

## Consultation on HIV Care and Support Services – Summary Report

### 1. Introduction

Lambeth Council, in their role as joint sexual health commissioners across Lambeth, Lewisham and Southwark, has undertaken public consultation about proposals to change the pathways for care and support services that are available to people living with HIV. These services are funded jointly by Southwark CCG, Lewisham CCG and Lambeth council. The funding passed to these organisations from Primary Care Trusts in 2013.

The services which are included within the proposals and related consultation are:

- Peer support and mentoring provided by Metro
- Children and Families services for families affected by HIV provided by Metro/Positive Parenting
- First Point (assessment/signposting service) provided by Metro
- Advice and Advocacy provided by the Terrence Higgins Trust
- Counselling provided by the Terrence Higgins Trust

The proposals which are being consulted on are as follows:

- A continuation of the peer support service provided by Metro with the service having a slightly different emphasis/role
- A continuation of the Children and Families services for families affected by HIV provided by Metro/PPC as is
- An enhanced role for the peer support service to support people to access the new pathways and to undertake initial assessments which would lead to the decommissioning of the First Point service being decommissioned
- Providing new pathways for people living with HIV to access counselling via IAPT which would lead to the decommissioning of the Terrence Higgins Trust service
- Providing new pathways for people living with HIV to access advice and advocacy via mainstream advice services which would lead to the decommissioning of the Terrence Higgins Trust service

The consultation has included: a paper/online survey for people living with HIV, including but not limited to those who use the above services; focus groups with service users and others living with HIV; public and service users' events and meetings with all affected providers. Healthwatch in each borough were engaged in the process. The consultation exercise commenced on 9th May 2016 and continued until 28th June 2016.

### 2. Why we conducted the consultation

The proposed changes to these HIV Care and Support services follow the recommendations of the comprehensive 2012 NHS-led review of HIV Care and Support across Lambeth, Southwark and Lewisham. The finding of the review (which included extensive engagement with providers and service users at the time) was that the HIV Care and Support service model (which relied on stand-alone specialist services) was no longer fit for purpose as the natural course of HIV infection had changed radically since the services were set up. The review identified that the success of HIV treatments meant people with HIV were living longer and healthier lives and that HIV was an episodic condition, much like other long term conditions. It determined that people with HIV are best served by ensuring they have better access to mainstream health and social care services rather than being directed down a specialist

pathway for all their health and social care needs. Due to the high prevalence of HIV across LSL, and the treatment advances that enable the majority of people with HIV to live a long and healthy life, the review pointed to the desirability of ensuring mainstream services could meet needs in a way that would serve to further normalise and de-stigmatise HIV. The growth in the numbers of people living with HIV, and the difficult funding environment, provides a further impetus for moving away from relying on a small number of specialist services to meet needs.

### **3. Why were these services established?**

The HIV specialist services for advice and advocacy and for counselling were established when most people living with HIV felt unable to access mainstream services because they feared being treated in a judgmental or discriminatory manner due to the high levels of stigma and ignorance in wider society. Over time, society's level of ignorance and attitudes towards people living with HIV has vastly improved and in places like Lambeth, Lewisham and Southwark – where prevalence is high – service providers and health professionals are much more likely to already be supporting people living with HIV.

The specialist HIV counselling service was also established to support people to deal with being diagnosed with HIV and related issues. While not to be minimised, the psychological impact of a HIV diagnosis has subsided considerably due to the improvements in HIV treatment and the HIV counselling service now meets more generalised mental health needs that are not particularly related to HIV and which typically existed prior to the diagnosis (e.g. anxiety or depression).

The service First Point was established to widen the scope of the assessments undertaken by clinics at the point of HIV diagnosis and to provide support to such patients in identifying appropriate resources that could help to meet their needs. While this remains a need, there are now other ways of achieving the desired outcomes at lower cost.

### **4. Methodology**

#### **How we engaged with service users**

In order to facilitate the engagement of service users, meetings were held with the managers of the services affected by the proposals - Metro, PPC and THT. At these meetings it was agreed how we would work together to enable service users to participate; dates for engagement events were agreed, we discussed how to ensure that the questionnaire would reach people who were unable to get to events and agreed locations for the events. Additionally, a meeting was held with the Clinical Lead at the Harrison Wing to discuss the feasibility of holding an event there too.

Three HIV specific service user events were held, with each provider hosting an event. The events were open to any HIV positive service user from any of the affected providers. Each was slightly different to suit the needs of the host services users. The events were promoted via the providers, local HIV treatment centres and via HIV forums. Information about the service user engagement was sent to Healthwatch in each borough, CCG Patient Involvement staff and communications teams and to some out of borough HIV support services.

The following HIV service user engagement events took place:

- 11<sup>th</sup> May 2016 1-8pm with THT at Lighthouse South London, Waterloo
- 14<sup>th</sup> May 2016 12-5pm with Positive Parenting and Children at Stockwell Community Centre
- 18<sup>th</sup> May 2016 2-8pm with Metro at African Advocacy Foundation, Catford

The attendees at the events reflected the demographic of PLWH. They were mainly African people, gay men and women. The PPC event was mainly women and adolescents from BAME communities. The Metro event at AAF was predominantly older African women and some African MSM. The THT event was more mixed, the majority being people from BAME backgrounds of both genders. The format of the event varied, all events were designed so that people could drop in and chat about the proposals. The Metro event at AAF was run as a large group discussion, after which people completed paper copies of the questionnaire. At Lighthouse South one to one conversations took place with service users while at PPC we used a mixed method of group and one to one conversations.

The Patient Representative at the Harrison Wing actively distributed printed copies of the questionnaires to their patients. A box was placed in the waiting area for patients to put their completed questionnaires into. There was more of a mix of gay men and African people completing the survey at Harrison Wing. A link to the online questionnaire was sent by the providers to their service users, this link was distributed to HIV treatment centres and services, online via council and CCG websites, Healthwatch plus was promoted heavily by HIV activists via social media and HIV forums, such as UK CAB. In addition to the HIV service specific events the public health consultation events held at the Karibu Centre (organised by Healthwatch Lambeth) and Mary Seacole Centre people were able to engage with the HIV consultation as part of the wider public health consultation.

