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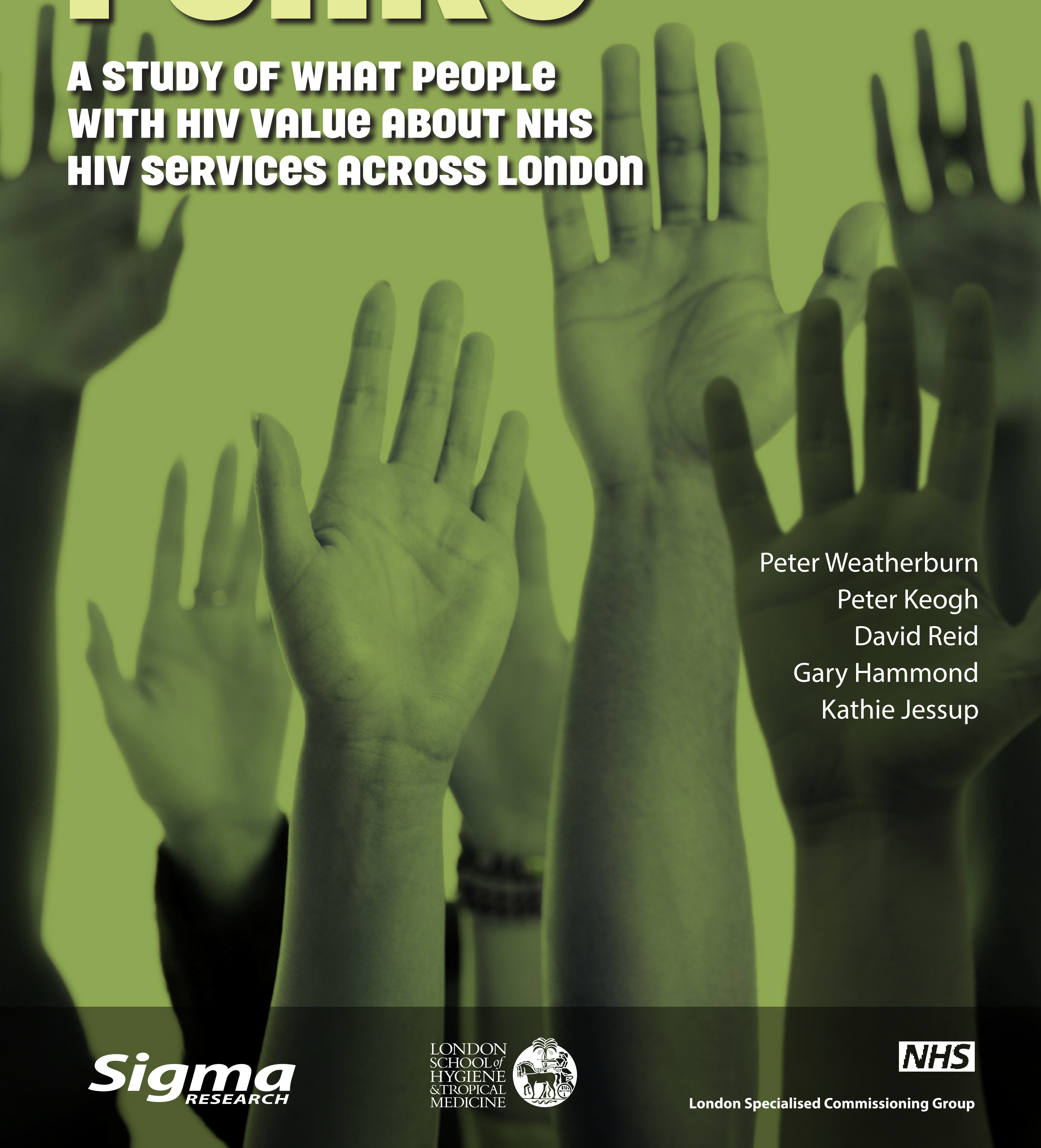
MY CARE, I CARE

A STUDY OF WHAT PEOPLE WITH HIV VALUE ABOUT NHS HIV SERVICES ACROSS LONDON



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Sigma RESEARCH

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

NHS
London Specialised Commissioning Group

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Analysis & text: Peter Weatherburn, Peter Keogh, David Reid and Gary Hammond.

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Preface

My Care, I Care was commissioned by London Specialised Commissioning Group as part of its review of HIV services in London. The aim was to gather data from patients using HIV clinical services in London to better understand their patterns of service use and what they value in HIV services. This information will be used to shape the way services change in the future. This study is one of the critical parts of our HIV Service Review – alongside the public health needs assessment and the clinical case for change being developed by the HIV Clinical Working Group. We are publishing this report so that the time and contribution of people living with HIV is recognised, valued and widely used by those commissioning and providing services. The findings are also being used to make suggestions about how services can improve to meet the current and future challenges of HIV care in London.

But why a review of HIV services in London? Data from the Health Protection Agency shows that London (and England) is a world leader in clinical outcomes of HIV treatment. Rates of people remaining in HIV care, reducing their virus to undetectable levels and improving their levels of immunity are extremely high. Patients report almost unprecedented levels of satisfaction with their HIV care services in London. Put simply, there are 2 reasons why change is important:

- New HIV treatments mean we can change the way care works to improve convenience, productivity and safety.
- As people with HIV live longer, they have other health needs that can't be met by HIV doctors alone.

There are now almost 35,000 adults (Health Protection Agency, 2012) who are using specialised HIV care and treatment services in London and this is increasing by almost 2,000 people a year. Evidence now suggests that as long as HIV is diagnosed and treated early, people with HIV can enjoy a near normal life expectancy. Although HIV remains a serious and life-long condition, better drugs with fewer side effects have reduced the medical complexity of the majority of patients.

But whilst the medical complexity of HIV infection is reducing, evidence shows that people with HIV will be disproportionately affected by other co-morbidities such as cancers, heart disease, osteoporosis and mental illness. Whether these complications are caused or made worse by HIV isn't clear. What is clear is that the health and care needs of people living with HIV are expanding far beyond the remit of HIV doctors. Ensuring that people with HIV have access to the right care in the right place at the right time for *all of their healthcare needs* is vital if we are to protect both HIV clinical outcomes but also general health outcomes of this group of patients.

HIV remains a stigmatising condition and those living with HIV continue to report prejudice. As this study shows, HIV services are excellent at supporting people to control their virus, to manage their HIV. But no matter how well HIV services do these things, they cannot be expected to be experts in managing patients with other co-morbidities or complexities. This would be unrealistic, unachievable and unsafe. Instead a model of care is required which connects HIV services and the people who use them into the wider health system to ensure people living with HIV continue to get access to the care they need.

The *My Care, I Care* study, examining what people with HIV value most about the HIV services currently available to them in London, provides a step towards a refined model of care for the next decade. Commissioners are now using this and other data to develop options for service changes. During 2013, they will be undertaking further consultation with stakeholders to design a model of care for people with HIV which builds on the excellence in HIV care and ensures their wider health needs can be effectively met. The intention is to begin to change the way London HIV services operate in 2014.

Finally, I'd like to thank everyone who participated in the *My Care, I Care* study, in particular:

- all those service users who helped design the survey who made sure it made sense from a user point of view;
- all users who gave time to tell us what they think, in the survey and the focus groups;
- all HIV service staff who helped promote the survey and encouraged their service users to participate;
- all voluntary organisations who promoted the survey and encouraged responses;
- The Sigma Research team for undertaking this novel approach.

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March 31st 2013

EXECUTIVE SUMMARY

INTRODUCTION AND METHODS

1. The London Specialised Commissioning Group (SCG) is responsible for commissioning HIV treatment and care services in London. It is keen to modernise services to be responsive to the changing epidemiology and demography of HIV, changes in life expectancy and morbidity and advances in antiretroviral treatment. This research project constitutes one element of this process of review.

2. Sigma Research (London School of Hygiene & Tropical Medicine) was commissioned to research the views of people with diagnosed HIV (PWHIV) about the clinical services in London they used. The research included an anonymous self-completion survey and eight focus groups to investigate motivations for service use, satisfaction with services and aspirations and suggestions for service development.

3. The survey was promoted in all London's 28 HIV out-patient clinics and was available for completion online, promoted by charitable HIV organisations. Recruitment sought to ensure as representative a sample of PWHIV in London as possible, and to ensure representation from all 28 London clinics. Priority was given to obtaining a large and geographically diverse sample to a questionnaire that had undergone extensive consultation and piloting.

4. In order to qualify, respondents had to have diagnosed HIV and used NHS HIV services in London in the last year or currently live in London. Recruitment ran from late February to late July 2012. By using multiple methods, 4-5% of people using London HIV clinics were recruited. After exclusions there were 1390 respondents to the survey, of which two thirds (64.5%) were recruited in clinics and a third (35.5%) were recruited online.

5. Ultimately, 51 people participated in eight focus groups. The composition of the groups was based around three variables: the size of HIV clinic attended, route of infection, and experience of physical or mental health co-morbidities.

SAMPLE DESCRIPTION

6. Residents of all 33 London Local Authorities took part. The majority lived in those London boroughs known to have the highest HIV prevalence, including Lambeth, Southwark, Croydon, Lewisham, Camden and Tower Hamlets.

7. Almost three quarters (74.2%) of the survey sample was male; a quarter (25.8%) female. More than a third (34.3%) were heterosexual, with 59.3% identifying as gay and 5.2% identifying as bisexual. A minority of females (5.7%) had a lesbian or bisexual identity compared to the majority of males (84.3%) who identified as gay or bisexual, or used a similar phrase to denote same sex attraction (henceforth this group is usually referred to as MSM for brevity).

8. The age of respondents ranged from 16 to 88 with an average of 43. The majority were in their 30s (25.5%) or 40s (40.5%).

9. Less than half (45.4%) considered themselves white British, but another fifth (18.9%) were white. Of the remainder, the majority defined as black African (22.7%), or black Caribbean (4.3%) or black other (0.9%). The remainder (8%) specified ethnicities which were not white.

10. People born in the UK accounted for half (51%) the survey sample, including three fifths (61%) of males but only a fifth (21%) of females. African-born respondents accounted for 24% of the

sample, including 12% of males and 60% of females. Among migrants (49% of the sample) the average length of time resident in the UK was almost 15 years. One migrant-in-twelve (8.1%) reported problems associated with immigration to the UK. African born migrants were considerably more likely to report problems with immigration compared to other migrants.

11. A small proportion had no educational qualifications (4.3%) at all, or left school after primary education (1.9%). Thereafter just under a fifth (18.2%) had GCSEs or equivalent, and slightly less (15.5%) had A-levels or equivalent. Almost half (48.6%) had a University degree or equivalent.

12. Five men and one woman (0.5%) reported having haemophilia or a similar bleeding disorder.

13. Previous experience of injecting drug use was reported by 7.6%, of which 42.7% reported injecting in the previous 12 months (3.2% of all). MSM were more likely to have ever injected compared to heterosexual men and women and to have done so in the last 12 months.

14. Just over a third currently lived alone (37.7%) and a similar proportion lived with a partner (36.6%). Two fifths (42.3%) of women and a fifth (19.3%) of heterosexual men lived with a child.

15. Across the whole survey sample 59.8% were in some form of paid employment, including 40.6% that worked full-time.

LIVING WITH DIAGNOSED HIV

16. The range of time since first HIV diagnosis was broad. One-in-ten were first diagnosed with HIV at least 20 years ago (10.3%) and a third were diagnosed in the last 5 years (31.2%). The longer people had diagnosed HIV the less likely they were to be in paid employment, even among those diagnosed in the age of HIV treatments.

17. 83% were first diagnosed with HIV in London, 7% were first diagnosed elsewhere in the UK and 10% were first diagnosed outside the UK. Of those first diagnosed in the UK, two thirds (67.0%) reported it was at a hospital in a GUM / STD / HIV clinic. Black respondents were less likely to have been diagnosed in GUM, and more likely to have been diagnosed as an in-patient.

18. 86.7% were currently taking HIV treatments, among which the majority (87.0%) felt they knew enough about the treatments they were taking. The majority of respondents not currently on treatments said either their doctor felt they did not need treatments at present and / or they personally felt they did not need treatments at present.

19. A fifth (20.3%) of those on treatments had missed doses in the previous two weeks. Those who felt that they did not know enough about the treatments they were taking were much more likely to have missed doses. Missing doses was also more common among younger people, African people, and those who had ever injected drugs.

20. Of those who knew the result of their last viral load test, 89% of those on treatments were undetectable. People under 25 were least likely to report undetectable viral load.

21. Two thirds (64.0%) of those on treatments reported their last CD4 test result was above 350 cells, including more than a third (38.0%) that had >500 cells. Black respondents were more likely to have <200 CD4 cells than Asian or white respondents.

22. Almost half (47.5%) of the survey sample reported at least one of fifteen co-infections or co-morbidities. The most common were high cholesterol, psychiatric or mental health problems and high blood pressure.

23. About half of all respondents reported problems with sleeping and /or with mental health issues such as anxiety, depression and self-confidence, in the last year. More than a third reported problems with relationships, with money and with sex in the last year.

24. Whilst broadly in line with SOPHID national surveillance data, the sample includes a higher proportion of homosexually active men and white people. However, the sample compares favourably with all other clinic or community samples of people with diagnosed HIV, conducted in English, as all such samples routinely display these biases.

HIV CLINIC USE

25. Attenders at small and medium sized clinics were more likely than those attending larger clinics to have been recruited to the survey in the clinic and less likely to have been recruited online. This suggests that clinic-based recruitment was important to ensure people using small (and medium) sized clinics were adequately represented.

26. Compared to respondents at small or large clinics, those at medium sized clinics were younger and more likely to be female; migrants and black. Compared to respondents at small and medium clinics, those at large clinics were much more likely to be white; to identify as gay or bisexual; to have ever injected drugs and to have a university degree.

27. The survey revealed substantial loyalty to their "main" clinic – almost half (47.0%) had either used the same clinic since first diagnosis or had used their current clinic for at least 11 years. Survey data suggest a churn rate of about one-in-fifteen people changing clinics in the last year.

28. The most important factors in people's choice of clinic were: a perception that staff were excellent and the clinic had a great reputation; their proximity to the clinic or ease of access; and a feeling of comfort there.

29. On a variety of measures satisfaction with their "main" clinic was very high. For example, the vast majority were very satisfied (86.1%) or somewhat satisfied (13.0%) with the way they and their clinic staff made decisions together about their care.

30. The vast majority (83.3%) had visited their clinic at least three times in the last year, including 41.1% that had visited at least five times, and 22.5% that had visited at least seven times.

31. The vast majority had attended their clinic very recently – almost half (45.9%) had attended in the last 4 weeks; more than three quarters (79.2%) had been in the last 3 months; and almost all (98.5%) within the last 6 months.

32. At their last visit, from their home (or workplace) almost half (46.0%) reached their clinic within 30 minutes; and more than two thirds (71.6%) within 45 minutes.

33. A third (33.6%) reported being in the clinic for less than 30 minutes at their last visit; more than half (60.1%) were in the clinic 45 minutes or less; and 81.8% were in the clinic an hour or less.

34. The levels of clinic loyalty and satisfaction found in the survey were reflected in the focus groups with nearly all participants listing their clinics as "the best" or "in the top 5".

35. The focus groups revealed positive reasons for remaining at the same clinic. Some MSM had sought large central London clinics because they perceived them to be 'gay-friendly'. Many in small clinics had been diagnosed near their home and having a local clinic was prized.

36. Participants with co-infections and co-morbidities reported changing clinics more frequently. A clinic's reputation in terms of standards of research and care was especially important to this group, as was the clinic's capacity to deliver a range of services in addition to HIV care. Many saw advantages to attending a clinic that was part of a large trust where they could access this broader range of services more easily.

37. Two aspects of clinical provision were most highly valued in the focus groups. The first was the atmosphere in the clinic: that is, feeling welcome and being treated with respect. The second was the individual consultant: their manner, skill, competency and the fact that there was continuity in the relationship between patient and consultant.

SHARED CARE – GPS AND OTHER HEALTH SERVICES USED

38. The majority of respondents (94.5%) were currently registered with a GP. Women, MSM, older respondents, those diagnosed for longer and those currently on treatment were more likely to be registered. Reasons for not registering included having recently moved home, a perceived lack of need for a GP or concerns about confidentiality in primary care.

39. More than half had been with their GP practice for more than five years; more than a third for eight years or more; and more than a quarter for eleven years or more.

40. Among those registered with a GP, the majority (86.4%) had disclosed their HIV infection there. Reasons for not disclosing included a lack of confidence in primary care staff, concerns about stigmatising attitudes or perceived lack of confidentiality in primary care settings.

41. The majority of those who reported their GPs knew of their HIV infection stated that they were not involved in their HIV care (83.6%). Women, heterosexual men, those of black or Asian ethnicity, and migrants were more likely to have their GP involved in their care than others.

42. The majority of respondents (79.1%) had used a GP or primary care service in the last year. About a fifth had used Accident & Emergency; a sexual health clinic; an outpatient clinic (not HIV) for an investigation or a NHS walk-in centre. One-in-seven (13.3%) had used an Outpatient clinic (not HIV) for monitoring or care. No other NHS setting had been used, in the last year, by more than 7% of all respondents.

43. For those experiencing co-morbidities or co-infections the extent to which care was shared between HIV specialists, other acute specialists and GP varied. With the exception of one condition (diabetes) HIV staff were always more likely to know about the problem than GPs.

44. HIV specialist staff were more likely than GPs to be involved in the management of high cholesterol, neurocognitive disorders; liver problems, hepatitis C; hepatitis B; kidney problems; problems with drugs and alcohol; ongoing and acute STIs and TB. Conversely GP staff were more likely than HIV specialist staff to be involved in the management of psychiatric or mental health problems; high blood pressure; diabetes; and heart problems.

45. Focus group participants revealed an additional barrier to consulting a GP: the perception that primary care settings were unable to deal with their complex health care needs. Participants cited being unable to get a prompt appointment, being unable to see the same doctor twice, slow or no logging of information on patient notes and fears about prescribing errors.

46. Focus group participants also perceived that GPs lacked confidence or knowledge when it came to interpreting their symptoms, or were unaware of their additional screening needs.

47. Participants lacked confidence in communication between HIV clinics and GPs, describing having to act as a go-between between HIV specialists and GPs, receiving contradictory advice, being referred from one to the other for certain symptoms or being sent to A&E by primary care.

48. Those with co-morbidities saw it as preferable that their care needs and referral were managed by their HIV clinician rather than their GP. Those whose HIV clinics were based within larger trusts felt that they had better access to specialist services through their HIV clinic than their GP.

49. Others reported positive experiences of primary care. Some, especially those who were older or experienced co-morbid conditions, had established a relationship of trust with their GP.

50. The fact that a new GP must be found if a person moves home was seen as a disincentive to building a relationship with a GP.

51. The factors that made GP involvement acceptable were continuity of care (that the same doctor is available on repeat visits and notes are promptly updated); high quality communication between GP and HIV clinician and that the GP defers to the HIV specialist in clinical decisions.

CHANGES TO HIV PROVISION: PERCEPTIONS & EXPECTATIONS

52. Participants were not opposed to developing HIV services in response to changes in the demographic make-up, size and needs of the population of people with HIV in London. Many saw it as the duty of commissioners to apply on-going scrutiny and improvements to services.

53. However, the majority were suspicious that proposals for change were based on cost pressures rather than questions of quality, equity or need.

54. Many stressed the importance of communication and consultation regarding any planned change and there was a perception that change was being planned without their involvement.

55. The strongest concern was about the possible increase in the role of primary care in any new model/s. Although most were not averse to considering innovative models for administering routine aspects of HIV care (blood tests, prescriptions and test results) locally, primary care was not seen as the appropriate setting for this.

56. Another concern was the potential loss of the relationship between patient and HIV consultant. Participants assumed that any change would lead to a reduction in the number of specialist consultants, and increased patient loads with patients having to transfer to other doctors. The majority were concerned about the potential loss of their current relationship with their consultant.

1 INTRODUCTION AND METHODS

1.1 INTRODUCTION

Human Immunodeficiency Virus (HIV) continues to be one of the most important communicable diseases in the UK. Highly active anti-retroviral therapy (ART) has resulted in substantial reductions in AIDS incidence and related deaths in the UK, but HIV is still associated with serious morbidity, high costs of treatment and care, significant mortality and a high number of potential years of life lost. While HIV is now commonly viewed as a manageable long-term condition, all these changes have an impact on the service uptake and needs of people with diagnosed HIV.

In 2011 31,147 people with diagnosed HIV accessed HIV care in London (SOPHID 2011), representing nearly half (46%) of all people accessing HIV care in England. The London Specialised Commissioning Group (SCG) is responsible for commissioning all HIV treatment and care services in London. The London SCG is keen to modernise services so as to be maximally responsive to the changing epidemiology and demography of HIV in London, changes in life expectancy and morbidity and advances in treatments. As part of this process they have conducted a range of reviews including a public health needs assessment and in-depth epidemiological data reviews. The research reported here constitutes another element of this process of review, the focus of which was research with people using HIV-specialist clinical services in London.

As the HIV Review is likely to result in a reorganisation of HIV clinical services in London, it was imperative to investigate what users valued with regard to HIV clinical services so that patient's views and aspirations regarding clinical services were central to the review process. Sigma Research was commissioned through open competitive tender, to research the views of people with diagnosed HIV (PWHIV) about the clinical services they used, including HIV specific services and generic primary care services, as well as patterns of service use. The research was planned to include a survey and eight qualitative focus groups and was conducted between late February and the end of July 2012.

The plan was to undertake an anonymous self-completion survey, via recruitment in the 28 HIV clinics in London by specialist fieldworkers. This was a novel approach. The survey was also available for completion online, promoted by London HIV service organisations. Sampling and recruitment sought to ensure as representative a sample of the population of PWHIV using clinical services in London as possible, and to ensure, where feasible, representation from all 28 London clinics. In addition, eight focus groups were undertaken to investigate in more detail motivations for service use, satisfaction with services and aspirations and suggestions for service development.

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 (see National Research Ethics Service).

