



# **Primary Care Access: How General Practice Can Better Respond to the Needs of People Living with HIV**

**Commissioned by:**  
NHS Kensington and Chelsea  
NHS Westminster

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# 1. Executive Summary

## Introduction

- 1.1 The project aimed to develop options for care models to support patients living with HIV access primary care services was commissioned by NHS Kensington and Chelsea and NHS Westminster. The commissioned was given to Positively UK (then Positively Women).

## Background / Policy / Literature Review

- 1.2 With the improved life expectancy of many patients living with HIV, HIV is now classified as a long-term medical condition. Within the NHS' long-term medical condition model GPs have a key role to play in supporting patient health.
- 1.3 NHS policy aims to move care closer to the community with increased diagnostics within primary care settings. This is accompanied by a drive to improve the uptake of GP services across the population and to increase outpatient care for long-term medical conditions in the community.
- 1.4 Previous research reports indicate that patients living with HIV (PLHIV) have reported instances of discrimination from healthcare services, and low trust in GPs resulting in low uptake of GP services. Previous consultations by Wharfside and Frontline Patients' Fora demonstrate this is particularly noticeable in those diagnosed long-term with HIV.

## Models of Care

- 1.5 The current model of care for patients living with HIV has developed historically and evolved over 25 years; with people accessing acute clinics of their choice for HIV management. This is contrast to GP services which can only be accessed locally.

- 1.6 Brighton and Hove PCT introduced a Local Enhanced Service (LES) in 2008 for provision of primary care for patients living with HIV. GPs can voluntarily enter into the LES and are reimbursed for activities undertaken under the terms of this contract which includes compulsory attendance at HIV awareness training, registering a minimum number of patients living with HIV and monitoring a prescribed list of health concerns e.g. cardiovascular disease.
- 1.7 In 2008 Manchester PCT, in a move to support the uptake of GP services by patients living with HIV, introduced compulsory training for GPs and incorporated this into existing contracts. Guidelines for the management of patients were also produced which encompassed disclosure and confidentiality. This was complemented by a mentor programme to support patients living with HIV access GPs.
- 1.8 A key policy objective of the healthcare reform is the formation of one-stop shops; with a central hub and links to GP practices, these centres will provide increased scope for diagnostics and healthcare with the community setting.
- 1.9 A recommendation put forward by the Frontline and Wharfside Patient Fora, is to bring GPs into the HIV clinics. Bringing healthcare professionals on to one site would improve communication between GPs and HIV clinicians. It would also allow patients to access GPs and keep their healthcare within the acute centre which the fora considered supported confidentiality,

## **Consultations**

- 1.10 For this project consultation was undertaken with three stakeholder groups: patients living with HIV, HIV clinicians, and General Practice staff (either practitioners or practice managers).
- 1.11 Clinic governance was the greatest area of concern for all groups consulted. The need for training for GPs to increase their awareness and knowledge of HIV and confidence in managing the primary care health needs of patients was identified. Improving communication between GPs and HIV clinicians was also paramount.

- 1.12 Issues of quality of care firstly highlighted the needs of patients in understanding the role of the GP in supporting their healthcare and how to access the GPs. Secondly general practices could develop knowledge of HIV and improve standards of care by establishing a wider approach to HIV and by offering testing alongside primary care of patients' diagnosed HIV positive.
- 1.13 Confidentiality breaches are of high concern for PLHIV. Reported breaches are rare but there is evidence of some practices labelling the files of patients living with HIV differently to other patients and inappropriate questioning by reception staff in public waiting rooms. This highlights the need to agree protocols for handling patients files and information within primary care.
- 1.14 In reviewing accessibility there were noted incidents of discrimination and inappropriate behaviour and language of GPs, often when a patient disclosed their HIV status. This experience, or hearsay of such practice, discourages patients from disclosing their HIV status to GPs. Practices that displayed HIV material demonstrated a greater awareness and level of trust with HIV patients to disclose. This alongside trained staff who demonstrated knowledge of HIV instilled greater confidence in patients.
- 1.15 Stakeholders were consulted on the models of care outlined in sections 1.5-1.9. No single model of care emerged as the favoured option by all groups. Patients with good experience of a GP favoured retaining the current system. There was support across all groups for provision of training and voluntary sign up introduced by Brighton and Hove PCT; not forcing GPs to sign up as adopted by Manchester PCT. The concept of one-stop shops and the ability to access a range of services in one location appealed to some patients, notably women.
- 1.16 Placing a GP in the HIV clinic received greatest support by patients and with some clinicians; however the latter group raised concerns over the sustainability of this model when healthcare was moving to local provision. An alternative approach suggested was to place a GP in the HIV clinic for a limited period of time to support

patients' make the transition from accessing all care at acute centres to accessing primary care with a GP locally.

## **Proposed Models**

1.17 In reviewing and recommending options for care a key challenge to consider is the dispersed nature of how HIV care is accessed across London. Only a third of Westminster residents and half of Kensington and Chelsea residents access HIV care within their respective boroughs. There are also high numbers of patients at Wharfside and Kobler clinics who are not local residents, choosing to access HIV care away from home. Implications for PCTs arise in commissioning care that is locally based and addresses only the needs of local residents. Consideration needs to be given as to how, and to what extent, it can meet the needs of people accessing HIV care within the PCT, but not resident in that locality.

1.18 The **current system** while in line with healthcare policy of providing care locally is failing to meet the needs and concerns of most patients living with HIV; a new approach is therefore required to improve care and increase uptake of patients not only in accessing primary care services but in disclosing HIV status and thereby receiving effective healthcare.

1.19 Taking steps to **enhance the current system** through compulsory training for all GP practices would increase awareness across primary care. This approach alone would not guarantee changes within practices and improved quality of care. Implementing a LES with comprehensive training for practices and quality standards that GPs entered into voluntarily would better identify practices seeking to improve the care they provided. The LES could also allow GPs to register patients outside of their catchment area, thereby reaching patients who had no access to a GP working within the LES in their locality. Consideration needs to be given to including in the LES a list of conditions GPs should treat, as listed in the Brighton and Hove contract. While not popular with many patients, the approach could be used to support GPs in identifying and addressing risk areas for patients living with HIV.

- 1.20 The concept of **one-stop shops** could provide scope for HIV clinicians to provide clinics locally, and within the community. However one-stop shops are in development, how they will operate and any remit for sexual health and HIV still undecided.
- 1.21 **Embedding a GP in the HIV clinic** would meet the needs of many patients living with HIV, in particular long-term diagnosed who are accustomed to accessing all healthcare at the acute centre. Benefits to this approach are the reassurances around confidentiality and increased scope for communication between the GP and clinician. However GPs are gateways to other local healthcare and social care services, and a GP in the clinic could not fulfil this role for patients drawn from such as wide geographical spread as found at HIV clinics. This approach is also in contrast to NHS policy of moving care closer to the community.
- 1.22 The **transition model of placing a GP in the clinic** could provide a means of supporting patients, accustomed to accessing all healthcare at the acute centre, make the adjustment to accessing primary care. This meets healthcare policy of establishing care within community settings and supporting under-represented groups access primary care. It also supports patient uptake of health and social care services that can only be accessed through referral from a local GP.
- 1.23 There are **financial implications** associated with all the proposed models and associated costs need to be identified for implementation of each approach. Two key considerations which will have significant impact are firstly identifying the commissioning body. Should commissioning rest with primary care who are responsible for GP contracts; HIV leads who commission acute services with HIV clinics; or is joint commissioning required? A second and related consideration is who will have access to the primary care services commissioned, and is it possible to develop a tariff with other PCTs to give access to patients not resident in that locality.
- 1.24 It is crucial that in implementing any system that a structure be established to identify who has **responsibility for care**. No patient should be placed in a position

where the HIV clinician and GP refer the patient to each other, without treating the patient. Increased and direct communication between HIV clinicians and GPs will address this to some extent. To fully address this concern there needs to be agreement as to which healthcare professional has ultimate responsibility, or a third party appointed to advocate when such issues arise.

1.25 The proposed models identified above address GP and clinical needs.

Consultation identified that **training and information for patients** is required to raise awareness of how to access a GP, how to manage complaints and make informed choices particularly around disclosing HIV status in primary care settings.

### **Recommendations:**

**Recommendation 1:** New models need to be implemented to increase take up and efficacy of primary care. The current provision of primary care to patients living with HIV does not provide sufficient support to patients or general practices.

**Recommendation 2:** Short training sessions delivered to all general practices raising awareness of HIV, patients' concerns and additional support for practices commissioned by PCTs.

**Recommendation 3:** Enhanced GP services are introduced to address provision of primary care to patients living with HIV through a 2-day training course and annual update training for practice clinical staff.

**Recommendation 4:** In GP surgeries offering enhanced services, all practice staff including receptionists attend HIV awareness training.

**Recommendation 5:** Quality standards be developed with basic information GPs should gather on patients' HIV health and medications; increasing standard length of appointments for patients living with HIV and agreeing protocols around patient confidentiality.

**Recommendation 6:** Incorporate the quality standards into the Quality Outcomes Framework, the reward and incentive programme for General Practices to support implementation and monitor progress.

**Recommendation 7:** GP's providing enhanced services to patients living with HIV open practice boundaries to provide primary care to patients outside their catchment area, where there no enhanced GP services provided in their catchment area.

**Recommendation 8:** General Practices currently operating within a sexual health LES and/or delivering HIV testing be targeted to deliver the enhanced services, as these practices already have an understanding of HIV, can provide continuity of care for patients and are more likely to generate trust in existing patients to disclose their HIV status.

**Recommendation 9:** PCTs review options for provision of healthcare for patients living with HIV within the 'one-stop shop' model as it is developed.

**Recommendation 10:** A GP be established at HIV clinics, to provide primary care to patients living with HIV for a limited period of time, providing a transition to patients accessing a GP locally in their community.

**Recommendation 11:** Operational and financial assessment are undertaken into providing the 'transition' GP to all patients at Kobler and Wharfside Clinics, where 85% of patients are non-residents of those PCTs.

**Recommendation 12:** A 'hotline' or dedicated telephone line is established at HIV clinics enabling GPs to call with questions to discuss concerns around care of a patient living with HIV.

**Recommendation 13:** The current CQUN standards are built upon to establish procedures for routine cross-posting of information between HIV clinics and General Practice where patients have consented to sharing information.

**Recommendation 14:** Building on recommendations from previous studies, a nurse specialist and community lead be appointed as 'champions' to promote good work practices and support advocacy of patients between General Practice and HIV Clinics.

**Recommendation 15:** Training and information be provided to patients living with HIV so address finding and accessing a GP, patient rights and disclosing HIV status to a GP.

## 2. Introduction

The project was commissioned by NHS Kensington and Chelsea, and NHS Westminster with the project scope as follows:

The Primary Care Access Project was informed by the following:

- Recommendations from Lord Darzi's Healthcare for London report, and the wrapping of care around patient needs and development of the patient choice agenda
- The move towards managing long-term conditions outside of acute settings and closer to home and supporting patients to become expert in managing their condition
- Consultation with both Frontline [Chelsea and Westminster Hospital] and Wharfside [Imperial College NHS Trust/St Mary's Hospital] Patient Forums, HIV clinicians and Practice Based Commissioning by Commissioners in NHS Kensington and Chelsea
- The outcome of an Equalities Impact Assessment by NHS Kensington and Chelsea on an initial proposal to develop a Pilot HIV Shared Care Scheme
- A review of current literature and survey of PLHIV undertaken by Positively Women's Access to Mainstream Services project commissioned by NHS Hammersmith and Fulham and the London Borough of Hammersmith and Fulham

### Aims

The project aims were to develop a proposed model of care and patient pathways to meet the primary care needs of people living with HIV within primary care settings and to achieve this by engaging all stakeholders

To achieve this, the project brief was to undertake the following;

- Engage and consult with stakeholders, patients, primary care and HIV centres
- Ensure that the model maintains confidentiality
- Identify the support and training needs of primary care services and staff
- Identify the impact of the proposed care model on primary care budgets and specialised HIV budgets

- Investigate the feasibility of placing a primary care service within the HIV centre and of developing a group of practices around Kensington and Chelsea and Westminster

## **Process**

The project team worked with a Steering group made up of stakeholders who included patient representatives from The Frontline HIV Forum at the Chelsea and Westminster Hospital and the Wharfside Clinic Patients Forum at Imperial College NHS Trust [St Mary's Hospital]; GPs and HIV clinicians; HIV nurse specialists and commissioners from the two Primary Care Trusts. Monthly consultation meetings were held between the project team and the Steering Group.

A literature review was undertaken to identify latest healthcare policies in England, research into healthcare practice and needs for PLHIV and demographics of patients living with HIV and accessing HIV care in NHS Kensington and Chelsea and NHS Westminster.

