role of specialist HIV support services in absorbing the impact of unmet social care need should be recognised by all bodies responsible for their commissioning.</li></ul>   |
| <b>Prescribing and dispensing</b>                  | <ul style="list-style-type: none"><li>• Establish a reimbursement system that allows ARV dispensing in pharmacies.</li><li>• Facilitate ARV prescription in drug services.</li></ul>   |
| <b>Mental health and drug and alcohol services</b> | <ul style="list-style-type: none"><li>• Improve provision of, and access to specialist mental health services and drug and alcohol services.</li><li>• Provide a psychiatric registrar in all HIV clinic Multidisciplinary Teams (MDTs) in South East London.</li></ul>  |
| <b>Involving people living with HIV</b>            | <ul style="list-style-type: none"><li>• Development and implementation of a comprehensive GP model of HIV care must incorporate involvement of people living with HIV in their own long-term condition management.</li><li>• The CCG must recognise the role of HIV support services in long-term condition management and meet its responsibility in ensuring these services are delivered.</li><li>• The care coordination work already undertaken by Clinical Nurse Specialists (CNS) should be acknowledged.</li></ul>   |

## 2 Recommendations for improving HIV care in South East London

### 2.1 Increasing testing

Increasing testing in emergency departments and primary care, in line with NICE guidance,<sup>8</sup> will reduce the numbers of late HIV diagnoses and people living with undiagnosed HIV.

#### RECOMMENDATIONS

- The ICS must commit to provide a sustainable funding model for HIV testing in emergency departments and primary care across SEL.
- Training that has been proven to be effective must be funded and delivered to GPs and other primary healthcare professionals to ensure that HIV tests are offered appropriately.
- Testing requirements must be included in any re-evaluation of the role of GPs in delivering HIV prevention and care.

#### WHY?

Prompt diagnosis is a cost saving measure as it avoids onward transmissions and hospitalisation.<sup>9</sup> HIV testing can also support people to re-engage with care. In SEL, late diagnosis is most prevalent among heterosexual men, who are predominantly from BAME communities. Missing the opportunity to identify people living with HIV who are undiagnosed is creating a health inequality in SEL.<sup>10</sup>

Improvements in diagnoses rates mean that those who remain undiagnosed are increasingly hard to find. Testing requires a new model.

Emergency departments (ED) are an important setting in which to test. This is because people coming to EDs are often very unwell and are clinically indicated (as distinct from primary care, for example).

Testing in primary care is recommended in national guidelines but does not often happen, even when people present to their GP with indicator conditions. While it is clearly not true for all GPs, there is a common perception that they do not feel responsible for, or empowered to implement all manner of HIV care, including testing.

#### HOW?

Routine testing should be implemented in all EDs. It must be properly evaluated across all hospitals; existing data could be used for preliminary evaluation.

ED testing is already being done in most SEL hospitals (although not Princess Royal and Queen Elizabeth). However programmes are funded through different mechanisms, including Elton John AIDS Foundation (EJAF) funding at Kings and Lewisham. Funding sources must be made more sustainable. It is an especially appropriate time to consider funding for testing given the transition to the unitary CCG as, until now, testing has been delivered under different contracts with different funding models.

**Universal testing** has been proven to be possible in National HIV Testing Week where IT prompts and phlebotomy opt out were used in Lambeth to ensure most patients were offered HIV tests.

Screening in primary care in high prevalence areas has also been shown to improve diagnosis rates<sup>11</sup> and should be considered a key strategy for reducing the numbers of people with undiagnosed HIV.

8 NICE, 2016, *HIV testing: increasing uptake among people who may have undiagnosed HIV*. NICE guideline NG60

9 Beck E.J, Mandalia S, Sangha R, et al. (2011) 'The cost-effectiveness of early access to HIV services and starting cART in the UK 1996-2008'. *PLoS ONE* 6: e27830

10 Public Health England, *Public Health Profiles* <https://fingertips.phe.org.uk/>

11 Leber W, Panovska-Griffiths J, Martin P, Morris S, Capelas Barbosa E, Estcourt E, et al. 'Evaluating the impact of post-trial implementation of RHIVA nurse-led HIV screening on HIV testing, diagnosis and earlier diagnosis in general practice in London, UK' *EClinicalMedicine* (2020) Volume 19, 100229

Sexual Health in Practice (SHIP) training for GPs has been proven to be effective elsewhere in London<sup>12</sup> and is now being provided in Lewisham and Lambeth, again funded by EJAF. Although HIV champions or leads are welcomed, training should extend to all GPs and practice nurses as people will only present to the practice lead by chance.

