

# **TITLE: Learning from the experiences of people with HIV using general practitioner services in London: a qualitative study**

Running header: Learning from the experiences of people with HIV

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## Abstract

**Aim:** To explore the experiences of people with HIV (PWHIV) using general practitioner (GP) services in order to identify barriers to use.

**Background:** Traditionally, GPs have little involvement in the care of PWHIV. However, as HIV becomes a chronic condition and the population of PWHIV ages, there is a need to increase this involvement. Despite high levels of GP registration, the majority of PWHIV in London report that their GP is not involved in their HIV care.

**Methods:** This paper presents qualitative findings from a mixed-method study of PWHIV's experiences of clinical services. Survey respondents were purposively sampled to recruit 51 PWHIV who took part in 8 focus groups. Participants were asked about their experience of using GP services.

**Findings:** Three factors emerged which mediated experiences of GP care.

*Competence:* Respondents were concerned about the potential for misdiagnosis of symptoms, lack of awareness of the health needs of PWHIV and experiences of prescribing which could lead to drug interactions.

*Continuity:* Not being able to get appointments quickly enough, not being able to see the same doctor twice and not being able to keep their GP when one changed address were experienced as impediments to use.

*Communication:* Lack of communication between GPs and HIV specialists led to what participants called 'patient ping-pong' where they found themselves acting as a go-between for different clinical specialists trying to make sense of their care.

**Conclusion:** Meaningful contact between HIV specialists and GPs is likely to allay concerns about competency as treatment and care decisions can be taken collaboratively between the GP, HIV specialist and patient. A key component of acceptable GP care for PWHIV is likely to be the application of long-term condition management approaches which includes empowered patient self-management.

**Keywords:** HIV, General practice, Service use, Service acceptability, Qualitative research

## Background

In London there are approximately 35,000 adults using specialised HIV treatment and care services across 28 clinics (Health Protection Agency, 2012). Improvements in HIV treatments over the past two decades have led to near-normal life expectancy for this patient group. Although HIV remains a serious and life-long condition, better drugs with fewer side effects have reduced medical complexity for the majority of patients (BHIVA, 2013). As the population of people with HIV (PWHIV) ages they are increasingly affected by other co-morbidities such as cancers, heart disease, osteoporosis and mental illness (Brown et al., 2004; Gupta et al., 2005; Arnsten et al., 2007; Triant et al., 2007; Patel et al., 2008; Collin et al., 2009; Butt et al., 2011; Durand et al., 2011; Oursler, et al.2011).

This means that the health and care needs of this group are expanding beyond the remit of specialist HIV clinics. A recent review of HIV clinical services conducted for the London HIV Specialised Commissioning Group concluded that a model of care is required which connects HIV services and the people who use them into the wider health system (Weatherburn, et al., 2013). Moreover, the British HIV Association's guidance on standards of care for people living with HIV emphasises the need for care for people with HIV to be planned and delivered by networks of clinical service providers including primary care services (BHIVA, 2013). Integrated and holistic care for PWHIV requiring significant General Practitioner (GP) involvement is now written into NHS commissioning arrangements for specialised HIV care services (NHS England, 2013).

However, GPs have traditionally had little involvement in the routine care of PWHIV or in the management of non-HIV related symptoms. Past studies have found that although the majority of people with HIV are registered with a GP and have disclosed their HIV status to their GP, there are barriers to GPs being involved in care (Elford, et al., 2008; Burns, et al., 2008; Weatherburn et al, 2013). Most of the research which examines these barriers in depth was carried out when HIV was considered an acute or fatal condition and this research is now comparatively old (Boyton & Scambler, 1988; King, 1988; King, et al., 1988; Mansfield & Singh, 1989; Wadsworth & McCann, 1992; Bradley, et al., 1994; Petchey, et al., 2000; Cant, 2002).

