

Towards Positive Practice

A report on the experiences of people living
with HIV when accessing primary healthcare



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Executive Summary

Commissioned by Manchester City Council's Population Health Team, George House Trust carried out a research and engagement exercise focused on the experiences of people living with HIV accessing primary healthcare. The resulting report focuses mainly on care provided by General Practitioners (GPs).

The focus of policy and decision makers, is often, understandably, on the provision of specialist HIV healthcare but it is also essential that the vital role of primary healthcare is recognised when considering the overall health and well-being of people living with HIV.

96% of people who engaged with this work had told their GP about their HIV status. People were willing to talk to their GP about HIV - and recognised the benefits of doing so - but 52% of survey respondents expressed a lack of confidence that GPs had an adequate level knowledge and understanding about HIV.

37% of people who completed the survey noted that the reason they had told their GP that they were living with HIV was in order to avoid medication contraindications. Another reason given, with 36% of respondents referencing it, was that people felt it would be beneficial for their overall health and wellbeing.

Other issues raised, including unnecessary referrals back to HIV clinics, continuity of care, information sharing and stigma, are explored in more detail in this report.

The way that people living with HIV engage with, and access, primary healthcare has changed over the last decade. Some participants diagnosed longer term with HIV spoke of a time when they required less support from their GP because, then, HIV clinics were able to provide a more "wrap-around" service including the prescribing of non-HIV related medication.

Looking to the future and bearing in mind the challenges facing the NHS and primary healthcare, the way that people living with HIV engage with their GP is likely to change further, with the growing use, for example, of more remote forms of consultation.

We would like to thank everyone who made this report possible - the people living with HIV who shared their views and experiences, the clinicians who gave their time and shared their knowledge and Manchester City Council for their generous funding for this work.

Key Findings

96% of survey respondents had told their GP about their HIV status

78% of survey respondents felt confident discussing HIV with their GP

52% reported feeling confident that their GP had sufficient understanding and knowledge about HIV

- A significant number of people expressed concern about contraindications with HIV medication when being prescribed medication by their GP and felt that their GP needed more knowledge in this area
- People reported being referred back to their HIV clinic for health issues that were not HIV-related
- People reported concerns about a lack of continuity of care in primary healthcare
- There was a limited understanding of how information about peoples' HIV status is shared
- The majority of people we spoke to reported positive experiences when accessing primary healthcare

Rationale

People living with HIV receive primary healthcare from a General Practitioner and specialist care from a HIV Consultant. Many people will also receive healthcare in other settings, but these services are universally used.

By the very nature of their role, GPs are not experts in HIV specifically. However, they do play an integral role in the holistic health care of people living with HIV.

It is important that we understand the experiences of people living with HIV in this particular healthcare setting and have the opportunity to outline the areas of focus, and make suggestions and recommendations about changes that need to be made in order to ensure that health care needs are being met.

Methods



4.1 Survey

An online survey was sent out in December 2021.

The survey was sent via email to approximately 1,000 people who access services at George House Trust, live in Greater Manchester and have given permission to receive emails. A total of 149 people completed the survey.

4.2 Focus Groups

Five separate focus groups were facilitated with the aim of engaging different demographic groups supported by George House Trust.

We recruited participants by promoting the groups in the George House Trust newsletter and sending targeted emails to specific demographic groups. We held most of the groups online, with the intention of ensuring maximum accessibility.

We facilitated focus groups for women, heterosexual men, African men, people aged 55+ and over and people who identify as LGBT+.

Each group was led by a staff member and focused on the questions detailed in the introduction.

22 people in total were engaged in the focus groups.

4.3

Roundtable Discussion

An online roundtable discussion was facilitated in March 2022.

The discussion was attended by two HIV clinicians (a consultant and a specialist nurse), the GP champion for HIV in Greater Manchester, two members of staff from George House Trust and seven people living with HIV.

The aim of the discussion was to provide a forum for healthcare professionals to hear about the experiences of people living with HIV, for the healthcare professionals to be part of the general discussion and to highlight specific issues and discuss how they should be addressed.