As the number of people undiagnosed continues to fall, positivity rates will also fall to a point where universal testing is no longer cost effective. However, alternative testing models allow a change over time from universal screening to case finding.

### 2.2 Establishing shared care and communications

Agreeing protocols for shared care and communications between specialists and primary care will clarify responsibilities and establish a system for knowledge sharing. This will avoid duplication of, or gaps in treatment, and reduce errors in care delivery.

#### RECOMMENDATIONS

- Agreement must be secured between secondary and primary care on responsibilities around delivery of HIV care and delivery of routine care to people living with HIV.
- An improved GP model of HIV care (see 2.3) must be in place to facilitate effective and trusted shared care.
- Where care coordination is required, especially for those with multimorbidity and older people living with HIV, clarification over where that role should sit must be decided on a case by case basis.
- A protocol must be put in place for consistent communications between primary and secondary care.
- Protocols for shared care must be extended beyond immediate clinical need to incorporate wider social need. A care coordinator should be available for those that need one, especially older people living with HIV.
- Information systems that support effective communications must be in place. SEL should support the development of a model of communication and shared care for HIV, with IT innovation or existing means of record sharing, as appropriate.

#### WHY?

Fragmentation of care for people living with HIV has consequences when left unmitigated by agreements regarding care arrangements and effective communication practices. There is significant potential for both duplication and gaps when assessing needs and delivering care. This has especially been a problem since the Health and Social Care Act 2012, and subsequent funding practices have limited the capacity of specialists to fulfil certain care needs for people living with HIV.

HIV consultants don't always feel confident that their patients are getting the best care and are uncertain about what primary care is being delivered. GPs are concerned that specialists are prescribing medication and generally delivering primary care that may clash with their own provision, and don't know enough about the HIV care that's being delivered. There are also inconsistent expectations concerning where primary care should be delivered, leading to people living with HIV being bounced back and forth between the GP and the HIV clinic.

"I have heard many stories of HIV consultants prescribing long-term hypertension medications and then these being mixed up with prescriptions from their GP."

South East London GP

The consequences for people living with HIV, especially for those with multimorbidity, can be unnecessary and costly testing, treatment and appointment burdens; errors or delays in care because of uncertainty around appropriate treatment or drug interaction; failure to meet monitoring and vaccination recommendations; lack of clarity over which provider is responsible for a particular element of care; and an absence of care coordination for long-term conditions including mental health care and wider complexity deriving from factors such as social care need or insecure housing status.<sup>13</sup>

12 Pillay K, Gardner M, Gould A, Otiti S, Mullineux J, Bärnighausen T, et al. (2018) 'Long term effect of primary health care training on HIV testing: A quasi-experimental evaluation of the Sexual Health in Practice (SHIP) intervention'. *PLoS ONE* 13(8): e0199891.

13 NAT, 2020, *op. cit.*

One person living with HIV told us that even though she's not sure her GP is clear on all the vaccinations she needs, she tries to get them from her GP because she's worried about the potential duplication caused by having two different vaccination records.

Some people living with HIV may experience a diminished quality of life even as viral suppression is maintained. Others, especially those who have received contradictory advice and lost confidence in the healthcare system, may fall out of certain elements of their care, undermining their health and wellbeing and in some cases threatening their life.

The principle of shared care as a response to fragmentation exists prior to the more contentious issue of whether GPs could take on more responsibility for providing basic HIV care (blood tests etc.) for stable patients. By adopting measures to address fragmented care and its consequences, SEL ICS could set a nationwide precedent on efficient and effective care delivery for people living with HIV.