There is a need for up-to-date research which explores barriers to involvement of GPs in the care of PWHIV. This paper presents results of recent research which identifies and explores the barriers to GP involvement in care by focusing on the perspectives and experiences of patients with HIV. The findings presented here are part of a larger mixed-method study investigating PWHIV's experiences of and attitudes towards their clinical care more generally. This is an applied research project and therefore makes recommendations for policy and practice innovations to overcome such barriers.

## Methods & Sample

In this paper we present qualitative findings from a mixed-method study of PWHIV's experiences of a range of clinical services. We focus on qualitative data pertaining to recent experiences of using GP practices in order to identify barriers to and facilitators of greater involvement of GP practices in care.

The overall research study consisted of an anonymous self-completion survey followed by qualitative focus groups undertaken with a purposive sub-sample of survey respondents. The study

received approval from the Research Ethics Committee of the London School of Hygiene & Tropical Medicine. As the research was judged to consist of an assessment of patient experiences and was part of a larger audit of clinical services, NHS Ethics approval (and Local R&D approval) was not required.

### Sample

As the qualitative sample was derived from a larger survey sample (n=1,309), it is relevant to briefly describe the survey sampling and recruitment approach. In the absence of a national sampling frame, multiple recruitment methods were employed to reduce the biases of opportunistic recruitment. The survey was available for completion online promoted by HIV community organisations and clinics. In addition, fieldworkers attended HIV-clinic sessions across all 28 specialist HIV out-patients clinics in greater London promoting the survey to patients and where appropriate helping respondents complete the survey.

Approximately two-thirds of the survey sample was recruited in HIV clinics and a third recruited online. This represents just over 4% of the entire patient load of the 28 clinics. A comparison of the survey sample with the National Survey of Prevalent HIV Infections Diagnosed (SOPHID), conducted annually by Public Health England revealed that whilst broadly in line with SOPHID data for London, our survey slightly over-represented males and white ethnicities and under-represented females and Black African ethnicity. Our sample also over-represented men who have sex with men (MSM) and injecting drug users. However, the survey sample compares favourably with other clinic or community samples of PWHIV conducted in English, as all such samples routinely display these biases (Anderson & Weatherburn, 2004). The survey sample was similar to SOPHID London data in terms of age groups of survey respondents and in terms of the proportion currently on HIV treatments.

Those completing the survey were invited to take part in focus groups to explore survey topics in more depth. Those agreeing completed a separate form which collected contact details and information required for purposive sampling. 366 people agreed to take part and the demographic profile of this group is similar to the larger survey sample. We then conducted purposive sampling of these volunteers based on demographic/ infection group and health status.

- *Demographic/infection group:* We focused on the two population groups which account for the majority of HIV diagnoses in London: undertaking two groups specific to MSM and three groups specific to African migrants.
- *Health status:* Our initial survey findings indicated that the presence of co-morbidities or co-infections was strongly associated with GP use. We therefore undertook one group with people with psychiatric or mental health problems and another two groups with individuals that had any of the following co-morbidities or co-infections: high cholesterol, high blood pressure, neurocognitive disorders, liver problems, hepatitis C, diabetes, kidney problems, hepatitis B, heart problems, cancer, tuberculosis (TB).

Ultimately, 51 participants took part in 8 focus groups. A detailed sample description is provided in Table 1.

[TABLE 1 HERE]

Purposive sampling can be used for a range of purposes. In this case, our aim was not necessarily to derive a sample that was representative either of our survey sample or of the population of PWHIV as described by SOPHID. Although we were successful at recruiting sufficient numbers to fill each cell of our purposive sampling frame, possible biases apparent in the survey followed through to our qualitative sample inasmuch as it consisted of three-fifths MSM (majority white) and two-fifths Black African (majority female). Like most research of people with diagnosed HIV in the UK, our qualitative sample is most probably also skewed away from people who are not literate in English, or wary of social research more generally.