### **How we engaged with stakeholders**

A generic email account for public health commissioning was publicised within all consultation materials through which stakeholders could contact the team to give their views in addition to the online survey. In addition some letters were sent directly to Lambeth Council, Southwark CCG and Lewisham CCG. This was especially useful for stakeholder organisations and democratic representatives. A total of 14 letters or written queries were received, including from:

- Vicky Foxcroft – MP for Lewisham Deptford
- Helen Hayes – MP for Dulwich and West Norwood
- Kate Hooey – MP for Vauxhall
- Chuka Umunna – MP for Streatham
- Andrew Gwynne – MP for Denton and Reddish
- Deborah Gold - Chief Executive of the National AIDS Trust
- Ian Green - Chief Executive of the Terrence Higgins Trust
- David Noakes - Opposition lead for Health, Southwark Council

We answered written parliamentary questions put to the Secretary of State for Health by Andrew Gwynne MP. All correspondents were provided with individual written responses to the issues they raised.

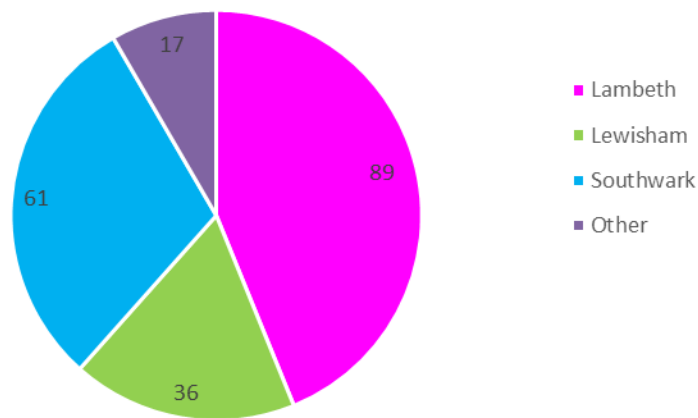
Meetings were held with key stakeholders, including the current provider organisations and those within the new pathways.

The consultation was mentioned on several news and current affairs television programmes. Articles about the proposals, with many including links to the survey, appeared in places including The Daily Mail, Nursing Times, The Voice website, Southwark News, the Brixton Blog, Gay Times online, Attitude online, the ITV News website and the Health Service Journal.

### **5. Who took part?**

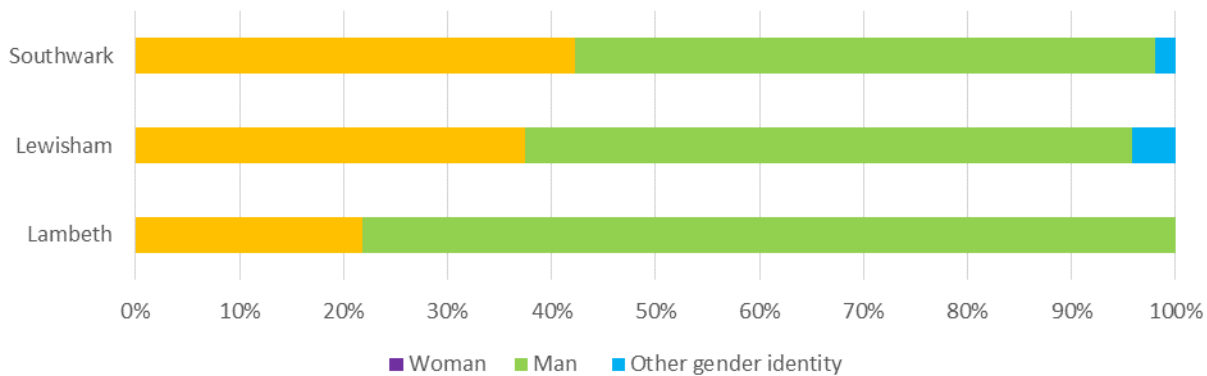
By the close of the consultation, 203 surveys had been completed. The largest group of respondents identified themselves as living in Lambeth (44%) followed by Southwark (30%) and Lewisham (18%). The remaining 8% of respondents identified themselves as living outside of LSL.

### Residence of respondents



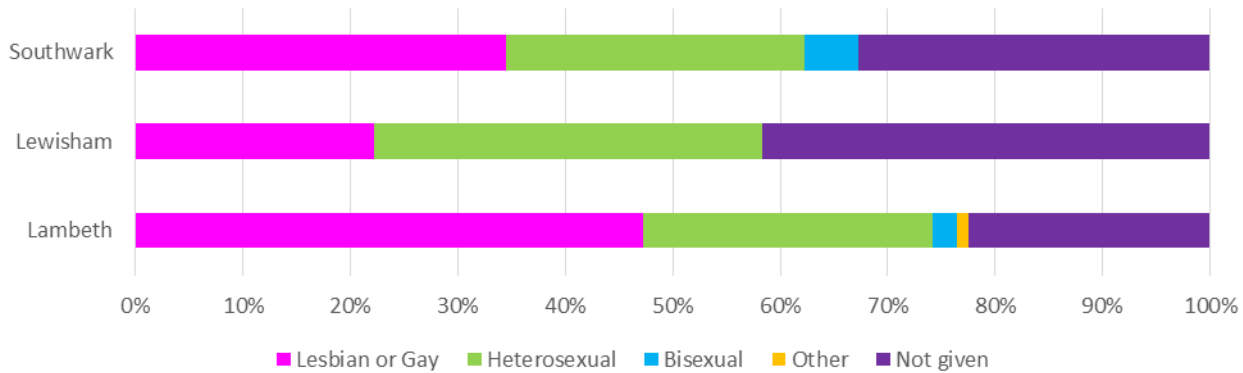
The gender identity options invited trans-gender people to identify as male or female, an additional category “other gender identity” was also available and was chosen by 3 persons. Respondents overall were more likely to be male (68%) than female (31%) although the proportions varied at borough level e.g. respondents from Lambeth were the most likely to identify as male while those from Southwark were the most likely to identify as female.