### HOW?

A model of shared care in SEL requires systemic change for some activities, whereas in others existing practice could be evaluated and scaled up to ensure consistency of patient experience. Both these types of activity require collaboration between primary and secondary providers and commissioners, and intervention, direction and support from the ICS.

Provisions for sharing care more effectively between specialists and primary care have been well modelled.<sup>14</sup> Clarity of responsibility, followed up with effective communication, is fundamental in its delivery.

A Lewisham resident who is living with HIV and diabetes told us how his GP and HIV consultant disagreed over his diabetes risk and whether he should start treatment. His main concern was that the healthcare professionals didn't communicate with each other to come to an agreement, rather the patient had to convey information between them. He is left feeling that a critical element of his care is not well managed.

Despite the existence of local care records, issues are reported with communication both to and from the HIV clinic. Protocols are needed to standardise communications around routine information, and procedures should be implemented to facilitate responses to specific queries.

Currently, the Local Care Record<sup>15</sup> covers just Kings, Guys, and Lewisham. This could be expanded out across SEL as a whole and include more GP surgeries. Further, GPs have asked for more standardised communication from secondary care detailing medications, latest labs, blood pressure, weight, BMI, smoking, smear, QRISK, vaccinations and bone density. Using a single letter template that matched fields in the EMIS patient record system across all healthcare providers in SEL would align care systems and support information sharing and joined up working.

There are reports from GPs that some HIV specialists do not write to them, even when a person living with HIV has requested it. It is suspected that this may be a result of historical records of withholding consent not being updated. Consultants should update consent records regularly and should explain to people living with HIV what will, or will not, be communicated to the GP and why.

HIV consultants report very poor levels of communication from primary care. In order that specialists can respond effectively to people living with HIV and multimorbidity, especially, it is vital that primary care ensure timely information is sent to HIV clinics.

Specialists could see better results if they tailored their communications with primary care, depending on the service required. For example, improvements in provision of pneumococcal and other vaccinations in primary care for people living with HIV could be achieved by sending the request for vaccinations to the practice nurses who deliver them.

For ad hoc communication, an SEL messaging group (via an app) could be used for HIV clinicians to respond to queries that GPs have on HIV-related issues. This has already been set up for other elements of specialist care.

<sup>14</sup> BHIVA, 2017, *op. cit.*

<sup>15</sup> The Local Care Record is an NHS system that shares information between all the local health and social care professionals involved in providing direct care to an individual.

*Consultant Connect* which has messaging, calling and confidential photo taking abilities is commissioned in Southwark and Lambeth, and could be rolled out more widely.

Beyond generalised principles, specific aspects of communication discussed here need to be established collaboratively, enshrined in protocols, and revisited as required. Healthcare practitioners need support from the ICS to enable these practices to be developed and implemented consistently.

### 2.3 Improving the GP model of HIV care

Ensuring that GPs across the ICS footprint are equipped to provide primary care and long-term condition management appropriate for people living with HIV will establish the ground for successful and trusted shared care.

#### RECOMMENDATIONS

- GPs and other relevant primary healthcare workers should receive sufficient training to enable them to deliver primary care that complements specialist HIV care. Support must be made available for implementation as well as training.
- People living with HIV must be involved in the process of transitioning their primary care to their GP.
- HIV clinics and primary care practices must collaborate to find safe and effective ways of delivering vaccinations according to BHIVA guidelines.
- The ICS should support care providers, PCNs and commissioners to work together to determine where HIV leads and champions should be introduced across the system.
- GP practices (especially those with HIV leads) should engage in quality improvement activities including audits to identify people lost to follow up, late diagnosis review and annual reviews, in collaboration with HIV clinics where appropriate.
- HIV clinics, primary care providers and commissioners should explore ways to support delivery of primary care, including locating CNSs in primary care and GPs in HIV clinics.
- The ICS should consider a pilot for GP delivery of routine HIV care for people with stable HIV.
- The ICS must ensure that financial and time resource is available to invest in projects that will improve effective and efficient care delivery for people living with HIV.

