Review of HIV Care & Support Provision (Lambeth, Southwark and Lewisham)

Consultation Response

February 2012
1. Introduction

1.1 Terrence Higgins Trust is the UK’s leading HIV and sexual health charity. THT is a membership and campaigning organisation which works with and advocates on behalf of people living with or affected by HIV. We are also a key partner in the delivery of HIV care and support in South East London and provide a range of services including advice and advocacy, counselling, health trainers and peer support. In 2010/11 Terrence Higgins Trust provided over 16,000 hours of services to 1,599 clients across Lambeth, Lewisham and Southwark.

1.2 We welcome this consultation on the review of service provision and care pathways and acknowledge that commissioners have sought to explore concerns and issues before making key decisions. We are supportive of this approach. We have reviewed all of the consultation questions set out in the document and we will aim to address all of these in our response. However, in order to avoid repetition we have chosen to address key areas and themes, rather than individual questions. We will limit our comments to areas where we feel further clarification or consideration is needed.

1.3 Terrence Higgins Trust has also contributed to the South London HIV Partnership joint response to this consultation and is a member of the South London HIV Partnership Peer Support Consortium, which has also submitted a response.

2. Overarching comments

2.1 We are pleased that a service user reference group has been used throughout the process and welcome the role they will play in making the final decisions. However, we feel it could have been beneficial to have a report from that group as part of the review. As it currently stands their voice is not discernible in the document.

2.2 We are very supportive of the priority that the review gives to developing strong care pathways and reducing borough boundaries for people living with HIV in SEL.

2.3 Equally we are pleased at the commitment which the review makes to the future of Advice and Advocacy services. As the document outlines, this service is highly subscribed and frequently exceeds its targets. We believe that the need for this service is likely to grow in coming years due Government initiated welfare reform and back to work programmes. Similarly, should mainstreaming of services go ahead in LSL, the Advice and Advocacy will have a role in supporting people to access the services they need.

2.4 We also welcome the fact that NHS SEL is proposing a staged handover approach. We do have a number of key concerns regarding mainstreaming of services that we will outline further in our response. However, we appreciate that a staged process will afford more opportunities to review the feasibility of handing over specialist services.

2.5 We appreciate the difficulties faced by NHS SEL in meeting the ongoing needs of a growing population of people living with HIV in the area. We also understand that some specialist services may be unsustainable in the longer term. However, we believe that the scale of the proposed transfer means that greater exploration of the needs of
people living with HIV in South East London is warranted. It is very difficult to properly assess, or support such wide ranging plans without proper modelling of what they will mean for people living with HIV in South East London or details of how any barriers or areas of difficulty will be addressed.

2.6 We would have welcomed a report from the service user reference group’s perspective on the mainstreaming aspects of the plans. We do not believe that the thoughts and concerns of people living with HIV in South East London have been fully explored and we would urge LSL to undertake a more detailed piece of research exploring attitudes and barriers towards accessing generic services and viable means to overcome these. South East London has the potential to develop best practice and lead the way on this issue in the UK. However, decisions have to be informed by a proper assessment of need. Otherwise they run the risk of removing vital support for the most vulnerable.

2.7 The document mentions reinvestment on page 9, but also references efficiency savings under the CSR. We would urge greater clarity on what the balance between these two aims will look like. The challenge of making savings in the face of levels of undiagnosed HIV, annual increases in new diagnoses of 8% and an ageing population of people receiving care is a significant one. We find it difficult to consider where savings can be made in this context. We are concerned that page 9 of the document does not reference scoping future need as an area for further investigation under the ‘financial implications’ section.

2.8 We have a number of concerns relating to the Financial Context as outlined on page 12 of the document. The suggestion is made that Local Authority contributions could reduce by 28% by April 2014. We would challenge this presumption and stress in the strongest terms that there is not adequate justification for such a cut back. Whilst the ring fence for the AIDS Support Grant has been removed, there is still earmarked allocation made for HIV care and support from central Government. Nationally the Grant will increase from £25.5 million in 2010/11 to £36.2 million in 2014/15. Inner London Borough's received an uplift of 5.5% between 2011/12 and 2012/13 for provision of HIV care and support. We therefore find it difficult to understand how a 28% decrease in funding could be explained.

2.9 The document suggests that savings may be redirected into testing initiatives. It doesn’t however recognise that Local Authorities are set to receive further ring fenced public health funding following the hand over of public health responsibilities from the NHS in 2013. This will mean that Local Authorities will have a key role to play in the delivery of HIV prevention and testing and will be funded specifically to do this work.