### Gender of respondents



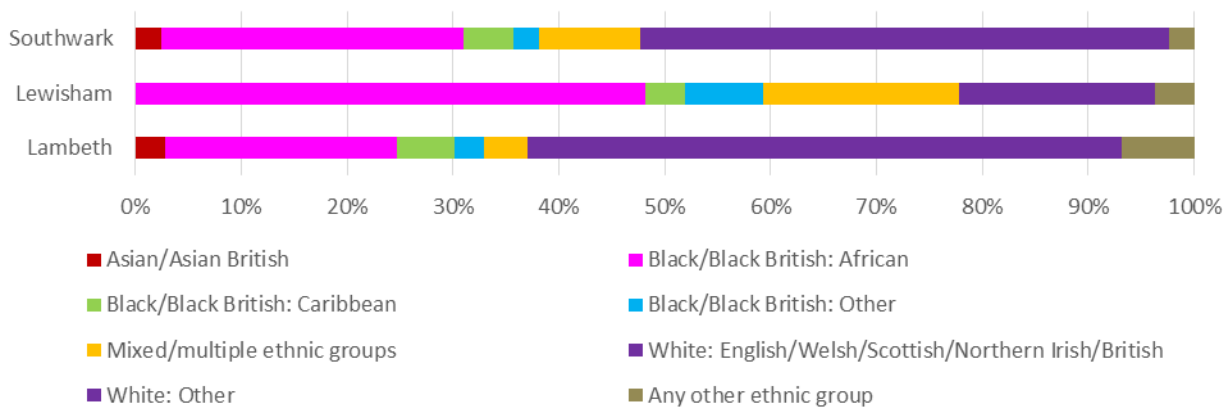
The largest single sexual orientation group that respondents identified with was Lesbian or Gay (38%). Of the 78 respondents identifying as Lesbian or Gay, only 4 of them identified as female. In addition to being more likely to be male, Lambeth respondents were the most likely to identify as lesbian or gay whilst Lewisham respondents were the most likely to identify as heterosexual. Lewisham respondents were also the most likely to not answer the question (42%).

### Sexual orientation of respondents



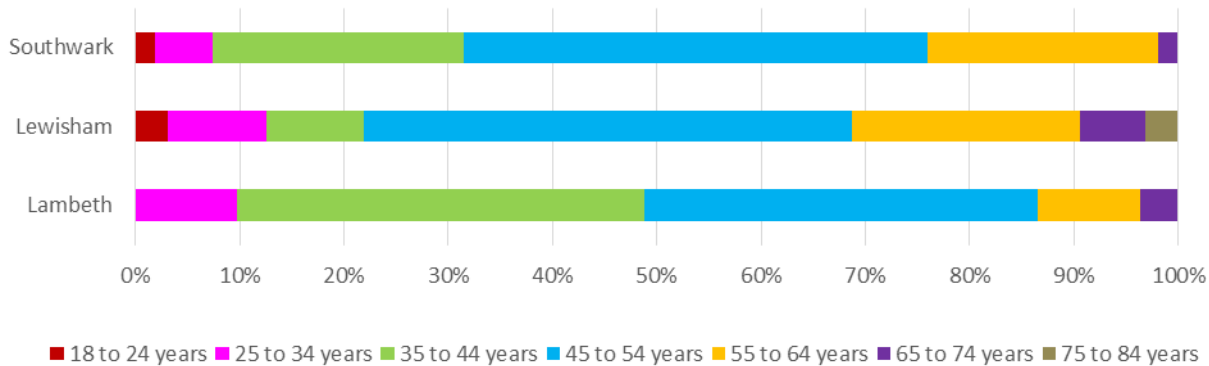
Respondents from Lewisham were the most likely to identify as Black African whereas those from Southwark were the most likely to identify as white English. Lambeth respondents represented the broadest range of ethnic diversity and also had the largest group identifying as “white other” - this includes the Portuguese and Latin American communities.

### Ethnicity of respondents



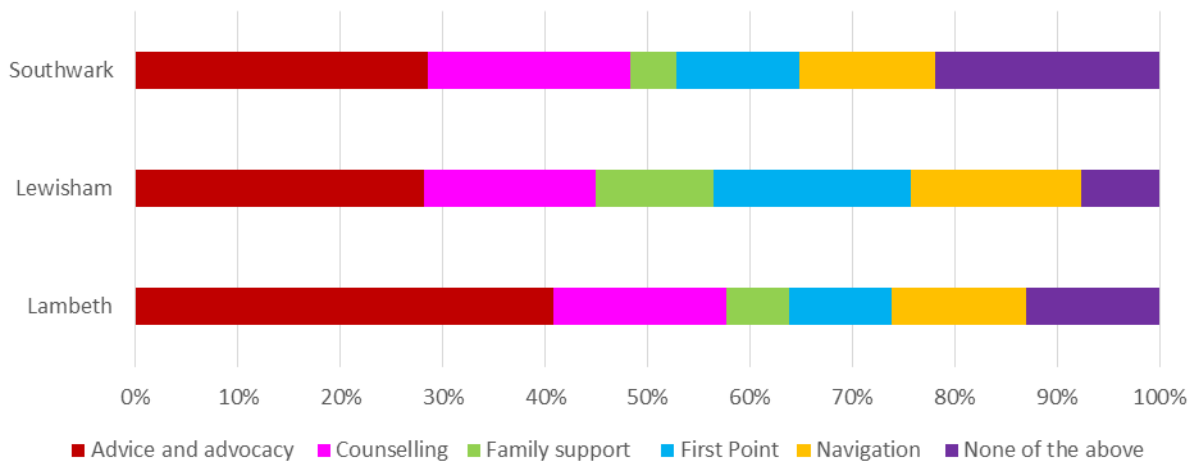
More than half of all respondents across LSL identified as being over 45 years of age. The age profile of respondents also differed at borough level, those from Lewisham were most likely to be older whereas Lambeth respondents were most likely to be younger.

### Age of respondents



The usage of current services again showed borough level variation, with usage of advice services much higher among Lambeth respondents. Lewisham respondents were most likely to use the children and families service, the signposting and the peer support services. Southwark respondents were the most likely to use the counselling service.

### Current service usage



## 6. What was said

There were a clear recurrent themes that came from the consultation, these were conveyed through the events with HIV affected people, stakeholder meetings, individual letters and the survey responses. A selection of comments, from the online surveys on these themes, are presented below to illustrate the issues that they raised:

**Confidentiality:** some service users had concerns about the ability of non-HIV services to be able to maintain confidentiality. This was often expressed as a result of previous experiences and inappropriate disclosure of their HIV status.

*“Having used and volunteered at other advice centres, I know that confidentiality and empathy are not offered. PLWHIV need these to be in place when seeking support as the social stigma around HIV continues.*

*“Feel comfortable coming to HIV service, feel like coming to family as don’t need to explain story. Confidentiality is a big issue using mainstream services”*

*“Counselling is supposed to be a confidential service anyway. As a qualified therapist I would expect providers of talking therapies to already be in a position to reassure PLHIV on this point, if they’re exercising their duties in line with the guidelines from their existing professional bodies.”*

**Stigma and discrimination:** there is still considerable stigma associated with HIV, and sexuality, this impacts on the ability of some people to be feel safe using mainstream services.