## Methods

This was an exploratory study which sought to describe PWHIV's over-arching experience of HIV and other clinical and social care services. Our choice of focus groups was pragmatic, informed by two considerations: (a) focus groups are quicker to run than a similar set of individual interviews and we had limited time in which to complete our study and (b) to use in-depth interviews to explore experiences of such a specific phenomenon would not, in our opinion, have been the best use of this approach in this instance. That is, we did not require the 'depth' that in-depth interviews provide to explore this relatively straightforward topic. Focus groups were advantageous in that they allowed us to maximise the size and heterogeneity of our qualitative sample whilst exploring experiences in depth and detail sufficient for our purposes.

All eight focus group covered three topics: perceptions of current HIV clinic, perceptions of GP services, and attitudes towards potential re-organisation of services. This paper focuses on perceptions of GP services. In the part of the focus group covering GPs, participants were asked about their experiences of registering with a GP, disclosing their positive HIV status in their GP practice and experiences of using their GP. Participants participated in an exercise whereby they were given a list of common symptoms and asked to consider who they would consult with initially for that symptom (for example, GP, nurse in HIV clinic, NHS Direct etc.) and why. Responses were then used to generate discussion about preferences and motivations for consulting with different specialists for different symptoms. Participants were encouraged to ground general statements in accounts of specific experiences; either their own or the experiences of others of which they had heard. Thus accounts of experiences predominated.

## Analysis

Our analytic approach did not aim to examine how perceptions are expressed or developed interactively (as would be the norm with focus group analysis). Rather we focussed on how the individual expressed their experiences of GP services. Moreover although, different groups displayed group level variation in their experience of GPs (for example, the co-morbidity groups discussion of GPs was inevitably influenced by their shared experiences of mental and physical co-morbidities), this is not the focus of this analysis. Rather than exploring how different experiences of health and HIV or different backgrounds influence experiences of GP services (the specificity of experience) we examine the factors that were common to a diverse set of individuals (the commonality of experience). This analytic approach is appropriate for a pragmatic, brief and exploratory piece of research and lays the groundwork for further analyses examining specificity of experience.

With the permission of participants all groups were audio-recorded. Recordings were annotated and transcribed by two researchers and any identifying features were removed from transcripts/

annotations. This facilitated a process of familiarisation with the transcripts. As befits applied research (Guest et al., 2012), our approach to analysis was guided by our analytic purpose: to explore the manifold experiences of GP services in order to identify patterns or commonalities. We therefore conducted an inductive analysis with a descriptive and exploratory orientation. Transcripts were carefully read and re-read by two researchers working independently searching for themes or ideas to inform the development of an analytic framework. We refined these ideas by reflecting on themes arising in one account of GP services and comparing these with those arising in subsequent accounts. This enabled us to develop an analytic framework (Gale, et al., 2013; Ritchie, et al., 2014) in which we coded data pertaining to individual accounts of GP services. Thus, the unit of analysis was the individual account rather than group discourses. Finally, a selection of transcripts was coded twice to check for inter-coder reliability.

## Results

Three themes emerged which covered perceptions and experiences of GP services. These were **competence** of GPs to manage co-morbidities within the context of HIV infection, **continuity** of care offered by GP services and the quality of **communication** between GP staff and HIV specialists.

### *Competence of GP services*

Respondents in all groups talked about issues of perceived competency which affected their confidence in their GPs with regard to HIV. Many reported experiences that had profoundly undermined this confidence with concerns focusing around the diagnosis of symptoms, prescribing and drug interactions and knowledge of the interactions between HIV and general health.

Respondents in all groups described instances where they felt that their GP had misdiagnosed their symptoms. Some described this as an overall tendency of GPs to ascribe all symptoms to HIV.

Once they know you are positive, everything you come to them with, they say, 'it's because you are positive'; without doing any investigation. (Woman, African Group)

However, others described the opposite tendency where the GP did not take into account the HIV status of the patient and either misdiagnosed the symptom or misjudged the possible impact of 'normal' symptoms on a patient who may be immunocompromised.