4.4

Areas of Focus

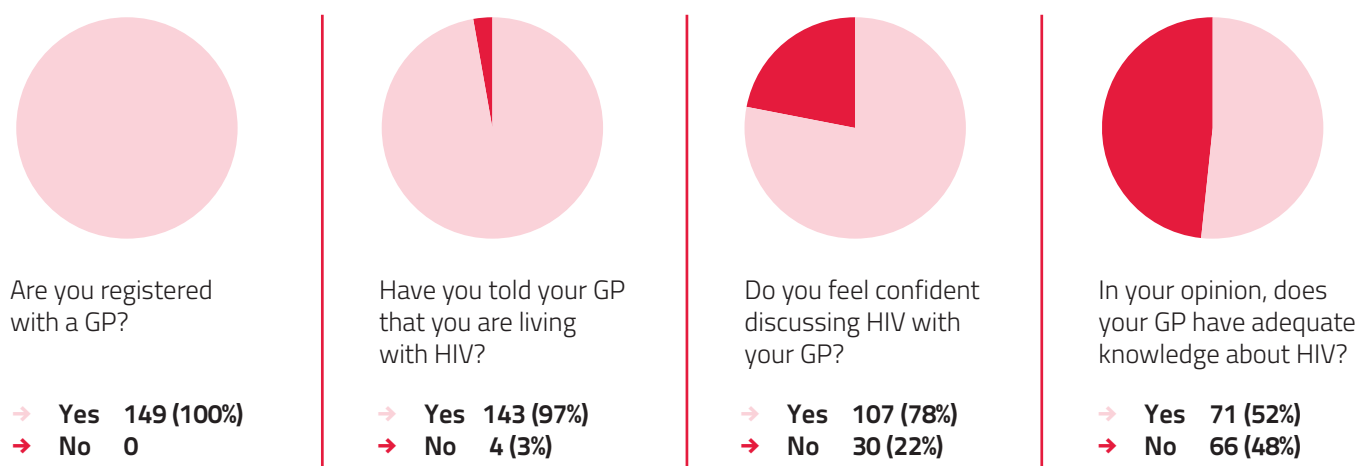
The questions asked in the survey, workshops and round table discussion were similar and were intended to discover:

- whether participants had told their GP that they are living with HIV
- if this was the case, whether participants felt confident discussing HIV with their GP
- whether participants felt that their GP had an adequate understanding of HIV
- whether people were happy with the way healthcare information is shared



Findings

Survey Results 149 Respondents



We had previously assumed that a significant number of people surveyed would not have talked about HIV with their GP because of possible concerns about stigma. This proved not to be the case with 97% of respondents having told their GP that they were living with HIV.

In total, only four people had *not* told their GP (3% of all survey respondents).

It is worth noting that survey 'selection bias' may have affected the results since all respondents were people living with HIV who access services at George House Trust. It is possible that those who had informed their GP were more likely to complete the survey and attend focus groups than those who hadn't.

The fact that so many respondents had felt confident enough to tell their GP about the fact that they are living with HIV – regardless of any selection bias that may have been at play – is to be welcomed.

People were asked **why** they told their GP and there were 99 responses.

The main reasons cited were:

Reason	Number of responses where reason cited
Medication prescribing and concern about possible contraindications	37
Beneficial for overall health	36
GP gave HIV diagnosis	7
HIV clinic notified GP	4
Mental support and emotional support	3

Participants in the focus group also gave similar reasons:

"Because he is my family doctor, I think it is necessary he knows to make informed and appropriate decisions concerning my health"

African male, focus group

As the survey results show, although most people were confident discussing HIV with their GP only 52% of people surveyed felt that their GP had the right level of knowledge about the condition.

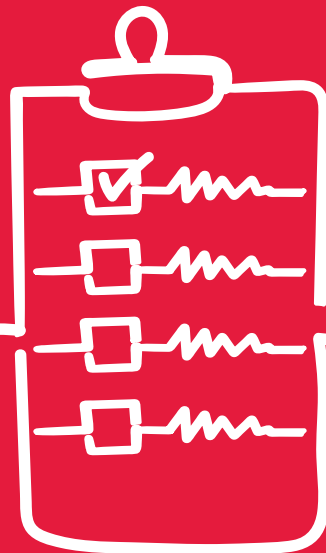
Similar views were expressed in the focus groups, with numerous participants commenting that they did not think their GP had a good enough understanding of HIV:

"I don't think they have adequate knowledge about HIV because there have been situations where I have been asked to speak with my HIV consultant when I raised concerns around my HIV with my GP" *African male, focus group*

"GPs don't have enough knowledge [about HIV] and need to know more." *Age+ focus group participant - echoed by all other participants.*



Themes



6.1 GP knowledge about HIV

It was encouraging that so many people had told their GP and that 78% felt confident discussing HIV with their GP, but concerning that such a low percentage of respondents surveyed felt confident that their GP had a good knowledge and understanding of HIV.