1.2 SURVEY METHODS AND ANALYSES

Priority was given to obtaining a large and geographically diverse sample. This required a questionnaire that was relatively easy to complete and a wide-ranging recruitment strategy. In order to maximise the speed with which the questionnaire could be completed, most of the questions only required a tick, unless the range of answers could not be prejudged from previous comparable surveys (Weatherburn *et al.* 2002; Weatherburn *et al.* 2009).

The paper version of the questionnaire was designed in A4 format and covered 27-pages, printed back-to-back. The questionnaire included 15 questions about the demographic characteristics of respondents and another 8 on their personal HIV history. It then asked 12 questions on their use of HIV out-patient clinics in London and another 6 on their last visit to their "main" HIV clinic and another 6 on their experience of HIV treatment taking. These were followed by 9 questions on their use of primary care services, and 2 on their experience of other NHS services in the last year. All respondents were also asked about their experience of 16 other health conditions and a final question on their other needs with regard to health and well-being. We estimate that, on average, the questionnaire took twenty minutes to complete.

The survey questionnaire underwent extensive consultation and piloting. A first version of the paper questionnaire was distributed to clinicians in all 28 London clinics as well as a range of voluntary sector HIV agencies seeking feedback on length, accessibility and feasibility as a fieldwork instrument in clinics. Feedback was very useful, suggesting that the instrument was too long and recommending that a range of questions were simplified. A second much shorter draft of the survey was produced and a series of cognitive testing sessions was undertaken with the two main groups targeted by the survey: African people and MSM with diagnosed HIV. Cognitive testing consists of the respondent completing the questionnaire under controlled conditions followed by a detailed interview exploring how they understood each question and focusing on any difficulties with completing them. After three such sessions, the instrument was further shortened and simplified. The final session of cognitive testing was conducted with the group we anticipated would have most difficulty comprehending and completing the survey: African migrants with English as a second language.

The final survey instrument was less than half the length of the original and considerably simplified, taking on average 20 minutes to complete the pen and paper version. A total of 21 respondents took part in the cognitive testing. Sessions were held at and facilitated by Positively UK and Positive East and each participant was paid £15 towards their travel and / or childcare costs and other expenses.

In addition, the lead researcher held face-to-face and/or phone meetings with senior clinicians and other key staff in all clinics to introduce the research, describe the fieldwork process and to discuss in detail how fieldwork was to be carried out in each clinic. This proved to be an essential process and this diagogue was continued throughout the fieldwork period by the research administrator on the project.

In order to qualify for the study all respondents had to have diagnosed HIV and used NHS HIV services in London in the last year or currently live in London. As there was no national sampling frame available, purposive recruitment was used using as many different sources as possible to reach as diverse a group as possible. Recruitment lasted five months, from 26th February 2012 until 30th July 2012.

1.2.1 ONLINE SURVEY RECRUITMENT

The questionnaire was also available to complete online. The online version was hosted by www.demographix.com with identical questions to the paper version. Its availability was promoted via banners and text on the Sigma Research website and the London SCG website, in addition to five of the main HIV-related websites used by London-residents: Terrence Higgins Trust (www.tht.org.uk and the landing page of www.myHIV.org.uk); NAM (www.aidsmap.com); Positive East (www.positiveeast.org.uk); and Positively UK (www.positivelyuk.org).

The survey was also promoted via Twitter by Baseline magazine; Body & Soul; Dr. Christian Jessen; NAM; National AIDS Trust (NAT); Sigma Research; and Terrence Higgins Trust. NAM also promoted the online version of the questionnaire in the print and online version of HIV Treatments Update

(HTU) and via an emailing list. While not everyone subscribing to HTU has diagnosed HIV infection, NAM estimates 70-75% of their mailing list has diagnosed HIV. GMFA promoted the survey via an email to volunteers with diagnosed HIV. Ultimately 494 people completed the survey online, which is a third (35.5%) of the total sample.

Some clinics also promoted the online version of the survey via emails to registered patients that would not be attending the clinic during the time of the fieldwork.

1.2.2 FACE-TO-FACE SURVEY RECRUITMENT

Our intention was to send a field-worker to 80 HIV-clinic sessions, across the 28 specialist HIV out-patients clinics in Greater London. Four established Sigma Research fieldworkers received extensive training to aid recruitment in a clinical environment. The fieldworkers' main task was to approach people with diagnosed HIV, explain the rationale for the survey and support respondents to self-complete the survey while they were in the clinic. Where there was sufficient privacy fieldworkers were allowed to help the respondent complete the survey, supporting those who felt uncomfortable self-completing or who struggled to understand any question/s. Where clinic visits from our fieldworkers did not lead to the intended volume of respondents, some clinics volunteered to use staff to recruit patients to complete the survey when no field-worker was present.

The aspiration was to recruit 3-5% of the patient cohort in each of the 28 clinics, based on SOPHID 2010 patient numbers. In all clinics the number of fieldworker visits estimated to be needed to achieve this was calculated, and further fieldworker visits were added, where feasible, if recruitment in a clinic proved harder than anticipated. A number of factors affected response rates at a clinic level including volume of patients present and the ways in which waiting areas were organised and patient flow managed.

This research was not a review of clinic performance or the satisfaction of patients with individual clinics and this report does not present findings by clinic. However, feedback on key findings by clinic has been made available to clinic staff. In this report analysis is presented by the size of clinics' patient cohorts. To facilitate this all clinics have been grouped into small, medium and large based on the scale of their registered HIV patient cohort in SOPHID 2010. Clinics with up to 600 registered patients were allocated to the category *small*; clinics with between 601 and 1199 registered patients were allocated to the category *medium*; and those with 1200 registered patients or more were allocated to *large*.

The *small* group includes twelve clinics with a combined cohort of 3,881 patients with HIV (SOPHID 2010). We recruited to the survey 167 people with diagnosed HIV who stated one of these 12 was their main clinic and this represents 4.3% of the entire patient load of *small* HIV clinics in London. The *medium* sized group includes seven clinics, with a combined cohort of 5,719 patients with HIV and our 251 recruits represent 4.4% of the patient load of medium-sized clinics in London. The large-sized group includes nine clinics, with a combined cohort of 22,593 patients – and our 947 recruits to the survey represent 4.2% of the patient load of *large* clinics in London.

1.2.3 QUANTITATIVE ANALYSIS

By using multiple recruitment methods, we sought to reduce the biases of opportunistic recruitment. However, like most surveys of people with diagnosed HIV, the sample will be skewed away from people who are not literate in English, or wary of social research more generally. In order to reassure people about confidentiality, our survey was anonymous and self-completed, and all potential clinic recruits were assured that no one outside the research team would have direct access to their data.

After exclusions there were 1390 respondents in the sample. Of all respondents, 60% (n=834) were recruited in clinics via Sigma Research fieldworkers; 4.5% (n=62) were recruited in clinics via NHS staff members and a third (35.5%, n=494) were recruited online, mainly via NAM and Terrence Higgins Trust. The sample description in chapter 2 demonstrates that the survey was successful in recruiting a diverse sample but the comparison with national data reveals biases towards people who were male, homosexually active and white.

Using SPSS 20 a full descriptive analysis of all variables was generated, and supplemented by cross-tabulations between core variables and all the demographic characteristics of the sample as described in chapter 2. In chapters 3-5 all pertinent demographic variation in key findings is reported where a significant association exists (at p <.05).Throughout chapters 3-5, our approach is to focus on significant differences that have some explanatory validity. We do not report, each time that there was no variation according to a,b,c,d *etc*. and instead report significant differences only. Where pertinent, and possible, we also compare findings to other surveys of people with diagnosed HIV, and with other surveys of the general population.

1.3 FOCUS GROUP METHODS AND ANALYSES

At the end of the main survey all respondents were asked if they would be interested in participating in focus groups in Central London, to consider similar topics in more depth. Those respondents that agreed were asked to complete an entirely separate form giving us contact details (email or telephone) and the selected demographic characteristics (gender, ethnicity, age, sexuality, HIV clinic used) needed to allocate people to focus groups. Contact details were not stored with the questionnaires and could not be linked back to them.

During the first two months of survey recruitment, approximately 270 of the 800 people participating in the survey agreed in principle to take part in the focus groups. All gave us contact details and information which allowed us to then allocate them to different groups and to invite them to take part on set dates.

Invitations to participate in focus groups were sent by email or made by telephone. After responses confirming an interest in participating, they were then sent information about a specific group and details of the wider project and a confirmation of the time, date and venue of the group.

Nine groups were arranged initially though one was cancelled when only three respondents were recruited and one of them withdrew just prior to the group. Ultimately, there were 51 participants in the 8 focus groups who both agreed to attend and did so, an average of 6 participants in each group. Participation numbers in each group ranged from 3 to 12 people. Focus group participants were paid £20 towards their travel costs and any other expenses.

In accordance with the study design and with the principles of purposive sampling, the composition of the groups was decided in consultation with the funder prior to recruitment. Thus, we did not seek to run groups that were 'representative' of the survey sample. Group composition was based around three variables that were considered to have most influence on the experience of using HIV services: the size of clinic attended, the route of infection, and the presence or not of physical or mental health co-morbidities.

Size of clinic was established with reference to SOPHID 2010 data on patient cohort for each clinic. In order to produce a viable qualitative sample, clinics were divided into large or small categories (unlike the survey sample where they were assigned to small, medium or large). We chose to focus on the two population groups which account for the majority of HIV diagnoses in London: MSM and African migrants. As health and co-morbidities are likely to profoundly influence need, we designated two groups to people with serious co-morbid conditions (such as cancers or acute cardio-vascular conditions) and one of people experiencing mental health problems (this being a very common co-morbidity among people with diagnosed HIV).

Initially, we proposed to run a group of those respondents experiencing, or having experienced 'transitional' HIV services (that is, had transferred from paediatric to adult HIV services). However, representation of this group in the survey sample was not large enough to allow purposive sampling and recruitment. A range of other recruitment strategies were tried, but after two unsuccessful attempts to convene groups, we discontinued recruitment and recommend that this group be researched separately. Instead, we ran a third African group as one of the previous two African groups had been sparsely attended.

Thus, our final sample consisted of three groups targeting Black African respondents (1 group from larger clinics, 1 group from smaller clinics and a mixed group). Two groups targeted MSM (1 group from smaller and 1 from larger clinics), 2 groups targeted those with other health problems, apart from psychiatric or mental health problems; (1 from smaller clinics and 1 group from larger clinics) and 1 group targeted those with psychiatric or mental health problems using larger clinics. A detailed sample composition is given in the table below.

Group	Type of group	Date 2012	Attendees	Notes
1	MSM. Large clinics	19th April	**8 attendees** out of 11 confirmed	All MSM. All white including one white other. None had other co-morbidities. Ages ranged from 35 to 59, with an average (median) of 43.
2	Psychiatric or mental health problems. Large clinics	1st May	**12 attendees** out of 12 confirmed.	10 MSM and 2 heterosexual women. 10 white, 1 African, 1 Asian. Age range 26 – 60, median 41.5. Ten had a co-morbidity in addition to psychiatric or mental health.
3	Black African. Large clinics.	2nd May	**4 attendees** out of 9 confirmed	4 people took part 1 came too late. All black African and heterosexual: 1 male and 3 female. Age range 45 – 53, median 50.
4	Co-morbidities. Large clinics.	3rd May	**6 attendees** out of 11 confirmed	All MSM, all co-morbid. Four were white, 1 Asian and 1 mixed ethnicity. Age range 31-67, median 48.
6	Co-morbidities apart from psychiatric or mental health. Smaller clinics	9th May	**4 attendees** out of 4 confirmed	3 males, 1 female. 2 heterosexual, 2 MSM; 2 African, 1 white and 1 mixed ethnicity. Age range 31 – 62, median 46.
7	Black African from smaller and medium clinics	10th May	**3 attendees** out of 5 confirmed	3 female, all African. 2 heterosexual, 1 lesbian. No other co-morbidities. Age range 35 – 49, median 45.
8	MSM small and medium	13th June	**7 attendees**	7 MSM. One mixed ethnicity, all others white. Age range 35 – 47, median 41. One had a co-morbidity.
9	Black African mixed	27th June	**7 attendees**	All black African; 6 women and 1 man. All heterosexual and mix of co-morbidities. Age range 18-45, median 35.

1.3.1 QUALITITATIVE ANALYSES

Recordings of focus groups were annotated and partially transcribed. The notes and transcriptions were used to generate a range of overarching themes. These were then developed into frameworks using NVivo software. Notes and transcriptions were then assigned to frameworks to facilitate a full thematic content analysis.

Qualitative findings are presented in chapters 4 to 6 in narrative form and illustrated by key quotations taken from the transcripts. All quotations are anonymised but tags identify the gender of the speaker where groups are of mixed gender, the patient group the speaker belongs to (i.e. MSM, African) and the type of group (for example Smaller Clinic Co-morbidity). In instances where groups are single gender and single patient group (as in the MSM groups), the detail of the tags reflect this.

2 SAMPLE DESCRIPTION

After exclusions there were 1390 respondents in the sample. This chapter provides a description of the characteristics of the entire sample.

2.1 GENDER

Almost three quarters (74.2%) of the entire sample was male, and just over a quarter (25.8%) were female. Among the clinic recruited sample, a higher proportion (32.1%) were female, but a lower proportion (14.3%) of the online sample were female.

2.2 SEXUALITY

Overall, more than a third (34.3%) of the sample identified themselves as straight or heterosexual, with 59.3% identifying as gay and 5.2% as bisexual. A minority of female respondents (5.7%) had a gay, lesbian or bisexual sexual identity compared to the majority of males (84.3%) who identified as gay or bisexual or used a similar term to denote same sex attraction (henceforth referred to as MSM).

Sexuality (N=1357, missing 33)	**% (n) overall**	**% by gender**	
		All females (n=332)	**All males** (n=993)
Heterosexual (straight)	34.3 (466)	92.8	14.7
Gay	59.3 (805)	0.6	79.0
Lesbian	0.1 (1)	0.3	0.0
Bisexual	5.2 (70)	4.8	5.3
Other	1.1 (15)	1.5	1.0

2.3 AGE

The age of respondents ranged from 16 to 88 with an average of 43 (mean 43.1, standard deviation (sd) = 10.4, median 43, range 16-88). The majority of respondents were in their 30s (25.5%) or 40s (40.5%). Only 3.1% were under 25 years of age, and 9.8% were under 30.

There was no significant difference in age between the online and clinic recruited samples, but women were significantly younger on average (mean 40.4, sd = 9.9) than either MSM (mean 43.7, sd = 10.4) or heterosexual men (mean 45.9, sd = 10.0).

Age groups (N=1374, missing 16)	**% (n) overall**	**% by gender & sexuality**		
		All females (n=346)	**Hetero. males** (n=146)	**MSM** (n=838)
under 25 years old	3.1 (43)	4.3	2.7	2.5
25 -29 years old	6.7 (92)	9.8	2.1	6.6
30 – 34 years old	10.8 (148)	14.2	4.1	10.6
35 – 39 years old	14.7 (202)	17.1	13.7	13.8
40 – 44 years old	19.7 (271)	20.8	23.3	19.0
45 – 49 years old	20.8 (286)	17.6	19.9	22.0
50 – 54 years old	11.4 (157)	9.5	18.5	10.7
55 – 59 years old	6.5 (89)	3.5	8.9	7.4
60 years old and over	6.3 (86)	3.2	6.8	7.4

2.4 AREA OF RESIDENCE

In order to qualify for the study people had to have diagnosed HIV, use an HIV out-patient clinic in London, and / or live in London. Not surprisingly, 93% lived in London. Residents of all 33 London Local Authorities were represented in the sample. The majority lived in those London boroughs known to have the highest HIV prevalence, including Lambeth, Southwark, Croydon, Lewisham, Camden and Tower Hamlets (all above 5% of the sample).

London sector of residence (N=1288, missing 102)	**% (n) overall**	**Local Authority of residence** (N=1265, missing 125)	**% (n) overall**	**% by gender & sexuality**		
				All females (n=315)	**Hetero. males** (n=134)	**MSM** (n=778)
North Central London	13.4 (173)	Barnet	1.2 (15)	1.6	2.2	0.9
		Camden	5.1 (65)	1.9	0.7	7.2
		Enfield	1.2 (15)	1.9	2.2	0.8
		Haringey	1.9 (24)	1.3	3.7	1.9
		Islington	4.0 (51)	1.3	2.2	5.5
North East London	20.8 (268)	Barking & Dagenham	1.9 (24)	4.1	5.2	0.5
		City of London	0.4 (5)	0.0	0.0	0.5
		Hackney	4.7 (59)	7.3	3.7	3.3
		Havering	1.3 (16)	2.2	3.7	0.5
		Newham	2.8 (36)	6.3	2.2	1.5
		Redbridge	2.3 (29)	3.2	3.7	1.8
		Tower Hamlets	5.1 (64)	1.6	2.2	6.9
		Waltham Forest	2.2 (28)	1.6	7.5	1.5
North West London	16.1 (207)	Brent	1.7 (22)	1.0	1.5	1.8
		Ealing	2.0 (25)	2.5	0.7	2.1
		Hammersmith & Fulham	2.9 (37)	2.5	0.7	3.6
		Kensington & Chelsea	2.5 (31)	1.3	0.7	3.1
		Harrow	0.6 (8)	1.3	0.0	0.5
		Hillingdon	0.6 (7)	0.0	3.0	0.4
		Hounslow	1.0 (13)	1.6	1.5	0.8
		Westminster	4.9 (62)	1.3	1.5	7.1
South East London	27.3 (351)	Bexley	0.9 (11)	1.9	0.7	0.5
		Bromley	2.3 (29)	1.9	4.5	1.9
		Greenwich	3.1 (39)	6.0	3.0	2.1
		Lambeth	8.9 (113)	4.8	6.0	11.2
		Lewisham	5.2 (66)	6.7	1.5	5.3
		Southwark	6.6 (84)	4.1	5.2	8.0
South West London	15.3 (197)	Croydon	6.4 (81)	11.14	14.9	2.7
		Kingston-upon-Thames	0.9 (12)	0.6	0.7	1.2
		Merton	1.8 (23)	2.2	3.0	1.3
		Richmond-upon-Thames	1.2 (15)	1.6	0.7	1.2
		Wandsworth	4.4 (56)	3.2	2.2	5.5
		Sutton	0.6 (8)	1.0	0.7	0.5
RESIDENT outside London			7.3 (92)	8.9	7.3	6.3

Aggregating the Local Authorities of residence into the five London NHS sectors, more than a quarter of all respondents lived in South East London (27.3%), with a fifth resident in North East London (20.8%) and smaller proportions resident in North West (16.1%); South West London (15.3%) and North Central London (13.4%). One-in-fourteen (7.3%, or 92) of all respondents lived outside London but used HIV out-patients services in London. The majority lived in the counties surrounding London, especially Surrey, Hertfordshire, Essex, Kent, Hampshire, East Sussex and West Sussex though a small number lived further afield.

2.5 ETHNICITY AND MIGRATION HISTORY

Less than half (45.4%) the sample considered themselves white British, although another fifth (18.9%) were white. Of the remainder, the majority defined themselves as black African (22.7%), or black Caribbean (4.3%) or black other (0.9%). The remaining 8% of the sample specified ethnicities which were not white, including 3.4% stating Asian ethnicities and 3.4% stating mixed ethnicities.

Ethnicity (N=1378, missing 12)		**% (n) overall**	**% by gender & sexuality**		
			All females (n=349)	**Hetero. males** (n=145)	**MSM** (n=834)
White	White British	45.4 (626)	12.6	24.1	62.2
	White Irish	3.8 (53)	0.6	1.4	5.6
	White other	15.1 (208)	9.7	6.2	19.2
Black	Black African	22.7 (313)	62.2	53.1	1.2
	Black Caribbean	4.3 (59)	7.2	4.8	3.0
	Black other	0.9 (12)	0.9	3.4	0.4
Mixed ethnicities	White & Black Caribbean	1.4 (19)	0.3	0.7	2.0
	White & Black African	0.9 (12)	2.3	1.4	0.2
	White & Asian	0.6 (8)	0.3	0.7	0.7
	Other mixed	0.5 (7)	0.3	0.0	0.6
Asian	Indian	1.6 (22)	1.4	2.8	1.3
	Pakistani	0.4 (5)	0.3	0.7	0.4
	Bangladeshi	0.2 (3)	0.6	0.7	0.0
	Chinese	0.7 (9)	0.9	0.0	0.7
	Other Asian background	0.6 (8)	0.3	0.0	0.8
Other: Arab		0.1 (2)	0.0	0.0	0.2
Other ethnic groups		0.9 (12)	0.3	0.0	1.3

Black (mean 41.1 years old, sd = 9.4) and Asian respondents (mean 42.2, sd = 11.0) were younger, on average, than white respondents (mean 44.4, sd = 10.6). White respondents were significantly more likely to identify as gay or bisexual (85.3%) compared to Asian (60.9%), or black African (13.5%) respondents.

2.5.1 COUNTRY OF BIRTH

Respondents were asked the question: *What country were you born in?* In total, 100 countries or territories were represented in the answers. The table below shows the 12 countries in which at least twenty respondents were born, the proportion of the total sample that group represents, and what proportion of people that were born there that were females and heterosexual males and MSM.

Top twelve countries of birth (N=1301, missing 89)	**% (n) overall**	**% by gender & sexuality**		
		All females (n=326)	**Hetero. males** (n=136)	**MSM** (n=789)
England	45.4 (591)	11.5	5.8	82.7
Zimbabwe	5.0 (65)	68.3	19.0	12.7
Uganda	4.8 (63)	65.6	31.1	3.3
Republic of Ireland	2.9 (38)	5.6	5.6	88.9
Scotland	2.5 (32)	6.2	6.2	87.5
Zambia	2.4 (31)	71.0	16.1	12.9
Nigeria	2.1 (27)	68.0	28.0	4.0
France	1.8 (23)	13.6	9.1	77.3
Kenya	1.8 (23)	63.6	22.7	13.6
Italy	1.7 (22)	13.6	4.5	81.8
Portugal	1.6 (21)	19.0	19.0	62.0
South Africa	1.6 (21)	20.0	30.0	50.0
All others	26.4 (344)	32.3	11.5	56.2

People born in the United Kingdom accounted for half (51%) of all respondents, including three fifths (61%) of males but only one fifth (21%) of females. African-born respondents accounted for 24% of the whole sample, including 12% of males and 60% of females. Other respondents were born in the rest of Europe (14%), North America (4%), South America (4%), Asia (3%) and Oceania (1%).