*“I am still worried about the stigma and discrimination. Some people are still unable to treat PLWHIV as human beings”*

*“The problem with HIV is stigma and shame. That’s what makes it different to other long term conditions. The HIV specific counsellors understand that like no other.”*

*“I am worried about revealing to the citizen’s advice bureau that I have HIV. There is still a lot of stigma and discrimination. Do you understand what it means to have HIV and people are treating you differently as if you are dirty? How many of you have HIV? Please, please, don’t cut our services.”*

*“Lots of staff, while being employed by Southwark have their own religious or cultural views that in my opinion make it incompatible with providing unbiased, supportive and nuanced HIV and gay advocacy.”*

**Competency:** there was a prevailing view that mainstream HIV services were not competent and did not have enough knowledge about the condition, and the communities it affects, to be able to provide services for PLWH

*“These other services lack the cultural competence and HIV awareness to work with the HIV+ community. They would training from Metro or Positive Parenting Group to ensure they are culturally competent.”*

**Convenience:** some respondents found the current points of access for the specialist services suited their convenience or they had grown used to using that service in that location and did not want to experience the inconvenience that might be caused by the proposals:

*“I want to move to Kennington or Waterloo to be close to my treatment and social issues. Transport is very difficult so I’m lonely and can’t visit or even go to pubs. Buses are difficult to come to my house after 11:30pm. So am literally on my own.”*

*“I have been with the same counsellor for 3 years and I feel confident in them and I would not want to start again from the beginning with a new counsellor. My counsellor knows my background and we have worked and overcome many issues that I would not want to do again with another counselling service.”!*

*“I have never experienced the same level of help and consistency with other forms of services, than I have experienced with organisations like THT. I am sure the people who work within these other services as dedicated and possess empathy, but with THT I found that having access to all possible assistance under one roof and in one building, made my personal situation so much easier for them to assist and for me to feel that I was properly taken care of.”*

**Pace of change:** Concerns about the pace of change came via stakeholder meetings and letters rather than through the online survey. This was tied to concerns about the readiness of mainstream services



to accommodate the activity and be sensitive to the client group. These concerns were also expressed in the absence of the transition plans that have now been drafted.

*“There is a telling lack of detail in the proposals provided. There is also no consideration of a phased approach to any transition – the proposal is a sudden end, with ill-equipped mainstream services expected to pick up the pieces from October.”*

**Counterviews:** While many comments were negative about changes that resulted in services being decommissioned, some respondents were less pessimistic and even optimistic- particularly in light of the proposal to maintain and build upon the HIV specialist peer support service:

*“Excellent attempt to stop replicating services”*

*“With the support of AAF and all the peer supports we can overcome them. AAF don't discriminate they treat equal rights”*

*“Whilst much has changed for PLHIV, HIV stigma remains high and a barrier to accessing services. While general advice services may provide adequate services an HIV specific entry point to accessing services is essential even if the service user is then handed over to borough based services.”*

*“I think there is a lack of fairness, with historical tendency to provide very "wraparound" services that are not available to other people living with chronic illness. As a GP I think this should be evened out .E.g. having specialist mental health services seems unnecessary, and actually PLHIV may get a less specialist appropriate service, depending on their need, because an HIV mental health worker won't be able to provide all the different therapies available to general mental health patients.”*

*“What does this [advice service] do? Is it value for money? How many access it anyway? Is it showing outcomes? SCRAP it and reinvest in PrEP and prevention and education”.*

All respondents were invited to offer their ideas for ensuring the new pathways worked:

*“I need to know for sure that they are HIV friendly and understand the complex issues I face. It would be good if there was a campaign and every service had posters up saying there is HIV in our communities and we respect people living with HIV and we are committed to be welcoming and not judgmental. As it is HIV is still pretty invisible, hidden and surrounded by shame and stigma, it will not just magically go away unless it is directly address it with education, campaigns, and visibility.”*

*“My ideas are to make sure the service provider who are going to deliver the service to work close to community and organisation which support PLHIV. My concerns luck of trust, confidentiality, knowledge and stigmatization attached to PLHIV. I have experience at job centre and housing so I don't want someone to go through what I went .It was painfully humiliate and more stressfully.”*

*“It will be necessary to ensure that staff in other centres understand and respect the confidentiality issues for PLHIV and are provided with appropriate training.”*

*“They would need to have HIV specialist workers within their teams. They would need to be trained to so that I not considered special or exotic. They will need to undertake casework and advocacy and not just be an advice only service.”*

*“A liaison person perhaps, by which I mean someone who is a dedicated first contact at each site who understands the issues and can support PLHIV on their initial visit, and subsequently too if necessary.”*



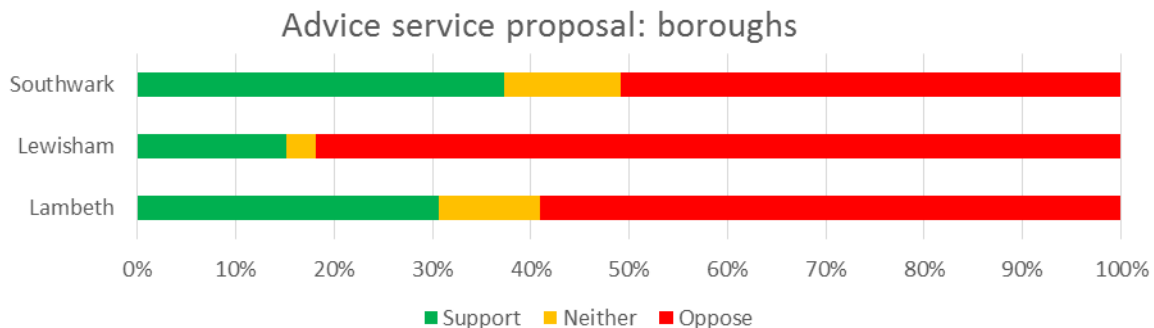
*“The counselling services would need to overtly promote their inclusivity of PLHIV and MSM / BME populations as these are sometimes a barrier to accessing services. The services would need to be seen as welcoming to such client groups”*

*“Nothing except knowing that the services are understanding of the needs of HIV positive patients - but why shouldn't they be in this day of age”*