Last year I had a bad chest infection. I went to my GP he said it's just something that's going around. He gave me antibiotics. Within a week the situation was bad. [...] I ended up being admitted to hospital. (Man, African Group).

This latter tendency spoke to a further concern that GPs were perceived to have an insufficient understanding of the ways in which long-term HIV infection and treatment impacts on general health. For example, GPs are perceived to have a limited knowledge of the ways in which common morbidities disproportionately affect patient populations with HIV or appear at younger ages in people with HIV than they do in the general population.

... for us who are on meds., our aging is faster than our age and the GPs need to understand that. They say 'no you are too young to have that!' (Woman, African group).

Moreover, participants reported GPs not being aware of screening needs of patients with HIV. For example, as there is a strong association between HIV disease and the development of cervical

abnormalities, annual cervical smears are recommended for all women with HIV and all abnormal smears should be referred to specialist colposcopy services (Fakoya, et al., 2009).

I had a cervical screen and it came back with a problem so the letter said to call my GP to make an appointment to get a referral. I kept calling and calling and no response and I was worried so I went to the HIV clinic and [the] clinical nurse specialist called [the GP practice] for me [...] and succeeded in getting them [to] give me a referral. (Woman, African Group)

Participants in all groups also reported a lack of confidence that their GP has sufficient understanding of possible interactions between HIV treatments and treatments for other morbidities.

There's one particular doctor, that without fail, the last 3 times I've seen [them], has screwed up my prescription. The last time I was at my GP and we were changing my bipolar meds, I showed him the HIV drug interaction checker and showed him how to use it. So I guess I was educating him. (MSM, Mental Health Group)

Allied to this were concerns that GP practices did not update individual patient prescription lists frequently enough leading to concerns that treatment interactions would be missed or that they would not receive essential treatments.

I'll find that I'll go through my prescriptions list with my GP and then when I go to reception for a repeat, I find it's not been updated and I'm being prescribed things I haven't been on for months and this is a frequent thing – battling with my GP to be on the ball. I'm on 29 pills a day and I have to always make sure my prescription is right because I'll miss an important medication if I don't. (MSM, Co-morbidity Group)

### *Continuity of Care*

The second concern that arose in all groups was that GP services were perceived as being unable to offer continuity of care with an individual named doctor. As many respondents perceived themselves to be living with a chronic condition where their health was variable, a strong and trusting relationship with an individual clinician was seen as paramount.

Well my GP service says you sign up to a practice, not to an individual doctor. But that's not good enough. I need an individual doctor to keep track of all my health needs, including my mental health. (MSM, Mental Health Group)

When participants were registered with an individual GP, they often described difficulties getting an appointment at short notice or that the durations of consultations once they did get an appointment were too short.

Before, my GP was very good. If I have an issue and call for an appointment, if they have nothing for today, they will fit me in the next day. With this one, they tell me to call back next day and each time I call, they tell me they are fully booked and to call back the next day. (Woman, African Group).

Many therefore experienced GP care as unpredictable. That is, they were never sure that they would be able to see their own GP quickly enough. Moreover, different doctors within GP surgeries were perceived to have greater or lesser knowledge and skills around health management for patients with HIV. This led to the impression that the kind of treatment one was likely to get would vary from

doctor to doctor. Some therefore called for basic competencies around care for patients with HIV in GP surgeries.

Look, there just needs to be a reassurance that there is a basic competency around HIV and a minimum number of appointments and monitoring with the same GP rather than just waiting in the queue. (MSM, Mental Health Group)

Participants frequently cited the fact that patients cannot stay with a GP if they move out of their area as a major disincentive to establishing a relationship with their GP.

I had a very good GP, but I moved literally a few streets outside of the catchment area and this is the problem. Although you can go to any HIV clinic, you can go all the way across London if you want to, you can't go to just any GP. I asked so nicely: 'please keep me', because she was so nice, and she said 'sorry'. (MSM, Mental Health Group)

Others reported falsifying their address to keep the continuity with a GP they valued.