2.5.2 LENGTH OF TIME RESIDENT IN THE UK

Among migrants to the UK (49%, n=647) the average length of time resident in the UK was just under 15 years (mean 177 months, sd = 122 months, median 144 months, range 4-732 months). On average, African migrants (51% of all migrants, n=325) had lived in the UK for a significantly shorter time (mean 156 months, sd = 92) than migrants from other areas of the world (mean 200, sd = 144) except those from South America, who were the most recent arrivals to the UK (mean 143, sd = 71).

2.5.3 PROBLEMS ASSOCIATED WITH IMMIGRATION TO THE UK

One migrant-in-twelve (8.1%) reported problems associated with immigration to the UK, which is equivalent to one-in-twenty-five (3.5%, n=49) of all respondents. African born migrants were considerably more likely to report problems with immigration compared to other migrants (13.0% of Africans compared to 3.0% of migrants from elsewhere). Expecting full disclosure of immigration problems, even in an anonymous self-completion survey, is somewhat naïve. However, these data reveal that at least one-in-eight Africans using HIV out-patients in London have a problem associated with immigration.

Most commonly respondents reported an uncertain immigration status because their case was pending (17), many of which had been waiting for a very long time. Next most commonly they described having an application for leave to remain or permanent residency – or to change or renew a visa – turned down and a long process or reapplication or waiting for an appeal, which was pending (7). A few people were going through the initial stages of application to change their status (3). Three people described having overstayed their visa or having no status.

2.6 EDUCATIONAL LEVEL

A small proportion of respondents had no educational qualifications (4.3%) at all, or left school after primary (1.9%) education. Thereafter just under a fifth (18.2%) had GCSEs or equivalent, having left school at 16 and slightly less (15.5%) had A-levels or equivalent, having left school are age 18. Just under half (48.5%) of all respondents had a University degree or equivalent.

Highest educational qualification (N=1364, missing 26)	**% (n) overall**	**% by gender & sexuality**		
		All females (n=342)	**Hetero. males** (n=142)	**MSM** (n=836)
No educational qualifications	4.3 (59)	7.0	6.3	2.9
Primary education only (left school at 11 or 12)	1.9 (26)	5.6	2.1	0.4
O-levels/ GCSEs/ CSEs or equivalent (left school at age 16)	18.2 (248)	20.5	21.1	16.4
A-levels or equivalent (left school at age 18)	15.5 (211)	14.9	14.1	16.0
University degree or higher	48.5 (662)	37.1	40.1	55.1
Other, such as vocational or professional qualifications	11.6 (158)	14.9	16.2	9.2

Online recruits were significantly more likely to have a university or college education than clinic recruits (60.0% compared to 42.2%). Men were significantly more likely to have a university education compared to women (52.9% compared to 37.1%). MSM were most likely to have a university education compared to heterosexual males and females (55.1% compared to 40.1% and 37.1%). Asian respondents were significantly more likely to have had a university education compared to white and black respondents (57.4% compared to 52.7% and 36.8%). Those who are in their early 50s were much more likely to have O levels only and those over 55 to have no education.

2.7 HAEMOPHILIA

Five men and one woman reported having haemophilia or a similar bleeding disorder (0.4% of all respondents).

2.8 INJECTING DRUG USE

Previous experience of injecting drug use was reported by 7.6% of respondents (n=104), of which 42.7% reported injecting drug use in the previous 12 months (3.2% of all respondents). Those with white ethnicity were significantly more likely to have ever injected drugs compared to those with Asian and black ethnicities (10.8% vs. 2.2% vs. 0.5%) and to have done so in the last 12 months (4.6% vs. 2.2% vs. 0.3%). Those who were UK-born were significantly more likely to have ever injected drugs (9.9% vs. 4.6%) and to have done so in the last 12 months (5.0% vs. 1.1%). MSM were most likely to have ever injected compared to heterosexual men and women (10.0% vs. 4.2% vs. 3.2%) and to have done so in the last 12 months (4.8% vs. 0.7% vs. 0.3%). Injecting drug use did not vary by age.

2.9 CURRENT LIVING ARRANGEMENTS

Just over a third (37.7%) of all respondents currently lived alone and a similar proportion lived with a partner (36.6%). MSM were significantly more likely to live alone than heterosexual males and females. Heterosexual males and females were significantly more likely to live with children. Two fifths (42.3%) of all women and one fifth (19.3%) of heterosexual men lived with a child they were responsible for. African born people were much less likely to live alone compared to others (24.8% vs. 41.8%). Black and Asian people were less likely to live alone compared to white and mixed and other ethnicities (28.8% vs. 23.9% compared to 42.2% and 40.7%).

Current living arrangements (N=1365, missing 25)	**% (n) overall**	**% by gender & sexuality**		
		All females (n=345)	**Hetero. males** (n=145)	**MSM** (n=835)
I live alone	37.7 (515)	24.9	35.2	43.5
I live with a partner	36.6 (500)	32.5	44.8	37.2
I live with a child / children I am responsible for	13.8 (188)	42.3	19.3	1.1
I live with housemates or people I share with	8.1 (111)	4.3	4.1	10.3
I live with friends	5.3 (73)	3.2	2.1	6.5
I live with other family members	4.2 (57)	7.5	11.0	1.6
I live with my parents / step parents	3.4 (47)	3.2	4.8	3.5
I live in a hostel or other temporary accommodation	0.7 (9)	0.9	1.4	0.4
I live in temporary accommodation	0.3 (4)	0.6	0.7	0.0
I am homeless	0.1 (2)	0.3	0.0	0.1
Other living arrangements	0.8 (11)	2.0	0.7	0.4

2.10 EMPLOYMENT, EDUCATION AND INCOME

Half (59.8%) of all respondents were in some form of paid employment (n=820), most of whom (67.9%, n=557) worked full-time. Others were working for themselves (18.6%, n=153), part-time (15.3%, n=126) or casually / cash-in-hand (1.9%, n=16).

Of respondents who were not in paid employment (40.2%, n=552), the largest proportion reported they were not in employment and were registered for benefits (37.7%, n=208); a smaller proportion (29.9%, n=165) were unable to work because of a long-term illness, disability or medical retirement but another 14.1% (n=78) described themselves as retired or a pensioner. Of those that were not in paid employment, 12.5% (n=69) said they were volunteering and 5.1% (28) were not allowed to work for immigration reasons. One-in-ten (9.4%, n=52) were not registered for benefits and 3.4% (n-19) described themselves as carers or homemakers.

Current activity: employment and education (N=1372, missing 18)	**% (n) overall**	**% by gender & sexuality**		
		All females (n=345)	**Hetero. males** (n=144)	**MSM** (n=838)
Full-time employment	40.6 (557)	27.8	40.3	46.8
Part-time employment	9.2 (126)	16.8	9.0	6.2
Self-employment	11.2 (154)	4.9	11.1	13.4
Casual / cash-in-hand	1.2 (16)	0.9	2.1	1.2
On a training scheme	0.6 (8)	0.9	1.4	0.4
Volunteering	7.5 (103)	9.3	7.6	6.9
Full-time education	4.9 (67)	8.1	6.9	3.2
Part-time education	5.4 (74)	7.2	6.2	4.8
Carer / homemaker	2.6 (35)	7.2	0.7	1.1
Not in employment and registered for benefits	15.5 (212)	14.2	21.5	14.3
Not in employment & not registered for benefits	3.9 (53)	5.8	4.9	2.6
Unable to work (long-term illness / disability / medically retired)	12.4 (170)	11	6.2	13.7
In employment and receiving tax credit	1.1 (15)	2.9	0.7	0.5
Retired / pensioner	6.0(82)	2.0	4.9	7.6
Not allowed to work (immigration reasons)	2.3 (31)	7.6	2.8	0.2
Other	0.7 (9)	1.7	0.0	0.2

Overall, women were less likely to be in any paid employment compared to men (50.4% compared to 63.5%). However, women were more likely to be in employment and receiving tax credit (2.9% vs. 0.5%) and less likely to be in full-time employment (28.1% vs. 45.6%); to be self-employed (4.9% vs. 13.1%); or to report they were retired or a pensioner (2.3% vs. 7.2%). Compared to men, women were more likely to be currently in education or on a training scheme (16.2% compared to 9.0%); more likely to report not being allowed to work due to immigration problems (7.2% vs. 0.6%); and to describe themselves as being a carer or homemaker (7.2% vs. 1.0%); to be in employment and receiving tax credits (2.9% vs. 0.5%) and not in employment and not registered for benefits (5.8% vs. 2.9%).

Compared to respondents recruited in clinics, respondents recruited online were more likely to be in full-time employment (47.4% vs. 36.8%) and less likely to be in employment and receiving tax credits (0.2% vs. 1.6%). Overall, online recruits were more likely to be in any paid work (64.8% vs. 56.9%).

Black respondents were less likely to be in paid employment (53.1%) compared to Asian (66.7%) and white respondents (62.3%). Moreover, black Africans were more likely to be in part-time employment (18.3%) compared to white (6.0%) and Asian respondents (4.4%); to be receiving tax credits and employed (2.4% compared to white 0.7% and Asian 0.0%) to be in full time education (8.5% compared to white 3.5% and Asian 2.2%) and part time education (7.7% compared to white 4.3% and Asian 4.4%); and least likely to be in full-time employment (28.8% compared to 44.5% and 53.3%); or to be self-employed (5.8% compared to 13.7% and 8.9%); or retired or on a pension (1.9% compared to 7.7% and 13.3%). African respondents were most likely to describe themselves as carers or homemakers (5.0%, compared to white 1.2% and Asian 2.2%) and to report being in education (16.7% compared to 8.9% or 8.2%). No white or Asian respondent reported not being able to work because of immigration problems compared to 7.9% of black African respondents.

Those with a gay, bisexual or other similar identity were more likely to be in paid employment (63.9%) compared to heterosexuals (52.8%); in particular full-time (45.9% vs. 32.2%), and self-employment (13.4% vs. 7.0%). They were less likely to be in part-time employment (6.4% vs. 13.8%); to describe themselves as a carer or homemaker (1.1% vs. 5.1%); to be in employment and receiving tax credit (0.3% vs. 2.3%); and to not be in employment and not registered for benefits (2.7% vs. 5.3%); or to say they were not allowed to work because of immigration issues (0.3% vs. 5.5%). Those with a gay or bisexual identity were also less likely to be in education (8.3 %) compared to heterosexuals (15.3%).

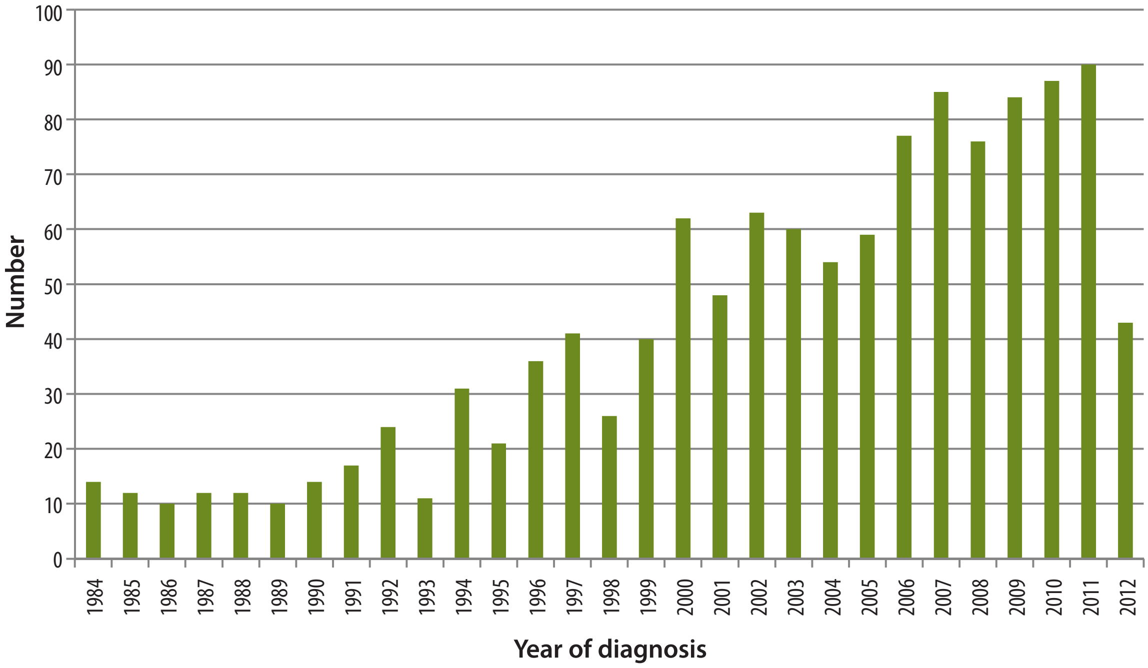
3 LIVING WITH DIAGNOSED HIV

This chapter describes the current health and well-being of the whole sample, in relation to both their HIV infection and other potential health problems and needs. In all that follows we describe self-reports of people's clinical status and their views and experiences. We have tried to maintain the authentic voice of the patient and include all reported experiences, even those that might be considered obvious in terms of the clinical management of HIV.

This chapter describes when respondents were first diagnosed with HIV and where; before proceeding to describe their HIV treatment taking and recent monitoring results for HIV viral load and CD4 counts. The chapter then describes the prevalence of other infections and conditions, before describing experiences of other health problems and needs of the people in our sample. It closes (section 3.6) with a comparison of the demographic profile of our sample and London data from the National Survey of Prevalent HIV Infections Diagnosed (SOPHID) undertaken by the Health Protection Agency.

3.1 FIRST DIAGNOSIS WITH HIV

Respondents had first been diagnosed with HIV as long ago as 1984 (1.2%, n =14) and as recently as the last 12 months (9.9%, n=120). Overall, one-in-ten were first diagnosed with HIV at least 20 years ago (10.3%, n=125, 1984-1992); and a similar proportion were first diagnosed 15 to 19 years ago (11.4%, n=140, 1993-1997); a fifth were first diagnosed 10 to 14 years ago (19.5%, n=238, 1998-2002); over a quarter were first diagnosed 5 to 9 years ago (27.5%, n=335, 2003-2007); and almost a third were first diagnosed in the last 5 years (31.2%, n=380, 2008-2012).



There were no gender, sexuality or recruitment differences in the average length of time since first HIV diagnosis. However, white (mean 9.6 years, sd = 7.4) and black respondents (mean 8.5, sd = 5.6) had been diagnosed with HIV for longer, on average, than Asian respondents (mean 6.9 , sd = 6.1). Also, migrants to the UK (mean 8.5 years, sd = 6.5) had been first diagnosed more recently compared to non-migrants (mean 9.7 years, sd = 7.2).

Even if we only consider those respondents first diagnosed with HIV after the widespread availability of HIV treatments (that is, from 1997 onwards), those not in full-time employment (mean 7.3 years, sd = 4.3) had been diagnosed for longer than those in full-time employment (mean 5.7 years, sd = 4.0). Similarly those who were not in any paid employment (mean 7.7 years, sd = 4.5) had been diagnosed longer than those in any paid employment (mean 6.0 years, sd = 4.0). While the perception of HIV infection as a long-term medical condition is widespread, the longer people had diagnosed HIV the less likely they were to be in employment.

3.1.1 PLACE OF INITIAL HIV DIAGNOSIS

One-in-ten (10.0%, n=136) of all respondents were first diagnosed with HIV outside the United Kingdom. Of those that were first diagnosed with HIV in the UK, the majority (91.5%) were first diagnosed in London. Hence, of the entire sample, 83% were first diagnosed in London, 7% were first diagnosed with HIV elsewhere in the UK; and 10% were first diagnosed with HIV outside the UK.

Venue for initial HIV positive diagnosis, among those diagnosed in the UK only (N=1229, missing 8)	**% (n) overall**	**% by gender & sexuality**		
		All females (n=295)	**Hetero. males** (n=129)	**MSM** (n=763)
at a hospital in a GUM / STD / HIV clinic	67.0 (824)	49.0	50.4	77.1
in hospital on a ward (as an in-patient)	8.9 (109)	10.9	13.2	7.2
at your General Practitioner / family doctor	6.3 (77)	10.9	8.5	4.3
at a hospital at another type of out-patient clinic	6.3 (77)	8.8	16.3	3.3
at an ante-natal clinic (during pregnancy)	3.3 (41)	13.6	0	0
at a private clinic	2.0 (25)	0.3	0.8	3.0
in hospital at Accident & Emergency (A&E)	2.6 (32)	3.4	4.7	1.8
at a community testing centre	2.0 (25)	1.0	3.1	2.4
while donating blood	0.7 (8)	1.4	0.8	0.4
I used a home testing kit	0.0 (0)	0	0	0
Somewhere else	0.9 (11)	0.7	2.3	0.5

Females were significantly more likely to have received their first HIV diagnosis while in hospital as an in-patient (10.9% vs. 8.3%); at a GP (10.9% vs. 5.0%) and an ante-natal clinic (13.6% vs. 0.1%). Males were more likely to have been diagnosed via GUM (73.0% vs. 49.0%). Those with a gay or bisexual identity were more likely to have been first diagnosed in GUM (76.6%) compared to heterosexuals (49.6%), and less likely to have been diagnosed in hospital (7.1% compared to 12.3%).

Black respondents were less likely to have been first diagnosed in GUM (51.5%) compared to white, (73.2%) and Asian (57.5%) respondents, and more likely to have been diagnosed as an in-patient (12.7%), compared to white (7.2%) and Asian (7.5%) respondents. Asian respondents were most likely to have been diagnosed at a GP or at hospital out-patients clinics (15.0% and 15.0%) compared to white (4.9% and 4.9%) and black respondents (8.6% and 9.2%).

Migrants to the UK were less likely to have been diagnosed in GUM (60.4% vs. 73.7%) and more likely to have been diagnosed at a GP (8.8% vs. 4.0%). Those born in Africa were less likely to be diagnosed in GUM (54.0% vs. 71.9%) than those born elsewhere. Those with immigration problems were more likely to have been diagnosed at an antenatal clinic (11.9 % vs. 4.9%) or A&E (14.3% vs. 2.7%).

3.2 HIV TREATMENTS

Across the whole sample, six respondents in seven (86.7%) were currently taking HIV treatments. There were no differences in the likelihood of currently taking treatments between those recruited online or through clinics; or by gender; or living arrangements; or ethnic groups or whether they were a migrant or UK-born; had problems with immigration, their education level or by sexual identity or injecting drug use.

Those born in Africa were more likely to be on treatments compared to those born elsewhere (90.4% vs. 85.3%), perhaps reflecting a higher proportion of African people being diagnosed late. Women and MSM were similarly likely to be currently taking treatments but less likely than heterosexual men (86.2% of women compared to 85.7% of MSM and 95.0% of heterosexual men). Those who were taking treatments had been diagnosed with HIV considerably longer (mean 10.0 years, sd = 6.9) than those who were not on treatments (mean 4.2 years, sd = 4.5). Those who were taking treatments were older (mean 44.0, sd = 10.2) on average, than those who were not (mean 37.4 years, sd = 9.5), probably reflecting a longer period of living with HIV.

3.2.1 CURRENT TREATMENT TAKERS

All those respondents who were currently taking treatments were asked *Do you feel you know enough about the antiretroviral treatments you are taking, at the moment?* The majority (87.0%) of those who were currently taking treatments felt they knew enough about the HIV treatments they were taking. This suggests that 13% feel that they do not know enough about the drugs they are taking. Satisfaction with treatment knowledge did not vary by most of the demographic characteristics including gender, sexuality, and ethnicity and migration status.

All those respondents who were currently taking treatments were asked *How many doses of HIV treatments have you missed in the last two weeks?* One in five respondents (20.3%) currently on treatments had missed some doses in the previous two weeks. Most commonly this was one or two doses (80% of those who had missed any doses).

How many doses of HIV treatments have you missed in the last two weeks? (N=1169, missing 10)	**% (n) overall**	**% by gender and sexuality**		
		All females (n=289)	**Hetero. males** (n=131)	**MSM** (n=708)
None	79.7% (932)	75.1	80.2	81.5
ONE or TWO doses	16.2% (190)	19.7	13.7	15.4
THREE or FOUR doses	2.2% (26)	2.8	1.5	2.0
FIVE or SIX doses	0.6% (7)	1.0	0.8	0.4
SEVEN or MORE doses	1.2% (14)	1.4	3.8	0.7

Those under 25 years old were significantly more likely to have missed doses of HIV treatment in the last two weeks. Average age decreased with increasing numbers of missed doses.

Black respondents were more likely to report missing doses compared to white and Asian respondents (26.5% missed a dose compared to 17.4% and 20.5%). Those who were born in African countries were more likely to report missing doses than others (23.8% vs. 19.3%). Those who had ever injected drugs were more likely to have missed doses in the last two weeks (30.8% vs. 19.5%). Those who felt that they did not know enough about the treatments they were taking were much more likely to miss doses (32.5% vs. 18.3%). Despite our finding that the vast majority of respondents felt they knew enough about the HIV treatments they were taking, these data suggest that a significant minority require more treatment information and support with adherence.

3.2.2 CURRENT NON-TREATMENT TAKERS

The 181 respondents not currently taking treatments were asked, *Why are you not currently taking HIV treatment?* Respondents were allowed to tick more than one reason for not taking treatments from the list in the first column of the table below.