#### WHY?

Certain elements of primary care that have historically been offered in HIV clinics are now more firmly within the remit of the GP. GPs excel at managing long term conditions and multimorbidity, and many are already committed to ensuring that extends to their patients living with HIV. This approach to care for people living with HIV challenges HIV exceptionalism, normalises and destigmatises HIV, and should ensure better prevention and management of multimorbidity.

Involvement of primary care clinicians in delivering integrated care for people living with HIV presents opportunities to respond to some of the problems related to fragmentation, such as detection of multimorbidity, medicines review for those experiencing polypharmacy, and identification of people who have been lost to follow up by HIV clinics. Primary care is also a key site for identifying people who are less likely to attend sexual health clinics but may benefit from PrEP use or HIV testing.

However, while some people living with HIV express interest in having GPs more involved in their care, many have concerns – some of which are echoed by GPs – over adequacy of their GP's HIV knowledge and capacity, and the possibility of stigma.<sup>16</sup>

“If you look though GP's websites you don't ever see anybody whose special interest is HIV.”

**Lewisham resident, living with HIV**

Shared care can only be effective when a viable GP model of care for people living with HIV is established, GPs are confident in delivering that care, and specialists and people living with HIV trust the care being delivered. The

<sup>16</sup> These findings reflect engagement with people living with HBIV and other stakeholders in SEL, but also reflect nationwide trends identified in NAT's care coordination research. (NAT, 2020, *op. cit.*)

key question is how can a consistent, good-quality GP offer for long-term condition management and appropriate primary care for all people living with HIV be implemented in SEL?

### HOW?

Guidelines are available for certain elements of care such as testing and vaccination protocols, but proven training and implementation support are vital for addressing GP's confidence and gaps in their knowledge to the extent that practice changes to meet guidance.

"The GP, I like him as a person, but I don't think he was confident dealing with me and my healthcare needs. He just wanted someone else to take the decisions".

**Southwark resident, living with HIV**

Patient confidence must also be addressed alongside upskilling of GPs, meaning that training must include how to speak to people about HIV, testing, treatment and stigma. People living with HIV tell us consistently that they would prefer having a named GP. Any systemic change in care provision must ensure that it allows choice for people living with HIV and avoids a situation that causes them to fall out of care. A transitional phase from specialist to primary care management of people living with HIV and other long-term conditions should be expected.<sup>17</sup>

"I used to have a named GP... in terms of having the conversation while I'm actually in the room that would make it easier. It would feel like an ongoing conversation with somebody, as opposed to maybe I need to give you more context, how much of my notes have you already read? I don't know how familiar they'd be".

**Greenwich resident, living with HIV**

There are various pieces of work that could improve the quality and efficiency of service provision. GPs and HIV clinics could collaborate to conduct an audit of people living with HIV, using HARS data, to re-engage those lost to follow up. GPs could also conduct late diagnosis reviews and annual reviews in conjunction with visiting pharmacists to support the ARV component of the annual review. Lambeth has produced an 'HIV Quality of Care' dashboard measuring care delivered, such as pneumococcal vaccination, smear rates and so forth at a practice level. To improve outcomes, information needs to be fed back to GP practices with support from the HIV team. However, all these efforts require additional resource, and to be offered consistently they also require leadership from the ICS.

A named lead for HIV in each GP practice would be beneficial, especially in practices with larger cohorts of people living with HIV. This may be more feasible at the level of the Primary Care Network rather than individual practices, especially in areas of lower prevalence. HIV leads can plan how to implement improved HIV care in their practices. This could include maintaining oversight of clinical issues and disseminating information, proactively responding to stigma and other barriers to care, fostering involvement of people living with HIV in their own care, and maintaining contact with specialist advice.

HIV champions can play a strong role leading initiatives around, for example, testing, integration with secondary care, training of primary care providers, reducing stigma and engaging patients. Across Lewisham's confederation of GP practices, one GP has been specifically designated to work on HIV for half a day a week. This could be replicated elsewhere across SEL.

HIV clinics could support the work of HIV champions and practice leads by visiting GP practices, especially those that have a high number of patients living with HIV. Interaction could be more formalised, with CNSs working in primary care settings or primary care being offered in HIV clinics. Locally-relevant models of care delivery need to be established by key providers and commissioners, with input from people living with HIV and support from the ICS.

