Update on Lambeth, Southwark & Lewisham's HIV Care & Support Redesign

1. Summary

- 1.1 This paper provides an update on the proposals, and related consultation, to redesign care and support pathways for people living with in Lambeth, Southwark and Lewisham (LSL) which is being led by Lambeth Council, on the behalf of all 3 CCGs.
- 1.2 Prior to Public Health transition from Primary Care Trusts to Local Authorities in 2013/14, a comprehensive service review of HIV care and support services was undertaken by LSL Sexual Health Commissioners (hosted by Lambeth PCT) with support from specialist Public Health colleagues. The findings suggested that the specialist service model was no longer fit for purpose as the natural course of HIV infection had changed so radically since the services were set up. In view of this, the recommendations of the review were to start to mainstream HIV care and support services as part of long term condition management. Many of the recommended service changes have already happened.
- 1.3 As a final component of this work, there are proposed service changes to locally commissioned HIV Care and Support Services, this includes the intention to decommission the Terrence Higgins Trust (THT) advice and advocacy service, the THT counselling service and the Metro First Point signposting service. Some specialist services will remain, including peer support, and non-statutory specialist HIV social work services for families with children that are affected by HIV.
- 1.4 To date, the LSL sexual health commissioning team have carried out targeted user and stakeholder consultation on these final proposals. The consultation closed on 29th June, analysis of the consultation findings are in progress, following which final recommendations will be considered by each commissioning body for decision in August. In Southwark, this is the CCG as they are the funders of the services.
- 1.5 The original review and associated consultation first came to the committee in 2011, and following public consultation in 2012.

2. Purpose

2.1 The purpose of this report is to update the Committee on the final stages of the implementation of the HIV Care and Support review and emerging findings from the consultation.

3. Recommendations

- 3.1 The committee is asked:
 - To note proposals for redesign and the consultation that has been undertaken to date, led by Lambeth's commissioning team, on behalf of Southwark and Lewisham CCGs
 - To note the extension of that consultation period for one month to enable further engagement to be undertaken
 - To note the emerging findings from the initial consultation analysis
 - To highlight any issues not addressed in the paper for consideration by Southwark CCG in reaching their decision to implement the changes outlined below following the consultation process.

4. Policy context

4.1 This paper supports the approach of the Southwark Health and Wellbeing Strategy 2015–2020 in reducing inequalities through a live process of engagement and development. It supports delivery of the strategy's priority for addressing long term conditions, including self-management and support. The proposals were also set out within the LSL Sexual Health Strategy 2014-2017 which Southwark council is a party to.

5. Background

- 5.1 Lambeth Council Public Health Commissioning team undertakes the strategic commissioning of all HIV prevention, HIV care and support and sexual health services across Lambeth, Southwark and Lewisham. This includes the following services for which the CCG is the responsible commissioner:
 - HIV care and support delivered by voluntary and community sector organisations, currently Terrence Higgins Trust, Metro and Positive Parenting and Children
 - HIV care and support mental health services delivered by SLaM NHS Trust
 - HIV care and support neuro-cognitive in-patient care and rehabilitation delivered by the Mildmay Mission Hospital
 - Abortion services delivered by BPAS and MSI
- 5.2 The team also commission Local Authority sexual health services across Lambeth, Southwark and Lewisham on behalf of all three Councils, for which Lambeth receives a payment from both Southwark and Lewisham Councils.
- 5.3 In 2011 LSL sexual health and HIV commissioners initiated a review of the existing portfolio of HIV care and support services and needs assessment to inform future commissioning intentions. The service review aimed to ensure that LSL provision for HIV care & support would be modernised to reflect the changing needs of people living with HIV in line with the epidemiological changes of HIV and advances of treatment. Updates from this workstream have previously been to Southwark Health and Adult Services Scrutiny Committee in October 2011 and May 2012.

6. HIV Care and Support Review Overview

- 6.1 The proposed changes to HIV care and support services, on which the three CCGs are consulting, follows the recommendations of the Lambeth, Southwark and Lewisham HIV Care and Support review. Final decisions on the proposal for Southwark will be made by Southwark CCG in August. All three CCG decision making processes have been aligned to ensure that a shared LSL decision can be achieved by the end of August.
- 6.2 The finding of the original review (which included extensive engagement with providers, service users and wider stakeholders) was that the HIV care and support service model was no longer fit for purpose. 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.