Reasons for not currently taking HIV treatments, among those not taking treatments (N=181)	**% (n) overall**	**% by gender and sexuality**		
		All females (n=47)	**Hetero. males** (n=7)	**MSM** (n=119)
My doctor says I don't need treatment at the moment	77.3 (140)	74.5	57.1	82.4
I don't feel I need treatment at the moment	21.0 (38)	21.3	14.3	21.8
To avoid the side-effects	11.0 (20)	6.4	0.0	13.4
Waiting to begin planned treatment	5.5 (10)	6.4	14.3	4.2
I don't want to be reminded about HIV every day	5.0 (9)	2.1	0.0	6.7
The decision is based on reaching a particular blood test result or CD4 count.	4.4 (8)	8.5	0.0	3.4
It would interfere with work / education / family	3.9 (7)	0.0	0.0	5.9
I'm afraid people will notice	2.8 (5)	2.1	0.0	3.4
I don't believe HIV treatments will help me	1.7 (3)	0.0	0.0	1.7
It interacts with my other medication/s	0.6 (1)	0.0	0.0	0.8
Because I would need to pay for them and I can't afford it	0.6 (1)	0.0	0.0	0.8
Due to cultural or religious beliefs	0.6 (1)	2.1	0.0	0
Other reasons	5.5 (10)	6.4	14.3	3.4

The vast majority not currently taking treatments, said either their doctor felt they did not need treatments at present (77.3%) and / or they personally felt they did not need treatments at present (21.0%). No other single reason for not currently taking treatment accounted for more than a few people.

3.3 MONITORING RESULTS FOR VIRAL LOAD AND CD4

All respondents were asked the results of their last viral load test and offered the responses in the first column of the table below. Less than one-in-ten (8.3%, n=112) did not know their viral load, of which almost half (3.9%, n=53) had been told but could not recall it. Those not on HIV treatments were much more likely to have reported that they had not been given their result or to have forgotten it.

The majority of respondents on treatments reported an undetectable viral load (83.6%), and three quarters of all respondents (74.5%) said that their last viral load test result was undetectable. Of those who said they knew the result of their last viral load test, 88.8% of those on treatments were undetectable and 16.8% of those who were not currently on treatments.

Last viral load test result (N=1352, missing 38)	**% (n) overall**	**% not on treatments** (n=173)	**% on treatments** (n=1170)	**% by gender (on treatments and tested, given and remembered result)**		
				All females (n=261)	**Hetero. males** (n=120)	**MSM** (n=681)
Undetectable	74.5 (1007)	12.7	83.6	87.4	84.2	90.3
Detectable	17.2 (233)	63.0	10.5	12.6	15.8	9.7
Told but doesn't remember result	3.9 (53)	11.6	2.8			
Measured but was not told the result	1.3 (17)	2.9	1.0			
Was not measured	0.4 (6)	2.9	0.1			
I don't remember	2.7 (36)	6.9	2.0			

Among the 1100 people who were currently on treatments, had their viral load monitored and were told and remembered their last result, those under 25 were most likely to describe their viral load as detectable (30.8%). Those with detectable viral load were significantly younger, on average (mean 39.1 years, sd = 10.5) than those who reported being undetectable (mean 44.4 years, sd = 10.0). Those with detectable viral load had been diagnosed on average for a shorter time (mean 5.6 years, sd = 6.1) than those with an undetectable viral load (mean 10.4, sd = 6.8). There were no other significant relationships with demographic characteristics except those with no educational qualifications seemed more likely to have a detectable viral load (though the relationship of viral load to education was not clear cut).

All respondents were also asked the results of their last CD4 test and offered the responses outlined in the first column of the table below. Some 10% of the sample could not remember their last CD4 result and another 2.3% had not been told the result. Two thirds (64.0%) of respondents on treatments reported a CD4 test result above 350 cells, including more than a third (38.0%) that had >500 cells.

Last CD4 test result (N=1352, missing 38)	**% (n) overall**	**% (n) not on treatments** (n=176)	**% (n) on treatments** (n=1166)	**% by gender and sexuality (among respondents on treatments and given and remembered last CD4 result)**		
				All females (n=240)	**Hetero. males** (n=106)	**MSM** (n=647)
< 200 cells	7.2 (97)	5.1 (9)	7.5 (88)	13.3	14.2	5.7
200-349 cells	15.1 (204)	6.8 (12)	16.3 (190)	17.5	28.3	17.0
350-499 cells	26.7 (361)	32.4 (57)	26.0 (303)	28.8	27.4	29.8
> 500 cells	38.8 (525)	42.6 (75)	38.1 (444)	40.4	30.2	47.4
Not told result	2.3 (31)	1.7 (3)	2.4 (28)			
Told but doesn't remember	9.9 (134)	11.4 (20)	9.7 (113)			

Among those currently on treatments, women were more likely to have <200 cells compared to men (13.3% vs. 6.8%).

Black respondents were more likely (13.1%) to have <200 CD4 cells than Asian (6.5%) or white respondents (6.1%). Asian respondents were least likely to have >500 cells (29.0%) compared to black (37.3%) and white (46.4%) respondents. All migrants, and especially those born in Africa, were significantly more likely to have fewer CD4 cells. Heterosexual males had a larger proportion with fewer CD4 cells compared to all women and MSM. Those who had ever injected drugs had higher levels of CD4 cells.

Of respondents not currently taking treatments, 5.1% had a CD4 of <200 cells and 6.8% had a CD4 of 200-349. Of the 21 people not currently on treatments and with a CD4 count <350, nine reported that their reason for not taking treatments was that "My doctor says I don't need treatment at the moment", and another one stated "I don't feel I need treatment at the moment". Of the remaining eleven, four said "To avoid the side-effects" only. Only one of these 21 people reported that they were not taking treatments "due to cultural or religious beliefs" but they also said "to avoid the side effects". No one with a CD4 <350 reported that they were not currently taking treatment "because I would need to pay for them and I can't afford it".

3.4 OTHER INFECTIONS AND CONDITIONS

All respondents were asked whether they had any of 16 listed conditions, co-infections or co-morbidities in addition to HIV, at the time of participating in the survey. These questions were important in our emerging understanding of the ways in which respondents used HIV out-patients clinics and other NHS services. The presence of any of these co-infections or co-morbidities suggest HIV care may involve a degree of 'medical complexity' that is no longer always present in the care of people with diagnosed HIV. Even in the year it has taken to complete this project it is notable how debate about co-infections and co-morbidities among people with HIV has increased. Some, but not all, of these co-infections or co-morbidities probably need to involve or be managed by clinicians other than (or in addition to) HIV physicians. Some are likely to be on-going, others episodic for the patient. Some need to be addressed within the current model of HIV care with other clinicians or specialists involved – or even leading the care.

The table below reveals the proportion of the whole sample that had each of the 16 given conditions, and the proportion among all females; heterosexual males and MSM.

Any of these conditions at the moment	**% (n) overall**	**% by gender & sexuality**		
		All females (n=350)	**Hetero. males** (n=146)	**MSM** (n=840)
High cholesterol	17.3 (240)	14.0	13.0	19.3
Psychiatric or mental health problems	13.7 (191)	8.0	6.8	17.1
High blood pressure	11.8 (164)	10.6	18.5	11.1
Neurocognitive disorders	6.0 (84)	5.7	6.2	6.3
Liver problems	5.8 (80)	1.4	8.2	7.4
Pregnancy (women only)	5.4 (19)	5.4		
Hepatitis C	5.1 (71)	2.3	4.8	6.5
Diabetes	4.2 (58)	3.4	10.3	3.2
Hepatitis B	3.7 (52)	3.1	10.3	3.0
Kidney problems	3.7 (52)	2.9	3.4	4.0
Ongoing sexually transmitted infection/s	3.6 (50)	2.6	2.7	4.3
Problems with drug or alcohol	3.5 (48)	0.3	2.1	5.1
Heart problems	3.4 (47)	1.4	4.1	4.2
Cancer	2.2 (31)	1.4	2.7	2.4
Acute sexually transmitted infection/s	1.4 (19)	0.3	0.0	2.1
Tuberculosis (TB)	0.3 (4)	0.6	0.7	0.1

Some of these co-infections or co-morbidities are relatively common: one-in-six (17.3%) respondents reported problems with high cholesterol; one-in-seven (13.7%) reported psychiatric or mental health problems; and one-in-nine (11.8%) reported high blood pressure. No other co-infection or co-morbidity was reported by more than 6% of respondents.

Compared to heterosexuals, men that had sex with men were more likely to report problems with high cholesterol; psychiatric or mental health problems; hepatitis C; kidney problems; problems with drugs and alcohol; high cholesterol and on-going and acute sexually transmitted infections. Apart from issues related to pregnancy, no health problem was more common among women than men. However, among men, several health problems were more common among heterosexuals than MSM – these included high blood pressure; liver problems; hepatitis B and diabetes.

In chapter 5.6 we examine NHS service use among respondents that reported any of the above co-infections or co-morbidities, based on follow-up questions on disclosure of that specific problem and who was involved in the management of the problem.

If we exclude pregnancy from the list, then just under half (47.5%) report at least one of these co-infections or co-morbidities at the time they completed the survey.

Any current co-infection or co-morbidity (high cholesterol, psychiatric or mental health problems, high blood pressure, neurocognitive disorders, liver problems, hepatitis C, diabetes, hepatitis B, kidney problems, on-going sexually transmitted infection/s , problems with drugs or alcohol, heart problems, cancer, acute sexually transmitted infections/s and tuberculosis)	**% (n) overall**	**% by gender & sexuality**		
		All females (n=350)	**Hetero. males** (n=146)	**MSM** (n=840)
No current co-infection of co-morbidity	52.5 (730)	64.0%	51.4%	47.9%
A current co-infection or co-morbidity	47.5 (660)	36.0%	48.6%	52.1%

Perhaps reflecting common morbidities of ageing and the increased opportunity for infection, reporting a current co-infection or co-morbidity was more common with increasing age: a third (32.6%) of those under 25 reported any co-morbidity compared to almost three quarters (72.1%) of those over 60. Having any co-infection or co-morbidity was less common among women (36.0%) than among heterosexual males (48.6%) or MSM (52.1%).

Those with a white ethnicity were more likely to report any co-infection or co-morbidity (50.6%) compared to black (41.9%) and Asian (40.4%) participants. Migrants were less likely to report any co-morbidity (43.7%) compared to UK-born respondents (50.2%).

Those who had ever injected drugs, and those who had done so in the last 12 months, were more likely to report a current co-morbidity (ever 69.2% vs. 46.2% and in the last 12 months 75.0% vs. 47.1%). Those with a co-morbidity had been diagnosed with HIV for longer, on average (mean 10.7 years, sd = 10.0), than those without a co-morbidity (mean 7.8 years, sd = 6.3).

3.5 OTHER NEEDS AND PROBLEMS

All respondents were also asked whether *In the last 12 months, have you had any problems (for ANY reason) in relation to* 13 other common problems and needs that formed the basis of previous needs assessments with people with diagnosed HIV. These included self-reported measures of mental health, social relationships and self-care for which we have comparable measures from 2001-02 and 2007-08. While high proportions of respondents report these problems and needs, all are substantially less common than in 2007-08.

About half of all respondents reported problems with sleeping and with mental health issues such as anxiety and depression and self-confidence, in the last year. All these problems were most common among MSM, and least common among heterosexual males.

More than a third of respondents reported problems with relationships, with money and with sex, in the last year. Problems with sex were most common among men, especially MSM, but problems with money were most common among women and heterosexual males. A similar pattern was observed with problems with housing and living conditions.

In the last 12 months, have you had any problems (for ANY reason) in relation to …	**% (n) overall**	**% by gender & sexuality**		
		All females (n=350)	**Hetero. males** (n=146)	**MSM** (n=840)
Sleeping	52.6 (674)	45.0	29.5	59.3
Anxiety and depression	52.4 (670)	44.0	34.9	58.4
Self-confidence	48.9 (622)	45.0	37.3	52.3
Sex	39.3 (494)	25.7	38.0	44.9
Money – having enough to live on	36.3 (465)	44.8	50.4	30.2
Relationships	34.9 (441)	30.9	29.2	37.3
Friendships	29.6 (372)	24.2	24.8	32.4
Housing & living conditions	23.2 (301)	30.5	34.8	18.0
Eating and drinking	22.7 (288)	20.7	15.6	24.2
Mobility – ability to get about	22.7 (284)	22.9	20.3	22.3
Household chores and self-care	20.0 (249)	20.3	12.0	21.0
Discrimination	16.7 (209)	17.6	13.2	16.9
Looking after children	5.6 (69)	16.6	9.1	1.0

While relatively high proportions of the survey sample reveal a range of additional needs that undermine their capacity to live well with HIV, the needs described here are almost universally lower than our previous national surveys of people with diagnosed HIV (Weatherburn *et al.* 2002; Weatherburn *et al.* 2009). While these surveys were not designed to assess changes in need over time, it seems very likely that improvements in medical treatments have improved health and well-being across arrange of needs including those described above. Despite apparent reductions in need across the whole population of people with diagnosed HIV, the extent of needs revealed here challenge anyone with an interest in the lives of people with diagnosed HIV to examine their assumptions about the reality of living with HIV in London today.

3.6 COMPARISON WITH NATIONAL DATA

The difference between our sample and the population of people with diagnosed HIV using London HIV services was estimated by comparing our sample with the National Survey of Prevalent HIV Infections Diagnosed (SOPHID), conducted annually by the Health Protection Agency's Centre for Infections. SOPHID is a cross-sectional survey of all persons who attend for HIV-related care at an NHS site in England, Wales and Northern Ireland within a calendar year. SOPHID 2011 data for London was used.

This comparison reveals that whilst broadly in line with SOPHID, our sample includes a higher proportion of gay or bisexual men and white people. The Table below shows our sample over-represents males (74.2% vs. 68.7%) and under-represents females (25.8% vs. 31.3%) and over-represents white ethnicities (64.3% vs. 47.1%) and under-represents Black African (22.8% vs. 34.3%); Black other (0.9% vs. 3.3%) and other / mixed ethnicities (4.2% vs. 6.3%).

Our survey over-represents MSM (62.9% vs. 49.7%) and injecting drug users (7.6% vs. 1.8%) and under-represents heterosexual men (10.1% vs. 17.4%) and heterosexual women (23.2% vs. 30.7%). However, the comparison of our sample with SOPHID "exposure category" is complex, not least because we did not ask respondents how they thought they acquired HIV. In HPA terms "exposure category" refers to the likely mode of HIV infection. In surveillance terms all patients have one "exposure category" entry such that they cannot be recorded as homosexually active and African. Moreover, all women are recorded as heterosexual unless they are an injecting drug user. In our survey data in the table below, all men are either MSM or heterosexual. Heterosexual women in our survey are represented in the table but we do not distinguish them from lesbian and bisexual women (1.3% of our sample) as there is no equivalent in the SOPHID data. Our 7.6% figure for injecting drug use is lifetime experience, but all these 104 respondents are also included in the MSM or heterosexual categories. The exact relationship of injecting drug user in the SOPHID "exposure category" and ever used injecting drugs is impossible to ascertain, but our figure being higher is predictable.

Comparison of I Care, My Care and SOPHID London data from 2011		% (n) My care, I care	% (n) SOPHID London 2011
Gender	Female	25.8 (350)	31.3 (9,752)
	Male	74.2 (1006)	68.7 (21,395)
Ethnicity	White	64.3 (887)	47.1 (14,549)
	Black-Caribbean	4.3 (59)	5.0 (1,531)
	Black-African	22.7 (313)	34.3 (10,602)
	Black-Other	0.9 (12)	3.3 (1,021)
	Indian / Pakistani / Bangladeshi	2.2 (30)	1.9 (591)
	Other Asian /Oriental	1.5 (17)	2.1 (647)
	Other /mixed	4.2 (58)	6.3 (1,948)
Sexual exposure categories (mirroring SOPHID)	Men that have sex with men	62.9 (840)	49.7 (14,767)
	Heterosexual men	10.9 (146)	17.4 (5,172)
	Heterosexual women	23.2 (308)	30.7 (9,103)
	Injecting drug use	7.6 (104)	1.8 (529)
	Blood / Blood product recipient	0.4 (6)	0.4 (115)
Age groups	15 – 24	3.1 (43)	3.2 (992)
	25 – 29	6.7 (92)	6.3 (1,932)
	30 – 34	10.8 (148)	11.4 (3,515)
	35 – 39	14.8 (203)	16.7 (5,161)
	40 – 44	19.7 (271)	20.3 (6,261)
	45 – 49	20.8 (286)	19.5 (6,012)
	50 – 54	11.4 (157)	11.4 (3,516)
	55 +	12.8 (175)	11.2 (3,454)
Area of residence	North Central London	13.4 (173)	23.2 (7,549)
	North East London	20.8 (268)	15.1 (4,901)
	North West London	16.1 (207)	34.1 (11,085)
	South East London	27.2 (351)	19.1 (6,231)
	South West London	15.3 (197)	8.5 (2,759)

Effectively we have been more successful at recruiting white men, the majority of whom are homosexually active; and less effective at enabling participation from Black African people. However, we have enabled the participation of more than 300 African people with diagnosed HIV and 350 females. It is also worth noting that the SOPHID category of "White" masks considerable variations in ethnicity. Of the two thirds of our sample (64.4%) that were white almost a third (29.4%) were not white British or less than half (45.4%) of our entire sample considered themselves white British, although another fifth (18.9%) were white. However, our sample compares favourably with all other clinic or community samples of people with diagnosed HIV, conducted in English, as all such samples routinely display these biases. Moreover, in the context of this survey these biases have a limited impact on the data reported in the chapters 4-6.

Our sample is remarkably similar to the SOPHID London data in terms of age groups of survey respondents and people with diagnosed HIV using services in the capital. Our sample over-represents people with diagnosed HIV living in North East London and South East and South West London and under-represents people living in North Central and North West London.

Finally, if we examine the proportions currently on HIV treatments and most recent CD4 result (for those currently on treatment and those currently not on treatment) then again, our survey sample is broadly similar to SOPHID London. The only significant difference between our sample and SOPHID, is that among those respondents on treatment a higher proportion of survey respondents have a CD4 <200 (8.6% vs. 7.2%); CD4 200-349 (18.6% vs. 15.5%) and CD4 350-499 (29.6% vs. 25.0%) and a lower proportion of survey respondents have a CD4 of 500 or more (43.3% vs. 52.2%). However, a survey sample recruited mainly from HIV clinics has to be expected to be slightly more likely to be unwell than the population of all people with diagnosed HIV. Our goal was to represent voices of those people using London HIV clinics most frequently, and this will skew the sample towards more ill-health than the entire population of people with diagnosed HIV.

Comparison of I Care, My Care and SOPHID London data from 2011		**% (n) My care, I care**	**% (n) SOPHID London 2011**
Currently on antiretroviral therapy	No antiretroviral therapy	13.3 (181)	15.3 (4,773)
	Receiving antiretroviral therapy	86.7 (1179)	84.7 (26,365)
Last CD4 test result among those NOT on treatments	< 200 cells	5.9 (9)	4.8 (550)
	200-349 cells	7.8 (12)	11.3 (1,288)
	350-499 cells	37.3 (57)	31.7 (3,616)
	> 500 cells	49.0 (75)	52.2 (5,956)
Last CD4 test result among those on treatments	< 200 cells	8.6 (88)	7.2 (4,235)
	200-349 cells	18.6 (190)	15.5 (9,106)
	350-499 cells	29.6 (303)	25.0 (14,655)
	> 500 cells	43.3 (444)	52.2 (30,588)

4 HIV CLINIC USE

This chapter presents the main findings of the study with regard to use of, and perceptions of HIV out-patients clinics in London. This chapter describes experiences of HIV clinic use, including details and perceptions of their last visit to their clinic. It starts with survey findings and proceeds to describe in more detail, perceptions arising from the eight focus groups.

4.1 NUMBER OF CLINICS USED IN THE LAST YEAR

All respondents were shown a full list of London's 28 specialist HIV clinics and asked, *How many of these different HIV clinics did you attend in the last 12 months?* One-in-fifty (2.1%, n=25) London-resident respondents reported visiting no London HIV clinic in the last 12 months. They were asked, *Why did you not attend any of these HIV clinics in the last 12 months?* and offered a free-text box for their response. Of the 25 people that went to no London HIV clinic in the last year, seventeen explained why. More than half simply said there had been no reason to go to the clinic in the last year, of which some reported relatively recent HIV diagnoses. Others had been away from London (travelling or working) or had used private healthcare in the last year. Two revealed that they had not been aware they could attend any NHS HIV clinic in London. Only one respondent reported being too scared to attend an HIV clinic and another revealed no faith in medicine or doctors.

The vast majority (89.6%, n=1246) of respondents had attended one London HIV out-patients clinic in the last year, with relatively small proportions reporting visiting two clinics (6.8%, n=94); three (1.1%, n=15); or four or more (0.6%, n=9). Respondents who reported visiting two or more HIV clinics in the last year were asked, *Why did you attend more than one of these HIV clinics in the last 12 months?* They were offered a free-text box to write-in their response. There were three main reasons respondents gave for attending more than one London HIV clinic in the last year. Either they had transferred during the year; or they had been referred for (or sought) specialist attention in a clinic that was not their "main" clinic; or they routinely sought diagnosis, treatment and care in more than one clinic (often within the same trust).

Most respondents that used two or more clinics had transferred from one clinic to another during the year, often because they had moved house or job and were seeking a more convenient clinic. Some had moved clinic to seek a different clinical perspective or because they were dissatisfied with their original clinic, though this was not common. Others had been diagnosed with HIV in one clinic – then referred to, or chose to move to another for their routine monitoring and care.

A slightly smaller proportion of respondents that had used two or more clinics had not changed their "main" clinic but had been referred for (or sought) specialist attention in a clinic that was not their "main" clinic. Often the referral had been for specialist diagnosis or treatment related to a specific illness, such as cancer. Finally, a small proportion routinely used two (or more) clinics, rather than as a one-off event. Some varied their attendance depending on access to appointments or because one clinic was local to their work and the other was local to home, or because they frequently wanted a second opinion. Some used secondary clinics for specialist diagnosis or care (such as cancer care) or because they were in a trial in a clinic that was not their "main" clinic. More commonly, respondents sought routine HIV care in one clinic and routine STI checks, diagnosis and treatment in another.

Prior to a more substantial set of questions about use of their specific clinic, all respondents were asked, *Did you know that you could use any of these 28 HIV out-patients clinics for free, if you wanted to?* While more than half of all respondents (53.7%, n=735) said *YES I knew this;* a third (33.9%, n=464) reported that they did not know this; and 12.4% (n=169) reported that they were *not sure about this*.