Models of shared care introduced in the UK and Europe were identified and where possible site visits undertaken.

Commissioning practice for both primary and specialised/acute services were reviewed.

In adhering to the GIPA<sup>1</sup> principle, people living with HIV were involved at all levels of the development of the project.

A series of in depth one-to-one and focus group interviews/consultations were carried out with a total of 82 patients either resident or accessing HIV care in NHS Kensington and Chelsea or NHS Westminster, three GPs, two Practice Managers and six HIV clinicians. Details of those consulted are listed in Chapter 4.

Patients interviewed were asked a series of questions in order to explore their healthcare needs, their experiences accessing primary and acute health care, identify barriers to

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<sup>1</sup> GIPA – Greater Involvement of People Living with HIV

accessing care and how these could be addressed. Patients were also presented with proposed models of shared care and asked to identify their preferred model (for a list of questions please see Appendix 1).

GPs and Practice Managers questions focused upon the levels of care they currently provided for people living with HIV; what concerns, if any, they had around providing care for people living with HIV; how they thought these could be addressed and support needs identified. GPs were also presented with models of shared care and their preferences sought (Appendix 2)

HIV Clinicians were asked to describe the current system of care and what their roles and responsibilities are towards patients' care and GPs; any concerns they had about the current set up; their experiences of working with GPs and what elements of care they felt should be provided by GPs (Appendix 3).

### 3. Context and Policy

#### Literature review

The majority of research with PLHIV around GP access has been undertaken by Sigma Research who specialise in HIV and sexual health. The survey *What do you need? 2007-2008*, asked respondents whether they had encountered discrimination from healthcare staff including GPs and dentists, in the last 12 months<sup>2</sup>. Nearly one in five reported discrimination, the majority 83% stated the discrimination was due to their HIV status. In addition 27% also cited discrimination on the basis of sexuality. Others reported discrimination on the grounds that they were perceived as challenging health practitioners when seeking to be involved in their own healthcare decisions.

'It Makes Me Sick'<sup>3</sup>, again by Sigma Research, explored attitudes of gay men in accessing GP services; this included gay men who were HIV positive. The study found that 50% of gay men did not disclose their sexuality to their GP. There were a variety of reasons for this; the fact that GPs were known to and accessed by other family members; patients' raised concerns they would be discriminated against, upon grounds of their age, gender and religion; and the patients' assessment as to whether their sexuality was relevant to their care. Concerns and complaints about accessing GPs included the lack of understanding by GPs of HIV and their ability to provide effective healthcare to PLHIV. There were also concerns about the lack of continuity and care, and patients can be seen by a different practitioner when accessing the service. The time people had to wait for an appointment was a key concern, in some cases people had to wait over a week, which they felt inappropriate when managing a compromised immune system and when seeking immediate attention. Confidentiality arose as an area of concern and in particular 'HIV' being written on the front of case folders which are often left in public spaces and viewed by other patients. An element of good practice was identified in a setting where patients can act as a point of contact between GP and

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<sup>2</sup> Weatherburn et al, *What do you need? 2007-2008*, Findings from a national survey of people living with diagnosed HIV, Sigma Research, March 2009

<sup>3</sup> Dodds, C. et al, *It Makes Me Sick: Heterosexism, homophobia and the health of Gay men and Bisexual men*, Sigma Research (May 2005)

clinical specialist; however this was reliant on proactive patients and their ability to manage clinic relationships.

*The Framework For Better Living with HIV in England*<sup>4</sup> states that expertise in HIV and patient access has been developed through GUM services and acute centres, in contrast to other conditions where the first point of contact is normally through primary care services including GPs. As a result the latter have not specialised in HIV and primary care is often set apart from HIV care. Despite this the report perceives a role for GPs in managing 'medical and social problems' including access to community support services and palliative care. It also recognises a role for pharmacists in understanding interactions between prescription drugs and HIV medications. However there are barriers to PLHIV accessing and disclosing their status to primary care providers, notably concerns around competency of staff, HIV-related discrimination and breaches of confidentiality.

A Comprehensive Needs Assessment of sexual health and HIV services in Kensington and Chelsea undertaken on behalf of the PCT by Design Options in 2008<sup>5</sup> explored the role and perceptions of primary care providers, notably GPs. The assessment reported on a survey conducted by the patient led Frontline Patients' Forum. Overall it was found that the service provided by GPs across the borough was variable in terms of quality, access, availability and trained staff within the practice. In some instances discrimination was encountered with patients being refused access to GP lists once they had disclosed their HIV status or in one case being examined from the other side of the room. The survey found that majority of PLHIV in Kensington and Chelsea are reticent to access GP services, on the assumption that GPs would be discriminatory towards HIV, and that GPs do not have sufficient knowledge to treat PLHIV. In the latter there was concern that GPs did not understand how to treat HIV or other related symptoms when combined with HIV and there was a lack of understanding of how treatments interact with prescription drugs. Again this reluctance to access GPs meant that PLHIV preferred to have all their healthcare needs met by their specialist HIV clinics. Kensington and Chelsea has 43 General Practices and 112 GPs, but the Comprehensive Needs

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<sup>4</sup> Keogh et al, Framework For Better Living with HIV in England, Sigma Research, May 2009

<sup>5</sup> Design Options, A Comprehensive Sexual Health Needs Assessment on behalf of NHS Kensington and Chelsea and The Royal Borough of Kensington and Chelsea, (Sept 2008)

Assessment also found that “only 8 GPs and 10 practice nurses had had some form of sexual health training in the last 5 years”.

The draft BHIVA briefing paper on *Extending the role of primary and community care in HIV*<sup>6</sup> sets out principles and points to consider when planning any extension of the role of primary care and community health services in HIV. It considers different models of GP involvement, including:

- Shared care, whereby GPs take on the role of primary care and specialist clinics continue to see patients regularly for their HIV
- GPs take on responsibility for some aspects of monitoring HIV infection for patients who are stable and doing well i.e. adhering to medications with low viral load and high CD4 counts, within the context of a clearly defined shared care model. As a minimum, patients would still be assessed annually within a specialist HIV service
- GPs work in conventional outpatient HIV clinic settings. They would see patients who present with primary care needs and liaise closely with specialists to ensure clinical safety and to avoid problems such as drug interactions. Similar to the arrangements by which some GPs work in Accident and Emergency departments
- Specialist nurses or physicians undertake clinic sessions. This would include virtual clinics, alongside GPs in Community Health Centres

In 2007 a study of 124 GPs from practices the South of England in 2007 explored GPs' perceptions of barriers to involvement in managing patients with HIV<sup>7</sup>. The study suggested that the majority of GPs were comfortable in managing other illnesses in patients with HIV. It concluded that although there remained some uncertainty over how to differentiate other illnesses from HIV related health issues, a considerable proportion of GPs were interested in having an increased role in the care of patients with HIV. Understanding barriers for GPs is crucial if GP involvement is to be increased. Effective interventions to address these barriers would include training updates focusing on

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<sup>6</sup> Williams, I., Briefing paper: Extending the role of primary and community care in HIV; <http://www.bhiva.org/documents/Guidelines/Standards/090320%20PCBriefingPaper.pdf>

<sup>7</sup> Defty H, Smith H, Kennedy M, Perry N, Fisher M. GPs perceived barriers to their involvement in caring for patients with HIV: a questionnaire based study.2007.

distinguishing HIV illness from other health concerns and managing patients taking HAART.

One research paper, not specific to HIV, but worth noting is the GP Patient Survey, undertaken by the Department of Health<sup>8</sup>. Key findings from this were that 94% of patients have confidence and trust in their GP and over 80% stated that GPs gave them enough time and listened to them. However, questions were asked within the survey around the confidentiality of reception areas, with more than one out of every five respondents stating that patients could be overheard when they spoke to the receptionist; local data shows this finding is mirrored in Kensington and Chelsea and Westminster. Specific questions to people with long-term medical condition or disability found that the majority (83%) had discussed their condition with their GP or nurse and their views were taken on board, but only one patient in 10 had discussed a care plan with their GP to discuss managing their long-standing health problem.

### **NHS Policy and Strategic Reviews**

At a national level *High Quality Care for All* published 2009, cites a move across the NHS towards delivery of health services from primary care<sup>9</sup>. Primary care is best placed to support patients in accessing the range of other local services and patient choice in health services such as acute care. The report states: “The public trust their GP more than any other profession and they have strong bonds of trust with other primary care staff”. The report recognises some groups are excluded from primary care and PCTs need to develop plans to support further engagement. The report states that it is the GP’s role to act as a gatekeeper, supporting patients’ access wider services and influencing choice of healthcare services accessed. This should be considered alongside Sigma Research’s *Framework For Better Living*, which identifies that unlike other health conditions, PLHIV do not typically access GPs as their route into testing and healthcare.

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<sup>8</sup> GP Patient Survey, April to September 2009, Department of Health (January 2010)

<sup>9</sup> High Quality Care for All – Primary Care and Community Services: Improving GP Services, Department of Health, (January 2009)

A number of NHS strategies and reviews have identified the increased role primary care could play in the healthcare of PLHIV. The first *National Strategy for Sexual Health and HIV*<sup>10</sup>, published in 2001, identified key aims of reducing transmission of HIV, improving the health and social care for PLHIV and reducing stigma associated with HIV. It proposed then that there was a broader role for primary care providers in delivering sexual health services, notably HIV testing and counselling, but also identifying and developing clinical networks, across primary and acute care, for the management of HIV.

A review of the Strategy in 2008<sup>11</sup> identified that substantial progress in the field of HIV had led to HIV becoming a 'long-term management condition'. However competition and conflict between primary care, community and hospital-based services, and variable progress in engaging GPs in providing sexual health services are two key areas still to be addressed. The review recommends through implementing a long-term condition management model for HIV, and supporting access to primary care for health conditions unrelated to patients' HIV diagnosis. Standards for care should also be specified locally, in accordance with national standards and Quality and Outcomes Framework (QOF). A review produced by the Independent Advisory Group on Sexual Health and AIDS in 2009<sup>12</sup>, is one of several to identify that increased numbers of PLHIV, will lead to increased volumes of patients accessing and putting demands on acute clinics. A strategic approach is required to shift elements of diagnosis and care to primary and community settings and support self-care. This requires education to fill gaps in knowledge of staff, particularly within 'primary care where there is scope for the development of HIV services', thereby developing an 'HIV literate' health and social care workforce.

Testing and healthcare of patients should not be considered in isolation. For those undiagnosed earlier uptake of treatments will result in increased health outcomes and reduced costs of treatment in the longer-term. Engaging primary care to undertake HIV testing, will increase practitioners' knowledge of HIV and confidence to healthcare to

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<sup>10</sup> The National Strategy for Sexual Health and HIV, Department of Health, (July 2001)

<sup>11</sup> Progress and Priorities – working together for high quality sexual health; Review of the National Strategy for Sexual Health and HIV; MedFASH, on behalf of the Independent Advisory Group on Sexual Health and HIV (July 2008)

<sup>12</sup> Independent Advisory Group on Sexual Health and HIV; Building on Progress, Enhancing the Response in England, Department of Health, (November 2009)

patients living with HIV; whilst support retention of patients living with HIV accessing primary care.

London HIV Strategy<sup>13</sup> sets HIV in context, stating that 50% of people in England living with HIV reside and access treatment in London, with incidences of HIV rising, there is increased pressure on clinical provision and funding. The strategy reiterates the need to develop shared care between acute centres, primary care and community-based settings. The strategy sets out nine strategic aims; one of which includes “Ensuring accessible and appropriate services in primary care”, with the further aim of introducing “at least one ‘London-wide local enhanced services’ initiative’ within primary care contracts and developing special interest HIV services.”

*Sex and the City* published by MEDFash<sup>14</sup> cites Sexual Health and HIV as one of London’s public health priorities, with inner London PCTs having higher incidences of HIV. An accompanying paper, *Sexual Health Indicators*<sup>15</sup>, shows rising prevalence between 2002 and 2006, with Kensington and Chelsea witnessing a 15% increase in that period and Westminster an increase of nearly 29%. *Sex and the City* also recommends extending HIV testing into non-traditional settings including testing for everyone registering with a GP. The report recommends the establishment of information infrastructures, including IT systems for data collection and analysis.