Commissioning models need to reflect expectations on primary care. There are examples of locally enhanced service (LES) agreements with primary care being used, although some claim that incentives should not be awarded for GPs to provide already-commissioned services such as long-term condition management.<sup>18</sup>

<sup>17</sup> BHIVA 2017, *op. cit.*

<sup>18</sup> BHIVA 2017, *op. cit.*



Nevertheless, the additional costs of training practice leads, ensuring ongoing peer support, and enabling annual reviews and audits needs to be factored into any development programme (in the same way that diabetes services are funded).

**Vaccination** is one area where shared care and the GP model of care come together. BHIVA guidelines state that “the HIV specialist should provide overall guidance on vaccine use and enlist the help of primary care physicians for vaccine administration”.<sup>19</sup> However, despite guidance, a 2015 audit showed that only a quarter of people living with HIV had received the pneumococcus vaccine. About 20% had received a flu vaccination in an HIV clinic, with a further 36% being advised to get it from their GP.<sup>20</sup>

In light of vaccinations not being delivered in primary care, some HIV clinics have been offering them with the intention of improving patient safety, but that may inadvertently be hindering the GP. For vaccinations to be offered safely in primary care, GPs need to be confident that they have not been given elsewhere and know the recipient’s CD4 count (for replicating vaccines). They also need to be confident of BHIVA guidelines which makes this a training issue.

One GP practice has developed a pop-up alert to prompt GPs to offer vaccinations according to BHIVA guidelines. Another possible prompt is for HIV clinicians to send vaccination requests to the practice nurses who deliver the care. However, to ensure a consistent offer, an improved communication system is vital for making delivery of vaccinations more viable.

While the discussion here is limited to delivery of primary care and long-term condition management, some people living with HIV have also raised the possibility of receiving their HIV care from their GP. This is likely to involve routine care for people classified as ‘stable’, such as viral load testing, which would free up time for specialists to engage further with those with complex needs while also being convenient for people living with HIV. This approach could be piloted with ICS support.

## 2.4 Supporting communication and referral between specialists

Until effective shared care models are in place, facilitating referral processes between specialists will avoid delays in care and help to decrease duplication of care and an excessive treatment burden for people with co-morbidities.

### RECOMMENDATIONS

- Clearer referral pathways should be established on where to refer patients assessed by the HIV clinic.
- Referrals to specialists should be managed in primary care, except for in complex cases where communication and direct referrals between specialists would improve delivery of care.
- The CCG should facilitate funding models that allow HIV clinicians to make referrals into other secondary care (both within their own hospital and to other hospitals) where appropriate, without the need for referral from a GP practice.

### WHY?

Owing to payment models, HIV clinicians are unable to make direct referrals for most comorbidities. Specialists often ask GPs to refer people living with HIV and co-morbidities back into departments in their own hospitals. This adds avoidable layers of communications causing times delays, and discourages interaction between consultants that supports holistic, integrated treatment and care. This problem is only likely to become more pronounced as the cohort living with HIV ages.

There is a clear divide in opinion between those who support direct referrals between consultants as a way of making care provision simpler, faster and more efficient (largely HIV specialists), and those who recognise it as perpetuating an exceptionalism that undermines established systems of long-term condition management and

19 BHIVA, 2015, *British HIV Association guidelines on the use of vaccines in HIV-positive adults*. <https://www.bhiva.org/vaccination-guidelines>

20 Molloy, A. et. al., 2017, ‘Routine monitoring and assessment of adults living with HIV: results of the British HIV Association (BHIVA) national audit 2015’ *BMC Infect Dis.* 17: 619.

the GP's role in supporting that (largely primary care providers). Simply ignoring this problem lays the groundwork for a piecemeal approach which only exacerbates uncertainty and the potential for sub-optimal care.

### HOW?

There should be a presumption of long-term condition management being organised within primary care, as for all other health conditions.