This could be for multiple reasons, not all of which we could explore in this piece of research. It does highlight the possible need for further research and discussion about why some people feel this way:

"I have to educate them a lot about HIV to be honest, which is fine sometimes, but I expect them to know more and to be interested in finding out more about it themselves" *Survey respondent*

This was a commonly expressed view, with a significant number of people expressing frustrations about their perceived need to be the 'educators' of their GP about HIV and the realities of living with HIV.

"My GP admits that their knowledge of HIV is not 'expert'."

Survey respondent

"HIV doesn't actually form a huge part of the GP education syllabus."

GP, roundtable discussion

In contrast, there were people who reported very positive experiences with their GP.

"My GP admits that their knowledge of HIV is not 'expert'. We discuss treatments and possibilities together. If I feel there are questions my GP and I cannot answer together I consult my HIV team. I felt that this joined up approach has served me well"

Survey respondent

This is an example of how healthcare should work. GPs are not specialists in HIV and it is unrealistic to expect them to have a comprehensive understanding of HIV and HIV treatment.

Not every health issue presented to a GP by someone living with HIV relates to HIV and so there is a clear need for GPs to have confidence diagnosing and treating health issues that are outside of HIV clinics, this includes prescribing medication.

This stands out as being particularly important considering the ageing cohort of people living with HIV and the added physical, and often mental, health needs of this population.

A recent report on care co-ordination, published by the National Aids Trust (NAT) and with which George House Trust collaborated, noted that "as people living with HIV age, they are more likely to have multiple health conditions (comorbidities) as well as increased psychosocial needs. Some may also have difficulties with capacity for self-care and decision-making" (National AIDS Trust 'Improving care for people ageing with HIV in Greater Manchester, June 2021).

"Every GP will be different – HIV doesn't actually form a huge part of the GP education syllabus. There are thousands of areas of medicine, many of which will not be examined. In this country, the diagnosis of HIV by a GP is relatively rare compared to other countries where it is a lot more prevalent" *GP, roundtable discussion*

This GP also made the important point that primary healthcare should be considered as more than just GPs. Primary healthcare is delivered by a practice team and includes practice nurses, healthcare assistants and administrative staff.

A further point for consideration is that the way primary healthcare is delivered is also changing, with a move to providing more services online and over the phone. This will potentially change how people living with HIV engage with and experience the primary healthcare system.

6.2

Medication Prescribing

"Despite me telling my GP that they should always check if any medication interacts with my HIV meds, I have on 2 occasions been prescribed medications which had a negative impact on my health."

Survey respondent

At the end of the online survey, participants were given an opportunity to provide narrative feedback about their experiences when accessing primary healthcare.

The most common issue discussed, in negative terms predominantly, was medication prescribing by GPs and the potential for contraindications due to a lack of knowledge on the part of the GP:

"Despite me telling my GP that they should always check if any medication interacts with my HIV meds, I have on 2 occasions been prescribed medications which had a negative impact on my health i.e. – I was prescribed statins which did not help in lowering my cholesterol until the HIV consultant picked it up" *Survey respondent*

This concern was also consistently raised in the focus groups, with participants bringing it up in each of the groups. Some worrying examples of possible negative consequences to health were cited:

"Their knowledge of HIV is minimal, and when it comes to HIV medication, they seem to have insufficient knowledge" *Age+ focus group participant*

"I was prescribed a certain drug with contradicted with my HIV treatment and after four months, I was told by my HIV clinic that my HIV medication was not working and when they checked what other medications I was on, the clinic realised I was taking something I shouldn't be" *Female, focus group*

A number of people said that they routinely checked for medication interactions independently, even when they had been advised by their GP to contact their HIV clinic for further guidance.

A significant number of participants reported using the Liverpool Drug Interactions Chart themselves to check for contraindications with GP prescribed medication.

This website - www.hiv-druginteractions.org - was developed by Liverpool University to provide a "clinically useful, reliable, comprehensive, up-to-date, evidence-based drug-drug interaction resource, freely available to healthcare workers, patients and researchers". The tool can be accessed online or via an app that can be downloaded on to a smart phone:

"They still make prescription errors, thank goodness for the Liverpool App!" *Survey respondent*

"He seems uncomfortable talking about this and I had to direct him to the contraindications website at Liverpool University" *Survey respondent*

"GP knew to ask about certain vaccinations and made sure I had received them. Their understanding of where to go for drug interactions was slow – I had to tell them to use the Liverpool University app" *Survey respondent*

"After each appointment with my HIV consultant, I am often told that a letter would be sent to my GP."