The *London-Wide Sexual Health Framework*<sup>16</sup> echoes the key factors raised by other reports; that increasing numbers of people diagnosed and living with HIV are putting pressure on HIV acute services, and the need to address late diagnosis to support good health outcomes. It also recognises the social aspects of HIV in affecting already experiencing health inequalities such as BME communities. The Framework sets its

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<sup>13</sup> London HIV Strategy, London HIV Commissioning Group (January 2005); <http://www.swagnet.nhs.uk/Resources/Nat%20documents/London%20HIV%20strategy%20version%206%20-%2013%20jan%2005.doc>

<sup>14</sup> Sex and our city: Achieving better sexual health services for London Project findings and recommendations Medical Foundation for AIDS and Sexual Health (MedFASH) with London Health (Observatory And Health Protection Agency for London Sexual Health Programme (Published Online Nov 2008)

<sup>15</sup> London sexual health indicators A data-driven needs assessment, London Health Observatory and Health Protection Agency commissioned by MedFASH and the London Sexual Health Programme (Nov 2008)

<sup>16</sup> London-Wide Sexual Health Framework, North West London Strategic Health Authority on behalf of the London Strategic Health Authorities (2005)

vision within the policy and structural changes to the NHS; the new General Medical Services contracts which provide scope to develop sexual health services and provision within primary care. The Framework developed in 2009<sup>17</sup> sets clear objectives around HIV firstly for reducing late HIV diagnosis through increasing testing in community and primary care settings. Secondly in providing better care for patients with HIV through high quality chronic disease management with access to HIV testing, referral to specialist HIV treatment and care services, and self-management programmes for people living with HIV.

*Healthcare for London's Framework for Action*<sup>18</sup>, identifies HIV as a specific health challenge for the capital. Healthcare for London established a series of working groups to explore specific areas. The Long-Term Conditions (LTC) Working Group states the need to improve care of people living with LTC, including people living with HIV. Recommendations incorporate structural changes in how healthcare is delivered in the capital:

- A key element in supporting patients manage their health condition and achieve good health outcomes is in diagnosing the condition in the first place, and tackling under-diagnosis should be a key priority.
- Care pathways and referral protocols are developed and introduced to support GPs manage patient care. In developing care pathways, greater recognition of patient need by using patient segmentation on the basis of severity would support referrals by GPs and access to effective care for patients.
- Introduce routine out-patient care for all LTC within the community, this could be achieved through patients requesting appointments, or through GPs and specialist nurses recalling patients. One annual review is currently required with each patient under the QOF.
- The report also recommends a designated consultant or nurse specialist and a community lead are identified for each major long-term condition in each PCT

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<sup>17</sup> London-Wide Sexual Health Framework, London Sexual Health Commissioning Board (2009)

<sup>18</sup> Healthcare for London, A Framework for Action, NHS London (July 2007)

area. Both roles would champion the implementation of protocols in their area and work to develop work practices between community and hospital care. The specialist would provide training to practices and advice to practitioners on an ongoing basis.

This report also recommends specialist outreach clinics be established, but only where there is sufficient volume of patients to justify commitments of the specialist doctor's and nurses' time. The report cites that clinics of 50,000 patients would be feasible as they would encompass approximately 1,750 diabetics and 450 patients with Chronic Obstructive Pulmonary Disease. However the sub-group recognises that this volume or critical mass will vary depending upon condition. The following table has been reproduced from the Healthcare for London report, and statistics for HIV have been added for comparison.

#### **LTC – Top 4 major LTCs in London compared to HIV**

<b>LTC</b>	<b>No. of diagnosed Londoners</b>	<b>% of London Population</b>
Congestive Heart Failure	111,548	1.5
Asthma	390,128	5.2
Chronic Obstructive Pulmonary Disease (COPD)	72,382	1.0
Diabetes	295,877	4.0
<i>HIV</i>	<i>26, 906<sup>19</sup></i>	<i>0.37</i>

In summary, one in 25 Londoners present with Diabetes, one in 20 with Asthma and approximately one in every 300 with HIV. Based on these figures a clinic of 50,000 patients would include approximately 160 patients with HIV. This raises issues around the feasibility of establishing clinics and what role primary care can play in meeting the wider healthcare needs of PLHIV.

All governmental healthcare agencies work within the *NHS Operating Framework*. The 2010/11 Framework<sup>20</sup> has five national priorities; three of particular relevance to this

<sup>19</sup> SOPHID 2008, National Tables by SHA of Residence, Health Protection Agency (issued 2009)

<sup>20</sup> The Operating Framework for the NHS in England 2010/11, Department of Health (December 2009)

report are; firstly improving access to GP services by developing innovative approaches to services and increasing accessibility through extended weekend and evening appointments. Secondly keeping adults and children well, improving their health and reducing health inequalities and thirdly improving patient experience, and staff satisfaction and engagement. The commissioning goals for clinical services are to develop care pathways that best promote health outcomes for patients. For long-term conditions there should be increased promotion and support for self-care and condition management.

Other operating guidelines that should be noted are those for commissioning. *Who Pays*<sup>21</sup>, sets out in its guiding principles that: “In general, the responsible commissioner will be determined on the basis of registration with a GP practice or, where a patient is not registered, their place of residence.” There are challenges to address in supporting patients to access primary care where they feel able to disclose their HIV status and address. This would also support accurate data collection and support commissioners across the NHS to understand the needs of local residents and commission effectively.

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<sup>21</sup> Who Pays? Establishing the Responsible Commissioner, Department of Health (September 2007)

## 4. Models of Care

Five models of care were identified and presented to all participants who took part in focus groups and one-to-one interviews. The models are as follows:

1. The Current Model of Care
2. Brighton and Hove PCT's Local Enhanced Services (LES)
3. Manchester PCT's approach to Equity Across Contracts
4. The German Model of GPs with an interest in HIV
5. Embedding GP services in the acute setting

### 4.1 The Current Model of Care

The current model of HIV care operating across the NHS today has evolved over 25 years. It is a model where patients have a choice, and open access, in where they access certain aspects of their health care, including HIV care. This is in contrast to primary care, where patients are required to register with a GP locally. Catchment areas are established for each GP and they will only register patients who fall into that geographical area.

Patients access acute HIV care at Imperial College Healthcare NHS Trust (at the St Mary's Hospital site in Westminster), at the Chelsea and Westminster Hospital NHS Foundation Trust (at their three clinics, John Hunter Clinic in Kensington and Chelsea, Dean Street Clinic in Westminster and the Nkosi Johnson clinic at Charing Cross Hospital in Hammersmith) and at the Mortimer Market at University College London. All aspects of HIV care are provided at the HIV clinics. Patients have freedom to choose which centre they access their care and this is not geographically bound. Hence the HIV centres can and do see patients from other parts of the capital and from outside London.

Patients are expected to access primary care locally. However it is recognised that patients living with HIV often won't access primary care locally or at all and historically many patients have obtained all healthcare from the HIV acute centres. Patients, in particular those with a long-term diagnosis, may have built up good relationships with their HIV clinic over the years and many have been with the same consultant for a long period of time.

The HIV Consortium patient pathway identifies primary care as an access point into HIV care and treatment (see section 6.7). The pathways also expect protocols for HIV services to support GPs through the provision of specialist advice and support where required. Funding to HIV services includes costs of some non ARV drugs for HIV related health needs, but not as an alternative provision for primary care.

#### **4.2 Brighton and Hove PCT's Local Enhanced Services (LES)**

In 2008 Brighton and Hove PCT introduced a Local Enhanced Service (LES) to address the primary care needs of PLHIV and support greater access to GPs. Elements of this LES include:

- Maintaining lists of PLHIV and all their drugs including HIV medications
- Monitoring patient adherence to HIV medications
- Managing cardio vascular disease (CVD) risk and mental health
- Providing sexual health checks and contraception, vaccinations and annual cervical cytology
- Advising on alcohol and recreational drug use and safer sex

All practices signing up to the LES are required to:

- Attend comprehensive 2-day training, accredited by the Royal College of Nursing, addressing managing specific conditions such as mental health and co-prescribing, attend HIV educational updates at least yearly
- Have at least five HIV positive patients registered
- Meet competencies in the Royal College of General Practitioners 'Minimum standards of care for HIV in General Practice 2003'

Initially only eight practices signed up when LES was introduced, this had risen to 26 practices by September 2009, out of a total of 48 practices in the PCT, an uptake of 54%.

Since the LES was introduced in 2003, it has been audited on a yearly basis by Brighton and Hove PCT. This has been the mechanism through which standards are set and through which GP practices show that they are meeting the requirements of the LES it

has consisted of collating information from each LES practice auditing their activity on certain indicators over the year. Further evaluation to measure impact and patient experience is yet to be undertaken.

#### **4.3 Manchester PCT's approach to Equity Across Contracts**

During a scoping exercise in 2008 by the Greater Manchester Sexual Health Network to agree a standard annual price for looking after an adult in an HIV outpatient department, it emerged that some people were using secondary care services that would be better dealt with in primary care, by GPs. It was agreed by clinicians and managers that primary care issues should be managed by primary care. A survey was used to seek a baseline measurement of people's attitudes to making best use of resources in primary care to treat everyday illnesses and reduce impact on specialist services<sup>22</sup>. Seven features were identified in the review:

1. Improved communication needed with clear structures and vision
2. Training for GPs and dentists; more information for GPs when prescribing medication for patients on anti-retroviral (ARV) medication: some non-specialists/GPs were not sufficiently aware of the drug interactions between HIV and medication for other conditions, and the effect of HIV medications
3. Hours and access to GP services were deemed restrictive and not conducive to patients' hours of work
4. Some staff require training and information to reduce discrimination and breaches of privacy and confidentiality
5. Development and use of a mentor programme provided by service users
6. Development of GPs' knowledge and close links with specialist services to enable development of skills

The review demonstrated that further work was required to ensure patient confidence during the transition to primary care. It was felt that education and training should be established and accredited at a sub-regional level including confidentiality and diversity training across Greater Manchester. Results of the consultation together with work with other health professionals led to the:

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<sup>22</sup> Positive Pathway: An independent review of comments collated during public consultation on HIV outpatient services in Greater Manchester; August – September 2008.

- Development and introduction of a service aimed at ensuring equity of access for all NHS patients to primary care across Greater Manchester, for all patients, regardless of their HIV status
- Compulsory training to all practices in to increase the knowledge of GPs in managing patients living with HIV
- Production of guidelines were for GPs addressing confidentiality and information sharing
- Involvement of patient groups in developing the model and the production of guidelines
- Implementation of a peer mentoring programme to support patients living with HIV to access primary care services was also introduced

An online resource for GPs which lists commonly prescribed drugs and their compatibility with HIV medications was proposed but not produced. This was on the basis that it would require constant updating placing greater demand on clinicians and clinical governance; GPs do not always have access to the internet in consultations, or access is sporadic, and finally that this approach was too prescriptive, and in individual cases clinical discretion was required. An evaluation of this model is yet to be undertaken.

#### **4.4 The German Model of GPs with an interest in HIV**

Germany has a long-established model in place whereby patients living with HIV access primary care at GP practices as follows:

- The majority of practices in Germany are large, with several GPs practicing on one site
- GPs within these practices can specialise in supporting patients living with HIV, by working for at least and up to two years in a hospital department of infectious diseases, and/or have a background in research work for instance epidemiology
- GPs are then required to gain one-and-a-half to two years experience of working in a GP surgery seeing PLHIV including the provision of home care
- GP practices also undertake HIV testing

- As a result of their size practices see a large number of patients overall, and a significant cohort who are living with HIV
- Specialist GP centres of this type have 100 plus patients living with HIV registered and accessing care
- There are no catchment areas so patients have free choice of GPs

Under the German model patients can access the GP of their choice regardless of area of residence, in contrast to the current system in the UK where patients have limited choice of GPs and this depends on their residence and catchment area of GP practices. However there are elements of this in place, or measure for reform already proposed within the UK. In March 2009, the NHS issued a consultation document reviewing GP boundaries:

- Shifting a significant proportion of hospital services into community settings is considered integral to the Government's aims
- One aim is to bring care to patients' local areas and improve links between different services and care providers
- A secondary aim is to improve patient experience, improve communication between services and reduce the costs associated with hospital-focused services
- A review is also underway to remove catchment areas, allowing patients to access any GP of their choice, regardless of their residency.

This approach is essentially an evolution of the concept and acknowledges the fact that streamlined, community services will not be based at a single site. This approach will be based around a central 'hub' (the 'one-stop shop') and then there will be 'branches' and referrals leading off to other services including other GP practices, hospital-based services, social services and other community based care organisations. In many respects this approach is similar to the systems we already have, in that is a network of pathways between different care services. This significant difference is that this approach will have GPs at the centre, commissioning services, assessing need and playing a key role in keeping services as community-based as possible.