My GP is fantastic. When I first came to the country I went to see him and when I was diagnosed, I switched to another doctor who was in the same area and nearer to the HIV clinic. And with them I never saw the same doctor twice. I wanted to build up a relationship with my GP. So I thought well, I'll go back to Dr. S. who wasn't in my catchment area so I had to use a different address. But I am happy now. (Woman, African Group)

It is not surprising therefore that GPs who sought to provide such continuity of care were valued. In the following case, the participant is highly satisfied with his GP. However it is not her confidence or clinical knowledge that is valued, but that she tries to ensure that the respondent always receives a consultation from her.

I've never seen another doctor. If she's going on holiday, she'll make sure to book in an appointment with me at the right time so that I never have to see another doctor or nurse at the GP practice. (MSM, Co-morbidity Group)

Many described putting substantial effort into finding a GP that was suitable.

I researched my GP. I asked some people locally and went to four different surgeries and stayed with one, but I never get to see my named GP. I found out that one of them used to work in [named London HIV clinic]. I went to seek him and seek him out each time and he's absolutely fantastic. (MSM Co-morbidity Group)

Others reported persevering with their GP in order to build a relationship.

Once [GP] kept taking my blood pressure five times and I was just sitting there and I said 'Is there a problem?' He is very bad at communicating. I am a patient that knows about my health. If you take my blood pressure five times I want to know what's going on! If he could communicate better, I think things would be OK. [...] We are getting there, but it has been bad. (African woman, Co-morbidity Group)

### *Communication between GPs and HIV specialists*

Participants in all groups were often highly critical of the level and quality of communication between different clinical specialisms. Specifically, communication between their GP practice and their HIV specialist services was often seen to be less than satisfactory and this led to very real inconveniences and struggles for patients. By far the most common experience was what came to be



called in the focus groups 'patient ping-pong'. That is, GPs who lacked confidence in diagnosing symptoms in HIV positive patients would often refer the patient back to their HIV clinic rather than communicating with the clinic itself. Thus symptomatic patients often described having to travel between clinical services to obtain treatment.

Whenever I go to my GP, he always refers me back to the HIV clinic. (Man, African Group).

What I find is that even if the GP is good in terms of their attitude, they will always ask first, 'have you brought this to your consultant?' So in general I find that it's not worth going to your GP, if you are going to need to see your consultant first. (MSM, Mental Health Group)

Others report being referred to Accident and Emergency Departments once their Primary Care practice knows that they have HIV or are on HIV medications.

*Participant 1:* A few months ago I went with an infection of the saliva glands and GP sent me to A&E.

*Participant 2:* But if you ring out of hours... In the past, they'd say we'll send you a doctor in the next 8 hours. But now, they say because you are HIV or are on [antiretroviral treatment], you need to go to A&E. (MSMs, Co-morbidity Group)

Participants also described instances where their GP and HIV specialist differed with regard to the significance of a symptom and treatment actions. However, rather than consulting each other, they communicated through the patient thus turning the patient into a 'go-between' in the management of their own health care.

I was diagnosed with high blood pressure. And my HIV consultant said I needed to get it monitored by my GP. My GP said it was fine, but then 6 months later, my HIV consultant said, 'This is still too high. Why aren't you getting it checked out with your GP?' So I'm a bit lost really. (African man, Co-morbidity Group)

Others described situations where prescribing practices meant that they had to either travel between clinicians themselves or mediate between them.

So now, my consultant gives me a letter saying 'you need to prescribe this' and I take it to my GP and that's the only contact I have with my GP! I don't even trust that the letter will be delivered so I take it there myself. For me it's a hassle and a waste of my time and their time. (MSM Group)

In the context of some negative experiences of primary care, and positive experience of expertise, access and continuity in HIV care, some participants saw HIV services as a more attractive option than primary care for their general health needs.