Not knowing or being unsure of this was more common among those recruited in clinics rather than online (52.2% vs. 35.6%); among women rather than men (57.4% vs. 42.2%), among black rather than Asian or white respondents (59.2% vs. 51.1% vs. 39.9%); among those born in Africa compared to elsewhere (59.0% vs. 41.1%); and among migrants compared to others (49.0% vs. 42.0%). Not being aware that they could use any clinics in London was more common among heterosexuals than MSM (59.0% vs. 39.2%); and among those who had ever injected drugs compared to others (47.4% vs. 32.0%). Knowledge did not vary by age group or average age, or by working status.

4.2 "MAIN" CLINIC USED

Using the same list of 28 specialist HIV clinics respondents were asked to indicate their "main" clinic, prior to a set of questions concerning their experience in that specific clinic. Due to the relatively small number of respondents using some of the clinics with a smaller HIV patient cohort, and to maintain the brevity of this report, in this chapter we group all the clinics into small, medium and large, based on their registered HIV patient cohort in SOPHID 2011. Clinics with up to 600 registered patients were allocated to the category *small*; clinics with between 601 and 1199 registered patients were allocated to the category *medium*; and those with 1200+ registered patients or more were allocated to *large*. The small-clinic group includes twelve clinics; the medium group includes seven clinics; the large group includes nine clinics.

Attendees at different sized clinics varied on many demographic characteristics. Attendees at small and medium sized clinics were more likely than those attending larger clinics to have been recruited in the clinic and less likely to have been recruited online (recruited from clinics 80.8% and 78.1% vs. 59.1%, recruited online 19.2% and 21.9% vs. 40.9%). This suggests that clinic-based recruitment was especially important to ensure people using small and medium clinics were adequately represented.

On average respondents using medium sized clinics were younger (mean 40.4 years, sd = 10.8) than those using small (mean 44.9, sd = 10.8) or large clinics (mean 43.5, sd = 10.0). As a consequence those attending medium sized clinics were far less likely to report any current co-infection or co-morbidity (31.1%) compared to those using large (51.0%) or small clinics (52.1%). Medium sized clinics also had the most equitable distribution of gender compared to smaller and larger clinics (47.1% female/ 52.9% male vs. 38.1% female/ 61.9% male and 17.7% female/82.3% male). Medium sized clinics were more likely to be attended by black people compared to small and large clinics (58.8% vs. 40.6% vs. 18.8%). Half of the participants from medium clinics were born in Africa (50.2%) compared to a third of those using small clinics (34.8%) and a minority using large clinics (16.0%). Medium sized clinics were used by a higher proportion of migrants compared to small and large clinics (67.2% vs. 54.4% vs. 43.9%). Small clinics were more likely to be attended by Asians compared to medium and large clinics (6.9% vs. 2.5% vs. 3.4%).

The vast majority of participants from large clinics were white compared to small and medium sized clinics (77.9% vs. 52.5% vs. 38.9%). Approximately half (50.7%) of those using large clinics had a university degree or higher compared to 42.2% of small and 38.0% of medium clinic attendees. Large clinics had the highest proportion of MSM attendees compared to small and medium clinics (76.7% vs. 45.1% vs. 36.4%). Larger clinics were significantly more likely to have attendees who have ever injected drugs compared to small and medium sized clinics (10.4% vs. 1.8% vs. 1.2%).

4.2.1 LENGTH OF TIME USING CLINIC

All respondents were asked 7 generic questions about their relationship to their "main" clinic. The first question concerned the length of time respondents had used their "main" clinic. Respondents were offered the time categories outlined in the table below, with the additional category since first diagnosis (never been to any other clinic).

How long have you been visiting your main clinic? (N=1271, missing 119)	**% (n) overall**	**% by size of "main" clinic**		
		SMALL clinics (n=159)	**MEDIUM clinics** (n=236)	**LARGE clinics** (n=876)
Less than a year	6.5 (83)	6.3	8.9	5.9
1-2 years	11.5 (146)	10.1	15.7	10.5
3-4 years	12.4 (158)	14.5	13.1	11.8
5-7 years	12.6 (160)	17.0	14.8	11.2
8-10 years	10.0 (128)	10.7	11.9	9.5
11+ years	18.8 (240)	12.6	7.2	23.1
Since first diagnosis (never been to any other clinic)	28.2 (359)	28.9	28.4	28.1

Responses revealed substantial loyalty to clinics with almost a third (28.2%) having used the same HIV clinic since they were first diagnosed and another fifth (18.8%) having used their current clinic for 11 years or more. This means almost half (47.0%) the sample had either used the same clinic since first diagnosis or had used their current "main" clinic for at least 11 years. The data also reveal a churn rate of only about one-in-fifteen people changing clinics in the last year.

Examining the data by clinic size reveals significant differences concerning length of time visiting their main clinic. While the proportion attending the same clinic since diagnosis did not vary by clinic size (all being around 28-29%), a greater proportion of those attending medium sized clinics had been attending under three years (24.6% vs. 16.4% for small clinics and 16.4% for large clinics) and fewer attended medium sized clinics for 11 years or more (7.2% vs. 12.6% for small clinics and 23.1% for large clinics). This suggests that users of large clinics were more likely to have been attending for a long period of time, almost a quarter having done so for 11 years or more.

There were few differences between those who had changed "main" clinic within the previous 3 years and those who did not, on a range of demographics including whether or not participants had a current co-infection or co-morbidity. However younger people were significantly more likely to have changed clinic recently, the average age of those who changed was 37 compared to 44 for those who had not. Those who had changed recently were more likely to attend a medium sized clinic (25.4% vs. 17.1%) and less likely to attend a large clinic (63.2% vs. 70.2%); but similarly likely to attend a small clinic (11.4% vs. 12.8%). We did not ask respondents which clinic they had moved from.

4.2.2 IMPORTANT FACTORS IN THE CHOICE OF CLINIC

All respondents were asked a pair of questions about the important factors in their decision to use their "main" clinic. Using the closed responses outlined in the first column of the table below all respondents were asked two questions:

- *What are the most important factors in your decision to use your main clinic?* Tick as many reasons as apply; and
- *For you personally, what is the SINGLE most important factor in your decision to use your main clinic?* Tick one answer only.

The overall answers to each question are highlighted in columns two and three of the table below. Columns four to six examine variation in answers to the question on the single most important factor, by the size of the "main" clinic attended.

Important factors in your decision to use your main clinic? (N=1273, missing 117)	**% (n) choosing reason at all**	**% (n) choosing as SINGLE factor**	**% by size of "main" clinic**		
			SMALL clinics (n=155)	**MEDIUM clinics** (n=220)	**LARGE clinics** (n=849)
The staff are excellent and the clinic has a great reputation	75.76 (964)	36.6 (448)	44.5	26.4	37.7
I feel comfortable there	69.0 (878)	17.1(209)	12.9	21.8	16.6
The clinic is close by or easy to get to	56.8 (723)	22.7 (278)	29.0	29.1	19.9
I feel involved in decisions about my care	48.9 (622)	7.1 (87)	3.9	8.2	7.4
The services on offer suit my needs very well (e.g. out of hours, email or phone clinics, home delivery)	44.9 (572)	6.9 (84)	2.6	7.7	7.4
It offers extra services which are important to me (e.g. co-infection clinics; newfill; pregnancy/ fertility services; in-patients care; links to other services).	22.4 (285)	3.8 (46)	0.6	1.4	4.9
No-one I know will see me going there so my privacy is protected	17.5 (223)	4.1 (50)	5.2	3.6	4.0
Other reason	5.9 (75)	1.9 (23)	1.3	1.8	2.0

While the overall order of responses changes somewhat depending on whether you consider the question with multiple answers or single answers, the broad order was very consistent. In both sets of questions the most common answer was "The staff are excellent and the clinic has a great reputation". While "I feel comfortable there" was next most often chosen it dropped slightly below "The clinic is close by and easy to get to" when only one answer was allowed.

When only one answer was allowed, the top two reasons account for far more than half (53.7%), and the top 3 account for three quarters (76.4%) of all answers. The fourth most common answer was "I feel involved in decisions about my care", and the fifth "The services on offer suit my needs very well (e.g. out of hours, email or phone clinics, home delivery)". Fewer ranked "It offers extra services which are important to me (e.g. co-infection clinics; newfill; pregnancy/ fertility services; in-patients care; links to other services)" or "No-one I know will see me going there so my privacy is protected".

The three most common answers occur far more often when only one answer was allowed, compared to when multiple answers were allowed. However, for all the other options, high scoring answers became far less common when only one answer was allowed. For example, when multiple answers were allowed more than half (48.9%) tick "I feel involved in decisions about my care", but this falls to 7.1% when only one answer was allowed.

For the single most important factor, the most common other answers were; personal recommendation from a friend or partner (often already attending there); consistency and continuity of staffing and care; and inertia. A slightly smaller number simply said they were diagnosed there and had not moved, or that they had not been aware of having any choice, or not been aware of where other choices were or how to transfer. When multiple answers were allowed, the most common other answers were slightly more diverse but broadly similar. Again personal recommendation from a friend or partner was important as was consistency and continuity of staffing and care; and inertia. Many reported moving to their clinic with a favoured doctor that had changed jobs. Again a slightly smaller number simply said they were diagnosed there and had not moved, or that they had not been aware of having any choice. Some felt irritated, that it had never been suggested to them that they had any choice in what clinic they went to. Finally several women stressed that the availability of female consultants was important in their choice of clinic.

4.2.3 SATISFACTION ABOUT DECISION MAKING AT THEIR MAIN CLINIC

All respondents were also asked, *How satisfied are you about the way you and the clinic staff make decisions together about your care (including HIV treatments)?* Just 1% of all respondents stated that they were *Not at all satisfied* (1.1%, n=14). The vast majority of all respondents were *very satisfied* (85.1%, n=1080) or *somewhat satisfied* (13.8%, n=175).

Those at either extreme of very satisfied or not had a similar distribution of attending small, medium and large clinics; however those who were somewhat satisfied were more likely to have attended larger clinics. Those who were somewhat satisfied had been diagnosed for longer than those who were very satisfied (10 yrs vs. 7 yrs). Satisfaction did not vary by age, gender, ethnic group, being born in Africa, being a migrant, education, sexual identity, having haemophilia. Those with a co-infection were slightly less likely to say very satisfied (82.7% vs. 87.3%) and more likely to state satisfied (15.5% vs. 12.2%).

4.2.4 USUAL MEANS OF RECEIVING BLOOD RESULTS

As a means of understanding the way in which people used services, respondents were also asked, *How do you usually receive blood results from your main clinic?* While re-attendance remains the most common way of receiving blood results, 16.1% report receiving results by talking on the phone and 8.2% by email. Respondents attending large clinics were less likely to report re-visiting the clinic to receive results, though this remains the norm even in large clinics, and were most likely to report receiving results by talking on the phone and by email. Those attending medium sized clinics were more likely to report receiving results by text, letter or via their GP. This should be a key area for further investigation to understand how consistently new technologies are been used across London services.

How do you usually receive blood results from your main clinic? (N=1316, missing 74)	**% (n) overall**	**% by size of "main" clinic**		
		SMALL clinics (n=165)	**MEDIUM clinics** (n=246)	**LARGE clinics** (n=902)
By visiting the clinic in person	81.5 (1073)	87.3	84.6	79.6
By talking on the phone	16.1 (212)	15.8	8.9	18.1
By email	8.2 (108)	1.8	4.5	10.4
By text	3.3 (44)	4.2	4.9	2.8
By letter	1.6 (21)	1.8	2.0	1.4
Via my GP	0.9 (12)	0.6	2.8	0.4

4.2.5 FREQUENCY OF ATTENDANCE AT THEIR MAIN CLINIC

Respondents were also asked, *In the last year, how many times did you visit your main clinic?* and offered the time categories outlined in the table below. Overall, the vast majority (83.3%) of respondents had visited their clinic at least three times in the last year, including 41.2% that had visited at least five times, and 22.5% had visited at least seven times.

In the last year, how many times did you visit your main clinic? (N=1278, missing 112)	**% (n) overall**	**% by size of "main" clinic**		
		SMALL clinics (n=161)	**MEDIUM clinics** (n=235)	**LARGE clinics** (n=879)
Not at all in the last year	1.1 (14)	1.2	2.1	0.8
Once or twice	15.6 (199)	14.9	12.3	16.6
Three or four times	42.2 (539)	50.3	47.2	39.5
Five or six times	18.7 (239)	21.7	13.2	19.7
Seven to nine times	8.3 (106)	5.6	9.8	8.4
More than ten times	14.2 (181)	6.2	15.3	15.0

The number of times clinic attendees had visited in the last year varied by clinic size with those using small clinics being less likely to attend more than six times compared to medium-sized and large clinics (11.8% compared to 25.1% and 23.4%). Those attending medium-sized clinics had a pattern of attendance more similar to those using large rather than small clinics. Frequency of attendance did not vary by source of recruitment, education, gender and sexual identity and having ever injected drugs.

Frequency of attendance varied by age in a complex way, the average age of those not going at all and going more than ten times was generally younger than for other frequencies. Women were more likely to have attended more than ten times compared to men (18.0% vs. 12.7%). The same is true of respondents from black ethnicities compared to those from white and Asian ethnicities (17.8% vs. 12.0% vs. 12.2%). Those with haemophilia were much more likely to report attending more than ten times (66.7% vs. 14.0%) as were those not in paid employment (20.2% vs. 10.2%) and those with a current co-infection or co-morbidity (16.9% vs. 11.6%). Those reporting not attending their clinic at all in the previous year had been diagnosed with HIV for a shorter time compared to all those with other attendance patterns.

4.3 YOUR LAST VISIT TO YOUR MAIN CLINIC

All respondents were asked six questions about their last visit to their "main" clinic. These questions sought to describe the relationship between the services provided in the clinic and the patients' experience of using them.

The first question concerned recency of attendance in their "main" clinic. All respondents were asked: *Before today, when did you last visit your main clinic?* and were offered the time categories outlined in the table below. The phrase "before today" was intended to force respondents recruited in clinics to consider their last completed visit, and not the one they were in the midst of.

The vast majority of respondents had attended their clinic very recently – almost half (45.9%) had attended in the last four weeks; more than three quarters (79.2%) had been in the last 3 months; and almost all (98.5%) within the last six months. This may be partly explained by the previous finding that most people receive test results in person.

Before today, when did you last visit your main clinic? (N=1271, missing 119)	**% (n) overall**	**% by size of "main" clinic**		
		SMALL clinics (n=159)	**MEDIUM clinics** (n=233)	**LARGE clinics** (n=877)
within the last 4 weeks	45.9 (584)	37.1	45.9	47.5
within last 3 months	33.3 (423)	36.5	33.9	32.5
within the last 6 months	19.3 (245)	25.2	18.9	18.4
within the last 12 months	1.1 (14)	1.3	0.9	1.1
more than a year ago	0.4 (5)	0	0.4	0.5

People attending small clinics were slightly less likely to have been in the last 4 weeks but differences between users of medium and large clinics were marginal. Recency of attendance did not vary by age, gender, ethnicity, African birth, migrancy, education, sexual identity and gender, haemophilia status and injecting drug history or co-moribidity.

Respondents were also asked how they got to their "main" clinic for their last visit and how long it took to get there. The overall measures of how people got to their clinic reveal relatively little except the popularity of various forms of public transport.

For that last visit, how did you get there? (N=1316, missing 74)	**% (n) overall**	**% by size of "main" clinic**		
		SMALL clinics (n=165)	**MEDIUM clinics** (n=246)	**LARGE clinics** (n=902)
Bus	38.1 (502)	52.1	49.6	32.6
Tube	34.2 (450)	4.2	14.2	45.2
Private car	16.5 (217)	28.5	19.5	13.5
Train	12.3 (162)	8.5	7.7	14.2
Walk only	11.9 (156)	11.5	12.6	11.8
Taxi / mini-cab	3.1 (41)	3.0	2.0	3.4

However, examining means of reaching the clinic by clinic size reveals that patients at small clinics were far more likely to take a bus or private car to their clinic, compared to patients attending medium and large clinics, and less likely to use the Tube or train. The obvious assumption is that patients travel greater distances to large (and medium) clinics compared to small clinics, which are assumed to be more local. However, this may be a reflection of the likelihood that larger (central London) clinics tend to be closer to tube stops and train stations, whereas small clinics are not.

All respondents were also asked, *For that last visit, how long did it take you to get there from your home (or workplace)?* Surprisingly perhaps, a reasonable proportion reached their clinic in less than 15 minutes (13.8%); with almost half (46.1%) reaching their clinic within 30 minutes; and more than two thirds (71.7%) within 45 minutes. Very few respondents (10.8%) took more than 60 minutes to get to their "main" clinic from their home (or their workplace).

Based on common assumptions about smaller local (outer London) clinics and larger (central London) clinics, and the findings concerning the mode of transport to "main" clinics, we might expect patients travelling to small clinics to get there more quickly than patients attending medium and especially large clinics. While a higher proportion of respondents using small clinics took thirty minutes or less to get to there, compared to those using medium and large clinics (54.4% compared to 53.4% and 42.6%), the differences are not huge. When we consider the proportion that take more than an hour to get to their "main" clinic a similar pattern emerges – while travelling for more than an hour is most common for large clinics (12.8%) it is not much less common for small (6.9%) and medium sized clinics (6.4%).

For that last visit, how long did it take you to get there from your home (or workplace)? (N=1272, missing 118)	**% (n) overall**	**% by size of "main" clinic**		
		SMALL clinics (n=160)	**MEDIUM clinics** (n=234)	**LARGE clinics** (n=877)
Less than 15 minutes	13.8 (176)	15.6	19.2	12.1
15 – 30 minutes	32.2 (410)	38.8	34.2	30.6
31 – 45 minutes	25.6 (326)	23.1	26.5	25.8
46 – 60 minutes	17.5 (222)	15.6	13.7	18.8
61 – 90 minutes	6.5 (83)	6.2	4.7	7.1
91 -120 minutes	2.3 (29)	0.6	1.3	2.9
2 – 3 hours	1.3 (16)	0	0	1.8
3 – 4 hours	0.3 (4)	0	0	0.5
more than 4 hours	0.5 (6)	0	0.4	0.6

All respondents were also asked why they attended for their last visit to their main clinic and were allowed to tick as many reasons as applied from the list in the table below. Not surprisingly, the majority of respondents (62.3%) last attended their main clinic for a routine appointment with a doctor. The only other reason given by more than a third was to give a blood sample (37.3%). The next three most common reasons were to receive test results (18.0%); to collect a prescription (16.8%); and because of a specific health problem / illness (10.4%). No other reason for attendance was mentioned by more than one-in-ten respondents.

Differences in response by clinic size were not the norm. Respondents attending large clinics were less likely to attend to "give a blood sample" but more likely than those attending medium clinics to have visited "to receive test results". Those attending medium sized clinics were less likely to attend to "receive blood results" or "for a sexual health (STI) check-up".

Why did you attend for that last visit? (N=1274, missing 116)	**% (n) overall**	**% by size of "main" clinic**		
		SMALL clinics (n=160)	**MEDIUM clinics** (n=235)	**LARGE clinics** (n=877)
for a routine appointment with a doctor	62.3 (794)	62.5	62.1	62.4
to give a blood sample	37.3 (475)	46.2	48.1	32.8
to receive test results	18.0 (229)	18.1	13.6	19.2
to collect a prescription	16.8 (214)	15.0	18.3	16.8
because you had a specific health problem / illness	10.4 (132)	3.8	8.5	12.1
for an investigation / diagnostic tests	6.3 (80)	6.2	5.5	6.5
for an appointment with another member of the HIV team e.g. dietician	5.5 (70)	3.1	7.2	5.2
for a sexual health (STI) check-up	4.6 (59)	5.6	3.4	4.8
for an emergency appointment	3.8 (49)	1.9	2.1	4.7
for a procedure (see below)	2.0 (26)	2.5	1.3	2.2
for treatment of a sexually transmitted infection	2.0 (25)	2.5	1.7	1.9
other reason (see below)	3.5 (44)	1.2	1.3	4.2

All respondents were also asked which staff members they saw at their last clinic visit and allowed to tick as many job roles as applied from the list in the table below. Not surprisingly, the majority of respondents saw a Receptionist (76.7%); an HIV doctor (67.8%) and nursing staff (60.2%). The only other staff type seen by more than a third of respondents was pharmacist (33.5%). No other staff type was mentioned by more than one-in-ten respondents.

At that last visit, which staff members did you see? (N=1316, missing 74)	**% (n) overall**	**% by size of "main" clinic**		
		SMALL clinics (n=165)	**MEDIUM clinics** (n=246)	**LARGE clinics** (n=902)
Receptionist	76.7 (1010)	84.8	73.6	76.3
an HIV doctor	67.8 (892)	67.9	62.6	69.2
Nursing staff	60.2 (792)	70.9	65.0	57.0
Pharmacist	33.5 (441)	26.1	24.4	37.4
Health advisor/s	7.1 (94)	9.1	11.0	5.8
a doctor from another speciality	6.2 (82)	3.0	1.6	8.1
Sexual health staff	3.3 (43)	5.5	3.3	2.9
Psychologist	2.8 (37)	1.8	3.3	2.9
Dietician / nutritionist	2.4 (32)	4.8	1.6	2.2
Other voluntary sector worker (not First Point or Health trainer)	2.0 (26)	0	1.6	2.4
First Point worker	0.7 (9)	4.8	0.4	0.0
Occupational therapist (OT)	0.6 (8)	1.2	0	0.7
Social worker	0.6 (8)	0.6	1.2	0.4
Peer Advisor / Patient representative	0.5 (6)	0	0.4	0.6
Health Trainer	0.4 (5)	0	0.8	0.3

Differences in response by clinic size were not the norm but respondents attending large clinics were less likely to report seeing nursing staff but more likely to see a pharmacist.

Finally, all respondents were asked *For that last visit, how long were you in the clinic?* and allowed to tick one response from the list in the table below. A third (33.6%) reported being in the clinic for less than 30 minutes at their last visit; more than half (60.1%) were in the clinic 45 minutes or less; and more than three quarters (81.8%) were in the clinic for an hour or less at their last visit.