#### **4.5 GP Services embedded in the Acute Setting**

Patient groups at the Kobler and Wharfside Clinics have proposed a model whereby a GP service would be introduced at hospitals and providing surgeries to patients living with HIV at the HIV clinics. This could provide a one-stop-shop for patients living with HIV. Situating practitioners together could provide closer relationships between the GP and the HIV clinic staff, and may facilitate clinical management of other conditions e.g. cardiovascular risk and depression. HIV specialist staff would be responsible for HIV care; allowing the GP to develop expertise in primary care of HIV disease and improve HIV clinicians' communication with an understanding of primary care.

This approach removes care from the community, reinstating it within acute centres; this runs contrary to current policy. It also makes HIV an exceptional case in terms of how patients access primary care compared to other long-term and chronic conditions. Community GPs are increasingly becoming gateways for patients to access services, and services increasingly moving from acute centres to the community. Another consideration for this model is how patients living with HIV access community based services e.g. community mental health services in their area of residence.

Provision of out-of-hours services also needs to be reviewed. With patients living across a wide geographical spread there would be implications in providing out-of-hour's services and home visits.

Another key issues to consider is how PCTs would be charged for the primary care accessed by residents within acute settings. This would require a tariff system to be developed and implemented and agreed by all PCTs concerned.

## 5. Stakeholder Consultation

Consultations were undertaken with the three stakeholder groups; patients living with HIV either resident or accessing services in Kensington and Chelsea or Westminster; GPs within those boroughs, and HIV clinicians from Imperial Healthcare, Chelsea and Westminster NHS Trust and the Royal Free. Main themes emerging throughout the consultations were:

### **Clinical Governance**

Who has overall medical responsibility for treating patients and managing specific aspects of their healthcare?

### **Quality of Care**

What standards do patients expect from healthcare practitioners and how do acute and primary healthcare practitioners' best deliver high standards of care? This also addresses the quality of communication between patients and multi-disciplinary healthcare teams.

### **Confidentiality and Trust**

How confidential is patient information, and who has access to this information? This is a particular issue for HIV, a condition still highly associated with stigma.

### **Accessibility and Choice**

How accessible are GP practice services in terms of registration, appointments and choice of practitioner and how could this be improved?

### **Models of Care**

Finally all stakeholders groups were presented with the models of care identified in Chapter 4, opinions sought as to the pros and cons of each and their preferences for how primary care could best be delivered for patients with HIV.

## 5.1 Patients living with HIV

Eighty-two patients either resident or accessing HIV care in NHS Kensington and Chelsea or NHS Westminster was engaged through focus groups or one-to-one interviews.

### Description of patients by gender and ethnicity

Gender	African	Afro Caribbean	Caucasian	All
Female	37	5	6	48
Male	9	3	22	34

Respondents by residence in PCT where HIV care is accessed (some respondents both lived in and accessed care in the borough hence total is greater than 82)

Resident in KandC	Accessing Care in KandC	Resident in Westminster	Accessing Care in Westminster	All
19	35	24	34	112*

There were no marked differences in responses or views of patients resident in Kensington and Chelsea and Westminster from those accessing care in those boroughs.

## 5.2 General Practitioners

One-to-one interviews were held with the General Practitioners (GPs) and two Practice Managers (PMs).

GP 1: A partner at a large practice in West Kensington. The practice has 11 GPs and over 15,500 patients. It has few patients living with HIV some have disclosed their HIV status some have specifically asked for HIV not to be on their notes. The practice deals with general primary needs for these patients. Currently, therefore they do not have any special provision for HIV patients.

GP 2: A single GP practice based in Kensington. The practice has 3,500 patients registered, and 10 of the GP's patients have disclosed their HIV status. Provides primary care support and views HIV as a long-term manageable condition.

GP 3: Group practice of three GPs, practice based in Kensington. The practice has approximately 3,000 patients registered, and the GP has patients living with HIV on their register. Practice also provides HIV testing.

PM1: Group GP Practice based in Kensington with a catchment area cross Kensington and Chelsea and Hammersmith and Fulham. The practice has five GPs and 6,600 patients. This practice has approximately 12 patients living with HIV who have disclosed their status to the practice. Services they provide include HIV testing and providing primary care for their HIV patients.

PM2 - Group GP Practice based in Kensington and Chelsea. The practice has two GPs and approximately 1,000 patients. About three patients living with HIV have disclosed their status. Services provided include HIV testing and ongoing primary care.

All the practices are close to main HIV clinics.

### **5.3 HIV Clinicians**

Interviews were done with six HIV clinicians from the Imperial College Healthcare Trust (St Mary's Hospital), the Chelsea and Westminster Hospital and the Royal Free Hospitals.

### **5.4 Summary of Consultations**

Analysis and conclusions of stakeholder consultations follow. Actions are identified after each key section and these are then brought forward into the final recommendations where they are considered alongside other issues such as equality and commissioning frameworks.

#### **5.4.1 Clinical Governance**

The greatest area of concern for all groups was that of clinical governance. Within this drug interactions were the over-riding concern identified by all groups, and how to avoid drug interactions by GPs prescribing medication that will not interact with HIV treatments. Need for communication between GP and specialist to support GP understand this should include a record of HIV treatments patients are currently accessing, and a 'hotline' for GPs to contact clinics to take effective action against prescribing drugs that would interact with HIV medications.

Many patients currently do not have confidence in GP's knowledge of HIV, the clarity of GPs to understand what is HIV related and therefore treat symptoms/conditions that are either unrelated to HIV or exacerbated by HIV. In addition GP's ability to manage the complication of co-infections casted further doubt on patients' confidence in GPs.

GPs and clinicians themselves recognised the need for training to be delivered to GPs and updates about latest developments in HIV to deliver best care. Alongside this was the need to establish clear clinical guidelines as to what is within GPs remit and what within HIV specialist.

Training for GPs to be introduced; both introductory training that provides a background in HIV, when to refer to HIV clinicians and avoiding drug interactions; and updates as approaches to HIV care change. Attendance at training to be designated protected learning time.

Sharing of patient information is often left to the individual responsibility of a GP or clinician and is the approach is ad hoc depending on the healthcare professional and clinic. Protocols for sharing patient information needs to be established to improve communication, meet the needs of both the HIV clinician and the GP thereby supporting patient outcomes.

#### **5.4.2 Quality**

Concerns for some patients around the perceived specialist versus non-specialist knowledge of HIV clinicians and GPs respectively; all treatment was better supported by the clinician as HIV was the dominant and over-riding health issue. HIV clinicians

however were clear of the 'specialist knowledge' that GPs bring in managing conditions beyond HIV, in particular conditions associated with ageing, mental health and effective signposting to other local services.

Training and information needs to be provided for patients in understanding the role the GP can play in managing their overall health and non-HIV health conditions.

There was clearly misunderstanding or misinformation in terms of patients rights to be seen by the same GP at each visit; patients perceived they had to take the GP presented forward by the receptionist and if different explain their situation all over again; in fact patients can request to be seen by the same GP at each visit although that GP may not be available and they may have to wait for an appointment. If taking an appointment with the first GP available, GPs felt it reasonable patients should be asked questions in order to ensure the practitioner understood the case and provided the best consultation.

Training and information should be provided to support patients understand how to access GPs, their rights when accessing a GP, and the expectations upon patients by the practice.

Patients were unhappy with length of appointments, with an average of 10 minutes consultation being insufficient to comprehensively address complex issues associated with HIV.

Consideration should be given to increasing appointment times from an average of 10 minutes to 20 minutes for patients living with HIV.

All stakeholders identified the benefits of GPs undertaking HIV testing and sexual health screening. Practices would then provide a continuum of care for patients, with GPs delivering healthcare to patients, pre and post diagnosis. This would improve knowledge of HIV and sexual health and embed care around patients with HIV in the practice.

There is value in GPs taking a wider approach to HIV, providing HIV and sexual screening alongside measures to support primary care of patients living with HIV.

GPs and Clinicians stated communication between both parties was unsatisfactory on both sides and procedures needed to be developed to improve this. This could range from the use of electronic patient records that both practitioners could access; to records cards that are carried by patients listing outcomes of consultations and prescribed medications.

Systems for improving communication between GPs and HIV Clinicians need to be developed. Consider implementation of a phone line whereby GPs can contact clinics for reference and guidance when managing the primary care needs of patients living with HIV, and crucially minimise risk of drug interactions.

It was suggested by clinical staff that each GP designate an 'HIV champion'; this person would be responsible for ensuring effective care of patients living with HIV across the practice, identifying training needs, and liaising with key stakeholders such as clinicians.

Finally, GPs stated that a key driver for delivery is the Quality Outcomes Framework (QOF). If care of HIV was written into QOF targets this would act as incentive for GPs and drive up quality of care delivered.

#### **5.4.3 Confidentiality and Trust**

Actual breaches of confidentiality of HIV status are rare; however the perception and fear of confidentiality breaches are common amongst patients living with HIV. Patients perceived reception staff as the main risk, followed by nurses, then GPs least of all. There was also evidence of practices labelling patients' case files in ways that identified them as HIV positive. Some GP practices have taken steps to address this through staff training and ensuring cases are coded e.g. HIV is classified as a 'retro-virus'. All groups consulted agreed that training to staff across the GP clinic in confidentiality would be of benefit. This training would also support patients in disclosing their HIV status to their GP.

*Training for all General Practice staff including receptionists be considered, with a view to reinforcing key issues such as confidentiality. Alongside this protocols be agreed for the handling and marking of patient files.*

Stakeholders identified a lack of clarity across general practices as to whether a patients' HIV status needed to be disclosed when notifying third parties such as employers and insurance companies of a patient's health. This can act as a barrier to patients disclosing their HIV status to their GP.

*Training for GPs should address areas of disclosure and guidelines issued to support patient confidentiality when dealing with third party notification.*

Patients have reported that they access GPs but withheld disclosing their HIV status. HIV clinicians and practice staff identified that are serious implications if patients choose not to disclose their HIV status to their GP; for example a GP would not know to review prescribed medications to avoid drug interactions with HIV treatments.

*Training and information should be developed for patients advising them of the implication of not disclosing and supporting patients to make informed choices on disclosure to GPs.*

There was a suggestion by some GPs and HIV Clinicians that clinicians provide HIV clinics within GP practices on set days. This approach was not favoured by patients who raised concerns around confidentiality, other patients at the practice seeing them attending an HIV specialist, and that HIV care was best provided separately.

*HIV clinics within GP practices are not pursued at this time as this could pose a greater risk to breaching patient confidentiality.*

#### **5.4.4 Accessibility and Choice**

There is a wide variation in GPs approach and attitude to managing healthcare of people living with HIV. Evidence was presented by patients, HIV clinicians and GP practices of

prejudice by some General Practices, ranging from inappropriate comments to direct discrimination. This behaviour acts as a barrier to patients disclosing their HIV status to GPs and patients who have experienced prejudice with a GP in the past are increasingly unlikely to disclose in future.

*Training should be provided for GPs and practice staff in correct language to use with patients living with HIV and; systems to report instances of discrimination.*

Patients and practice staff both reported evidence that a practice understands HIV through display of materials and offering HIV testing, and GPs publicise experience in managing patients with HIV gave patients confidence to disclose and discuss their status with their GP.

*General practices could take steps to actively demonstrate their accessibility to PLHIV.*

Patients can experience problems registering with a GP. This could be because the patient has attempted to access a GP outside their catchment area or the GP is turning them away on the basis of their HIV status. Patients living with HIV face discrimination in many aspects of life. When turned away a patient may interpret this as discrimination, even if this is not the case. This can deter patients from registering with other practices.

*Training should be provided for patients living with HIV in finding a GP, identifying GPs within their catchment areas and how to gain feedback and take complaints if unfairly denied access to a GP.*

#### **5.4.5 Models of Care**

No one model of care emerged as the most popular by all groups.

#### **Existing System**

For a small number of patients the existing system meets all their healthcare needs; they feel confident in disclosing their status and the standard of care given by their GP and the practice. However this was by no means a common response, and the evidence

gained from stakeholder consultations clearly identifies the need to develop new approaches to managing the primary care needs of patients living with HIV.

### **LES and Contract Equity**

The proposal of a LES was popular with all groups. The element that received greatest support was the provision of training to all GP practices; there were strong views across all groups, particularly patients and HIV clinicians that training should be extended to all practice staff including receptionists to address issues of confidentiality.

The list of areas that GP's should address, as provided in the Brighton LES was not popular with any of the groups on the basis it was akin to a 'tick-box' exercise and did not necessarily provide quality of care.

Concerns however were raised by HIV clinicians and general practice staff that offering financial incentives could lead to practices signing up for monetary reward only and delivering minimum standards of care. An alternative approach suggested was that in place of financial incentives, practices that wanted investment through training and support to develop and deliver high quality care for patients were targeted.