African male, focus group

6.3

Who is Responsible?

Some people indicated that they didn't feel that it was clear who was responsible for their general healthcare. There was a strong feeling that some GPs appeared to lack confidence treating general health conditions which had no clear link to HIV.

A number of respondents said that they were told by their HIV clinic to see their GP about a non-HIV related health issue, only to be referred back to their HIV clinic again by the GP.


This "to-ing and fro-ing" potentially creates concerning delays in receiving timely treatment and reduces peoples' confidence when accessing primary healthcare:

"No matter what I go to see my GP about, it's almost always the same response and they always ask if I've spoken to my HIV Consultant... I'm sure an ingrowing toenail would get this response" *Survey respondent*

Conversely, there were some very good examples cited of "joined up" work between HIV clinics and GPs:

"After each appointment with my HIV consultant, I am often told that a letter would be sent to my GP informing them of what was discussed. That makes me feel that the communication is efficient" *African male, focus group*

It is also worth noting that, historically, many people living with HIV had more, if not all, of their healthcare needs addressed by their HIV clinic than is the case now and were able to be prescribed medication for 'general' health conditions by their HIV Consultant.



"He feels that every GP falls short when compared to what was referred to as "the old way of doing things". "

LGBT male, reported by focus group facilitator

There was less reliance on primary healthcare at that time, with many people reporting little or no engagement with their GP until relatively recently:

"Another attendee was diagnosed in 1988 and really enjoyed the 'wrap around' medical care that was provided by HIV clinics until around 10 years ago. Essentially HIV consultants acted also as primary physicians and were able to prescribe medication for all the patient's health conditions. He feels that every GP falls short when compared to what was referred to as "the old way of doing things" *LGBT male, reported by focus group facilitator*

It is clearly essential that the healthcare needs of people living with HIV are addressed in a timely fashion, especially considering the comparatively high rates of comorbidities experienced amongst people living with HIV.

There was a strong feeling amongst people consulted that all GPs need to have a clear understanding of what their healthcare responsibilities are and that people living with HIV should be able to feel confident that, when accessing primary healthcare, GPs will be able, and confident, to treat them for the presenting health issue without needing to refer back to their HIV clinic.

The fact that GPs are able to contact HIV clinics relatively easily for guidance when needed was discussed at the round table session and there was a clear agreement amongst participants that this should not be the responsibility of the patient, as was experienced by one respondent.

Where information has been shared between a HIV clinic and GP surgery (an option offered to people accessing HIV clinics) it should not be difficult for a GP to contact the relevant HIV consultant or clinic in situations where a discussion, or advice, would benefit the patient.

6.4 Continuity of Care

Many survey respondents and focus group participants raised the issue of continuity of care and the impact it had on their confidence when seeing their GP, with people reporting often seeing different GPs, or not knowing who their named GP was at the practice they attend:

"Seeing different doctors came up as another reason they are not confident discussing HIV with them, noting that it felt like starting your story again, about your treatment etc" Female participant reported by group facilitator

Whilst this was raised as an issue in relation to GPs, it was also highlighted as an issue at HIV clinics with some people unhappy with the fact that seeing the same HIV Consultant at each appointment was not always guaranteed.

This issue was also highlighted in the previously mentioned NAT study, with the report finding that "many noted the difficulties that come from having no continuity of care at the GP and, for some, at the HIV service. This is especially relevant for recurring issues, which they felt would increase as they got older"

There was discussion about this at the roundtable discussion attended by NHS representatives.

The GP in attendance commented on the ongoing issue of GP retention in the English healthcare system, with an estimated shortfall of 6,000 GPs across the country. This shortfall has an ongoing impact on GP surgeries and is a contributory factor to the perceived lack of continuity of care.

It was noted that this is an area of frustration for many people, not just people living with HIV, and there was recognition that this is unlikely to change in the near future.

Whilst acknowledging these facts, it was clear from the discussions with participants that there was a clear preference for seeing the same GP at each visit in order to ensure an ongoing relationship with one trusted person.

"In my opinion,
I don't think the
communication
between my GP
[and HIV clinic]
is good enough."

African male, focus group

6.5

Information Sharing and Confidentiality

As part of the focus groups, participants were asked if, in their experience, communication between their GP and HIV clinic was good enough and whether they were confident with the way their HIV information was shared.