3. Epidemiology: People Living with HIV in LSL

Epidemiological Groups

3.1 We appreciate that ‘Black Africans’ is a commonly used epidemiological grouping. However we would suggest that it would be useful to explore the extent to which this
group in LSL encompasses people from a large number of countries, with a variety of different cultural backgrounds who may have differing needs as a result.

3.2 According to the HPA there have been around 526 UK acquired heterosexual diagnoses in South East London since 2002. Similarly, there have been approximately 602 new diagnoses (Heterosexual, MSM and IDU) of HIV infections acquired in other regions of the world. It would be useful to determine whether there are any specific needs emerging from within these groups. For example, are there any identifiable issues or service requirements among the population of people living with HIV who are of Eastern European origin or who acquired their infection heterosexually within the UK?

3.3 The epidemiology section does reference the Caribbean community, pointing out that Southwark has a high prevalence rate of Black Caribbean males, many of whom are MSM. However, the specific needs of this group do not appear to be explored further and are not captured under service planning elsewhere in the document.

Older people

3.4 The key themes acknowledge that there will be an increasing number of older people living with HIV in coming years in LSL. The epidemiology section also states that this group are likely to have other co-morbidities associated with ageing. A study undertaken by Terrence Higgins Trust and the Joseph Rowntree Foundation found that people living with HIV over 50 report twice as many other long term conditions as their peers. This study also found that this group are less economically active and more likely to be affected by poverty. The review does acknowledge that this will have implications for Primary Care. However, we would recommend further exploration and more detailed mapping of the implications for service planning and in particular the level of social care and community support need that this is likely to generate in coming years.

Patterns of Service Use

3.5 The themes in this section suggest that ‘over 70% of people living with HIV are stable’. This figure refers to HIV treatment which is not in itself a direct proxy for a lack of additional need. We would urge caution in using this figure in isolation.

3.6 We would welcome further clarity on the figures relating to the 35% of MSM resident in LSL who access their care there. This is presumably a measurement of specialist clinical services only and not all care services, particularly those provided via Local Authority commissioning. We would be concerned that this figure does not provide a complete picture of MSM engagement with services in South East London.

3.7 The pattern of MSM clinical service usage, does however underline the fact that people living with HIV in London do often choose to use services away from their place of residence. We are strongly supportive of commissioning across borough boundaries and believe that in many instances a pan London approach is needed to provide continuity of care for people across the city. This is particularly true in terms of HIV prevention work.

3.7 Throughout the ‘Introduction’ and ‘Epidemiology’ sections a number of references are made to the 8% annual increase in diagnoses that LSL experiences. However the
document does not include any further modelling of what the needs of this group are likely to be and what this could mean in terms of future demand for services. Whilst some of the implications are unknown, we would suggest that more consideration needs to be given to this issue before final decisions are made.

4. Needs and Evidence Review

4.1 Unfortunately, we do not feel that the needs assessment contained in the review includes enough detail. It refers to general findings about the needs of people living with HIV and further specific observations from the ‘What do you need?’ Sigma study. These are useful; however, we would suggest that more in depth mapping of the actual needs of people living with and at risk of HIV in LSL should be done before developing proposed models of services and care. Without this, any models are unlikely to be able to adequately address the true level of need in LSL.

4.2 We are concerned that the decisions on the proposed model have been based on a very simple exploration of need and a review of the evidence base for services. We are unclear how these findings work together to determine the proposed model and prioritisation of services. For example, the review of evidence table on page 26 states that psychological services are ‘proven effective when a range of HIV services are all located at the same site as counselling and testing’. However, page 27 then states that there is ‘no evidence about whether this [psychological] support is best provided in an HIV specific location’. This is contradictory and does not support the argument for subsuming HIV counselling and psychological support into generic provision.

Socio-economic considerations

4.3 The review makes little reference to the socio-economic status of people living with HIV in south London. We know that economic hardship is an issue for many people from Black African communities living with HIV in this area. Similarly, Sigma’s report into the findings from the 2008 Gay Men’s Sex survey suggests that men with lower levels of formal education were more likely to have been diagnosed with HIV within the last year, even though they have lower levels of testing than men with higher levels of formal education. As the scope of the review includes provision beyond clinical services, we would suggest that further exploration of the economic status of people living with HIV in South East London is needed as this has significant implications for service provision.

4.4 The next three years will see significant changes implemented in the welfare system, with up to 20% cuts in benefits provision. This will undoubtedly have an impact on people living with HIV in LSL and will affect the levels of support they may need, for example in advice and advocacy, back to work support and potentially in counselling and mental health. The review does not consider this. We think that an attempt should be made to determine how many people in LSL could be affected by changes in welfare provision.