*Emphasis should be given to training of GP and practice staff; and list of conditions to be addressed be subject to further review.*

Concern raised by HIV clinicians as whether this approach meets all the needs of their patients; Manchester and Brighton in particular are smaller areas and the majority of patients accessing HIV clinics are local residents; in Westminster and Kensington and Chelsea there a large number of patients who are not residents of the borough and patients travel from across London and beyond to access these HIV centres.

*The needs of residents of Westminster and Kensington and Chelsea and non-residents accessing care need to be considered when developing enhanced services.*

### **GPs with Special Interests**

In considering the level of expertise of GPs there was no clear evidence from stakeholders that a GP with a special interest, i.e. with a background and history of

working in HIV, was necessary. Although GPs with Special Interests had gained experience and were able to meet the needs of patients, it was deemed sufficient for GPs to attend training in managing patients with HIV and building up experience by treating patients in their surgeries. Experience of treating patients was deemed essential and this would only occur if there was sufficient volume of patients on a GPs register enabling the GPs to develop and expertise in treating patients living with HIV.

*Smaller numbers of GPs specialising in primary care of PLHIV will support higher numbers to access those practices, and GPs to build up specialism in treating PLHIV.*

### **One-stop shops**

There is support for this model amongst the patient group. This centred on the potential to provide a range of diagnostic services, in particularly for female patients who access a range of services, such as gynaecology. GPs raised concerns that as these new centres would be larger and operating across different sites, i.e. the hub and spoke model, where patients were at great risk confidentiality being breached. If these claims were addressed, the 'one-stop shop' approach could be able to meet some of the primary healthcare needs of patients living with HIV.

*Options for supporting patients living with HIV, access range of primary care services be considered when developing 'one-stop shop' models.*

### **Embedding a GP in the HIV Clinic**

Within the patient group there was a skew in opinion towards establishing a GP in the clinic; allowing primary care to be accessed alongside their HIV care, and providing reassurances around confidentiality. However this model did not meet the needs of all patients, notably those who wanted to access services locally, and parents who accessed the GP as a family unit.

GPs gave some support for this approach but pointed out that a GP in the clinic full-time would become isolated for their peers and de-skilled in other areas of healthcare, in

addition there may not be demand for a full-time GP. The role would best be suited for a GP on part-time basis, or/and on secondment.

Clinicians considered the GP practice within the clinic a good approach, however raised concerns that this was not sustainable under healthcare policy to shift care to community settings. An alternative approach of the 'transition GP' was raised by clinicians. Under this model a GP would provide care to patients for a limited period of time, this care would support patients who have not accessed a GP for many years to understand the role of the GP in the management of their healthcare and act as a bridge, supporting patients to then move on to accessing a GP within the community.

*Two models for a GP in the clinic should be considered; firstly establishing the GP on a permanent basis; secondly establishing a 'transition' service that would run for a limited time and support patients access a GP in the community.*

## **5.5 Patients, Residency and Centres of Care**

### **5.5.1 Residents not accessing healthcare locally**

In considering stakeholder views and impact upon patients it is necessary to review who accesses HIV care within the boroughs.

In Kensington and Chelsea, there are 1,026<sup>23</sup> residents diagnosed and living with HIV. Just over half the population, 558 (54%), access care within the borough.

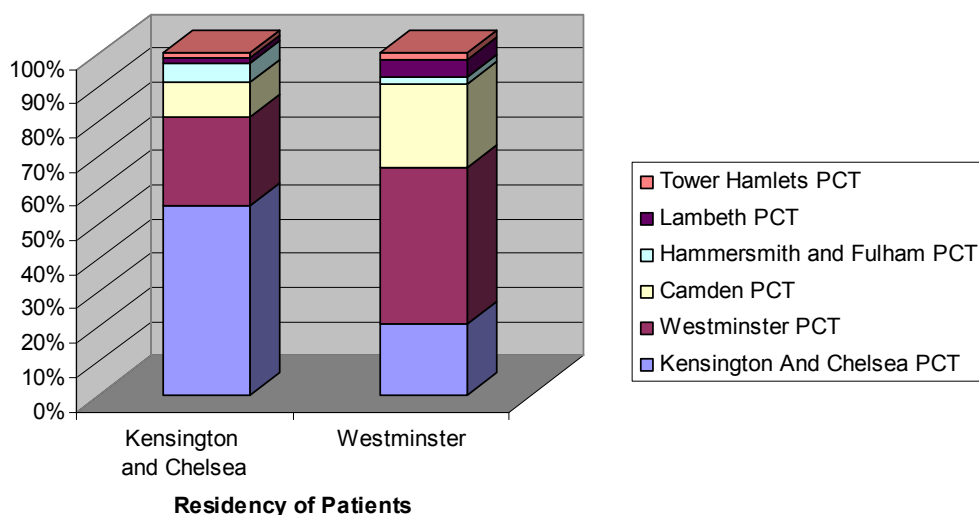
In Westminster, there are 1,302 residents diagnosed and living with HIV. Just under half, 585 (37%) access care within their borough.

There are high numbers of residents accessing care outside of their borough of residence. However for the vast majority, these centres are limited to firstly high numbers of Westminster residents' access care in Kensington and Chelsea, and vice versa. For Westminster there are also high numbers 317 patients, accessing care in Camden PCT. Overall care centres accessed by patients living with HIV in the boroughs are consolidated over a limited geographical area and number of PCTs.

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<sup>23</sup> \*All figures quoted are provided by SOPHID; there will be variance as the breakdown for areas with populations of less than 10 are not reported.

**Patients Resident in Kensington and Chelsea and Westminster  
and PCT's accessed for Acute Care**



Data tables for the above chart are as follows:

	Kensington and Chelsea	Westminster
Kensington and Chelsea PCT	558	267
Westminster PCT	262	585
Camden PCT	102	317
Hammersmith and Fulham PCT	54	24
Lambeth PCT	17	65
Tower Hamlets PCT	15	27
Brent Teaching PCT*	<10	<10
Ealing PCT*	<10	<10
South West London*	<10	10
Outside London*	<10	<10
<b>Total</b>	<b>1026</b>	<b>1302</b>

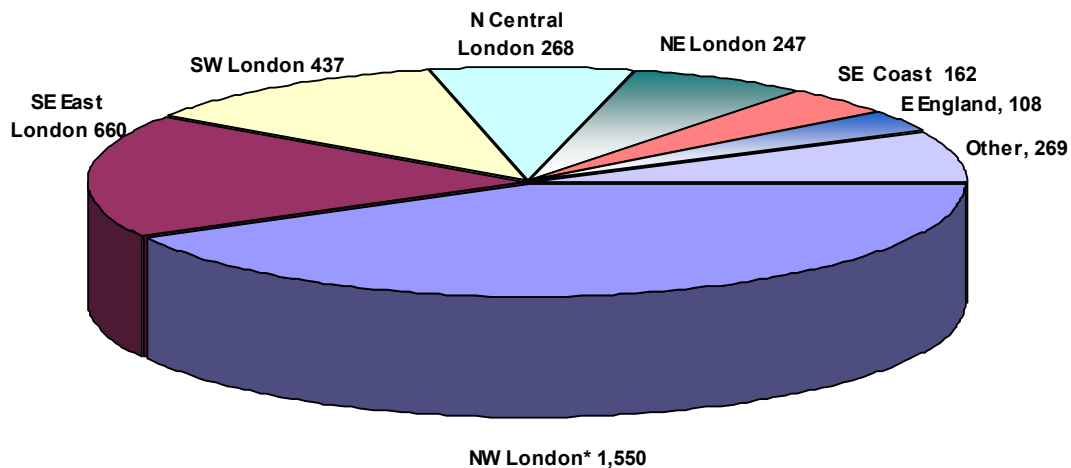
When commissioning primary care for patients living with HIV it is important to recognise that many do not access care at their local acute centre. Therefore situating a GP in the acute centre will not meet the needs of these patients, unless all centres adopt this approach. A range of options need to be considered to meet the needs of all patients. There is therefore an opportunity to improve access to local primary care centres to support this group of patients continue to access the acute centre of their choice and have access to primary care locally.

### 5.5.2 Patients who are non-residents

As patients living with HIV have a choice of where they access their HIV care, this has an impact not only on considering residents of the borough, but also the potential impact upon those accessing care within Kensington and Chelsea, but are not residents, when commissioning new models of care. Currently there are 3,714 people accessing HIV care with Kensington and Chelsea PCT. There are currently 3,848 patients accessing care at the Westminster PCT as follows.

While residents of Kensington and Chelsea and Westminster tend to access care at a limited number of centres, the picture is very different in looking at those accessing care within the boroughs. Acute HIV centres in Kensington and Chelsea and Westminster are attended by patients not just from across London but across England.

#### Patients Accessing Care in Kensington and Chelsea By Sector (Patients resident in London) and Strategic Health Authority (Patients resident in England)

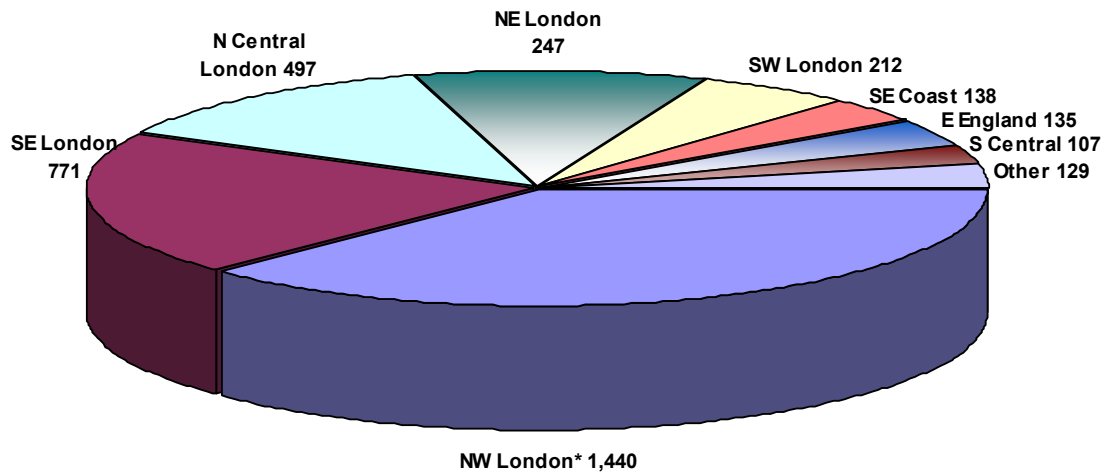


\* North West London encompasses both Kensington and Chelsea and Westminster PCTs

#### Other

South Central	86	South West England	63
East Midlands	26	West Midlands	17
Rest of the United Kingdom	16	North West England	14
Yorkshire and The Humber	10	North East England	10
Other/Not Known	27		

**Patients Accessing Care in Westminster by Sector (Patients resident in London) and Strategic Health Authority (Patients resident in England)**



\* North West London encompasses both Kensington and Chelsea and Westminster PCTs

**Other**

South West England	36	East Midlands	23
West Midlands	11	Rest of the United Kingdom	11
North East England	10	North West England	10
Yorkshire and The Humber	10	Other/Not Known	18

These figures need to be taken into consideration as they could impact upon how models of care are commissioned and delivered. If primary care services are commissioned for local residents only, it would exclude a large proportion of patients who currently access HIV care in Westminster and Kensington and Chelsea.

If a GP is placed in the acute centre will it be commissioned by the local PCT for residents only? Can arrangements be made to ensure it is accessible to all who access the centre and would this require specialist commissioning arrangements to be set in place and a tariff system established to recover costs from the patients' PCT? If not what provision needs to be made to ensure that patient has equity of access to high quality primary care that is non-discriminatory and meets patients' needs?

Opening up GP boundaries and enabling people to access practices outside would require commissioning structures to be reviewed. The latter has already been identified as the Government's direction of travel for healthcare policy and this issue is likely to be addressed through the restructuring of the NHS in the coming years. This will provide greater access to GPs and establish structures for payment of primary healthcare for non-residents.

## 6. Options for Care

### 6.1 Existing system

The existing system can provide good care to a patients living with HIV, notably where the GP has a background in, or some knowledge of HIV. Where this is not the case this places patients at risk and non-disclosure can lead to GPs, placing them at risk of not receiving effective healthcare and being prescribed drug that interact wit HIV medications. GPs and clinicians have also identified additional areas of support that would provide better care for patients living with HIV and improved health outcomes.

The advantages to the current set up are that it recognises patients healthcare needs are best met by different practitioners, with HIV clinicians meeting HIV healthcare needs and General Practitioners responsible for wider health concerns.

It provides primary care close to the patient's home and deliver is in line with current policy such as Healthcare for London (2005).