- 6.3 The review 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 which leads to fragmentation of care. This in turn would serve to increase HIV awareness in mainstream services and support destignatising of HIV. This is particularly important in Lambeth, Southwark and Lewisham where HIV prevalence is so high that in an average GP practice each full time equivalent GP would have between 16-30 patients registered with them living with HIV.
- 6.4 To this end, the review recommended decommissioning certain health and social care services including advice and advocacy, counselling and assessment and signposting. The Lambeth, Southwark and Lewisham Sexual Health Strategy (2014-17) committed to delivering on the recommendations of the review and work has been undertaken to ensure the readiness of mainstream services to manage the change in pathways.

7. Implementation to date

- 7.1 Post transition of Public Health into local authorities (since April 2013) the changes recommended in the review have been implemented in a staged way and have included:
 - Procuring a new LSL-wide peer support and mentoring service. The new service was procured in 2015 and is delivered by a partnership of local community and voluntary sector organisations.
 - Reconfiguring, in 2015, the CASCAID mental health service delivered by South London and Maudsley NHS Trust (SLaM).

8. Current proposals under consultation

- 8.1 Lambeth, Southwark and Lewisham are currently consulting on a new service model which will see advice and advocacy and counselling being provided by local non-HIV specialist services and assessment and signposting provided by the peer support service. Currently these services are provided as follows:
 - Counselling Terrence Higgins Trust
 - Advice and Advocacy Terrence Higgins Trust
 - Assessment and signposting Metro
- 8.2 The proposed new pathway for counselling and mental health support is:
 - CASCAID specialist mental health service at South London & Maudsley (SLaM)
 NHS Trust will see urgent and complex cases e.g. complex late diagnosis.
 - Non-urgent cases will go via Improving Access to Psychological Therapies services (IAPT) which is provided in all 3 boroughs by SLaM. Staff in the individual IAPT services will be supported by CASCAID's liaison function.
- 8.3 Within the proposed new pathway people with urgent psychological needs would be seen without delay by the SLAM CASCAID service. All other people living with HIV with non-urgent needs will wait the local IAPT waiting time to access a service. This wait time is governed by a national standard.
- 8.4 The proposed new pathway for advice and advocacy would be:
 - Local advice services in each borough provided by the Citizens Advice Bureau will triage the service user and provide a service. If they need to be seen by a more specialist advisor they will be referred onto the appropriate organisation

- within the local network of advice agencies (eg. law centres). These pathways cover need relating to benefits, immigration, housing, debt, employment and immigration.
- Support with charitable applications (a significant proportion of the work of THT's advice service) will be provided through the Peer Support and Mentoring Service at Metro across all three boroughs.
- 8.5 The Peer Support service provide assessment and signposting for all people newly diagnosed with HIV. The Peer Support service currently already provides this service and will simply extend their offer.
- 8.6 It should be noted that there is no change proposed to the Positive Parenting and Children's service which provides enhanced specialist HIV social care support (non-statutory) to families affected by HIV.

9. Consultation Process

- 9.1 The consultation on these proposals commenced on 9th May 2016 and ended on 29th June 2016. The Public Health Commissioning Team made contact with Healthwatch in each borough at the outset and have liaised with them to ensure that service users would feel confident about accessing engagement events and to ensure that people living with HIV who don't use the affected services could provide their views online.
- 9.2 User Consultation has included surveys, focus groups, and drop-ins across Lambeth, Lewisham and Southwark. A survey has been made available online (hosted through Lambeth Council website) and hard copies and has been promoted to relevant agencies and service users. Paper copies of the proposals and feedback form have also been available and these have been delivered to HIV treatment centres HIV clinics and Guys and St Thomas's, Kings and Lewisham Hospital. An engagement event was held at the Harrison Wing at Guys and St Thomas's hospital.
- 9.3 In addition there have been facilitated engagement events and focus groups with service users across the three boroughs to better understand any potential negative impacts so as to inform the final decision and make recommendations for mitigation where deemed necessary.
- 9.4 As part of the consultation process, Lambeth Public Health Commissioners and Southwark CCG lead commissioners met with the Providers affected by the proposals, Metro and THT. This provided commissioners with an opportunity to hear provider concerns directly.
- 9.5 At the close of the extended consultation period, 203 surveys have been completed, of which 30% were Southwark residents. The consultation period was due to end in late May but was extended by a further four weeks to enable further opportunity for feedback and in recognition of the complexity of the commissioning arrangements across three boroughs.
- 9.6 The demographics of respondents to date are broadly in line with the overall profile of people living with HIV in the 3 boroughs:

Gender	Sexual Orientation	Ethnicity
Male – 68%	Heterosexual -35%	Black/Black British, African – 29%

		Black/Black British,Caribbean-5% Black British Other – 4%
Female – 31%	Gay male – 61%	White (UK) – 34% White Other- 13%
Other -1%	Bisexual/Other -4%	Mixed – 8% All other ethnic groups – 7%

9.7 Demographics of participants at engagement events were not formally collected, however these were considered by facilitators of these events to be reflective of those communities most affected by HIV.

10 Emerging findings

10.1 The proposal receiving strongest support, from Southwark residents, was to maintain the Peer Support Service and this was followed by the proposal to maintain the Families Service. Of the proposals to decommission a current service: a majority of respondents supported the proposal concerning ending the signposting service and more respondents supported the proposal concerning ending the specialist counselling service than opposed it. Only the proposal to decommission the specialist advice service was opposed by more respondents than supported it, although those opposed were no more than 50% of responses.

	Support	Oppose	Unsure/no opinion
Peer Support	84%	2%	14%
Families	63%	17%	20%
Signposting	56%	27%	17%
Counselling	43%	35%	22%
Advice	38%	50%	12%

- 10.2 These results should be considered in light of the campaign to mobilise opposition through social and mainstream media via #stopthehivcuts in general and by THT specifically. Broadly speaking, the majority of respondents did not oppose the proposals and, for all but one proposal, support outweighed opposition. Overall, our proposals to keep some services and lose others appear to have received support.
- 10.3 The survey's free text boxes did provide people who opposed the proposals with an opportunity to articulate their concerns about losing HIV specific services and using mainstream alternatives, these concerns largely focussed on:
 - Stigma fear of discriminatory behaviour and judgemental attitudes from staff in mainstream services.
 - Confidentiality fear of disclosure of their HIV status (without consent) by the mainstream service to their employer, landlord, other agencies or the wider community.
 - Competency worries that mainstream agencies would have insufficient or outdated knowledge about the impact of HIV and how it affects different communities e.g. Black Africans and gay men.

11 Next Steps & Implementation

- 11.1 A detailed analysis of the consultation processes is underway, these findings are currently being collated to inform final recommendations and transition plans. Following which a decision will be made by Southwark CCG on the new model in August. Decisions across all three boroughs have been aligned to ensure a consistent decision across Lambeth, Southwark & Lewisham. Should a decision be made to terminate any of the existing contracts in line with the proposals then a three month notice of termination will be provided and a "Succession Plan" will be drawn up in line with the standard contract clauses.
- 11.2 Subject to the outcome of the consultation, transition plans will be developed to ensure clients who access current services, and any new clients wishing to access services in future, are aware of the new pathways. Information and signposting on the new service model would be provided by the peer support service, which currently offers this facility and which may be funded to extend this offer during the transition period.
- All non-HIV specialist advice and counselling services (that will meet needs in the new pathway) would be offered additional training on HIV competency delivered by an independent HIV organisation, to ensure they can confidently support people living with HIV. Many have received training on HIV in the recent past and are familiar with working with people with HIV given the local prevalence.
- 11.4 CAB across Lambeth, Southwark and Lewisham can provide training for the peer support service on managing referrals into advice and advocacy services. CAB can also offer a quality assurance programme across the system to measure the performance of the new service model during the first year. CCGs have agreed in principle to fund this. In addition, Lambeth, Southwark and Lewisham would commission a quality assurance programme from an independent HIV organisation to measure the performance of the new service model and pathways across all of the HIV Care and Support system in the three boroughs.
- 11.5 The non-HIV specialist services that form the proposed new pathway are already providing advice and advocacy and counselling services to people living with HIV. The numbers of people who are affected by these proposals are small in comparison to the numbers already being seen by non-HIV specialist services. All mental health and advice services commissioned across Lambeth, Southwark and Lewisham are non-discriminatory of people living with HIV and offer the same standard of quality and access to all sections of our communities and all groups with long term conditions.
- A number of voluntary sector organisations affected by the proposals, and those who advocate for people living with HIV, have made representations to the CCG in the consultation period to share their concerns around the loss of the specialist services. There has also been local and national media coverage of the proposals. These views will feed into the final consultation report.
- 11.7 At meetings with affected service providers, it has been suggested that a steering group of key stakeholders is established to oversee the transition to the new service model and provide assurance that the changes do not have adverse impacts on