For that last visit, how long were you in the clinic? (N=1262, missing 128)	**% (n) overall**	**% by size of "main" clinic**		
		SMALL clinics (n=158)	**MEDIUM clinics** (n=231)	**LARGE clinics** (n=871)
less than 15 minutes	5.9 (75)	10.8	6.5	4.9
15 – 30 minutes	27.7 (349)	29.7	33.3	25.8
31 – 45 minutes	26.5 (334)	25.9	25.5	26.6
46 – 60 minutes	21.7 (274)	14.6	20.3	23.4
61 – 90 minutes	9.9 (125)	10.8	7.8	10.3
91 -120 minutes	4.3 (54)	5.1	3.0	4.5
2 – 3 hours	2.9 (37)	2.5	2.6	3.1
3 – 4 hours	0.6 (7)	0.6	0.4	0.6
More than 4 hours	0.6 (7)	0	0.4	0.7

A higher proportion of respondents using small and medium sized clinics were in the clinic thirty minutes or less for their last visit, compared to respondents using large clinics (small 40.5%, medium 39.8% and large 30.7%), and a smaller proportion were in the clinic 30-60 minutes (small 40.5% compared to medium at 45.9% and large at 50.1%). However, the differences in time spent in clinics were not huge and this data needs to be understood in relation to the complexity of the needs of the patients. People with a current co-infection or co-morbidity were less likely to report being in the clinic for 30 minutes or less (30.6% vs. 36.3%) and more likely to report being in for more than one hour (22.4% vs. 14.4%).

The length of time in the clinic on the last visit did not vary by recruitment source, age, gender, ethnic group, education, having haemophilia, injecting drug use, being in paid employment. Those of African birth were more likely to report being in the clinic for 30 minutes or less (38.9% vs. 31.5%) and less likely to report being in for more than one hour (14.2% vs. 19.9%). Migrants in general were also more likely to report being in clinics for 30 minutes or less (37.1% vs. 29.4%). Heterosexual males were more likely to report being in clinic for less than 30 minutes compared to women and MSM (47.2% vs. 32.9% vs. 31.5%) and least likely to report being there for more than one hour (9.6% vs. 17.9% vs. 19.9%).

4.4 WHAT IS MOST VALUED ABOUT HIV CLINICAL SERVICES

The survey data show substantial loyalty to clinics and minimal churn in terms of clinic change. We now turn to the qualitative focus group data to investigate this further. We start with an analysis of how people came to attend their clinic, what they valued in their clinic and why they remain there. We then move on to look at what prompts people to change their clinic. Finally, we examine what people feel about future changes to the ways that their clinic services are organised and delivered.

In order to investigate the aspects of clinics that participants valued, two exercises were undertaken in each focus group. First, each group were shown a list of all 28 clinics in London and asked, without thinking to say whether they thought their own clinic was 'the best', in 'the top five', was 'somewhere in between' or in 'the bottom 5'. The purpose of this exercise was to elicit a quick, unmediated judgement around which to generate discussion. The second exercise consisted of asking the group whether they had ever changed clinics and if not, to consider the circumstances under which they would consider changing clinics.

The levels of clinic loyalty and satisfaction found in the survey were reflected in the groups. With two notable exceptions, participants in all groups listed their clinics as "the best" or "in the top 5". Likewise, few had actually changed their clinics.

4.4.1 DID PATIENTS 'CHOOSE' THEIR CLINICS?

The question of how patients came to be at their clinic is important. We start by looking at whether the participants in the different groups said they knew whether they had a choice of clinic and then move on to explore how the majority came to remain in the clinic in which they were diagnosed.

The majority of participants in the MSM and African groups had remained at the clinic where they were first diagnosed or referred to on first diagnosis. On one hand, such clinic loyalty could be interpreted as apathy. However, in all groups, this masked more positive reasons for remaining at the same clinic.

Whereas participants in the MSM Large Clinic, Co-morbidity Large Clinic and Mental Health Groups reported being aware that they had a choice of clinics when they were diagnosed, not all of those who used small clinics were similarly aware.

> **I was shocked when I took part in the survey that I had a choice. Why had no-one told me? Because there was a time when I was considering changing but I thought it was very difficult. (MSM, Smaller Clinic Group)**

None of those in the African groups (large or small) were aware that they could use any clinic when they were diagnosed. However, those in the large clinic groups had gained this information before filling out the survey whereas those in the African small clinic group had not. For some of the participants in the small clinic group, the information that they could access any clinic came as a relief as they were occasionally concerned about accessing HIV care if they were away from home.

> **In the summer, I usually go to my cousin in [area across London] and that fear about where I could go to locally is not there anymore because I know that I could go to the clinic there and I would be safe. (Woman, African Smaller Clinic Group).**

The MSM large clinic group differed from MSM in the small clinic group and others in that they reported a previous relationship with the GUM clinic they attended for sexual health check-ups (and in which they were subsequently diagnosed with HIV). So, for example, the men in the MSM large clinic group had accessed large central London GUM clinics because they perceived these clinics to cater mainly for MSM or to be 'gay-friendly'. When diagnosed, they therefore found themselves at similarly large and 'gay-friendly' HIV clinics. However, some were circumspect about the perceived 'gay-friendliness' of the clinic.

> **It's a two-edged sword. I remember not wanting to go to [clinic]. It was gay and a clubby atmosphere and I am happier in a lower key environment where it's a bit more anonymous. (MSM, Large Clinic Group)**

Those in the small clinic groups (including the MSM) tended to have been diagnosed in clinical settings that were near to where they lived at the time, and in time, were referred to local HIV services. For many the fact that the clinic was local was most prized

> **Good service, local and convenient. (African man, Co-morbidity Smaller Clinic Group)**

However, over time, the fact that the clinic was local became less important.

> **I commute a lot. I don't live near the clinic anymore and I work in South London and now have a 1.5 hour commute, but I still prefer to stay at that clinic. (African woman, Co-morbidity Smaller Clinic Group)**
>
> **I've thought if I retired to [area far outside London where family lives], I'd still stay with the clinic in London and commute in from [town name] as it's only 4 times a year. (MSM, Co-morbidity Smaller Clinic Group)**

The participants in the African small clinic group and some in the large clinic group tended to remain where they were diagnosed (or where they were referred to on diagnosis). However, several of the African large clinic group participants had chosen to change clinics. For the most part this was associated with moving home. However, in all cases, they had chosen their new clinic with care often relying on recommendations.

> **I was admitted at [clinic outside London] because it was where I lived, but when I went to London, I moved to [small London clinic] for some months. Then I went to [large London clinic] because it was more comfortable. In other clinics there was not much privacy. Like you collect your medications at [clinic outside London] and they explain things to you in front of everyone visiting the pharmacy (open general hospital pharmacy). Compared to [large clinic], where we have our own pharmacy. (Man, African Large Clinic Group)**
>
> **My friend told me that [Small clinic] was good. The doctor and the midwife were really good. They give milk for the babies – then I was pregnant. [Large clinic], they don't give milk. (African woman, African Smaller Clinic Group)**

The groups who could also be described as actively choosing their clinics were those in the Co-morbidity Large Clinic Group and those in the Mental Health group. As participants in both groups had experienced specific health needs over and above HIV infection, they tended to be more selective and informed in terms of which HIV clinics they used. For those in the Co-morbidity Large Clinic group, the clinic reputation was the most important factor. Some had experienced these clinics through partners or friends who had been ill.

> **I was diagnosed [outside London] in 1992. I wanted to go somewhere more upfront and in the midst of the battle as it were so I chose [Large clinic]. Several of my friends in the 80's had been treated there and I was very impressed with the treatment they got. (MSM, Co-morbidity Large Clinic Group)**

For this group more than the others, the reputation of an individual named consultant was also important. That is, they were highly aware of the need not only to attend a world class clinic, but to see the best consultant in that clinic.

> **I was at [clinic name] and I really had a lot of troubles there as I was getting iller and it was actually my partner who took me to see [consultant's first name] at the [clinic name]. (MSM, Co-morbidity Large Clinic Group)**

Participants in the mental health group had chosen to change clinics frequently. The decision to change was motivated by a range of factors including convenience and standards of care generally.

> **I changed clinics because my old clinic was rundown but also about convenience to get to as I was moving jobs. (MSM, Mental Health Group)**
>
> **I'm thinking of changing clinics because of distance. I don't have a car so I have to use bus so have to travel from [home] to [clinic] and it takes 90 minutes which is difficult because of lower back pain. It's tormenting. So I'm thinking of changing. (African woman, Mental Health Group)**

In conclusion we can observe several ways in which patients come to use particular clinics. It is clear that for those with elevated health needs (physical or psychological co-morbidities) having a choice is very important. Whilst the data suggests little movement of clinic, qualitative feedback suggests that for some, a deliberate choice had been made. For many, and especially the MSM, they had already 'chosen' their HIV clinic based on their choice of previous GUM clinics: either gay-friendly or near to where they lived or worked. However, some respondents still lacked basic knowledge regarding their right to choice.

4.4.2 WHAT WAS VALUED IN CLINICS?

We move on to consider what focus group participants said they valued about their clinics. Although there was substantial difference between the MSM Large Clinic, the Co-morbidity Large Clinic and the Mental Health groups on one side and the remaining groups on the other, there was more commonality in terms of what was valued than differences. We describe the differences between the two sets of groups first before concluding with what was common to all groups.

The MSM Large Clinic, the Co-morbidity Large Clinic and the Mental Health Group all discussed the importance of their clinic's good reputation, in terms of standards of research and clinical care.

> **It's also about research. [Clinic name] have all the trials going on and I can take advantage of these. (MSM, Large Clinic Group)**

However, of perhaps more importance was the clinic's capacity to deliver a range of services in addition to, or allied to HIV care. This was especially the case with the Mental Health Group who valued clinical psychology services. One participant sought clinical services in London rather than where she lived for this reason.

> **I was being treated at (local hospital outside of London) and wanted to be referred to a psychologist. And [consultant] was trying to refer me 'til he was blue in the face until we discovered that there was only one psychologist in the town and he only specialised in children. I didn't want to see a psychiatrist and get drugs so I met an activist in London and she recommended [clinic name] and I wasn't ten minutes in the door and I got an immediate referral to a psychologist. (UK woman, Mental Health Group)**

Another participant had the same experience in reverse. She was considering changing her HIV clinic to the hospital where she was on the waiting list for psychological treatment in the hope that this might speed up her access to psychological treatment at that hospital.

> **I was referred (by community nurse) to [hospital name]. Originally I was looking for psych. services in [HIV clinic name] but they weren't available by the time I got there, so they referred me back to my local trust and it was the community nurse who then referred me to [hospital] for**

> **psych. services. But I've been on the waiting list for psych. support at [hospital name] for over a year. (African woman, Mental Health Group)**

Others simply changed clinics because they were not satisfied with psychological services there or they could not gain access; as demonstrated by this exchange.

> ***Participant 1*: I was very unhappy with psych. support at the [clinic], so that's why I moved to [clinic]. I ended up almost dying and telling them I was suicidal. They weren't listening. I ended taking an overdose.**
>
> ***Participant 2*: Yeah, I had a pretty awful experience too with psychologist services. I wasn't happy with the care so changed to [clinic name].**

The comprehensiveness of the service on offer was also important. Many saw distinct advantages to attending an HIV clinic that was part of a large and well-resourced trust. That is, they could access a range of services in addition to their HIV care.

> **I had minor surgery a couple of years ago that my HIV consultant indirectly referred me for and it all stayed within [Trust]. So I can't imagine there being a better service. (MSM, Large Clinic)**
>
> **But for me having the whole package, the facilities that [Trust] overall can offer is important with a dedicated ward at [clinic]. It's all in the same place and you are not going to be referred somewhere else. (MSM, Large Clinic)**

Some participants in the larger central London clinics had negative perceptions of the clinics nearer home. This was associated both with the HIV clinic itself, but also the reputation of the hospital or even the Trust.

> **I live in [area], so my local HIV clinic would be [name] which would be very easy for me to get to. It takes over an hour to get to [my current clinic] but I still see it as a centre of excellence. I don't see [local clinic name] as a centre of excellence and a lot of people have had bad experiences there. Not just on the HIV side, but on the general side. Kind of, gone in and never come out again. (MSM, Large Clinic)**

This participant feels he needs to go to a local clinic, but fears that the staff will have negative attitudes.

> **I feel that if I went to my local clinic, both the staff and other patients would be discriminatory against gay men and when my mental health is not very good, I need to be able to walk to where I'm going. I'm not able to leave the house at times (referring to mental health difficulty). If I am going to run at the last minute, I need somewhere local. (MSM, Mental Health Group)**

However, there were two aspects of clinical provision that were valued by all groups. The first was the atmosphere in the clinic. We have seen how the men in the MSM Large Clinic group had already chosen clinics for their 'gay-friendliness'. However, for the African groups (large and smaller clinics) feeling welcome and being treated with respect was similarly important.

> **They care about me, not only about my condition but they also want to know how I'm doing generally and getting out there. When I was diagnosed, I didn't socialise and they want to know now that I'm getting on. (African woman, Smaller Clinic Group)**

Likewise many in the Mental Health group felt they needed a welcoming clinical environment where they had time to discuss their concerns and fears around managing their health and HIV.

> **[Former clinic] were rushing me in and out of appointments at a time when I was really going through it mentally and I needed longer visits whereas at [current clinic] I get decent appointments. I ended up overdosing and went into [hospital] and because the treatment was so good there (in A&E), I decided to switch over to the hospital [HIV clinic]. (MSM, Mental Health Group)**

The second and arguably most important factor was the individual consultant: their manner, perceived competence and the fact that there was continuity to the relationship between patient and consultant. For both the MSM and Co-morbidity Large Clinic Groups, the competence of the consultant (and other physicians) was paramount.

> **Well I know my doctor is a leading sexual health researcher and that's reassuring. For example, I went through a period of not wanting to start treatment and I knew that if she said 'well I respect your opinion but I really think that this is the right thing to do'. Well I knew that that was the best advice I could get because of who it was coming from and I took it. (MSM, Large Clinic Group)**
>
> **[Consultant name] has been my HIV consultant for 25 years. He used to be at the [clinic name 1] and then moved to [clinic name 2] and I moved with him. When I was ill in '95, I went to [clinic name 3] where I was treated by the ophthalmologist and I stayed there for my ophthalmological care. I am where I am because of where various clinicians are and where they've moved. I've followed them. (MSM, Co-morbidity Group)**

Participants in all groups also focused on the 'bedside manner' of their consultant and the fact that they were treated with respect or as equals. The following quote is from a woman who sought out a clinic for a test because she had been told that the lead consultant would attend to her personally.

> **When I went to [clinic], it was the welcoming effect that I got. On the first consultation I was treated like an ordinary person and I was met by [lead consultant's name] and sat down and told all the steps. […] Even before I knew I was positive, I felt that whatever happens, you are welcome here. [Lead consultant] was careful to give me my results and had made sure I was prepared and that whatever happened things would be alright. Then I was told exactly what was going to happen and even... [African woman, Large Clinic Group]**
>
> **[Consultant name] is somebody you can relate to, not just HIV, but anything she can take on board. And whatever you're entitled to, she makes sure you'll get it. (African woman, African Mixed Clinic Group)**

In addition to reputation, continuity and the ability to establish a relationship of trust and confidence with one consultant was important in all groups.

> **I changed my doctor early on. Not that he wasn't good but I had no rapport with him. The rapport I have now makes all the big decisions easier. (MSM, Large Clinic Group)**
>
> **Seeing the same doctor is very important because we become friends. He asks me about my family which I think is more important. (Man, African Large Clinic Group)**

5 SHARED CARE – GPS AND OTHER HEALTH SERVICES USED

In this chapter, we examine survey data addressing respondents' use of GP and primary care services, including GP registration and frequency of use; HIV disclosure to GPs and their involvement in HIV care; suggestions for improvement in primary care services; other NHS service uptake and the extent of "shared care" between HIV specialists, primary care and other specialists when a respondent had other co-infections or co-morbidities. We then use focus group data to describe respondents' experiences and perceptions of GPs and other health services in more detail and to expand on, and validate the survey data.

5.1 GP REGISTRATION

Contrary to expectations the vast majority (94.5%, n=1288) of all respondents were currently registered with a GP or primary care service. Women were slightly more likely to be registered with a GP than men (97.6% compared to 93.6%). Among men, MSM were slightly more likely to be registered than heterosexuals (93.9% compared to 92.9%). Younger respondents were less likely to be registered with a GP compared to older respondents and the average age of those who were unregistered (mean 38.8, sd = 10.7) was considerably younger than those who were registered (mean 43.4, sd = 10.3). Those who had been diagnosed with HIV for a shorter time were less likely to be registered with a GP, as were those without a co-infection or co-morbidity (93.1% registered) compared to those with a co-infection or co-morbidity (96.0% registered). Those who were currently taking treatment were more likely to be registered with a GP (95.6%) compared to those not currently on treatment (87.8%).

All the 75 respondents who were not registered were asked, *Why are you not registered with a GP / primary care service?* Of the 53 that gave an answer, more than a third reported that they were not registered with a GP because they had recently moved home and had not yet done so. The next most common answers concerned lack of need for a GP (usually because they used their HIV clinic for all care) and / or concerns about confidentiality or privacy. Other answers included those that felt that the high quality specialist HIV service received in HIV out-patients clinics could not be matched in primary care; those who perceived that there was a lack of expertise in primary care and those who had had difficulty gaining on-going access to the same GP. Finally some had struggled to find a GP or register when they had found one and others with immigration difficulties found it impossible to access a GP. These answers all also arose in the focus groups and are be explored further in section 5.8 below.

5.2 GP USE IN THE LAST YEAR

All those respondents that were currently registered with a GP were asked, *How long have you been using this GP or primary care service?* As shown in the table below, one-in-six (11.8%) had registered with their current GP within the last year and one in seven (13.7%) had registered 1-2 years ago. However, the majority of respondents had been with their current GP services some considerable time – more than half had been with their GP practice for more than five years; more than a third for 8 years or more; and more than a quarter for eleven years or more.

How long have you been using this GP or primary care service? (n=1259, missing 29)	**% (n) overall**	**% by gender & sexuality**		
		All females (n=319)	**Hetero. males** (n=126)	**MSM** (n=771)
Since I was diagnosed (not been to any other since diagnosis)	5.3 (67)	6.6	4.0	5.2
11+ years	26.5 (334)	23.5	28.6	27.0
8-10 years	12.7 (160)	13.8	14.3	11.8
5-7 years	14.5 (183)	15.7	15.9	14.0
3-4 years	15.3 (193)	15.0	12.7	16.2
1-2 years	13.7 (173)	14.4	14.3	13.4
Less than a year	11.8 (149)	11.0	10.3	12.5

As would be expected the length of time using their current GP or primary care service varied by age, in that older people (45 and above) were much more likely to have been visiting the same GP for 8 years or more and those under 30 were more likely to have been visiting them less than a year. As expected those with longer average time since HIV diagnosis were more likely to have been using their GP for a longer time.

Respondents registered with a GP were also asked, *How many times have you used this GP service in the last year?* As shown in the table below, in the last year, the majority of respondents used their current GP services relatively infrequently – one in six (16.2%) had not been to their GP at all in the last year and another third (36.7%) had been once or twice. Overall, more than half (52.9%) of people with diagnosed HIV who were registered with a GP had visited primary care twice, or less, in the last year.

How many times have you used this GP service in the last year? (n=1263, missing 25)	**% (n) overall**	**% by gender & sexuality**		
		All females (n=319)	**Hetero. males** (n=127)	**MSM** (n=773)
More than ten times	7.4 (93)	10.7	8.7	5.4
Seven to nine times	4.6 (58)	4.7	7.1	4.1
Five or six times	11.1 (140)	11.0	14.2	11.1
Three or four times	24.1 (304)	27.3	28.3	22.0
Once or twice	36.7 (463)	33.2	30.7	39.3
Not at all in the last year	16.2 (205)	13.2	11.0	18.0

Respondents with a co-infection or co-morbidity were less likely to have not been to their GP service at all in the last year (10.1% vs. 22.1%) and more likely to have been five times or more (32.7% vs.13.9%). Average age significantly increased with increasing visits to the GP.

Numbers of visits to their GP service also varied by ethnicity whereby those with black compared to white and Asian ethnicity were less likely to have not visited the GP at all (13.2% vs. 17.7% vs. 18.6%) or once or twice. Black respondents were also the most likely to have visited more than 10 times (11.1% vs. 5.5% vs. 4.7%). Migrants in general were most likely to have attended in the last year (15.4% vs. 17.2%) and to have attended 10 times or more (9.6% vs. 5.1%).

5.3 HIV DISCLOSURE TO GPs

All those respondents that were currently registered with a GP were asked, *Does your GP / primary care service know that you have HIV?* The vast majority of respondents with a GP had disclosed their HIV infection to them – one-in-ten (11.2%, n=143) had not, and a small proportion (2.4%, n=30) stated they did not know if their GP knew of their HIV diagnosis. Among those registered with a GP, seven-in-eight (86.4%, n=1101) had disclosed their HIV infection to them.

Those respondents that were registered with a GP, but had not disclosed their HIV infection in that context were asked, *Why do they not know?* (n =120, missing 23). Leaving aside a minority who had not disclosed because they were recently diagnosed (and had not yet had the opportunity to do so) by far the most common answer was that people did not feel comfortable disclosing HIV infection in a primary care context. This discomfort was associated with their lack of confidence that primary care staff could manage HIV or their perception that they would be stigmatised because of their HIV infection. Many responses also mentioned specific concerns about confidentiality in primary care. That is concerns about who would have access to information about their HIV infection. In particular, there were widespread assumptions that disclosure in a primary care setting would mean that information would be available to employers, financial service providers (insurance, mortgage *etc.*) and all other NHS staff. Others had a similar concern about information about their HIV infection becoming known locally to family or neighbours. This was common where the respondent shared their GP practice with other family or friends. Finally some respondents simply argued that their HIV-related needs were best met in HIV specialist care. They did not want to deal with HIV-related needs in any other context. The question of disclosing (or not) ones HIV status to GPs is explored further in section 5.8.

5.4 GP INVOLVEMENT IN HIV CARE

All those respondents that had disclosed their HIV infection to their GP or primary care service were asked *Is your GP involved in your HIV care*? The majority of those who reported their GPs knew of their HIV infection stated that they were not involved in their HIV care (83.6%, n = 896). Only one-in-six (16.4%) of those that had disclosed to their GP stated that their GP was involved in their HIV care, meaning in the whole sample only about one-in-eight (13.3%, n=176) reported that they had disclosed to their GP or primary care provider, and that they were involved in their HIV care.