4.5 It is also likely that there will be an increasing need among people living with HIV to access support in finding or returning to work. Generic services are unlikely to provide learning and advice in relation to HIV specific issues such as disclosure in the work place and knowing your employment rights. This will have an impact on the levels of advice and advocacy services required in LSL.
5. Review of Current Service Provision

5.1 We would agree that there are benefits to having peer led services that recognise specific faiths, cultures or sexualities. Our experience tells us that these services can build rapport by demonstrating a common understanding of issues and ability to deal sensitively and expertly with specific concerns. This often means that people in these settings are more likely to feel willing to openly discuss problems, and are able to access support in building wider networks within their communities. In addition to peer support targeted for MSM and the range of African communities, we would also suggest exploration of the need for support focussed on some religious communities.

5.2 The review refers to counselling and African emotional support services stating that they have highest usage amongst white British MSM. Whilst this is true we would argue that Black African communities frequently demonstrate a reluctance to engage proactively with counselling. People from Black African communities who are living with HIV in London often face a number of financial, housing and immigration issues that take precedence over counselling needs. We consider that there are therefore benefits to having services that are able to link these issues together in order to ensure people also receive the psychological support that they need.

5.3 We would therefore advocate for retention of a specific African counselling function. The current service has undertaken a considerable amount of outreach in order to support the number of Black African people that it currently does. Any future mainstream or specialist counselling service would needs to take this outreach requirement into account when providing services for this client group. We are not convinced that this is something general services will be in a position to do.

5.5 The document states that NHS SEL are still awaiting Terrence Higgins Trust’s breakdown of numbers for the services that we provide by borough. We provided these before the consultation and have listed them again below:

I. Advice and Advocacy – 25% Lambeth, 11.71% Lewisham, 24.44% Southwark
II. Counselling – 32% Lambeth, 13.6% Lewisham, 20% Southwark
III. HIV Health Support – 19.3% Lambeth, 13.3% Lewisham, 14.4% Southwark

6. Going Forward: Service Model and Recommendations

Stigma

6.1 The review states that there are 'no additional cost pressures envisaged as a result of the changes'. We are concerned that this may not be the case. Should the mainstreaming of services go ahead as proposed, we believe that this will have a significant impact on the need for advice and advocacy as people may lack confidence in accessing services, may need sign posting to them or support in challenging poor treatment. This service is already operating at capacity so we would encourage a more
detailed consideration of the impact the planned changes may have on it and how people living with HIV are supported to access mainstream services.

6.2 We would also welcome further detail on where interventions tackling stigma and discrimination sit within the model. This is something that could be addressed via a number of routes including advice and advocacy, peer support, counselling and health trainers. Building confidence, self esteem and improving people's ability to challenge real or perceived stigma is a considerable challenge, but it is also fundamental to improving the experiences of and outcomes for people living with HIV in South East London.

6.3 Sigma’s ‘What do you Need?’ study found that 19% of people living with HIV report having encountered stigma or poor treatment in health care settings in the last 12 months. This suggests that raising standards in general services to meet the needs of people living with HIV could prove challenging. The review lacks detail on how standards can be improved. In particular, further outline is needed on:

- Who will find it most challenging to access general services and how will their needs best be met
- The impact that mainstreaming of services will have on an advice and advocacy service that is already operating at capacity
- Whether the levels of integrated commissioning are achievable and how this will operate
- How GPs can be successfully engaged to deliver a case management role
- The scale of training need across primary, social care and community services and the cost and resource implications of this work.
- What further policies or procedures need to be put in place to ensure standards are met

Mainstreaming

6.4 The key themes identified on page 29 state that: ‘there is strong evidence for interventions that support ...mainstreaming services within wider health and social care services.’ We do not feel that this evidence has been demonstrated by the review. There is some indication of what works well from an assessment of models of care for other long term conditions. However, the review does not state what these conditions are or whether there is parity with HIV. We would suggest that HIV differs from most other long term conditions due to the stigma that is still attached to the condition and that straightforward comparisons cannot always be relied upon.

6.5 Throughout the document, reference is made to the unique concerns and barriers that people living with HIV face in accessing mainstream services. However, we do not feel

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that the review of evidence and need provides an adequate exploration of how these problems can be meaningfully addressed. We are supportive of improving access to mainstream services for people living with HIV, for example in general practice and primary care. However, the review provides little practical detail as to how this can successfully be achieved. This detail is fundamental to promoting confidence and support for any restructuring plans SEL have moving forward.