individuals or groups of individuals. This group will include service users, clinicians, third sector providers and providers of the new pathways.

12 Financial implications

12.1 The services under review are provided by national voluntary sector organisations. The financial contribution from Southwark CCG to the services under review is:

Terrence Higgins Trust – Advice and Advocacy	£48,451
Terrence Higgins Trust – Counselling	£33, 298
Metro - First Point	£47,197
Metro – Peer Support	£31,284
Metro/PPC – Children & Families Service	£70,645

12.2 There is inconsistency across LSL on where these budgets are held and which organisation acts as responsible commissioner. This is a legacy of the transition of public health services from PCTs. In Lambeth the council is the responsible commissioner, but in Lewisham and Southwark the CCG is the responsible commissioner. The contracts issued to the providers are joint contracts.

13 Equalities implications

- 13.1 People living with HIV are predominately from groups with protected characteristics including ethnic minority groups and men who identify as gay or bisexual. For this reason these groups are almost exclusively impacted by the proposals outlined in this paper. In view of this, ensuring that there is very good representation from these communities in the consultation has been essential to ensuring it is robust enough to inform decision making.
- 13.2 In 2014, 2,935 adult residents (aged 15 years and older) in Southwark received HIV-related care: 2,195 men and 740 women. Among these, 51.2% were white, 28.6% black African and 4.9% black Caribbean. With regards to exposure, 57% probably acquired their infection through sex between men and 38.4% through sex between men and women. Southwark has a higher proportion of HIV diagnosis in heterosexual men and women compared to London and England rates (LASER 2014).
- 13.3 A total of 70 Southwark residents used the counselling service provided by THT (29 of these were new clients) and 286 Southwark residents used the advice and advocacy service (excluding those applying for grants).
- 13.4 The proposed changes are not considered substantial. The shift of activity to mainstream services is relatively small, the services that will receive these clients in future are confident they can meet demand and therefore the impact on the wider system is expected to be minimal. A profile of the users of the individual services is provided below.
- 13.5 The pattern of usage varies across the services, the counselling service is more heavily used by gay men, the advice service is more heavily used by women and First Point is more reflective of the cohort of people living with HIV.
- 13.6 Counselling user profile

Gender	Sexual Orientation	Ethnicity
Male – 82%	Heterosexual -24%	Black/Black British, African – 15% Black/Black British (Caribbean) -
		6%
Female – 18%	Gay male – 72%	White (UK) – 37%
		White Other- 31%
Other/withheld-0%	Other/withheld -4%	Mixed – 5%
		Others/withheld – 6%

13.7 Advice and Advocacy user profile

Gender	Sexual Orientation	Ethnicity
Male – 33%	Heterosexual -50%	Black/Black British, African – 34% Black/Black British (Caribbean) - 10%
Female – 67%	Gay male – 53%	White (UK) – 24% White Other- 16%
Other/withheld-0%	Other/withheld -7%	Mixed – 3% Others/withheld – 13%

13.8 First Point user profile

Gender	Sexual Orientation	Ethnicity
Male – 68%	Heterosexual -48%	Black/Black British, African – 32%
		Black/Black British (Caribbean) -
		7%
Female – 28%	Gay male – 44%	White (UK) – 21%
		White Other- 15%
Other/withheld-4%	Other/withheld -8%	Mixed – 0%
		Others/withheld – 23%

13.9 A draft Equality Impact Assessment is enclosed in Appendix A. This will be reviewed by Southwark CCG's Equality & Human Rights Committee, before informing final CCG decisions.

Appendix A:Southwark's Equality Impact Assessment