## 7. Lambeth’s feedback on specific proposals

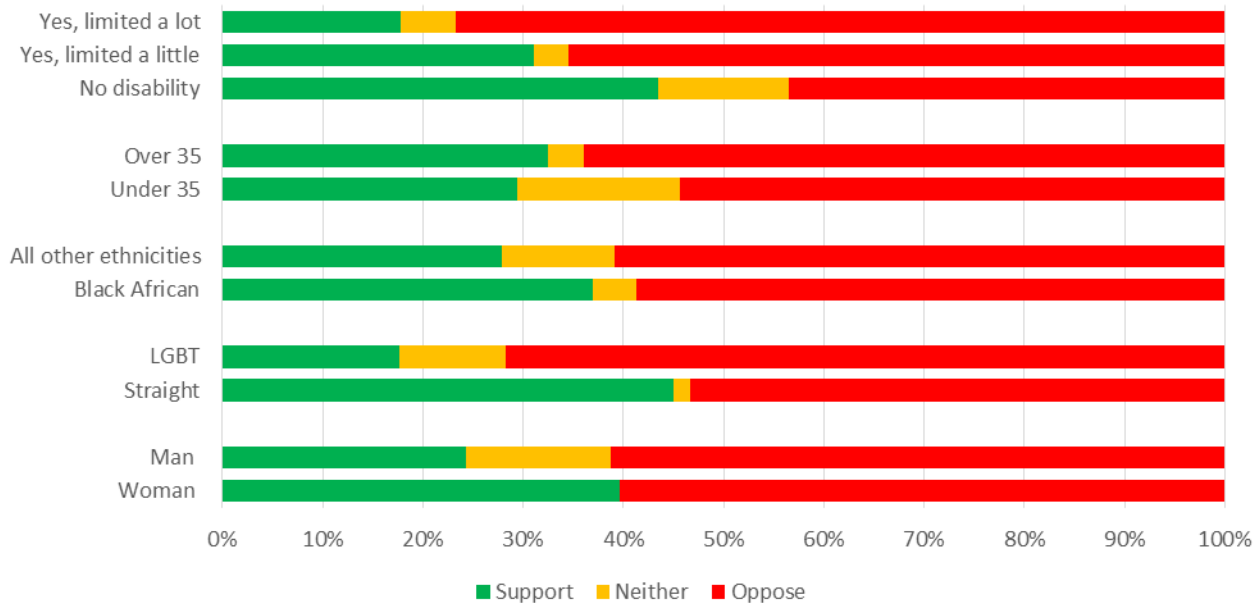
### Advice and advocacy

We proposed that in the future PLWH would access advice and advocacy services from the specialist borough based services (eg: Law Centres, CABs, specialist advice agencies like Every Pound Counts) rather than through an HIV specialist advice service. A majority (60%) of respondents overall opposed the proposal to decommission the HIV specialist advice service with a significant minority (30%) supporting this proposal, the remaining 10% were unsure. Opposition was strongest among Lewisham respondents and weakest among those from Southwark.



Analysis of all responses by protected characteristics shows that opposition was greatest among people who said they had a disability that limited their day to day functioning a lot and among Lesbian and Gay people. Heterosexuals were the group most likely to support the proposal followed by respondents who did not identify as having a disability and then by women – although they were no more likely to oppose it. Younger people were more likely to be unsure, whereas women were least likely to be unsure.

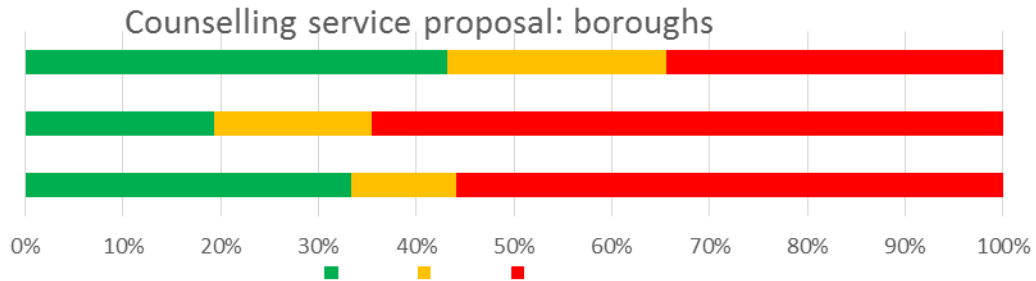
### Advice service proposal: equalities



*We will work with treatment centres and current HIV service providers to ensure that service users know where and how to access borough based services. We will also undertake work with the specialist borough based services to ensure that they are able to reassure PLWH that they are welcoming and competent to provide services for them. We will provide non-recurrent funds to support this. We will ask the peer support service to: support service users in applications for charitable funds, to support service users in identifying and accessing the most appropriate mainstream service. We will provide non-recurrent funds to support this if needed.*