However there are limitations to this approach. Stakeholder interviews identified that the current model does not meet the needs of all patients. As a result there are cohorts of patients who are either not accessing GPs, or accessing but not disclosing their HIV status.

Provision of primary health care services to patients living with HIV therefore varies within GPs across the PCTs with no set standards for care. There is no provision of training and support for GPs to manage HIV in primary care.

As high numbers of patients are not accessing or utilising GPs effectively, there are additional demands placed on acute care.

Patients may be accessing HIV care far from home, not accessing a GP receiving limited signposting and support accessing local services that would support their health and social care.

Retaining the current model has no financial implications in terms of restructuring costs. However the cost of providing care in acute settings is greater than that of providing care within the community. Retaining the current model, with cohorts of patients having primary care related health needs met in acute settings, carries cost implications over the longer term.

***Recommendation 1: New models need to be implemented to increase take up and efficacy of primary care. The current provision of primary care to patients living with HIV does not provide sufficient support to patients or general practices.***

## **6.2 Enhanced Services and Contract Equity**

All stakeholders agree that enhancing the current system would provide benefits to the health outcomes of patients living with HIV. This could be implemented through compulsory measures under existing contracts, or incentives offered to enhance current service provision.

There are benefits to enhancing the current systems of primary care and supporting patients to access GP's locally.

This is in line with current policy such as *London HIV Strategy (2005)* and *Healthcare for London (2007)* in developing new approaches and providing greater access to GPs by patients living with HIV.

Taking a compulsory approach to training for GPs, would raise awareness of HIV across practices and maximise opportunities for testing and diagnosis. This could lead to improvements in provision of care to patients living with HIV and may encourage patients living with HIV to register with GPs and disclose their HIV status.

However provision of training does not necessarily entail learning will be put into practice. Nor does it follow that, where necessary, GPs will implement anti-discriminatory practices or put in place continuous service improvements.

Nevertheless widespread provision of short training and awareness sessions for general practices could increase understanding of HIV and raise awareness of patients concerns with GPs. It would also address GP's concerns regarding lack of support in meeting the primary care needs of people living with HIV if it was known that further training and support was available.

***Recommendation 2: Short training sessions delivered to all general practices raising awareness of HIV, patients' concerns and additional support for practices commissioned by PCTs.***

In taking steps to enhance services, all stakeholders urged for the need to support GPs to focus on patient care and health outcomes. GPs incentives should be not solely on a financial basis financial gain nor driven by outputs

The first step would be the provision of comprehensive training over 2-days, similar to that developed by Brighton and Hove PCT as part of their HIV LES. A proposed outline of the training is give in Appendix 4. This would address all issues of HIV from testing, managing primary care needs of patients, and avoiding drug interactions. There should also be requirement for practices to attend annual updates to keep abreast of new research and changes to HIV care.

***Recommendation 3: Enhanced GP services are introduced to address provision of primary care to patients living with HIV through a 2-day training course and annual update training for practice clinical staff.***

To support good practice across surgeries, short training and awareness sessions should be delivered to all staff in the practice, including receptionists, to address issues of confidentiality and address HIV-related stigma such as use of language by staff.

***Recommendation 4: In GP surgeries offering enhanced services, all practice staff attend HIV awareness training.***

Standards of measuring quality of care provided in general practices should be introduced. This should address basic information regarding patients HIV health and

medications notably CD4 count, viral load and HIV medications, to support GPs provide effective care and prescribe to avoid drug interactions. Standards should entail signing up to protocols to ensure confidentiality around file management and that no identifiers are placed on patient's files. Consideration should also be given to increasing the length of appointments from 10 to 20 minutes.

***Recommendation 5: Quality standards be implemented with basic information GPs should gather on patients' HIV health and medications; increasing standard length of appointments for patients living and agreeing protocols around patient confidentiality.***

All GPs and Practice Managers consulted stated that for quality standards to have any weight they should be incorporated into the Quality Outcomes Framework (QOF). Specific HIV standards would support existing QOF outcomes, and verify that patients had received an annual review. As the QOF already has an established reporting framework, incorporating HIV quality standards into the QOF would provide mechanisms for monitoring and assessing quality of care for PLHIV in primary care.

***Recommendation 6: Incorporate the quality standards into the Quality Outcomes Framework, the reward and incentive programme for General Practices to support implementation and monitor progress.***

A proposal for the monitoring of quality standards of HIV in primary care is set out in Appendix 6.

Currently patients can only access GPs within their local catchment area. If in a designated catchment area no practice provides enhanced services, a patient could be disadvantaged and unable to access effective GP care. There are mechanisms for general practices to provide services borough-wide, and not restrict registration to those within a designated local catchment area. In the short-term agreements could be developed with GPs providing enhanced services to extend registration to PLHIV outside their catchment area. In the longer term, with the proposed removal of GP catchment areas and open access to GPs, patient would have more choice, and local agreements would not be required.

***Recommendation 7: GP's providing enhanced services to patients living with HIV open practice boundaries to provide primary care to patients outside their catchment area, where there no enhanced GP services provided in their catchment area.***

All stakeholders recognised the merit in general practices providing a comprehensive approach to HIV and sexual health. Practices that offered HIV testing already had awareness of HIV, and could provide continuous care to newly diagnosed patients, post diagnosis. For existing patients, knowledge that a practice offered HIV testing and information pertaining to HIV posted around clinics reassured patients the clinic was HIV aware and generated trust for patients to disclose their HIV status to their GP.

***Recommendation 8: GPs currently operating within a sexual health LES and/or delivering HIV testing be targeted to deliver the enhanced services, as these practices already have an understanding of HIV, can provide continuity of care for patients and are more likely to generate trust in existing patients to disclose their HIV status.***

There are however limitations to enhanced services. While this would support and encourage patients in accessing primary care it would not necessarily meet the needs of all patient groups. One group in particular are the long-term diagnosed who have traditionally accessed all healthcare at the acute HIV centres.

In addition 84% of patients accessing acute care at St Marys in Westminster and at Kobler in Kensington and Chelsea are not local residents. While a LES would addresses primary care provision for residents who are living with HIV it would not support patients living outside each borough. An agreement and tariff system could be established to address this, however this would result in potentially an additional 3,000 people seeking primary care in those boroughs which operationally may be untenable.

Further consideration needs to be given to effectively meeting the needs of these groups.

**Financial Implications for Enhancing Systems:**

- Time for GPs and nurses to attend training, possibly two-days in length around HIV awareness and treating patients living with HIV
- Training for practice staff such as receptionists around confidentiality and HIV awareness of approximately ½ day
- Extending GP sessions from 10 minutes to 20 minutes
- Annual screening as per Brighton LES, e.g. cardio, blood pressure etc.
- Bonus payment per patient living with HIV as per Brighton LES. Under the terms of the Brighton LES GPs receive a “one-off retainer of £1,032 to reflect training and set-up costs. In addition there is a fee of £120 for each patient that attends the practice’s surgery for a review
- Cost implications of GPs extending their remit and receiving patients living with HIV from beyond their existing catchment area

### **6.3 One-Stop Shop Approach**

There is evidence from patients and clinicians to suggest there could be a role for a 'one-stop shop' approach in supporting patients living with HIV. Firstly through diagnostics and provision of HIV testing, could help meet the PCT's targets of reducing late diagnosis; and care pathways then support patients diagnosed HIV positive to access both primary care and HIV acute care from the outset.

Secondly, there is scope for providing greater care within the hub or the 'one-stop shop'. Patients did not want to access an HIV clinician locally at their GP, for fear their confidentiality would be breached. However patients may access an HIV clinician at a hub which is not within their direct locality. Further incentives for patients would be knowledge that practitioners in the hub were trained in HIV awareness, operated non HIV-discriminatory practices, and if a range of other services such as general practice, dentists could be accessed.

'One-stop shop' approaches are in development, how the systems will operate and any remit for sexual health and HIV are still under decision. In the longer term these models could provide a new approach to providing both HIV care and primary care to patients living with HIV within the community and outside of acute settings.

***Recommendation 9: PCTs review options for provision of healthcare for patients living with HIV within the 'one-stop shop' model as it is developed.***

#### **6.4 GP embedded in Acute Centre**

There is support across patient groups and HIV clinicians for establishing a GP within the HIV clinic, providing primary care to patients alongside acute care.

There are merits to this model in that it is favoured by a group of patients, notably the longer-term diagnosed who are accustomed to accessing all healthcare at their acute HIV centre. This is also the group least likely to access a GP within the community. It provides patients reassurances in confidentiality as all information remains in the HIV centre, facilitates communication between HIV clinicians and GPs as they are all on the same site. If the primary care needs of these patients are met it would alleviate demands upon the time of HIV clinicians and acute care. This could also result in improved health outcomes for patients as have access to GPs and HIV clinicians to manage all aspects of their health.

GPs are referrals gateways to local healthcare services; and it may not be possible for a GP in the clinic to do this effectively, where they are supporting patients from outside the borough. A GP cannot build up knowledge and become a specialist for every patients' local area where patients hail from a wide geographical area.

In addition this approach is contrary to current health policy of delivering care closer to home and within the community. This poses questions over whether this model is sustainable.

A revised option put forward by HIV clinicians was that of a 'transition' model whereby a GP is established in the clinic for a limited period of time. The 'transition' GP would be based at the HIV clinic, as patients have confidence accessing services there, and this would support engagement of the target group: patients' reticent and not accessing health services outside the clinic. Patients would access this GP for an agreed and set period of time. Through this patients would be supported in understanding the role of the GP in managing their healthcare. This would act as practical training for patients who have traditionally access all healthcare at the HIV clinic and are reticent to access GPs. The GP would then support referral for patients to access a GP locally.

This model could also provides an interim measure to meet the primary care needs of patients living with HIV while enhanced services are developed and GPs in the community trained and confident in offering care to patients. This would alleviate pressure upon acute services.

***Recommendation 10: A GP be established at HIV clinics, to provide primary care to patients living with HIV for a limited period of time, providing a transition to patients accessing a GP locally in their community.***

The current model of delivery for primary care is that patient's access a GP with a local catchment area. However, as noted previously, 84% of patients accessing care at these centres are non-resident of the borough in which they access acute HIV care. Consideration needs be given to the accessibility of this model and how it will operate. Providing access to the GP to all patients at the clinics could act as an investment that supports patients reticent to access GPs to register with a local GP and in the long-term alleviate pressure upon acute services. Commissioning of this approach and agreements with other areas will need to be address prior to establishing this model of care.

***Recommendation 11: Operational and financial assessment are undertaken into providing the 'transition' GP to all patients at Kobler and Wharfside Clinics, where 84% of patients are non-residents of those PCTs.***

#### **Financial implications of the GP in the clinic transition model**

- Cost of engaging a GP to practice from the HIV clinic.
- Support costs of GP of practice nurse to work alongside the GP
- Overhead and other support costs, to review whether a specific receptionist is required or if this could be undertaken by staff the acute clinic

## 6.5 Additional Areas of Need

The above models focus upon improving care and supporting General Practices. There are two other areas identified in the consultations that need to be addressed.

### 6.5.1 Responsibility for Care

A major concern for patients is identifying who has responsibility for aspects of their healthcare. In accessing two healthcare professionals, an HIV Clinician and a GP, there concerns and reports that patients face the scenario whereby the HIV clinician refers the patient to the GP for treatment of a specific condition or symptom, only for the GP to refer the patient back to the HIV clinician. This could place the patient's health at risk and needs to be addressed a priority in implementing a model of shared care.

Communication between GPs and clinicians needs to be improved, and this was identified by both parties in the consultation. Where concerns or questions arise for a GP access to a contact in the HIV clinic would be beneficial. Systems already operate at Charing Cross Hospital and Mortimer Market. These offer a telephone number for GPs to call should they have any questions or concerns regarding a patients' treatment including implications of prescription drugs. This system should be implemented across all HIV clinics.

***Recommendation 12: A 'hotline' or dedicated telephone line is established at HIV clinics enabling GPs to call with questions to discuss concerns around care of a patient living with HIV.***

Sharing patient information between the HIV clinic and GP would support effective healthcare of patients, with each healthcare professional having access to a patient's history and knowing what medications had been prescribed by other parties.

BHIVA identify the need to share information between acute and primary care, where there is patient consent. The HIV Consortium has also included an element of this as a CQUIN in 2010/11, with the specific aim of 80% of patients who are registered with and disclosed to a GP having a letter about them sent to their GP by the HIV service in last 12 months. This could be taken further to ensure routine posting of information, to include the GP sending information to the HIV clinic.