Having a GP involved in HIV care varied by the source of recruitment whereby clinic recruits were more likely than online recruits to have a GP involved in their care (15.9% vs. 8.8%); as were women and heterosexual men compared to MSM (22.7% vs. 19.4% vs. 8.6%). Also those with a black or Asian ethnicity were more likely to have a GP involved in their care than white respondents (24.4% vs. 22.7% vs. 8.7%) as were migrants compared to non-migrants (16.8% vs. 10.1%). Those with only primary education were more likely to have a GP involved in their HIV care compared to those with university education (36.4% vs. 8.4%).

Those who reported having a GP who was involved in their care were asked: *How is your GP / primary care service involved in your HIV monitoring and care?* Of those who's GPs were aware of their status and involved in their care, the majority described the parameters of this involvement (n=176, missing 32). Involvement in HIV care varied considerably, from some GPs simply showing an interest in their HIV clinic care, to offering support and advice, and less commonly diagnosing and treating other health conditions. Some respondents reported that their primary care service were routinely kept informed by their HIV clinic or even that their GP and HIV clinic routinely liaised on their overall care package.

Many respondents reported simply that their GP or primary care service took an interest in their HIV care by asking about their results and checking on how they felt. Others reported a more substantial involvement including support and advice, which was more common than descriptions that could be truly classified as shared care. Some report getting other medicines (such as anti-depressants) or procedures (such as blood pressure or cholesterol monitoring or smear-tests) from their GP. GP involvement in HIV care was more common, and more substantial, among those respondents that had a co-infection or co-morbidity (see below).

While very few respondents said that their GP was their "first point of contact" if they were unwell, this was true for some. Many more revealed that their clinic and GP routinely shared information to ensure that they received the best possible care. While only about one-in-eight people (13.3%, n=176) in the whole sample reported that their GP or primary care provider was involved in their HIV care, among these, a reasonable proportion (more than a third but less than half, or about 5% of the whole sample) reported that the relationship between their GP and HIV clinic was strong and essential, often approaching shared care. Sometimes this was a source of frustration because of the added layers of bureaucracy, but far more often this approach was welcomed. The experience of this minority, for whom their GP was substantially involved in their HIV care, is explored further in section 5.8 below.

5.5 IMPROVING PRIMARY CARE PROVISION

All those respondents who had disclosed to their GP and who reported that their primary care service was involved in their care were asked: *For you personally, what is the single most important change that your GP / primary care service could make to improve the service?*

Of those that provided a response (n= 105, missing 71) more than a third said they were happy with the current service or could think of no potential improvements. The remainder described two types of change that could improve the service. The first concerned the way the primary care service was run. Many wanted it to be made easier to book appointments, for there to be shorter waiting times for appointments, longer opening hours or more appointments outside of working hours and some mentioned quieter waiting rooms. The second change desired by patients with HIV concerned how they as a person with HIV were treated in primary care. Some respondents wanted their GP to be more knowledgeable about HIV and more centrally involved in their care. In particular, some aspired to their primary care service taking blood samples for routine HIV monitoring and giving test results, with others wishing GPs were involved in prescribing HIV medication. Allied to these requests for greater HIV knowledge and involvement in HIV care, was a need for greater awareness of the impact of HIV and associated medication on other health needs and treatment complications. Difficulties with making appointments, lack of continuity of care and a desire for GPs to have greater confidence and capacity in dealing with HIV all emerged strongly in the qualitative focus groups and are explored more fully in section 5.8 below.

5.6 OTHER HEALTH SERVICE UTILISATION

All respondents were asked, *In the last year, what other NHS services have you used?* As shown in the table below, in the last year, the majority of respondents had used a GP or primary care service. In comparison, in the last year, about a fifth had used Accident & Emergency (A&E); a sexual health (STI / GUM) clinic; an outpatient clinic (not HIV) for an investigation and a NHS walk-in centre. No other NHS setting had been used, in the last year, by more than 7% of all respondents.

In the last year, what other NHS services have you used? (n = 1390)	**% (n) attended**	**% by gender & sexuality**		
		All females (n=350)	**Hetero.males** (n=146)	**MSM** (n=840)
GP or primary care service (n=1338, missing 52)	79.1 (1058)	15.3	17.5	23.1
Accident & Emergency (A&E)	22.5 (313)	21.1	20.5	23.0
Sexual health (STI / GUM)	20.4 (284)	13.4	13.0	25.2
Outpatient clinic (not HIV) for an investigation	19.0 (264)	14.0	11.0	22.9
NHS walk-in centre	18.3 (255)	21.7	13.0	18.0
Outpatient clinic (not HIV) for monitoring or care	13.3 (185)	12.3	9.6	14.6
Emergency (inpatient) admission to hospital	6.8 (94)	5.7	6.2	7.5
Planned (inpatient) admission to hospital	5.8 (80)	4.9	4.1	6.7
Substance misuse services	1.4 (19)	0.0	2.7	1.8
Maternity services	1.3 (18)	4.9	0.7	0
Intensive care	1.2 (16)	0.3	2.1	1.4
Other NHS services	7.8 (109)	10.3	6.8	7.0

Accident & Emergency (A&E): Those who reported visiting A&E in the last year were younger on average (mean 41.2 years, sd = 10.1) than those not using an A&E (mean 43.7, sd = 10.4). Similarly, the average length of time since diagnosis of those using an A&E was less (mean 8.3 years, sd = 6.8) than those who did not use an A&E (mean 9.4, sd = 6.9). Those who had ever injected drugs were more likely to have used A&E in the last year (34.6% vs. 21.7%) as were those with a current co-infection or co-morbidity (28.3% vs. 17.3%) and those not in paid employment (26.3% vs. 20.2%)

Sexual health (STI / GUM): Those who reported visiting an STI/GUM service in the last year were younger on average (mean 40.7 years, sd = 10.0) than those who did not (mean 43.7, sd = 10.4). Similarly, the average length of time since diagnosis of those using an STI/GUM service was less (mean 8.1 years, sd = 6.8) than those who did not use an STI/GUM service (mean 9.4, sd = 6.9). MSM were more likely to use GUM / STI services compared to women and heterosexual males (25.2% vs. 13.4% vs. 13.0%), as were white respondents compared to black and Asian (22.4% vs. 15.1% vs. 14.9%). Those born in Africa were also less likely to have used a sexual health clinic in the preceding year (14.5%) compared to those born elsewhere (23.2%).

Outpatient clinic (not HIV) for an investigation: Those who used an outpatient clinic (not HIV) for an investigation in the last year were older on average (mean 44.7 years, sd = 10.4) than those that did not (mean 42.7, sd = 10.3). The average length of time since diagnosis of those using an outpatient clinic (not HIV) for an investigation was more (mean 10.4 years, sd = 7.2) than those who did not (mean 8.8, sd = 6.8). Those living alone were more likely to attend (23.1% vs. 16.8%) as were Asian or white compared to black respondents (23.4% vs. 23.2% vs. 9.6%); as were those who were not migrants (23.7% vs. 14.5%). MSM were more likely to attend compared to females and heterosexual males (22.9% vs. 14.0% vs. 11.0%) as were those not in paid employment (23.4% vs. 16.5%). Those with a current co-infection or co-morbidity were more likely to have attended an outpatient clinic in the last year (24.2%) than those that did not have one (14.2%).

NHS walk-in centre: Those respondents reporting having used an NHS walk-in centre in the last year were younger on average (mean 39.4 years, sd = 9.8) than those who had not (mean 43.9, sd = 10.3). Similarly, those using a NHS walk-in centre in the last year had been diagnosed with HIV for a shorter period (mean 7.7 years, sd = 6.1) than those who had not (mean 9.4, sd = 7.0).

5.7 SHARED CARE

In section 3.4 we described respondents' self-reported experience of 16 specified co-infections or co-morbidities. Here we examine service use among respondents that reported any of these problems, based on follow-up questions on disclosure of that specific problem and who was involved in its management. Whenever a respondent reported any of the co-infections or co-morbidities they were asked two follow-up questions on that specific problem.

Who knows you have [co-infection / co-morbidity]? Please tick all that apply.

☐ General practitioner and primary care staff
☐ HIV consultant and / or HIV clinic staff
☐ A specialist doctor or nurse related to that condition

Who is involved in the management of your [co-infection / co-morbidity]? Tick all that apply.

☐ My General practitioner and primary care staff
☐ HIV consultant and / or HIV clinic staff
☐ A specialist doctor or nurse related to that condition

These additional questions allow us to examine the patterns of disclosure and patient-reported involvement in care for each of the specified co-infections and co-morbidities. We do not assume that all co-infections and co-morbidities automatically require involvement in care from GPs, HIV specialists and specific specialists as this would depend on clinical indication.

Any of these conditions at the moment	% overall	% GP staff know	% HIV staff know	% Specialist staff know	% GP staff involved	% HIV staff involved	% Specialist staff involved
High cholesterol	17.3	62	93	14	45	78	9
Psychiatric or mental health problems	13.7	70	84	50	60	44	46
High blood pressure	11.8	56	83	22	79	44	17
Neurocognitive disorders	6.0	42	78	43	34	57	39
Liver problems	5.8	50	89	58	28	81	54
Pregnancy (women)	5.4	79	100	68	58	84	63
Hepatitis C	5.2	65	93	58	18	82	54
Diabetes	4.2	95	93	57	88	36	47
Kidney problems	3.7	61	94	49	26	77	47
Hepatitis B	3.7	52	92	27	8	87	25
Ongoing STI	3.6	32	86	20	18	76	22
Problems with drugs or alcohol	3.5	43	60	36	34	45	28
Heart problems	3.4	89	93	64	67	53	51
Cancer	2.2	87	97	77	61	65	71
Acute STI	1.4	6	72	39	6	67	39
Tuberculosis (TB)	0.3	25	75	25	0	75	0

For 15 of the 16 co-infections and co-morbidities HIV specialist staff were more likely to know of the problem than GP or primary care staff (diabetes being the only exception). In most co-infections and co-morbidities, specialist staff were less likely to be involved in care than HIV specific staff.

A distinct pattern is revealed for active involvement in the management of some of the co-infections / co-morbidities. HIV specialist staff were more likely than GPs to be involved in the management of some conditions – high cholesterol, neurocognitive disorders; liver problems hepatitis C; Hepatitis B; kidney problems; problems with drugs and alcohol; ongoing and acute STIs and TB. Conversely GP staff were more likely than HIV specialist staff to be involved in the management of other conditions – psychiatric or mental health problems; high blood pressure; diabetes; and heart problems.

Considering just those respondents reporting problems with **high cholesterol**, those whose GPs knew about their problem with high cholesterol were older on average (mean 49.9 years, sd = 8.8) than those whose GPs did not know (mean 45.7, sd = 9.4). GP involvement in managing cholesterol conditions followed a very similar pattern, with only older age predicting GPs being involved in managing the problem.

Among those respondents reporting **psychiatric or mental health problems**, whether their GP practice was aware of these problems varied by ethnicity: those of white ethnicity were more likely to report a GP knowing about their psychiatric or mental health problems compared to Asian and black respondents (75.2% vs. 46.2% vs. 50.0%); as were MSM compared to heterosexual men and women (73.6% vs. 55.6% vs. 50.0%). However, GP involvement in managing psychiatric or mental health problems did not vary by any other demographic characteristics.

5.8 EXPERIENCES AND PERCEPTIONS OF GPs AND OTHER HEALTH SERVICES

In order to investigate our quantitative findings and provide more detail on the variations in use we observed in the survey, we turn to the focus groups. At these groups, we elicited discussion around GPs using a range of exercises and prompts. However, such prompts were unnecessary because in all groups participants were eager to talk about their experiences in primary care and held a range of opinions and positions, positive and negative.

5.8.1 DISCLOSURE TO GPs

Similar to the survey data, the vast majority of participants in all groups had disclosed their HIV infection to their GPs. In all groups, participants also reported having been told by their HIV clinics that they should be consulting their GPs for non-HIV care. Respondents differed in terms of whether or not they were happy to do so. In general, those with other health conditions (excepting mental health) or who were older tended to have the most productive relationships with their GPs.

> **One of the things about getting older is that you need to see your GP more. I like the fact if there's anything I am worried about with my health, it's only a 5 minute walk and that is a great reassurance to me rather than having to go all the way across town to my clinic. And for something like 15 years I never went near my GP. (MSM, Large Clinic Group)**

Those who had not disclosed tended to emphasise the issues of privacy as a disincentive.

> **The way that I've managed living with HIV is that it's very important that I have ownership of who I tell about my diagnosis. That's from only telling people who need to know. So I've told some friends and some work colleagues. Maybe I'm being overly cautious but I have a good GP inasmuch as she's nice to me on the rare occasions that I need to see her. But I don't feel that she needs to know right now. I'd be prepared to tell her at a time when I feel she needs to know, but I don't want to be told to tell my GP because that's my decision. My consultant said it in a throwaway way and someone called from the clinic asking can we tell your GP and I said 'no, never'. (MSM, Large Clinic Group)**

The question of privacy touched on issues additional to HIV.

> **I'm very open with my HIV doctor about my lifestyle and the fact that I take recreational drugs. I wouldn't be comfortable telling my GP that 'cos I know it would go in my records and I wouldn't want anyone who has access to my records, like [an] insurance company and all that, being able to see that. But I wouldn't like to have to hide things that might be relevant to my GP. (MSM, Large Clinic Group)**

Finally, the issue of stigma was frequently cited. Participants in most groups had either experienced or anticipated negative or stigmatising attitudes from their GPs.

> **My GP is useless. I haven't told him I have HIV because years ago I needed an HIV test for a work permit and he said 'someone like you would never be stupid enough to get HIV'. I wasn't positive at the time and I thought if I was, you'd be the last person I'd go to'. So I've made a point of not communicating with him. (MSM, Smaller Clinic Group)**
>
> *Participant 1*: **I have a GP and I go to GP for arthritis and to check my cholesterol. I don't want my GP to know my status. Once I tell them, the care that I get now is not going to be the same.**
>
> *Participant 2*: **Sometime when you say you are Pos, then everything changes. GPs who have not specialised in HIV have their own issues of being naïve. That is what most people say when we talk. (Women, African Large Clinic Group)**

5.8.2 PERCEIVED BARRIERS TO CONSULTING YOUR GP

Analysis of group discourse revealed a number of factors that underlined people's willingness to attend their GP practice for both general and HIV-related health care and their experiences when they did so. We present those factors that we identified to be negative or that were perceived to present obstacles to consulting with GPs first before moving on to those that were positive or facilitators to consultation.

A most frequently discussed negative factor in all groups was the perception that GP practices are not sufficiently responsive to cope with their varying health needs as people with HIV. The first concern was access and participants discussed it taking too long to get an appointment with a GP

> **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 Smaller Clinic Group).**

They also talked about GP practices not logging information from their HIV clinic fast enough.

> **I had a great GP in [area]; very caring and knowledgeable about HIV. But here, even when I am referred by my HIV consultant or I have to start medication, even months later my GP still doesn't know that I am on these drugs and the interactions. (MSM, Mental Health Group)**

Linked to this were concerns about lack of continuity. Participants in all groups described difficulties with seeing the same GP more than once.

> **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)**

Participants frequently cited the fact that you cannot stay with a GP if you 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 it's a PCT thing'. (MSM, Mental Health Group)**

By far the most frequently cited concern about consulting a GP was a lack of confidence in the ability of a GP to manage the health care of a patient with HIV. Participants in all groups talked about a tendency to ascribe all symptoms to HIV.

> **15 years ago I went to see [GP] with a sore throat and it was the lady in the practice who was supposed to be the HIV specialist and she looked and thought 'gay man with HIV, I've got to find something serious'. And she just looked at my throat and saw these red spots and said 'I think that might be KS' and scared the shit out of me! She was looking only for an HIV-related reason for the problem. (MSM, Large Clinic Group)**
>
> **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 Large Clinic Group)**

Others reported having negative experiences with regard to GPs misdiagnosing problems

> **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. So from that time I am careful when I go to my GP. I know it's not just a flu, I know my chest, and I say 'I know what I need for my chest'. I ended up being admitted to hospital. (Man, African Large Clinic Group).**

This might also pre-date HIV diagnosis or indeed concern mis-diagnosing HIV.

> **When I was misdiagnosed with glandular fever [rather than HIV] for a year, there were articles in the Lancet about my demographics (middle-aged white women), but they just use them as a doorstop (UK woman, Mental Health Group).**

GPs were also not perceived to understand the ways in which HIV interacts with general health, including co-morbidities and ageing.

> **... 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 Smaller Clinic Group).**

Participants reported GPs not being aware of differential screening needs or appropriate responses to symptoms with regard to patients with HIV.

> **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 for me and asked me if it was OK if he called the practice. He called and spoke with a nurse who said they were just about to call me and anyway he succeeded in getting them to call me and give me a referral. (Woman, African Smaller Clinic Group)**

Participants generally did not consider GPs as the appropriate clinician for the management of some co-infections.

> **I have Hep C and it's all managed very well at the [clinic name]. I don't want to deal with that at my GP surgery. I really don't, because there are issues around confidentiality. I'm far more concerned about confidentiality around my Hep C because there is more stigma around that than HIV. But GPs are never going to be able to provide the care that specialists can. (MSM, Co-morbidity Large Clinic Group)**

Whilst participants in both co-morbidity groups experienced the most functional relationships with their GPs, even in these groups, participants gave examples of difficulties with the care they received from their GPs. Lack of confidence and knowledge was frequently discussed.

> **[My] GP is really reticent saying 'I don't have your medical notes, I don't know what the interactions with your other meds. would be', even to get something as basic as antibiotics. She's really lovely, don't get me wrong, but she says, you know, 'I'm really lost'. So I have to tell her 'look, it's another chest infection. I get chest infections'. (MSM, Co-morbidity Large Clinic Group)**

One particular concern was prescribing errors from GP practices.

> **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 Large Clinic Group)**

These concerns were shared by those in the Mental Health Group.

> **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. 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)**

A further area of concern for patients was poor communication between GPs and HIV clinicians, sometimes resulting in the patient having to act as the go-between between them. Participants were particularly concerned when 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, Smaller Clinic Group)**

There were also very frequent accounts of patients attempting to consult their GP with a symptom only to be sent immediately to their HIV clinic.

> **Whenever I go to my GP, he always refers me back to the [Clinic]. (Man, African Large Clinic 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 A&E 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 he sent me to A&E.**
>
> ***Participant 2*: But if you ring out of hours, if you ring your GP practice or you're in [named out-of-hours service]. 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 ARV, you need to go to A&E. (MSMs, Co-morbidity Large Clinic Group)**

Finally some participants reported GPs and HIV consultants giving contradictory advice but not consulting with each other.

> **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, 'no 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 Smaller Clinic Group)**

In the context of some negative experiences of primary care, participants described how they sometimes considered HIV services to be better placed to deal with all of their health care needs. Positive experience of expertise, access and continuity in HIV care meant participants saw HIV services as a more attractive option than primary care, even for their wider health needs.

> **I would err towards HIV care because at [clinic name], they always have an on-call doctor where you can go at any time and put your name down and see them. (MSM, Large Clinic Group)**

> **It's made clear that you should go to your GP with a cold *etc*. But if you do go there (HIV clinic) and you have happened to have been ill at some point, then they will do the tests no matter that. 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, Smaller Clinic Group)**

Issues regarding the referral by GPs to access specialist care were also raised, especially by those managing complex health needs. A good example were those in the Co-morbid Large Clinic Group who, in the past, had seen their complex health needs managed either through their HIV clinic or via consultant to consultant referrals within the Trust where they attended for HIV care. They feared having to depend on GP referrals to hospitals in their local trust that were far removed from their HIV care. They were also concerned that the standards of care would not be as good at local hospitals as it would be in the trust they use for their HIV care.

> ***Participant 1*: At [named trust], everything is internal. If you get KS, you get a doctor there who is amazing and deals with all cancers. Everything within [named trust] is doled out internally whether its cancer or osteoporosis and you see everyone internally which for me, that's amazing. I get three appointments in one day. Not running all over London.**
>
> ***Participant 2*: [Clinic at hospital 2] is under the umbrella of [named trust]. I have my coronary care at [hospital 3], my HIV at [clinic at hospital 2] but I also have my chest and allergy at [hospital 2] at bronchology and the communication between them is fantastic. It really is. (MSMs, Co-Morbidity Large Clinic Group)**

It is instructive to compare the experiences just described with those in the Co-morbidity Smaller Clinic Group where participants were largely dependent on their GP to manage their care. They reported often having repeated tests and attempting to manage communication between clinicians in different hospitals.

> ***Participant 1*: I had three separate blood tests for the same thing recently – the GP, the specialist at the kidney clinic at [hospital 1] and the HIV consultant. Why couldn't they all look at the same result? (MSM)**
>
> ***Participant 2*: I also see a kidney doctor. When I go to see the nephrologists, I see the kidney nurse specialist every 2 months. I also see my HIV consultant every 2 months. So I ask the kidney nurse specialist to list what tests she has done because I'm not going to have the same tests done twice. You need to tell them 'I had them done last week'. (African Woman)**
>
> ***Participant 1*: See my kidney specialist is in a different hospital – [hospital 1]. And I was seeing a cancer specialist at [hospital 2] and had a surgical operation at [hospital 3]. So at one point I had 5 consultants for different things all taking blood – with the GP in the middle getting bombarded with all the information. I just thought they could coordinate a bit more. Before when I was ill, the HIV clinic consultant referred me and then 3 years later when there was a change of policy, the HIV consultant told me that I'd need to get my GP to refer me. (MSM, Co-morbidity Smaller Clinic Group)**

5.8.3 PERCEIVED BENEFITS OF CONSULTING GPS

Those in smaller clinic and co-morbidity groups tended to report a more functional relationship with their GP. We finish this chapter by examining the positive factors influencing their experiences.

Participants often described having a good relationship with their GP that pre-dated their HIV diagnosis, where they were used to consulting their GP and trusted them.