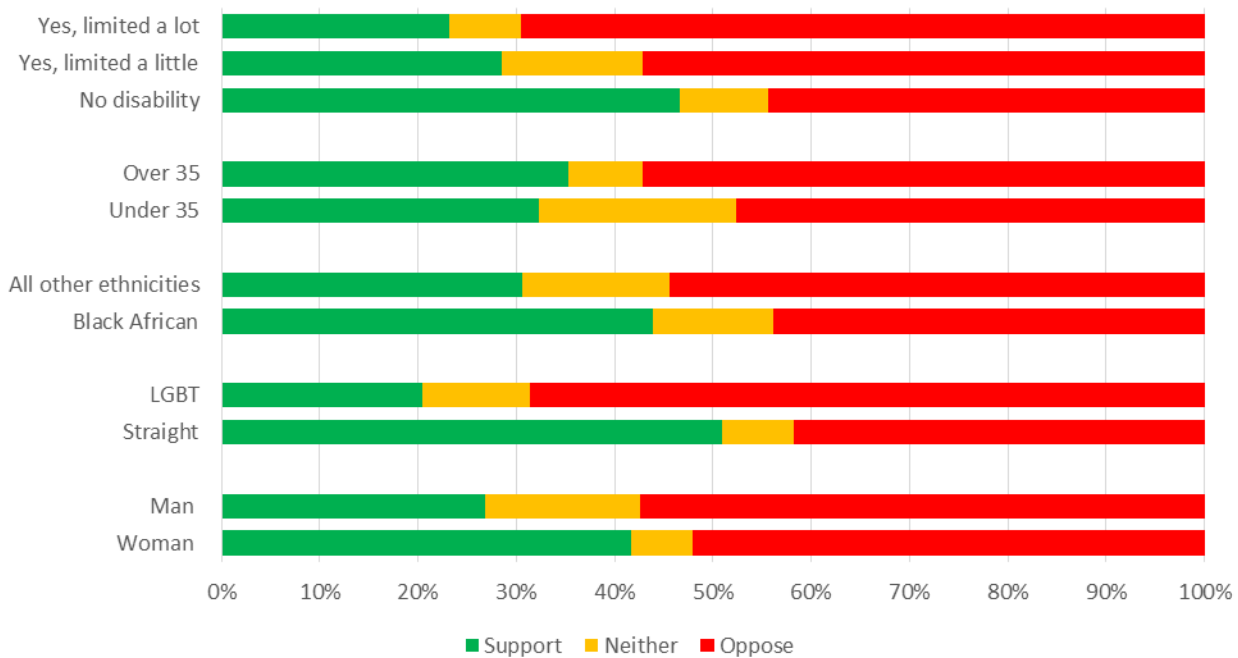
#### Counselling

The proposal was that PLWH would access counselling through their local talking therapies service in place of the specialist HIV counselling service that exists now. Talking therapies are available at many sites across the boroughs and people can self-refer if they do not wish to speak with their GP. People with ongoing mental health needs will continue to be supported through community mental health teams while people with urgent HIV related need e.g. due to a complex HIV diagnoses will be seen by the CASCAID service at South London and Maudsley. A slight majority (52%) of respondents overall opposed the proposal to decommission the HIV specialist counselling service with a significant minority (34%) supporting this proposal, the remaining 14% were unsure. Opposition was strongest again among Lewisham respondents and weakest among those from Southwark where more respondents supported the proposal than did oppose it.



Analysis of all responses by protected characteristics shows that opposition was greatest among people who said they had a disability that limited their day to day functioning a lot and among Lesbian and Gay people. Respondents who identified themselves as not having a disability were the group most likely to support the proposal followed by respondents who identified as heterosexual. Uncertainty was lower among women and among older people.

Counselling service proposal: equalities



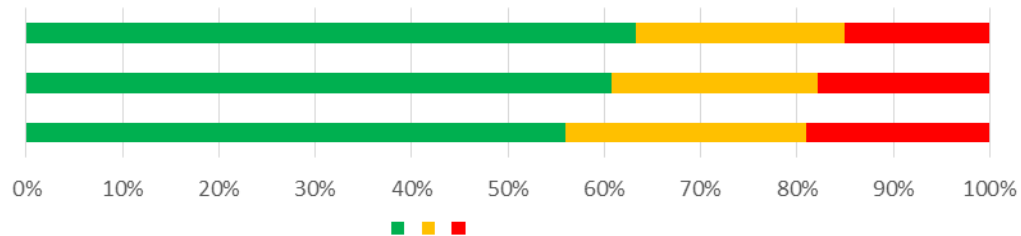
*We will work with the borough/CCG based talking therapies service to ensure that they are able to reassure those service users who have concerns about disclosing their HIV status or information about their lifestyle to make sure they are welcoming and competent in providing services for PLWH. We will ask the peer support service to consider running a support group for people with ongoing mental health need or are waiting for talking therapies.*

Family Support

One HIV service provider is funded to provide social care to families affected by HIV. This typically complements input from children’s social care who are also usually involved, often for child protection concerns. They also provide support to adolescents transitioning to adult services. No changes were

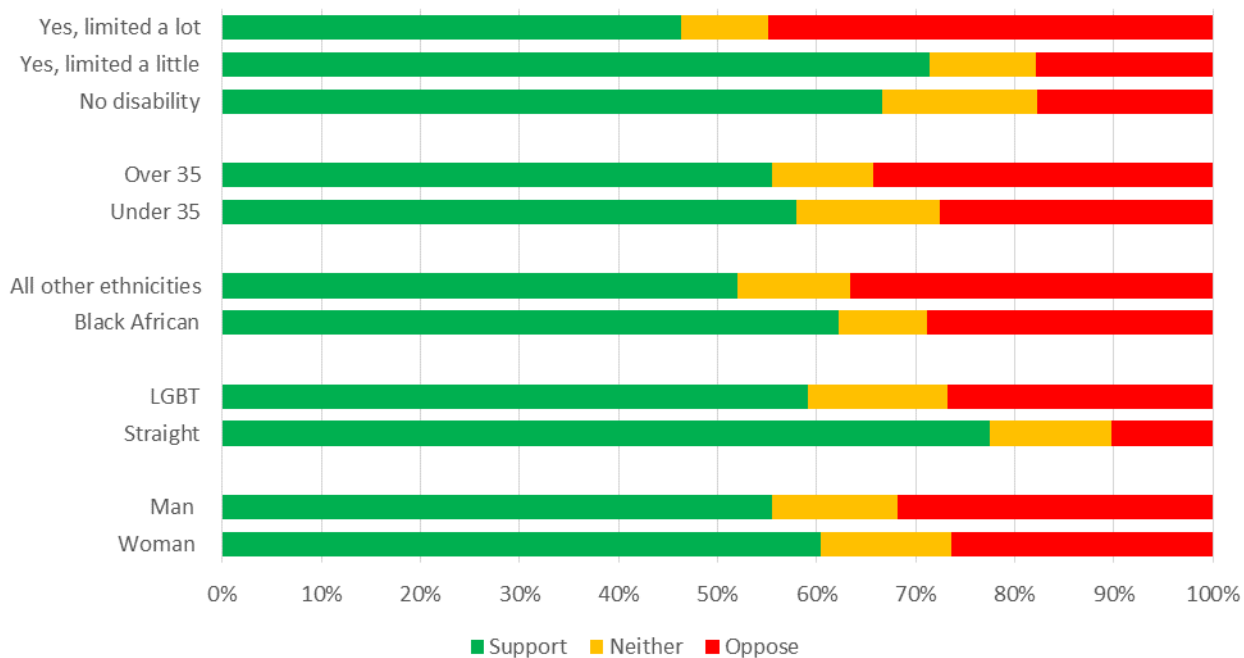
proposed in this area as no alternative provision had been identified. A majority (59%) of respondents overall supported the proposal to maintain the HIV specialist social care service for children and families with a small minority (17%) opposing this proposal, the remaining 24% were unsure. A majority of respondents in all 3 boroughs supported this proposal, it was strongest among Southwark respondents and weakest among those from Lambeth.

Children and families' service proposal: boroughs



Support for this proposal was highest among the heterosexual group and exceeded 50% for all groups with the exception of respondents who identified as having a greater degree of disability.