It's made clear that you should go to your GP with a cold *etc.* But if you do go to (HIV clinic) and you have happened to have been ill at some point, then they will do the tests no matter what. That was very helpful for me with blood pressure. A locum GP wasn't worried and said 'oh, that's not too high', but my HIV consultant got me some decent diagnostic tests via the hospital. (MSM Group)

It is not surprising therefore, that participants valued GPs who were willing to communicate directly with their HIV clinic.

## Discussion

Clinical policy and commissioning guidance in the UK now stress the co-ordinated care, clear and effective care pathways and active GP involvement as HIV transitions from an acute to a chronic illness. Our research has identified profound concerns that will limit confidence in GP services and hence their use.

Previous studies have highlighted fear of discriminatory behaviours of GP staff or concerns around confidentiality (Cant, 2002; Elford, et al., 2008) as barriers to PWHIV accessing GP services. However, our study suggests that although such concerns may present an obstacle to *disclosure* for some PWHIV, they may not be the primary obstacle to *use*. Our own survey found high rates of disclosure of HIV status to GPs in London with fears around confidentiality and discrimination limited to the small minority of people who had not disclosed their status (Weatherburn, et al., 2013). High rates of disclosure are undoubtedly driven by quality improvement targets (CQUINS) for specialist HIV services which specify the proportion of HIV patients whose HIV status is shared with GPs (NHS England, 2013). However, such disclosure cannot take place without the full consent of the patient. Our survey findings were borne out in our focus groups: confidentiality was cited primarily as a disincentive to disclosure. In contrast however, concerns around competence, continuity of care and communication eclipsed those about discrimination and confidentiality when it came to the experience of actually *using* GP services.

Concerns around **competence** revolve around potential for misdiagnosis of symptoms, a lack of awareness of the general health and screening needs of PWHIV and prescribing practices that do not take account of potentially serious drug interactions. A lack of **continuity** was also cited as a serious impediment to use. That is, patients not being able to see the same doctor twice and not being able to stay registered at a GP if they changed address. Finally, lack of **communication** between GPs and HIV specialists led to 'patient ping-pong'. That is, where patients experiencing worrying, debilitating and non-specific symptoms found themselves going between different clinical specialists trying to make sense of their own care.

Awareness of these problems is growing however. For example, the most recent BHIVA Standards of Care has stressed the problem of possible prescribing errors within the context of primary care stating that:

Mechanisms should be in place to alert primary care to HIV drug–drug interactions and for primary care to verify non-HIV-related prescriptions issued to people with HIV (BHIVA, 2013, p. 27).

The same document also recognises that:

...lack of communication with GPs is an important patient safety concern. Establishment of clear protocols and pathways for care between both primary and secondary care is essential for safe delivery of care, and regular communication is strongly recommended (BHIVA, 2013, p. 20).

Moreover, there may be some scope for patients in London to take advantage of changes under the Choice of GP Practice Scheme which allows out of area patients to register with participating

practices (Mays, et al., 2014). However, this scheme is not primarily meant for patients with complex or chronic illness and remains strongly contested by GP professional bodies (British Medical Association, 2014).

It is not surprising therefore that our respondents showed little enthusiasm for a GP-led model of HIV care or for GP co-ordination of general care. However, we also found many instances of PWHIV who were satisfied with their GP and had functioning and productive relationships. It is clear from their experiences that the relationship with primary care works best when GPs are well linked to the HIV service. If GPs are in meaningful contact with HIV specialists, concerns over GP competency are likely to abate as treatment and care decisions are taken collaboratively between the GP, HIV specialist and patient.

Moreover, the requirement that GPs provide a continuity of care in line with the treatment of HIV as a chronic illness suggests that GP care would be more acceptable if long-term condition management approaches are applied. Our research indicates that PWHIV are engaged with primary care and invested in improving their experiences of GP care. By learning from this experience, we can better define the role of primary care in supporting the health of people with HIV.

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