> **When I was diagnosed, I had the same GP for 15 years and he was brilliant when I told him and since then, he's taken a step back from my HIV treatment but has been involved and interested. (MSM, Smaller Clinic Group)**

Others reported having to falsify 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 which 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 Smaller Clinic Group)**

Many of those in both of the co-morbidity groups had put great efforts into finding a GP that was suitable for them and maintaining or cultivating a relationship with that GP.

> **I researched my GP. I asked some people locally and went to 4 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 [Large London HIV clinic]. I went to seek him and seek him out each time and he's absolutely fantastic. (MSM, Co-morbidity Large Clinic 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. Like once when I went in with a really sore throat. He didn't even ask me to open my mouth [...] He just said take painkillers and gargle. I know when I am ill. So I went to my HIV consultant and he wrote to my GP to complain and since then it's been OK. (African woman, Co-morbidity Smaller Clinic Group)**

Others mentioned that despite good relationships with their GPs and a willingness to support them, structural barriers make life very difficult.

> **My problems are more to do with the system. Because my HIV drugs are prescribed by one system, the HIV clinic, they can't be amended or added to by my GP so I have to be the repository of all the information and I have to carry that across. […] I don't mind supporting my GP and knowing best about me but it's often the issue about the way that the medical systems don't align. (MSM, Co-morbidity Large Clinic Group)**

However, an overriding factor in making GP involvement acceptable was the extent of communication / coordination between the GP and the HIV clinic.

> **My care is joined up. My GP is on board and he has all the letters from the hospital so there is a good two-way communication. He steps back when it comes to HIV and I prefer that. I prefer my HIV clinic to be in charge. (MSM, Smaller Clinic Group)**

Some patients were content for their GP to be involved in, or even coordinate their care, so long as they were sure that the GP consulted with the HIV clinician before making any clinical decisions. However, they recognised this required good communication between doctors and that their GP deferred to the HIV specialist in all clinical decisions.

> **My GP is fantastic. She deals with my neurologist and my HIV clinic. If she is going to prescribe something, she gets straight onto the pharmacist at the HIV clinic and asks about whether this will be OK. (MSM, Co-morbidity Smaller Clinic Group)**

Moreover, a perception that GP practices were diligent in maintaining notes and that individual clinicians at a primary care practice would attend to these notes was seen as important.

> **Our local GP practice has eight GPs and not seen my official GP in about five years. They're excellent, they know I've got HIV and the clinic writes to them and it comes straight up on the screen. If I've had a lipid done at the clinic, I don't have to repeat it. It all meshes very well together. (MSM, Smaller Clinic Group)**

Finally, GPs that sought to provide continuity of care were also valued.

> **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 Smaller Clinic Group)**

6 CHANGES TO HIV PROVISION: PERCEPTIONS & EXPECTATIONS

In all eight focus groups, a range of scenarios were presented in order to generate discussion around possible changes in the way specialist HIV services might be delivered. These consisted of notions of centralising clinical services and reducing the overall number of clinics; redistributing clinics around London to more closely mirror where the main populations of patients with HIV lived; and some proposals for an increased role for primary and community care in HIV care and monitoring, perhaps through local satellite clinics, primary care based HIV clinics, greater involvement of Community Nurse Specialists *etc*. All focus groups were asked to consider any changes in relation to three key indicators.

- how might any change affect **equity** of service access and provision for all people with HIV?
- how might it improve **quality** of service?; and
- how might **cost-effectiveness** of service provision be enhanced?

Finally, the groups were also prompted to consider how they thought service delivery might change and how they would like to see it change.

6.1 ATTITUDES TOWARDS CHANGE IN GENERAL

None of the groups were opposed to the idea of developing HIV services in response to changes in the demographic make-up, size and clinical needs of the population of people with diagnosed HIV in London. Indeed, there was strong view that commissioners and clinicians would not be doing their job properly unless there was on-going scrutiny and improvements to the services.

> **I hope services will always be changing with the demands of the time. I know with [clinic name] the interest is in giving the best care they can, so I don't see them not moving with the time. (Woman, African Large Clinic Group)**
>
> **If you stop changing you're finished. For example, bulk buying meds. to get them at a better price makes sense. (MSM Large Clinic Group)**

Others stressed the question of equity in terms of service change.

> **There are increasing numbers of newly diagnosed people coming in from all over the world. We cannot sit here and assume that services that were tailored for us; for our specific needs 20 years ago can be maintained for forever. That means that we are suggesting that newly diagnosed people are not going to get the same level of care as we do. (MSM Large Clinic Group)**
>
> **But it's not really working. I went into [Large Clinic] recently. I was appalled by how it looks, so dishevelled and the system is so confused and creaky. If you want to get better care, you become a clinical trial patient. But the bulk of patients are not. And they tend to be Africans, women *etc*. They don't seem to figure very much in the trials I participate in. When I step outside of my [Large Clinic] bubble and see a lot of the other clinics, it's quite frightening and it does feel very hit and miss about the kind or standard of care you do get, although I know there are standard care models. It doesn't necessarily mean I will also get it. (MSM Co-morbidity Large Clinic Group).**

Many thought that whilst change is appropriate in terms of the 'back office' (commissioning or administrative aspects), there was concern that change needed to be managed carefully and the impact of any change on the patient's experience of care minimised.

> **I can't see a problem with the service at the moment that would be improved by such radical changes. Group buying, putting more people on home delivering, doing admin. centrally: that makes sense. But from a patient point of view, unless there are good reasons, then rationalising for the sake of it is not a good thing because inevitably there will be a year or two of change and bedding in and each time they change it gets more confusing and some people may be put off actually going. That's what it comes down to. You don't want to bring about a situation where more people are not attending a clinic. (MSM, Large Clinic Group)**

There was also concern that any major change would need to be managed incrementally.

> **Evolution rather than revolution. There may be cases for merging and rationalising some services and some clinics, and it's good if people are happy and trust their GPs. But to go for a sea-change of everything changing could lead to drastic loss of quality and trust. (MSM, Large Clinic Group)**

6.2 ATTITUDES TOWARDS CHANGE IN PARTICULAR

The consensus that service development in response to changing need was a positive thing did not necessarily translate into positive attitudes towards the possible changes discussed in the groups. As we have seen, participants in all groups were more or less aware of changes in terms of size, make-up and clinical need of the population of people with diagnosed HIV; that HIV was becoming normalised and there were strong debates in some groups about the implications of this change as exemplified by this exchange in the Co-morbidity Large Clinic Group.

> *Participant 1:* **So what we are defending is better care for people with HIV and the reason we have that better care is because we were a very politically active group of people in the past. We fought for it and now the health service doesn't want to pay for it and wants to take it away.**
>
> *Participant 2:* **Yes you are right but it is also the fact that people died very quickly and physicians wanted to give us the best standard of care for that short period. As we are now a much larger patient group with a condition that is much more easily treated and chronic, the idea of having expensive premises for us to use seems to me difficult to defend, when most of us are now getting conditions that are not HIV related but to do with getting old.**

In all groups, the questions 'why change?' and 'why now?' were repeated. As a consequence it will be important for the clinical and financial case for change to be clearly explained to service users, as the Service Review progresses. An overwhelming assumption in every group was that changes in need would simply translate into a diminution in the quality of care: that by 'normalising' HIV care, they were just reducing the quality and accessibility of specialist services.

The majority of participants were suspicious that proposals for change were solely in response to cost concerns rather than questions of quality or equity. All participants recognised that changes in need required changes in care. The concern expressed by many was how that would be managed to ensure it did not turn into cost cutting for the sake of it.

> **What's the reason for wanting to change? If the current model is not inequitable and not failing in terms of quality but just costs too much, then find ways of economising like compulsory group buying. But if the only driver is cost, then you need to find a way of economising without disturbing the set-up as it is because otherwise the other two (equity and quality) will suffer. (MSM, Large Clinic Group)**

It was precisely their awareness that they were in receipt of a very high standard of care that led so many to suspect that this standard would be compromised in the name of efficiency or cost-saving in the current economic climate.

> **It shouldn't be a "race to the bottom". One of the reasons that a lot of people with HIV live in London is that they can access the quality of care that they can't get in a small general hospital GUM unit. (MSM, Large Clinic Group)**

All groups were asked how, in reality they thought services would look in five years. The most common perception was that, despite reviews, any change was likely to be solely in response to funding limitations and cost-savings. That is, services will not be more smartly designed, but rather just have less funding and that this will impact on the health and experiences of the patient. The following participant used his experience of managing his complex health needs to inform this view.

> **[In five years' time] it will look different and that will be purely influenced by finance. There'll be fewer, shorter appointments. More restrictions around what they could prescribe. I get chest infections and [HIV consultant] was very good. As long as I was a responsible patient, I could have antibiotics at home on standby. Now I need to get the chest infection first and then get them prescribed by my GP. My fear is that 2017, it'll be more fragmented and more work for me to get things done. (MSM, Co-morbidity Large Clinic Group)**

As a result of these concerns about cost-cutting, it was difficult to generate discussion regarding the real pros and cons of different service models. The following exchange in the Mental Health Group was very atypical:

> *Participant 1*: **In terms of equity and rights to privacy, for certain sections of the community, having centralised clinics will not be good for them. There'll be more travelling and increased danger. If you remove a local clinic from communities that depend on having a local clinic, then attendance will go down and you increase onward transmission risk with people. Also paying for travel or being disabled would find it difficult to get to central London for appointments.**
>
> *Participant 2*: **For me I think they should have centralised clinics and an 'outreach' model to local hospitals. That would be great. The trouble with a lot of local hospitals though is that often transport is worse! [...] But you need to have that backed-up by satellites in local hospitals for those who for whatever reason can't visit their central clinics.**
>
> *Participant 1*: **But that's what we've got now: several central ones with outlying ones used by local people.**

Despite this, the same group returned to the over-arching impression that services would change not in a planned way in response to need, but would simply be 'cut back'.

Many stressed the importance of communication and consultation regarding any planned change. At the time of the groups (early summer 2012), there was a perception that change was being planned without the involvement of patients and that the current exercise (including this research project) does not constitute consultation. The following respondent summed up the sentiments of many.

> **It depends on what level of involvement the patient has: if we are consulted and given options and also if they show us why they are doing things. At the moment, everyone is talking about saving money and if we (the patients) feel that things are being changed just to save money, then it doesn't come out well to us. We just think that they are just trying to deprive us of stuff. So if there are any changes there needs to be a lot of patient involvement. (African woman, Co-morbidity Smaller Clinic Group)**

6.3 CONCERNS ABOUT CHANGE

All groups expressed concern about any changes that may affect the way HIV out-patients services were organised in London. The first and most frequently discussed concern was the possible increase in the role of primary care in any new models. The main concern was the possibility of a loss of the high levels of expertise in specialist HIV clinics.

> **I really believe that I am only as well as I am now because of the quality of the clinical care that I've been receiving and if I were diagnosed in two years' time and it was a case of going to a GP and deal with nosey receptionists or see a nurse *etc*., I wouldn't be as well as I am and I wouldn't access those services. (MSM, Large Clinic Group)**

Others could see the utility of primary care models at least for patients whose conditions were stable.

> **In 5 years, I would like to see stable people managed by a specialist nurse. You know your bloods are OK, your viral load is low and everything is OK. You don't need to see a doctor. (Woman, African Large Clinic Group)**
>
> **Once you are stable and on meds., I can see that there'll be a strong argument that you go to your GP for bloods and results *etc*. Acute care will be pushed out to primary and you see your specialist once a year. (MSM, Mental Health Group)**

Many were aware of the need for greater GP involvement and suggested that this might work with the active oversight of HIV-specialist clinicians.

> **It would be great if the GP was better at dealing with HIV because as we get older, we're going to need them more and it should be that if the GP can't handle something, he then refers you to your consultant. (Woman, African Smaller Clinic Group).**

However, a concern repeatedly expressed by participants was the clinical competence of GPs to deal with the needs of people with HIV. Some made the point that although HIV was manageable as a condition, clinical advances required specialist oversight.

> **A lot of the drugs are still very new and you know, [...] if you are on this [drug] and there is a risk of heart disease, this is something you want to discuss with a specialist who is on top of [the] research. Not with a GP who's going to look at the BNF if it's in date even. And then if you want to get this question answered you need to track down and make an appointment with your consultant and it all becomes messy. (MSM, Large Clinic Group)**

Others cited situations where GPs showed a lack of confidence/ability to respond to their needs.

> **I wanted a test for diabetes because it runs in my family and I asked for a test and the nurse at my GP told me to go to my HIV clinic. That she could not do that because of my HIV. (Woman, African Smaller Clinic Group).**

This was a particular concern for many of the participants in the Mental Health Group who had had particularly negative experiences with their GPs.

> **If I'm in my clinic, there isn't just the consultant but other people and the environment is positive; talking here in terms of my mental health. At your GP you are just another ticket holder. Having HIV can be isolating and would be worse if you are one of four people at that practice. You won't get the same social support. (MSM, Mental Health Group)**
>
> **I think what's terrifying is going to your GP with mental health issues and them being terrible about it (others agree). (UK woman, Mental Health Group)**

The African groups in particular were concerned that in practice GPs and local community health services held stigmatising attitudes.

> **It's not a matter that HIV is special, but it is complicated because it deals with emotions and privacy. Some people that are clinicians, especially nurses have forgotten their oath to treat people with respect and they have no empathy and they just talk openly sometimes. (Man, African Large Clinic Group)**

Overall, participants were not averse to considering innovative models for administering routine aspects of care (such as blood tests, prescriptions and test results) locally. They were clear that this could not simply be handed over to primary care as currently constituted. In view of the current levels and state of communication between GPs and HIV clinics, fears around coordination were raised.

> **As long as my blood test goes to the right file and to my consultant and does not get lost. But the infrastructure would need to be improved. (Woman, African Smaller Clinic Group)**

The second concern raised was connected to the quality of the relationship between patient and HIV consultant. Participants assumed that any rationalising or merging of HIV clinics would inevitably lead to a reduction in the number of specialist consultants and therefore to increased patient loads and some patients having to transfer to the care of other doctors. Therefore, many anticipated seeing their consultant for less time and less frequently.

> **Instead of a corner-shop which is what we have at the moment you get a supermarket. At a supermarket you are running around trying to find staff or someone to tell you where something is whereas at least at a corner-shop there is someone there to help you. You feel more at home. (MSM, Co-morbidity Smaller Clinic Group)**

Others (in large clinics) thought that clinic size would not make a difference and could see advantages in terms of the continuity of nursing staff.

> **If I was still keeping the same doctor, I don't see why it would matter too much that the clinic is twice as big. It would be good if there was some continuity with the nursing staff too. (MSM, Large Clinic Group)**

Those in smaller clinics were mixed in their views. For many, they reported that having to change to a new clinic would affect their confidence in the quality and accessibility of their care.

> **We may have no viral load and good CD4 counts, but there is also wellbeing and the way you feel confident about your care and going to the same clinic that you trust each time. How are they going to ensure that? If you know that you have a caring environment: that makes a huge difference. (MSM, Smaller Clinic Group)**

Others stated that seeing less of their consultant would be acceptable as long as it was clinically indicated for them as illustrated by this exchange in the African Smaller Clinic Group.

> *Participant 1*: **In the past I used to get my meds from the pharmacy and waiting for an hour but now it's home delivery which is so convenient. So a time will come when we don't need to see our consultant all the time. When I was diagnosed, it was every month and now every 6 months. I look forward to the time when they'll only call if there is something wrong and I need to see my consultant.**
>
> *Participant 2*: **It all depends on your health. If you are physically OK, then there is no fear about not seeing the consultant. But if you are sick and see the consultant, then one will be made available.**

The third concern raised was connected to accessibility of clinics. For the most part, this concerned travel times. In most groups, participants discussed the pros and cons of visiting a clinic locally versus travelling to central London. On one hand, local clinics were seen as highly convenient for some.

> **If you centralise services, mothers with children will be badly affected. You know, leaving the kids into school, travelling an hour or more in and then having several hours for your appointment and then having to be back in time to pick the kids up. These are the kind of things that need to be considered. (African woman, Co-morbidity Smaller Clinic Group).**

However, others highlighted difficulties with local travel connections.

> **Sometimes it's easier to travel into the centre than travel across areas even locally. (Woman, African Smaller Clinic Group).**

However, in some groups, the question of locality of services took on another dimension: this was the potential impact of the loss of HIV as a local clinical specialism. That is, if there were no longer

HIV specialists in local hospitals, patients with HIV would have less confidence in using these hospitals, especially in emergencies.

> ***Participant 1*: And also to know that if anything goes wrong, you don't have to get to central London to see a consultant in an emergency. That happened to me, I was rushed into [small outer London clinic] and then to [large inner London clinic].**
>
> ***Participant 2*: For me to get into central London, it'll take me an hour and a half. I could die on a bus. It's a bit mad going all that way. They should keep 2-3 smaller units in each area of London [MSM, Smaller Clinic Group].**

This perception is part of a much larger debate that emerged in many of the groups: what is the clinical status of HIV? Is it a highly specialised area requiring centres of excellence or is it a manageable condition that can be treated locally? This also depends on the relative numbers of patients in an area. Participants questioned why all hospitals in a high prevalence area like London should not have an HIV specialist alongside centres of excellence elsewhere. The following exchange in the MSM Smaller Clinic Group illustrates this debate.

> ***Participant 1*: I think that integrated care would be great. A local clinic would be better even if I didn't see the specialist so often... so long as I can see the specialist very easily if the need arises. At the moment it's not convenient because I have to go to several doctors taking letters from one to another and that is not working at all.**
>
> ***Participant 2*: You wouldn't expect your GP to treat you for cancer, well why would you expect them to treat you for HIV?**
>
> ***Participant 1*: I don't expect my GP to be able to treat me for HIV. I expect them to be able to take my bloods and prescribe my meds., so long as I'm on stable meds. Why would I see my specialist for that?**
>
> ***Participant 2*: But you would if you had cancer. You'd go to the specialist who would prescribe your medications and give them to you. Because cancer is a disease that can kill you, as HIV can?**
>
> ***Participant 1*: But with cancer you're treated for a limited period of time. Diabetes is a good example. Your GP would give you your diabetes meds.**
>
> ***Participant 2*: But your diabetic consultant would not be the other side of London. They'd be in your local hospital and that's the difference.**

7 CONCLUSION

My Care, I Care reveals a lot about the views, experiences and preferences of adults with diagnosed HIV using specialised NHS services in London. Using a novel approach to gathering the views of people across most London HIV clinics, it provides a rich account of the views and preferences of almost 1,400 adults with diagnosed HIV. It consolidates many things we already know about patients' views of HIV services. It also uncovers a number of surprising findings.

The survey sample was in line with the known profile of people with diagnosed HIV in London and highlighted key issues for commissioners – and providers – to consider in designing effective models of HIV care for the future. Unsurprisingly, people with HIV believe London HIV clinical services to be second to none. The survey showed that people change service infrequently and the vast majority believe their service to be exemplary. Reported clinical outcomes demonstrate this is indeed the case. Whilst changes in the nature and availability of antiretroviral drugs have played a part in this success, the way in which care services support people with diagnosed HIV cannot be underestimated. Patients clearly value consultant and other clinical staff who are able to show empathy and understanding. Having quick and consistent access to consultant and clinical staff is also seen as important. Patients also have great confidence in the ability of HIV services to facilitate access to other care services, to maintain their confidentiality and to meet their wider health care needs.

Respondents in the *My Care, I Care* study revealed that while in principle, they were not opposed to well-planned service development, the current case for change had not been made clearly to them. Many thought that the primary purpose of change was cuts in funding. Any proposal for service change raises anxieties about whether the result will be a diminution of quality or access. There was some recognition of the impact of the continuous increase in the number of patients and some suggestions were given of service changes to improve productivity. Ensuring the clinical need for change is clearly understood will be a challenge during consultation on any proposed re-configuration of services.

The lack of support for a GP-led model of HIV care and treatment was not unexpected. In line with previous studies, patients expressed concerns about the ability of primary care to maintain confidentiality, of their competence in managing complications of HIV and of continuity of care.

My Care, I Care also contains a number of surprising results. First is the extent to which people with diagnosed HIV are registered with, disclosed to and using GPs and primary care services. The focus groups also revealed some examples of high levels of satisfaction with GPs and the factors which secured this. Those who have been living with HIV the longest and who had co-infections or co-morbidities were most likely to use primary care. The relationship with primary care works best where GPs are well linked to the HIV service and where long-term condition management approaches – including empowered self-management – were evident. The fact that people with diagnosed HIV were engaged with primary care is a key finding. This provides an important opportunity to move forward the debate about the proper role of primary care in supporting the health of people with HIV.

The extent to which the survey sample was involved in employment was also surprising, particularly given that many were experiencing co-infections or co-morbidities. This finding is important because services will need to respond to the challenge of providing services 7 days a week so that people with HIV can lead full lives and access care at times and in ways that are convenient to them.

Perhaps the most surprising finding was the extent to which people with diagnosed HIV enjoy 'Right Care' (see www.ic.nhs.uk/rightcare). The concept of 'Right Care' emphasises the importance of patients receiving the right care, at the right time and in the right place. It aims to match expertise to need, including the role of self-management. In our survey, whatever the co-infection or co-morbidity, experts in conditions other than HIV were much less likely to be involved in care than HIV doctors. This goes to the heart of why a new model of care for HIV is needed. Up to half of people with diagnosed HIV are also living with other conditions which need appropriate management if they are to enjoy clinical outcomes equal to the rest of the population. The risk of the current model of care is that people with HIV have poorer health outcomes than the general population, not because they have HIV but because they are not accessing the appropriate care for all their needs.

The report also makes important reading for commissioners on a number of other fronts. Firstly, people with HIV report that the clinical case for change is unclear. This is the first challenge to address in all consultation on change options. Secondly, people with HIV want to be at the heart of debate about how services are changed. This means that consultation on new models of care needs to be meaningful and especially robust, sharing information widely and encouraging participation from all. Thirdly, people with HIV want to see a more HIV aware and engaged local health economy. This goes to the heart of issues of prejudice and stigma, as well as education and training. Whilst these issues go far beyond the scope of the current London Specialised Commissioning Group HIV Service Review, the process of consultation and implementation gives all those involved in HIV care and treatment the opportunity to take this important agenda forward.

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