Across all of the groups, participants lacked confidence in this area.

There was recognition and understanding that information-sharing needed to happen, but people generally stated that the kind of information that was shared was not always appropriate and that there was some inconsistency in the amount of information that was shared.

Participants also reported limited confidence in how information is shared, with a number of people saying that they felt that their HIV information had been shared inappropriately:

"I received a letter from another hospital department about a test I was to do and they mentioned HIV in the letter, and yet the test they were to take had nothing to do with HIV"

Female, focus group

"In my opinion, I don't think the communication between my GP [and my HIV clinic] is good enough. Periodically, I am being asked by my HIV consultant to tell them about other health conditions I have and the medications I am on. I shouldn't be the one to pass this information as there should be a database where all my health records can be accessed"

African male, focus group

Similar research has found a limited understanding of what information is shared and when, especially once it has been included on a patient's general NHS record.

The NAT report, previously mentioned, stated that "people generally do not know what health-related information is shared about them, and who with". This was reflected in the experiences of people who engaged with this work.



"Some people live in the same village as healthcare staff."

GP, roundtable discussion

It is highly likely that a greater understanding, on the part of people living with HIV, of how and why information is shared would help improve peoples' confidence and make people feel more comfortable when accessing primary healthcare. Participants overwhelmingly felt that GPs have a clear responsibility to explain this to their patients.

Some participants raised concerns about confidentiality and, more generally, who can and cannot access information about their HIV status at their practice. One focus group attendee said that her child attended the same school as the daughter of one of the practice nurses at her GP surgery and that this made her feel uncomfortable. This is an area in which the stigmatisation of HIV was evident as a source of some concern amongst participants.

It was recognised that experiences vary based on the location of a persons' GP surgery – with people living in suburban and rural locations more likely to know someone working at their practice compared to people in urban areas:

"George House Trust covers all of Greater Manchester – a GP practice in the gay village in central Manchester, such as The Docs, is very different to one in a small town elsewhere in the region, for example. Some people live in the same village as healthcare staff. It is important that people know that information on the system is confidential – people have access to it but it's worth bearing in mind that they will lose their job if information is disclosed" *GP, roundtable discussion*

"One attendee had no confidence in how information about his status was shared. He believed that 'anyone' could find out about this status and that info is 'in the public domain'" *LGBT male, focus group reported by facilitator*

6.6 Stigma

Examples of stigma in healthcare settings and concerns about stigma did come up in the survey and as part of the focus groups.

Despite the stigma related issues already noted in this report, the majority of responses were positive and most people reported feeling supported by their GP – even if they felt they should be more knowledgeable about HIV.

A few people said that they had experienced discriminatory behaviour, or what they perceived as discriminatory behaviour, when accessing treatment:

“My present GP is fine with everything, but my previous GP practice treated me like an outcast. If I had an appointment, I was deliberately left to the last to be seen, and patients who should have been seen after me were seen first” *Survey respondent*

In one of the focus groups and during the roundtable discussion, two people mentioned being asked about their HIV status before intimate examinations.

Both participants said this made them feel uncomfortable, especially given that the fact that they were living with HIV was on their medical record and was available to the clinician. They also questioned the necessity of the GP needing to know this information before conducting the examination.

It is worth noting that some people, in discussion and in the survey, highlighted quite disturbing instances of discriminatory behaviour from their GP.

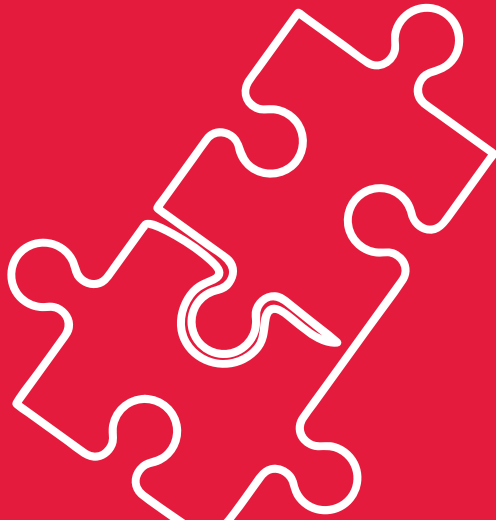
However, further discussion revealed that, in most cases, this had happened a considerable number of years ago and often during the very early days of the epidemic in the UK when knowledge about HIV and HIV transmission was still developing. We have therefore chosen not to include these examples in this report.



“My present GP is fine with everything, but my previous GP treated me like an outcast.”