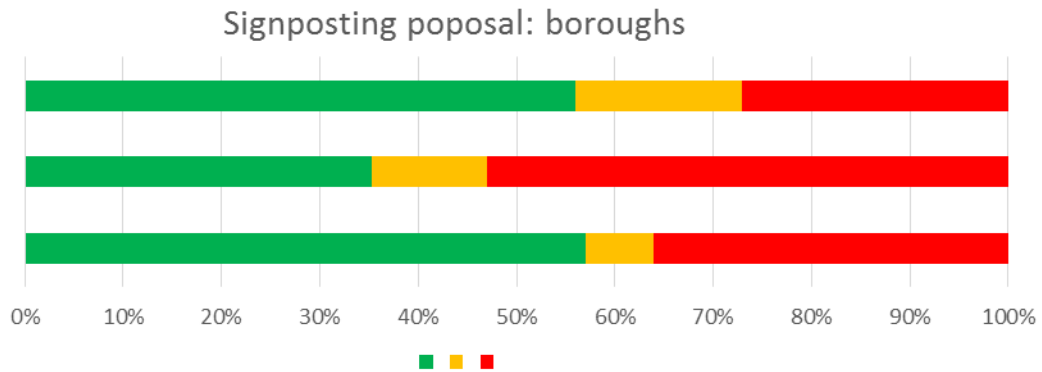
Children & families service proposal: equalities



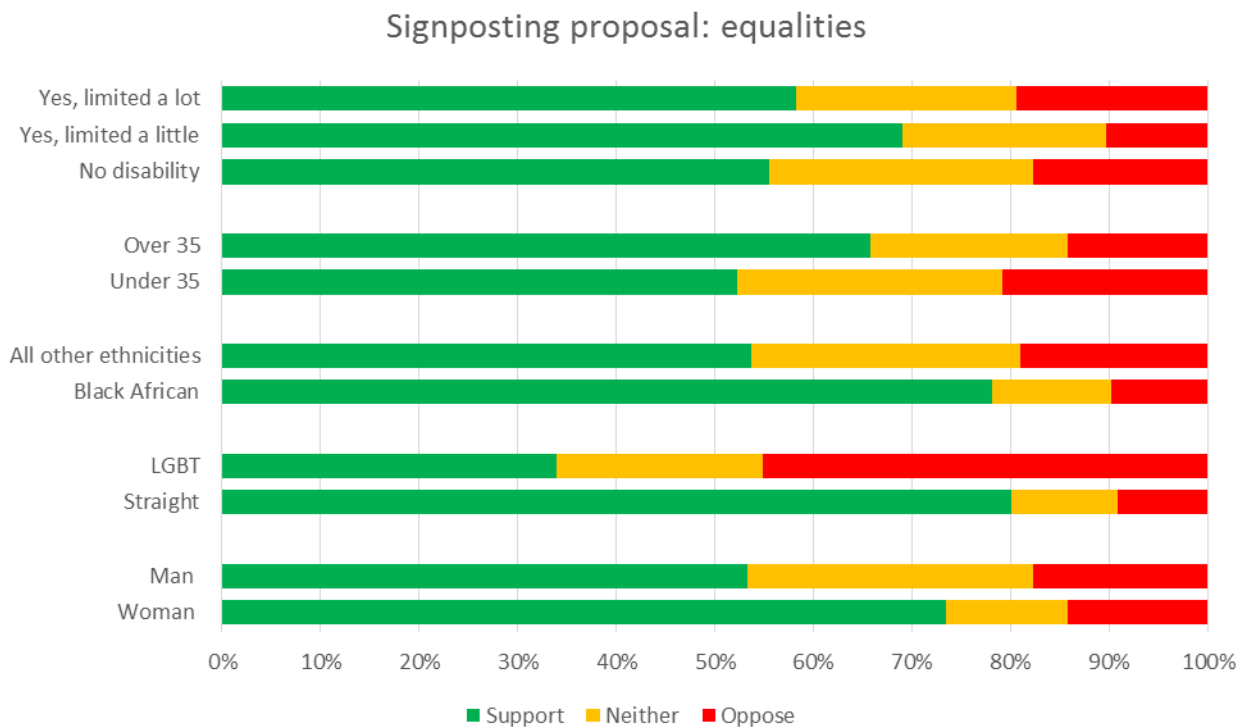
Signposting (First Point)

The proposal was to work with HIV treatment centres so that all newly diagnosed patients are offered referral to peer support and that the treatment centres have access to the range of service information that First Point provided.

A majority (54%) of respondents overall supported the proposal to decommission the HIV specialist signposting service with a significant minority (35%) opposing this proposal, the remaining 11% were unsure. A majority opposing the proposal was only seen among Lewisham respondents.



Analysis of all responses by protected characteristics shows that support was greatest among heterosexual people, Black African people and women. A majority opposing the proposal was only seen among gay (male) people.

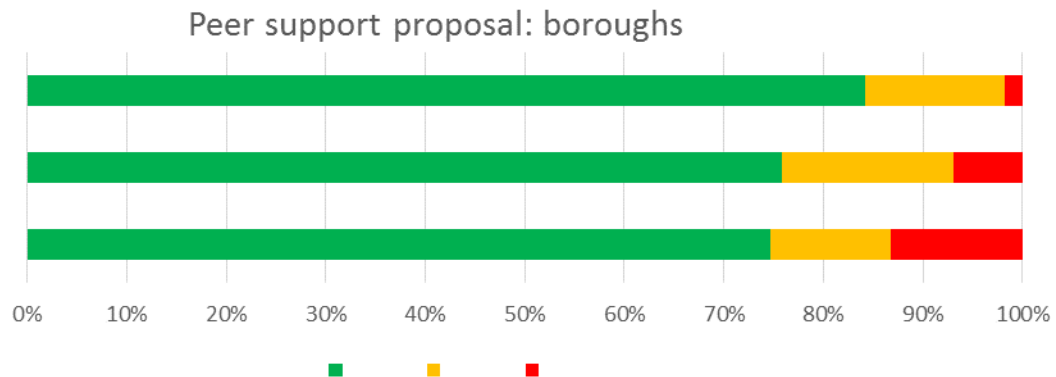


*We will ask the peer support service to further strengthen their links with the HIV treatment centres and help ensure that potential service users are provided with information on what is available them and the assistance, which includes 1-2-1 mentoring, they can access from the peer support service.*