If and when effective shared care models are in place, the imperative for direct referrals should be limited, perhaps to scenarios where complex cases require direct communication between specialists. It might also be that models of direct referral would be more relevant in the lower prevalence outer boroughs where GPs are likely to have fewer patients living with HIV and less demand for expertise around their long-term condition management.

However, the presumption of referrals being managed through primary care should be part of a more flexible system that also allows for direct referrals from HIV consultants when necessary. These referrals need to be accompanied by close communication with primary care. To allow for this, CCGs need to be engaged in discussion on reimbursement.

A Lambeth resident who is living with HIV told us about his frustrations at the delays and appointment burdens associated with referrals passing through GPs when he's been sitting in front of a clinician who could have provided treatment or make a direct referral.

An interim solution is for HIV clinicians to send GP practices the referral letters for patients, allowing the GP to send them straight on to right department in the NHS Trust. This would save time, and should mean that people living with HIV would not need to attend a GP appointment before the referral could take place, which would minimise patients falling through gaps. In practice, some GPs already implement this by passing on the clinical referral with a note attached.

Improved referral systems and communication between HIV consultants and primary care should also be accompanied by effective communication between secondary care practitioners to facilitate good, holistic care for people with multimorbidity. Where the person living with HIV experiences frailty, for example, the introduction of wider support, care coordination, training and the implementation of appropriate guidelines should be wrapped into specific protocols.

## 2.5 Delivering social care

To facilitate holistic, person-centred care, social care that is well integrated with the healthcare system must be provided for those who need it. Carers must be adequately trained to ensure that people living with HIV have confidence in the care provided.

### RECOMMENDATIONS

- Integration of social care must be recognised as a priority for the individual, as well as for the system.
- Local authorities must ensure that social care providers train their staff appropriately.
- The role of specialist HIV support services in absorbing the impact of unmet social care need should be recognised by all bodies responsible for their commissioning.

### WHY?

Integration of health and social care, as mandated in the NHS Long-term Plan, is often understood at the system level, with investment in social care recognised as reducing demand on healthcare services. To ensure holistic care, integration of health and social care also needs to be understood at the individual scale. People living with HIV report that since the demise of the HIV social worker role there is little or no communication between healthcare and social care providers.

Further, the Government has announced plans to overhaul the social care system so the ICS needs to be prepared to implement forthcoming changes.

Inadequate social care support impacts people's capacity to engage in their healthcare, as well as their broader quality of life. People living with HIV who receive social care express concerns around the quality of care being provided. Meanwhile, eligibility thresholds for social care are high enough to leave significant unmet need.<sup>21</sup>

### HOW?

The ICS must recognise social care as a priority and ensure that local authorities are adequately represented within its structures.

To provide person-centred care, all healthcare providers need to consider the social care needs of their patients and be aware of statutory and other community services available, and how they can support access to care.

Local authorities must examine how their contracted suppliers meet the training needs of their staff, including ensuring appropriate understanding of confidentiality.

"I'd rather be able to go to a care agency where I absolutely knew that the staff had had HIV awareness training, where I knew that they were governed in a way that meant confidentiality breaches were treated very seriously but that people really did understand about confidentiality. It also concerns me because there's a lot of talk about budgets merging, and then healthcare's already a bit broken and fragmented, what's going to happen when you get the social care in with it on the same budget?"

**Lewisham resident, living with HIV**

The role of specialist HIV support services in absorbing the impact of unmet social care need, from emotional support to the provision of nutritious food, must be recognised when considering re-procurement of support services.

## 2.6 Improving prescribing and dispensing services

### RECOMMENDATIONS

- Establish a reimbursement system that allows ARV dispensing in pharmacies.
- Facilitate ARV prescription in drug services.

### WHY?

Some people living with HIV find it harder to manage their medications. This can be due to multimorbidity requiring multiple medications or where people have more chaotic lives. To avoid adherence problems, prescribing and dispensing services need to be in place that allow for easier access to ARVs.

### HOW?

ARV dispensing in pharmacies could be beneficial for people with HIV and other long-term conditions who can then pick up all their medication from the same pharmacy. Similarly, dispensing ARV prescriptions with opioid substitution treatment (OST) prescriptions would help engage patients with chaotic lives.