***Recommendation 13: The current CQUN standards are built upon to establish procedures for routine cross-posting of information between HIV clinics and General Practice where patients have consented to sharing information.***

Managing HIV as a long-term medication condition is new approach in the field of HIV healthcare. Similarly living long-term with HIV is relatively new development and there is much research being undertaken into the effects of ageing and living long-term with the condition. It is inevitable questions will arise as to who has responsibility for care and patients need support mechanisms to manage this. Healthcare for London, A Framework for Action put forward an advocacy model to support patients with long-term conditions as act as 'champions' in the field; a nurse specialist and a community lead should be identified to champion the implementation of protocols in their area and work to develop work practices between community and hospital care. These 'champions' could take on an advocacy role where patients find themselves passed between general practice and HIV clinic, establish protocols and share these across the sector for future reference.

***Recommendation 14: Building on recommendations from previous studies, a nurse specialist and community lead be appointed as 'champions' to promote good work practices and support advocacy of patients between General Practice and HIV Clinics.***

#### **6.5.2 Training and Information for patients;**

Consultation identified that patients would benefit from direct support through information and training to make informed decision to access General Practice.

Training for patients living with HIV in finding a GP, identifying GPs within their catchment areas, including GPs who have signed up to a LES and how gain feedback and take complaints if unfairly denied access to a general practice. Patients would also benefit in understanding the role the GP can play in managing their overall health and non-HIV health conditions. Alongside this would be information exploring the implications of not disclosing their HIV status to their GP and making an informed

decision around disclosure. Patient rights would be also be addressed informing patients of what they can expect in terms of requesting appointments with one GP and the expectations upon patients by the practice. A proposed outline for PLHIV training needs is set out in Appendix 5.

***Recommendation 15: Training and information be provided to patients living with HIV so address finding and accessing a GP, patient rights and disclosing HIV status to a GP.***

#### **Financial implications for Additional Areas of Need**

- Allocation of a nurse specialist and community lead to champion implementation of good practice and take on advocacy role for patients
- Production of information for patients around accessing GPs such as leaflets, web materials
- Workshops and information sessions for patients in accessing primary care

## 6.6 Implementing Recommendations

The following briefly set out implementing the recommendations, identifying what could be developed and introduced at local level:

1. now
2. in the medium term as they require greater consideration due to level of resources
3. in the long-term as they are driven by strategic changes in healthcare delivery

It also identifies which recommendations need consideration at:

4. regional or national level

### 6.6.1 Local Implementation Now

Several of the recommendations could be implemented over a short period of time. They require resources but will not require severe changes in operational procedures.

**Recommendation 1** identifies the need to implement change, and PCTs have demonstrated intent to do this through the commissioning of this report.

Introducing short training sessions for GPs, **Recommendation 2**, at protected training days could raise awareness of, and encourage uptake of the comprehensive 2-day training courses, **Recommendation 3**. In turn this could also raise awareness of and support implementation of training for all practice staff, **Recommendation 4**. Implementing **Recommendation 8** alongside this and targeting GPs currently operating within a sexual health LES and/or delivering HIV testing to address their ongoing training needs and that of their staff. To support GPs post-training, **Recommendation 12** and the introduction of a 'hotline' between GPs and HIV clinics would support practices as they put their learning into practice.

**Recommendation 15** identified that training for GPs was not sufficient, and PLHIV required support in how to access their GP. Running in tandem with the training for GPs, workshops for PLHIV both providing training to patients and disseminate information about the GP training. Patients should then be supported in accessing GPs through the implementation of **Recommendation 14** with, a nurse specialist and

community lead appointed as 'champions' and advocate between patients and GPs where required.

These steps would both support GPs in providing better healthcare for PLHIV and PLHIV take a greater role in accessing GPs and managing their primary health care needs.

Finally **Recommendation 7** addresses opening up GP catchment areas. At a local level commissioning structures could consider how GPs who have completed the training and are providing enhanced services to PLHIV can be accessed by all residents of Kensington and Chelsea, and Westminster. Non-residents of those boroughs are addressed under sub-heading 4 of this section.

#### **6.6.2 Local Medium Term**

**Recommendations 10 and 11**, address the introduction of a GP in the acute clinic to support PLHIV make the transition to accessing primary care in the community. Implementing these recommendations requires substantial investment and PCTs must decide whether this is a priority at this time.

Over time transitioning PLHIV into GPs may be achieved through other actions. There are changes in commissioning structures with greater responsibilities placed with GPs, and they are considered the 'gateway' to accessing further health and social care services. HIV clinicians continue to urge patients to access primary care. These alongside the suggested recommendations to be implemented at local level now may support, may provide sufficient support to a cohort of patients to make the transition.

#### **6.6.3. Local Longer-Term**

The proposed 'one-stop shop' models are still in development, and **Recommendation 9**, is to continue reviewing how HIV and sexual health can be effectively addressed by this model if, and when, implemented.

#### **6.6.4. Regional or National Level Implementation**

The Specialised Commissioning group for London has already introduced a standard through CQUIN for 80% of patients who are registered with and disclosed to GP have letter about them sent to GP by HIV service annually. The report proposes cross posting be established through **Recommendation 13**.

The Department of Health have responsibility for the Quality Outcomes Framework, QOF, under which GPs operate. The changes to quality standards stated in **Recommendations 5 and 6** needs to be addressed at national level.

**Recommendation 7** has already been considered at local level (see above 6.6.1). Healthcare policy at national level is already proposing to abolish GP catchment areas. If this is achieved Recommendation 7 will be addressed through this.

## 6.7 Shared Care Responsibilities

In developing a model for shared care, there needs to be clear parameters as to who is responsible for what aspect of healthcare. This will support GPs and HIV clinicians in understanding their responsibilities, and patients in taking greater responsibility for their healthcare and identifying which healthcare practitioner to access. While shared care models are in operation across other conditions, HIV is still a relatively new condition, and the affects of living long-term and ageing with HIV are only being realised. As this report was being published BHIVA had established a working group to review areas of shared care, the group includes healthcare practitioners and patient representatives. A summary of the key areas for shared care identified to date are as follows:

General Practices	HIV Acute Centres
<p><b>CVD</b> risk assessment and lifestyle advice to reduce CVD risk</p> <p><b>Vaccinations</b> To include but not limited to flu vaccination And pneumococcal vaccinations Mental health reviewed in the last 12 months</p> <p><b>Blood Pressure</b> checks, and whether the latest recorded blood pressure is 150/90 or less</p> <p><b>Diabetes</b> checks</p> <p><b>Cholesterol</b> including cholesterol:HDL record</p> <p><b>General health promotion</b> including but not limited to smoking cessation, diet, health implications associated with ageing</p> <p><b>Referrals</b> and linking to local services and facilitating referrals</p>	<p><b>Antiretroviral therapies</b> to address all aspects of stopping, starting and changing treatments</p> <p><b>Opportunistic Infections</b> associated with HIV or side effects of treatments</p> <p><b>Areas that impact directly upon HIV</b> to include sexual health and risk taking; recreational drugs which affect adherence.</p>

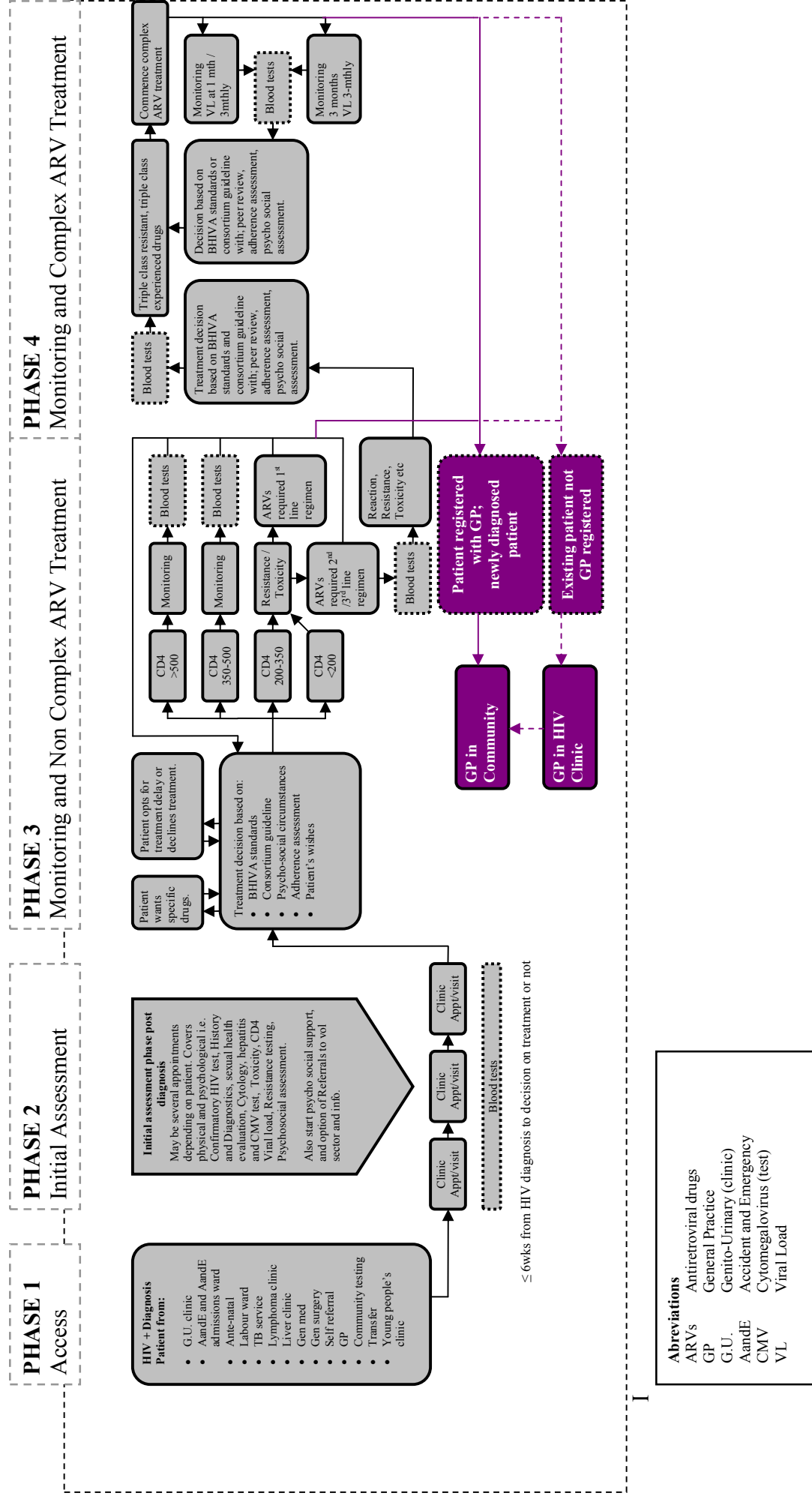
## 6.8 Care Pathways

In developing models of care, the pathways for accessing all aspects of healthcare including GPs and HIV acute centres should be considered. Pathways have already been developed by the London HIV Consortium. These already recognise the role of the GP in HIV testing, referral to HIV clinics and primary care in providing for the primary care needs of patients. The remit of this review is to address the primary care needs of people living with HIV and not to review or recommend models for the shift of HIV care from acute to community settings. The proposed models do this by inserting the General Practice into existing care pathways and recognising:

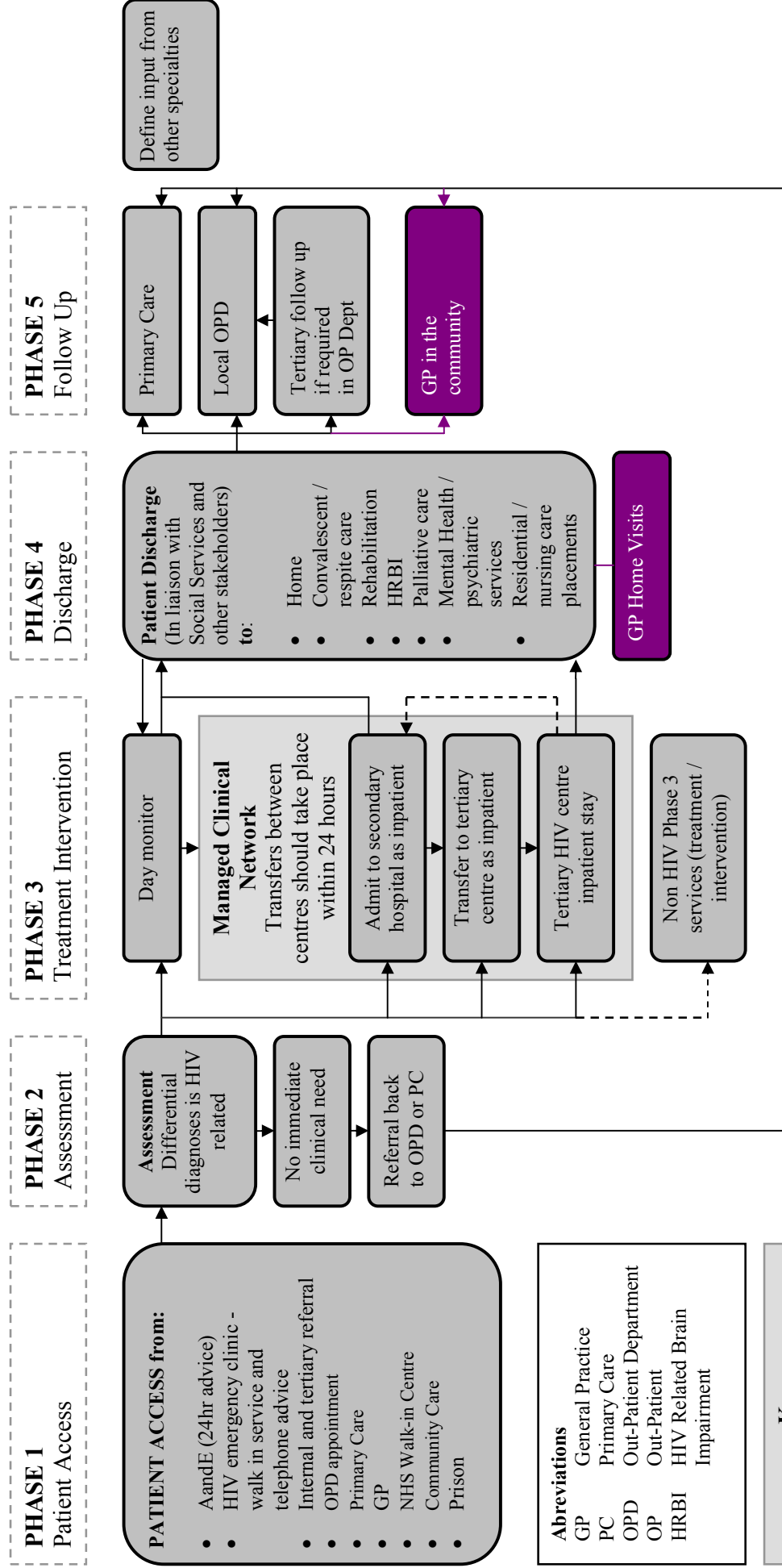
1. The role of HIV clinicians in continuing to provide all care around assessment of people newly diagnosed and managing all aspects of ARV treatments is acknowledged
2. The role of the GP in providing care around non-HIV conditions

The first care pathway '**Generic Patient Pathway**' is for outpatient care. Whilst interfaces with primary care are reflected in relation to access into HIV care and in the role of primary care in meeting the primary care needs of patients, the pathway assumes in line with BHIVA Standard that patients are registered with a GP sets out care model which requires no inpatient care.

The following takes the outpatient care pathway, and demonstrates how the GP within the clinic, if introduced, would be accessed. It is on the assumption that by only patients who are not registered with a general practice and therefore not accessing care from a GP would access this model, while patients already accessing a GP would continue to do so. The GP in the clinic could be an end itself, but acts as a transition to support patients to register with and access a GP in the community.



The second London care pathway is for 'unscheduled care' recognising that some patients will present with urgent needs and require inpatient care. This can be as a result of late diagnosis, opportunistic infections or other HIV related complications. The pathway again recognises the role primary care plays in supporting access to inpatient care, discharge and follow-up. Any implications for the commissioning of HIV outpatient or inpatient care arising from these recommendations would need to be worked through with PCTs and the London Specialised Commissioning Group.



Input from other specialities

Trust IT infrastructure strategy to support patient records, transfer of patient information and confidentiality (to support referral and shared care arrangements)

Relevant standards for HIV Clinical Care Apply (BHIVA, BASHH, BIS and RCP 2007)

## 7. Equality Impact

All statutory bodies including the Department of Health are charged by law to undertake Equality Impact Assessments considering how policies will affect equality groups either positively or negatively<sup>24</sup>. The following should be taken into consideration for implementation of policy changes to how people living with HIV access primary care services:

### **Age**

Older age brings with it new medical conditions and an increased need for medical care and support of a GP. People long-term diagnosed have traditionally accessed all healthcare at their HIV clinic and there is evidence this group are reticent to access GPs in the community. Moving all primary care to the community without provision for support to make this transition will impact negatively upon this group.

### **Disability**

Medically HIV is now classed as a long-term condition, however under the Disability Discrimination Act is considered a disability from point of diagnosis. HIV remains a stigmatised condition, people diagnosed HIV positive encounter HIV related discrimination and for the purposes of this assessment, the report considers HIV as a disability. Patients with HIV have experienced prejudice within GP practices and encounter prejudice in the community when their HIV status is known. Confidentiality and fair treatment of all patients living with HIV needs to be assured when accessing General Practices. Patients also need to feel able disclose their HIV status without fear of recriminations or prejudice, to support GPs treat conditions effectively and minimise risk of GPs prescribing drugs that will interact with HIV medications.

### **Ethnicity**

HIV affects all races, however a large proportion of patients diagnosed and accessing HIV care are from Black African communities, and many are immigrants to the UK. This group face language barriers where English is not the first language and command of

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<sup>24</sup> Equality Impact Assessment; Summary, tool and guidance for policy makers, Department of Health (September 2009)

spoken and written English is low; in addition the group may lack knowledge of how to access General Practice and the role and responsibilities of different healthcare practitioners in the UK. Additional support programmes such as interpretation and information need to be in place to facilitate access for this group. One specific group to consider are MSM (men who have sex with men), a group who may present specific issues to discuss around sexual health and risk taking (see sexual orientation).

### **Gender**

Women in their role as mothers have specific requirements around primary healthcare, accessing it not as an individual only but within the context of the family unit. Pursuing the GP in the HIV clinic model alone, would discriminate against this group, who are more likely to access a GP within the community.

### **Religion or Belief**

The project views no impact upon this group as a result of changes to HIV and primary care policy.

### **Sexual Orientation**

Lifestyle factors for gay men and MSM living with HIV that can affect their health. Gay men need to be able to discuss sexual health, risk-taking and recreational drug use with their healthcare professional. Evidence shows that gay men are reluctant to disclose both their sexuality and where diagnosed, HIV status to their GP. Gay men are more likely to discuss such factors with their HIV clinicians and continuing this brief within HIV clinical settings will ensure effective health support for gay men. MSM, often from BME communities do not identify as gay and again may be reluctant to discuss sexual health with a GP.

### **Positive Impact upon Equality**

Implementation of effective policy to support people living with HIV access primary care services could have a positive impact upon the following:

There are a range of equality groups living with HIV experiencing different barriers to accessing primary care. Implementing a range of models to patients would promote **equal opportunities**, supporting people access primary care in a setting and an approach that meets a diverse range of needs.

Developing training programmes for GP staff from GPs to receptionists, to educate and raise awareness of HIV would tackle **discrimination** that exists in certain areas of general practice. This would also promote **positive attitudes** towards patients living with HIV amongst practice staff

Implementation of a LES with training for practice staff and setting out standards of care for patients living with HIV in primary care would support **more favourable treatment** of patients when accessing GPs.

Developing policy and practice to effectively support patients living with HIV access GPs will promote **human rights** by tackling barriers and encouraging access to the best healthcare possible and taking steps to safeguard patient confidentiality and dignity in their treatment by primary healthcare staff.

## Appendix 1

### Interview/Focus group questions for patients

1. How long have you been diagnosed; where do you live; where do you access your GP and HIV clinic?
2. Do you have any healthcare needs that are currently not being met?
3. Tell us your experience of using GPs, both good and not so good. If good, what works? If not so good, how can concerns be addressed?
4. The models of care, the existing system; the Brighton LES; GP embedded in the HIV clinic and one-stop shops were introduced and discussed after which patients were asked to vote for their preferred models

### Further exploratory questions for one-to-one interviews

- Patients were provided with a summary of some of the responses from focus group questions, above and asked if they agreed/or not with the findings, and whether they had anything else to add to the emerging themes.
- What are your current experiences of accessing GPs?
- How do you access currently access healthcare as a family [for patients with children]
- Depending on issues brought up, patients were then asked how those issues could be addressed.
- Are there any specific issues for families that we need to consider – e.g. concerns over disclosure of your HIV status and accessing GPs in the clinic with your children?
- Looking at your role as a patient and the link between acute centres and GPs – do you think you have a role to play in this and what do you think that role may be?
- Would it be useful to provide patients with resources and support in accessing primary care?
- If I was to give you a blank sheet of paper and asked you to say how healthcare could be best provided for you as a family, what would it look like?

## Appendix 2

### Interview/Focus group questions for GPs

1. Where is your practice located?
2. What level of service/care do you currently provide to people living with HIV?
3. How many patients living with HIV are registered with at your practice?
4. With regards to the shared care of patients living with HIV between acute and primary care settings – what would this look like?
5. What areas of concern, if any, do you have around providing services for people living with HIV?
6. How can such concerns be resolved?
7. What support needs might you have if you were to extend care and services to this client group?  
The models of care were introduced and GPs asked:
8. Which of these do you think would work best in achieving the care approach identified previously and why?
9. How could they be applied in your local area?

## Appendix 3

### Interview questions for clinicians

1. Can you describe the current system in terms of your role and responsibilities towards patients care and GPs?
2. Does this work and are there any concerns about this current set up?
3. Do you have any experience of working with GPs?
4. Do you have any feedback from patients about their experiences of GPs?
5. The term 'shared care' of people living with HIV between acute and primary care settings, is being used a lot at the moment: what does the term shared care mean to you?
6. Should any elements of the patient's care be provided by GPs?
7. What would such a system look like, how would it be structured?
8. Lines of communications between GPs and clinics have been highlighted as an area of concern by patients, often that relevant information is not shared when it could be, how could lines of communication be improved?
9. Any other comments regarding GPs and primary care?

## Appendix 4

### Training Needs of General Practitioners

<b>HIV testing</b>
Epidemiology Barriers to HIV testing within the community Identifying at risk groups How to take sexual history HIV indicators How to test Pre-test discussions Post-test discussions Referrals for people testing positive
<b>Understanding HIV Treatments and Related Health Conditions</b>
Co prescribing Recognising and managing side effects Referrals and communication Common conditions associated with HIV
<b>Understanding of social and psychological aspects of living with HIV</b>
Stigma associated with HIV Disclosing HIV status HIV as a 'disability' Discussing sexual health Onwards support available for patients living with HIV
<b>Operational Considerations</b>
Disclosure of patients HIV status and notifying third parties

## Appendix 5

### Training and Information Needs for Patients Living with HIV

<b>Accessing GPs</b>
Reasons to have a GP and how a GP can support your health How to register What to ask GPs (NAM resources) Complaints procedures PALS Communication –GP to Clinic and Clinic to GP Patient responsibility
<b>Disclosing to GPs</b>
Pros and Cons of disclosure How and when to disclose What information you need to share and why
<b>Increase ability to have control of your care</b>
Self-Management Doctor Patient Relationship Distinguishing HIV related illnesses and knowing what to bring to the GP

## Appendix 6

### Proposed Quality Monitoring Framework

The following is a proposed monitoring framework that could be incorporated or adapted to meet quality standards for primary care healthcare of people living with HIV. This is based upon the model developed by Brighton and Hove PCT, and feedback from consultations with patients, clinicians and general practices.

#### Part 1 – Practice Information

This gathers information about the practice itself, the key staff providing reviews and care of PLHIV, whether practice staff have attended a training course in HIV awareness, clinical staff attended a training course in managing patients, and date of the last training course. The latter will be applicable it is stipulated that clinical staff should attend update sessions e.g. annually, after attending the initial training.

- The number of patients with HIV aged 18 years and over included on the practice register (with patient consent)
- Name of GP/ nurse co-ordinator
- Name of GP attending the HIV education course.
- Name of Practice Nurse or other staff attending the HIV education course
- Name of GP and/or Practice Nurse providing care to patients living with HIV
- Date of last clinical HIV training course / HIV update session
- Date of last HIV awareness session for all practice staff
- Number of extended appointments provided
- Number of patients receiving annual review

#### Part 2 – Patient Information

This gathers information to demonstrate practices are providing effective care to patients living with HIV. Essential information relating to the patients HIV status should be obtained, as this is essential in general practice treating other conditions and safeguards against prescribing drugs that will interact with the patients' HIV medication.

For each patient review the following indicators should be recorded

- Record of patient's CD4 count; viral Load and HIV medication
- Medication review recorded including confirmation of checks against drug interactions
- Hepatitis C Co-infection

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