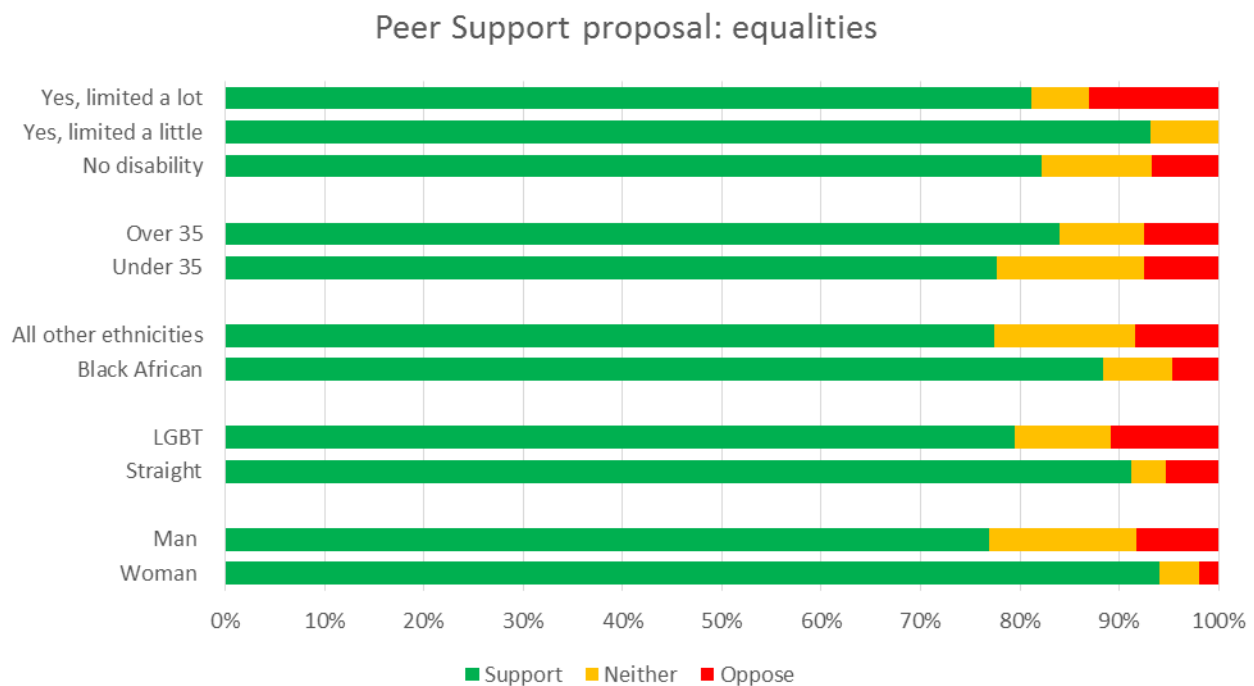
Peer Support

We proposed to maintain the HIV peer support service and to work with them on how they might assist service users with accessing services as a result of any of these proposals.

A majority (59%) of respondents overall supported the proposal to maintain the HIV specialist peer support service with a small minority (8%) opposing this proposal, the remaining 12% were unsure. This was the least contentious of all the proposals we made. A majority of respondents in all 3 boroughs supported this proposal, it was strongest among Southwark respondents and weakest among those from Lambeth.



Analysis of all responses by protected characteristics shows that support was greatest among women, people who identified as having a disability that limited their daily functioning a little and Black African people.



## 8. Equalities

Differences in support for the individual proposals largely reflected patterns of service usage by different groups:

- Men and women both recorded their lowest levels of support for the proposals to decommission the advice and counselling service although support for the proposal to decommission them was lower for men than women. Partly due to the high proportion of male respondents that were also

gay, lower support for the proposals to decommission the advice and counselling service were also seen among lesbian and gay people compared with heterosexuals.

- Black African respondents were more likely to support all the proposals, including the ones that concerned decommissioning existing providers, when compared with other ethnicities. This group registered especially high levels of support for decommissioning the Navigation (First Point Service) when compared with other ethnicities.
- The proposal to maintain the service for children and families saw the largest difference in levels of support between younger and older people, the latter group being more likely to support maintaining the service.
- People who identified themselves as having a disability which limited their daily functioning a lot showed the greatest degree of concern at our proposal to decommission services and this was especially related to the proposal about the advice and counselling services.

We will talk to commissioners of support for people with disabilities about the relatively high degree of concern about the availability of support for people with HIV who are significantly affected by disability. We will work with THT to help organise training on HIV for staff in care homes for older people.

## 9. Conclusions

The consultation exercise engaged a large number of people across Lambeth, Southwark and Lewisham: respondents broadly reflected the epidemiology of HIV in South East London and this in turn was reflected in service usage patterns and the difference in feedback they provided when analysed at a borough/CCG footprint. Unsurprisingly, our proposals to maintain some specialist HIV services, Peer Support and Children & Families, received the greatest support. Where we proposed decommissioning a specialist HIV service provider, the majority of respondents opposed the proposal, with the exception of the First Point service where an overall majority supported the proposal to decommission this service. Opposition to the proposals to decommission services was greatest among Lewisham residents and greatest among people with a more significant degree of disability. Support for the proposals overall was greatest among Southwark residents and among Black African people.

Opposition was largely associated with concerns about the sensitivity of mainstream services to deal with HIV and the communities that are most affected by it. Respondents identified training for staff as a mitigation against this risk combined with communication to affected communities that the mainstream services are able to meet their needs whilst respecting their dignity. Other suggestions for a liaison type function in mainstream service, as a transition measure, would help PLWH to feel more confident about using those services. The importance of communicating the new pathways and service model was highlighted repeatedly through various channels.

While a majority of respondents overall opposed the proposal to decommission the advice and counselling services, a significant minority in both cases supported the proposal. Opposition to these two specific proposals was more likely to come from gay men who still perceived mainstream alternatives as being discriminatory or judgmental about their sexuality. This perception, if more widely held by gay and bisexual men, needs to be addressed from an equalities perspective on mental health but also from the perspective of HIV prevention. Since the 2012 review, South London and Maudsley have independently undertaken work with Metro on sexual orientation ([The Four in Ten project](#)) and such initiatives should continue to receive board level support at the Trust.

Maintaining investment in HIV prevention interventions that seek to address HIV stigma within the most affected communities is shown, by this exercise, to be an important investment that will help to reduce the need for PLWH to draw upon external support agencies in the longer term.



The high approval rating for the Peer Support service was also evidenced through the suggestions for how it could be augmented to extend its scope and reach in light of the changes to others services.

We are grateful to the individuals and agencies that provided their time and their views to this consultation exercise, the findings provide rich data to inform commissioning decisions about the future service model for HIV care across Lambeth, Southwark and Lewisham and the steps that can be taken to mitigate the risk of any negative impact.



Maria Millwood  
26 August 2016