However, pharmacists are not reimbursed for ARV dispensing. HIV clinics currently charge NHS England for this service; this same system could be used for pharmacies.

Specialist pharmacists can help people living with HIV manage their medications, help identify the need for medicine review, and prevent drug interaction problems. Therefore there are additional benefits from engaging pharmacists in HIV care.

In addition, people who inject drugs get their OST prescription directly from drug services. Training a doctor in a drug service to prescribe ARV medication could allow ARV and OST prescriptions to be given together, increasing the likelihood of adherence to HIV treatment.

21 Public Health England, Positively UK, NAT & Watipa, 2019, *Changing Perceptions: Talking about HIV and our needs*.  
[https://www.nat.org.uk/sites/default/files/publications/web\\_PV\\_Changing%20Perceptions-needs-report.pdf](https://www.nat.org.uk/sites/default/files/publications/web_PV_Changing%20Perceptions-needs-report.pdf)

## 2.7 Tackling mental health and drug and alcohol issues

### RECOMMENDATIONS

- Improve provision of, and access to specialist mental health services and drug and alcohol services.
- Provide a psychiatric registrar in all HIV clinic Multidisciplinary Teams (MDTs) in South East London.

### WHY?

Among people living with HIV there are high rates of poor mental health and of drug and alcohol use, especially in London.<sup>22</sup> In addition to these matters needing support in their own right, they variously affect sexual behaviour as well as engagement with and retention in healthcare.

There are various ways of referring people into services, but there is insufficient provision of specialist support.

### HOW?

GPs are experienced in using validated mental health screening tools and linking people to supported self-help, psychological therapies and other local interventions. In addition, Kings are currently trialling the IMPARTS screening tool for mental health for people living with HIV. It more accurately assesses mental health needs amongst those with long term conditions. Appropriate services must be available to meet identified need.

Having a psychiatric registrar in HIV clinics (which has been hugely beneficial in Lewisham) and improving provision of and access to mental health and drug and alcohol support services in the HIV clinic and the community would support engagement.

Specialist services that are especially geared towards people living with HIV, such as HIV peer support and the tailored drug and alcohol support provided by London Friend, have been shown to be more effective for people living with HIV than generic provision. Continuity of service fosters trust among people living with HIV using them, but this is threatened by re-procurement exercises; specialist services need sustainable funding.

## 2.8 Supporting involvement of people living with HIV in their own care

### RECOMMENDATIONS

- Development and implementation of a comprehensive GP model of HIV care must incorporate involvement of people living with HIV in their own long-term condition management.
- The CCG must recognise the role of HIV support services in long-term condition management and meet its responsibility in ensuring these services are delivered.
- The care coordination work already undertaken by Clinical Nurse Specialists (CNS) should be acknowledged and properly resourced.

### WHY?

It is well accepted that people who are engaged in their own care have better health outcomes. Historically, people living with HIV have been well engaged through attendance at the HIV clinic. However the reduction in clinic visits for stable patients and the shift in responsibility for long-term condition management to primary care means that measures to support involvement of people living with HIV in their own care also need to shift.

In addition, people living with HIV report difficulties in negotiating a health and social care system that is not properly integrated. This is increasingly significant as the population living with HIV ages, escalating the need for management of multimorbidity.

22 NAT (National AIDS Trust), 2017, *Why we need HIV Support Services: A review of the evidence*  
[https://www.nat.org.uk/sites/default/files/publications/NAT\\_WHY%20WE%20NEED%20HIV%20SUPPORT%20SERVICES\\_2017\\_56%20pages\\_FINAL%20WEB\\_SINGLE%20PAGE....pdf](https://www.nat.org.uk/sites/default/files/publications/NAT_WHY%20WE%20NEED%20HIV%20SUPPORT%20SERVICES_2017_56%20pages_FINAL%20WEB_SINGLE%20PAGE....pdf)

### HOW?

Support for engaging with healthcare must be available from a range of sources to meet the variable needs of people living with HIV.