Survey respondent





Conclusion

Overall, respondents and participants reported generally positive experiences when accessing primary healthcare.

There was a general feeling that clinicians did try to understand the needs of their patients living with HIV. People also recognised that talking about HIV with their GP was beneficial to their overall health and wellbeing.

Some of the issues raised would appear to be a product of an overstretched healthcare system. There were also issues raised that are unique to people living with HIV and need to be addressed.

We were pleasantly surprised that the vast majority of people living with HIV involved in this research have told their GP. As with clinic staff, George House Trust advocates strongly that people living with HIV should talk to their GPs about HIV since this inevitably ensures better health outcomes and better 'joined up' working.

It was disappointing to see that although 78% of people reported feeling confident talking about HIV with their GP, only 52% said they were confident that their GP had the right level of knowledge to enable them to feel confident in their care.

This highlights a clear disconnect between peoples' willingness to talk about HIV and their experiences when doing so. The prescribing of medication was an issue that was raised repeatedly and was the area in which people reported the least confidence when seeing their GP.

Respondents reported feeling frustrated and there were examples of situations where people experienced, or could have experienced, harm.

There are tools that empower people living with HIV, such as the Liverpool Drug Interactions App, but effective use of this requires knowledge of it in the first place, access to information technology and the ability to navigate and understand the information.

We recognise that GPs will not, and should not be expected to have, a detailed knowledge about HIV medication but it is important that, when considering prescribing medication and considering potential contraindications with HIV medication, there is knowledge and understanding about where and how to access up-to-date information.

Some respondents to the survey and participants in the groups said they picked their GP based on the demographic profile of the surgery. For instance, a number of people specifically mentioned attending 'The Docs' in central Manchester because the practice has a high LGBT+ cohort and a significant number of patients who are living with HIV.

People said that they expected HIV care to be better if they knew that the GP practice already had experience of caring for people living with HIV. The veracity of this assumption is beyond the scope of this research, but it would be interesting, in future research, to compare the experiences of people attending different GP practices.

Within this piece of work attempts were made to engage people from varied backgrounds, this was mainly done through the focus groups.

After reviewing the information from the groups, it is not clear that there are themes or issues that are specific to, or more pronounced in, one particular demographic group. All participants were English speaking and therefore, presumably, better able to navigate the English healthcare system.

A reflection for future similar research is to ensure that demographic data is collected at the survey stage.

During the roundtable discussion, the need for clinicians to consider how they talk about HIV, and when, was discussed. What might seem like fairly routine or harmless to a clinician might be viewed differently by a person living with HIV.

It is important to recognise the perceived power dynamic that many people experience when accessing healthcare. The doctor or clinician has access to very sensitive information, which although necessary for the provision of healthcare, can present difficulties for the patient. A number of people living with HIV choose not to speak about HIV outside of a healthcare setting. Their experiences in primary healthcare, therefore, can have a major impact on how they view HIV and by extension themselves.

Recommendations



GP knowledge and understanding about HIV

- **We recommend** a survey of GPs across Greater Manchester to ascertain the precise levels of HIV knowledge and to identify any self-identified gaps in knowledge and understanding
- **We recommend** that there should be an agreed baseline level of HIV knowledge amongst GPs across Greater Manchester.

We also recommend that GPs in Greater Manchester:

- Are made aware of the need to check consistently for potential prescribed medication contraindications with HIV medication and are made aware of, and encouraged to use, the Liverpool Drug Interactions App
- Are made aware of the importance of explaining to patients living with HIV how their information may be shared, which information may be shared, and with whom
- Are made aware of when it may be appropriate to share details of a patient's HIV status and when it may not
- Are made aware of the necessity to treat presenting conditions in people living with HIV and that referral back to the patient's HIV consultant is not, in most cases, necessary or appropriate
- Are encouraged to use the George House Trust Positive Speaker service as a way of learning more about the lived experiences of HIV

People living with HIV

- **We recommend** that people living with HIV continue to be encouraged to discuss HIV status with their GP in order to ensure the best health outcomes
- **We recommend** that people living with HIV are made aware that, if they choose to tell their GP, the information will be widely available to other healthcare professionals in a way that it is not in HIV clinics

These recommendations are made in the full understanding that some of them are very wide in scope.

George House Trust would be happy to be part of any future discussions based on these recommendations and to play an active role in helping to make them a reality.

GEORGE HOUSE⁺ TRUST

HIV POSITIVE LIVING

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