6.6 Page 33 states that ‘...there is a debate to be had about where the HIV dimension ends and the need becomes ‘mainstream’ and how services can help users access what they are entitled to.' We agreed with this statement and consider that SEL have the opportunity to make vital progress on this issue. However, we would recommend strongly that a detailed piece of work should be undertaken that looks at needs, concerns and barriers and possible solutions. This could inform piloting work to build confidence in service plans.

Self management

6.7 Self management is identified as a key intervention within the document. However, it only appears to feature as an outcome of mainstreaming services. We believe that self management must feature much more prominently in the service plan and model. The self management needs of people living with HIV and the future sustainability of services both mean that long term condition management has to be a priority in NHS SEL.

6.8 The model as currently outlined appears very focussed on a biomedical model of responsive care. We would urge that long term condition management be included as a principle of the new service model as outlined on page 4 of the document. The plan to decommission the Health Trainer service suggests that Health Advisors or GPs as case managers should be able to take up this role. However, the document does not explore the levels of Health Advisor support available in LSL.

6.9 Similarly, it does not take account of the increasing strain on HIV specialist centres to deliver this kind of personalised support in the face of 8% annual increases in patient numbers. The assumption that GPs will automatically be able to fulfil this role is tenuous given their performance in this area historically and the increasing demands being placed on GPs. We would strongly suggest that long term condition management needs to receive greater priority within the proposed model and that this should be addressed through a re-commissioning of a health trainer/long term condition management function or service, or via an enhanced health trainer function within the peer support service. This would obviously have to be appropriately funded.

Psychological support

6.10 We remain concerned that general counselling and low level psychological support services and specialist mental health services will not be able to deliver the kind of personalised service that best supports the unique concerns of people living with HIV.

6.11 People living with HIV face particular barriers when accessing psychological support, linked to the stigma associated with HIV, and particularly issues around confidentiality and trust. This stigma is compounded by the fact that many people living with HIV come from marginalised groups in society, for example MSM, Black Minority Ethnic Communities, or refugees and asylum seekers. People from these groups may already experience poorer mental health outcomes than the general
population. Given that many come to counselling, or talking therapies, to explore their relationship with HIV stigma, issues with sex, sexuality and relationships, we feel that moving from a HIV specialist service which is set up to specifically cater for the needs of people living with HIV, and has an in-depth knowledge of the issues that people face, to a more mainstream environment risks alienating clients and increasing mental health vulnerability. We believe that altered provision for these groups should be staggered, contain proper risk management and be linked to a full equality impact assessment, in order to ensure that already marginalised and vulnerable clients do not fall further through the gap and are lost to mainstream provision.

6.11 There is little detail provided on the time frame or process of the proposed phased hand over for these services. We would strongly suggest if this does go ahead, then a pilot should be put in place to monitor the viability of this handover and to ensure that general services can actually deliver for people living with HIV. Without such safeguards in place, we think it is difficult to justify the redirection of funds from specialist to generic services.

Case management and referral

6.12 We would welcome further detail on the referral pathways outlined in the review. Specifically how they will be kept under review and who will monitor and promote their use.

6.13 Case management is only seen in the review in relation to managing the medical aspects of living with HIV, in reality PLHIV can face a range of other issues. We would argue that other organisations and professionals may be more appropriate to case manage these than CNS or GPs. We are also unclear as to how GPs will be engaged/ supported to take on this function.

Recommendations

7.1 We would welcome a a full and detailed needs assessment of people living with HIV in South East London. The needs assessment should take the following into account:

- Whether there are any specific or emerging needs in epidemiological groups beyond MSM and people from Black African communities.
- The needs of older people living with HIV and the implications for service planning.
- The potential needs of the undiagnosed population and the implications of the annual 8% increase in diagnoses on service planning
- The socio-economic needs of people living with HIV in South East London
- The self management needs of people living with HIV in South East London

7.2 We would welcome a detailed piece of work which explores the barriers that people living with HIV face in accessing mainstream services. This research should aim to work with people living with HIV in South East London to identify key ways in which mainstream services could be better equipped to meet the needs of this group. The findings of the
research should then inform pilot projects to build confidence in any hand over of services in future.

7.3 As a minimum NHS SEL should undertake more extensive modelling of what will be required in terms of training and buy in from other healthcare professionals, in order to effectively mainstream some services, and what the cost implications of this will be.

7.4 We would urge NHS SEL to revisit the issue of Local Authority cuts in funding from the perspective that the HIV allocation in the block grant has in fact been increased and that subsequently such a large scale cut cannot be justified.