“It’s really difficult to self-advocate when you’re feeling really ill... the system can’t rely on the fact that you’ve got the knowledge, the confidence... if you’re the only one coordinating things it can get very tangled and stressful and difficult”.

**Lewisham resident, living with HIV**

Generally, people living with HIV report strong relationships with their HIV clinicians, but historically that relationship has not been as strong in primary care. Although the numbers are dwindling, some people living with HIV still do not disclose their HIV status to their GP.<sup>23</sup> As the model of HIV care shifts long-term condition management responsibilities into primary care, resource must be available to facilitate the normalisation of good engagement and involvement of people living with HIV in their own care. This can include training for GPs, especially around stigma, and the provision of HIV leads and champions to support normalisation of long-term condition management for people living with HIV as a primary care activity.

In the HIV clinic, CNSs are most often involved in supporting care coordination and wider needs for people living with HIV, especially for those with more complex needs. Community CNS’s are especially important because of their regular support for people who are often less able to attend appointments. For some, face-to-face contact is crucial, and the role of the CNS must be acknowledged and appropriately funded. Increasing involvement of CNS’s in primary care may be a way of supporting improvements in care delivery.

Other roles (e.g. the HIV consultant, a social care coordinator embedded in the clinic, or the GP) may also be well placed to take on some of these coordinating functions. In fact, having had virtual appointments during the COVID-19 lockdown, some of the people living with HIV were enthusiastic about the possibility of remote care navigation and coordination.

“There could be someone overseeing your care in a remote way and ensuring that it gets shared among the different people providing it at different points. You don’t have to go to the clinic every 6 months”.

**Lambeth resident, living with HIV**

Non-clinical support in engaging with care has been provided in a highly cost-effective manner by specialist HIV support services. Access to these services is dwindling due to funding cuts but this is a false economy as absence of support can lead to greater dependence on clinical services. The CCG should recognise support services as part of the long-term condition management pathway and fund them accordingly. With the new congruence of a single CCG across its footprint, the ICS has an instrumental role in ensuring this happens.

23 Public Health England, 2020, *Positive Voices: data tables 2017*. <https://www.gov.uk/government/publications/hiv-positive-voices-survey>

### 3 A new long-term condition management model for SEL?: Next steps and priorities for change

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Some of the specific problems identified in this briefing have comparatively easy solutions that can be implemented through adapting existing ways of working, while others require systemic change. However, even the 'quick wins' require strategic level intervention to ensure ICS-wide coverage. Demand and capacity to respond will differ between the high prevalence boroughs and the lower prevalence outer boroughs. However people living with HIV are entitled to equivalent care regardless of their location.

Identifying existing examples of good practice and ensuring that they are replicated across South East London requires time and funding. There is a need for a convening function to support development and understanding across SEL, implement change and evaluate effectiveness. Although it is possible for the learning cycle – developing an overview of the issues, establishing shared understanding, development and application of interventions, and evaluating impact – to be driven from the bottom up rather than by the ICS, this requires resource.

In terms of systemic change, the various interfaces along the pathway from prevention, through diagnosis, entry into and retention in care, and longer term support, can be addressed individually, but must be understood as elements of the care pathway. The primary-specialist care interface has perhaps garnered the most attention and could be the best place to start. What is clear is that transformation in the ICS footprint must take into account the entire ICS footprint, considering the needs of all areas rather than focusing solely on the areas with the highest prevalence.

In terms of next steps for developing a new model of service delivery, SEL ICS needs to bring together providers and commissioners (from CCGs, Specialised Commissioning and local authorities) to ensure that the structural issues and existing barriers to integrated care within each interface are well understood, to establish what can be done differently, and to identify the partnerships and protocols that need to be in place to allow for change to be effective.

This project was almost complete when COVID-19 and its implications for healthcare reached the UK. Some of the urgent responses, such as remote care provision, could well have been unintended pilots for innovations in care delivery. As one Lambeth resident told us, "Maybe there's a way that this horrible situation we're in at the moment might actually tailor-make a better packaged health and care plan in the future". However, as valuable as those innovations might be, it is important to look back to the pre-existing set of underlying issues around integration that still need to be grappled with.

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