TRANSFORMING
THE UK'S
RESPONSE
TO HIV

NAT

25 May, 2016

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Dear Councillor Peck

Re: Lambeth, Southwark and Lewisham HIV Service User Consultation

I am writing as Chief Executive of NAT (National AIDS Trust), the UK's national HIV policy and campaigning charity, in response to the twin consultations on Public Health Services in Lambeth and on HIV support service provision in the London Boroughs of Lambeth, Southwark and Lewisham (LSL).

NAT has a strong commitment to ensure people living with HIV have the support they need. I have serious concerns about the impact the proposed changes will have on the support services that people living with HIV can access in the boroughs with the highest HIV prevalence in the country, as well as the wider effect such cuts could have on public health and HIV transmission.

I would start by pointing out an apparent discrepancy between the two consultations. The broader public health consultation states that *"We intend to reduce the funding to specialist HIV care and support services (providing advice, counselling and peer support)"*, targeting the remaining funding on maintaining a specialist service for children and families. The HIV specific consultation on the other hand states *"We intend to maintain the HIV peer support service and will work with the peer service providers on how peer support might assist service users as a result of any services changes elsewhere"* and also commits to maintain family support, with all other specialist provision (counselling, first point, advice services) ending, to be replaced by generic services.

It is crucial that interested parties are given accurate information about the changes that are being proposed. I will assume that the LSL HIV support services consultation reflects the current position and it is now agreed that peer support will continue for people with HIV in LSL (which is of course welcome).

The need and demand for HIV support services

I am also concerned about apparently contradictory underlying assumptions in the HIV specific consultation around demand. The consultation document states that:

> *"While there is still no cure for HIV, there are treatments to enable most people with the virus to live a long and healthy life. The number of HIV related deaths in the UK is now very low and the number of people living with HIV has therefore grown significantly.*
>
> *There is increasing pressure on public services due to rising need and increased financial pressures within the NHS and local councils. This, coupled with the fact that many people with HIV can live a long and normal life, means continuing to provide HIV specialist support services in the same way and at the same level that we do now is not sustainable."*

This seems to imply both that demand for support services is falling due to improvements in treatment, but also that demand is unsustainably high. In fact, as I go on to show below, despite treatment improvements there is still significant psychosocial need amongst people with HIV.

Great improvements have been made in HIV treatment in recent years but there are still many people living with HIV, especially older people, who were diagnosed before treatment became available or when treatment still had very severe side-effects and who have as a result permanent impairments and support needs. About one in five people with HIV are still diagnosed very late with far greater rates of ongoing ill-health and impairment as a result. With regard to mortality, whilst rates of death have of course declined massively from the early days of the epidemic, the mortality rate of people with HIV in this era of ART in the UK is still six times higher than that of the population as a whole and still over twice as high even when AIDS-deaths are excluded.[1]

Public Health England's Positive Voices 2014 survey of a representative HIV clinic population found that 68% of people with HIV have at least one other long-term co-morbidity, the most common being depression/anxiety (30% of the whole weighted sample), high cholesterol (20%) and hypertension (14%).[2] All of these percentages are very significantly higher than that of the general population. People with HIV need holistic long-term condition management support to self-manage effectively and access appropriate healthcare.

Still others who are living well with HIV are able to do so precisely because they are able to access the support services they need. Among these, many people living with HIV need support services episodically, at particular moments in their life such as

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[1] Sara Croxford, Public Health England, Non-AIDS mortality among people diagnosed with HIV in the era of HAART compared to the general population: England and Wales, 1997-2012, BHIVA 22nd Annual Conference 2016

[2] Kall M, Shahmanesh M, Nardone A, Gilson R, Delpech V on behalf of the Positive Voices Study Group. Self-reported prevalence of co-morbidities and use of non-HIV related medications among people living with HIV in England and Wales: results from the Positive Voices survey. *15th European AIDS Conference*. Barcelona, Spain; October 21-24 2015

when they are newly diagnosed, if they lose a job, become pregnant, need to think about disclosure, or experience discrimination.

I welcome your intention to maintain peer support services on the grounds that they are recommended by BHIVA. However, peer support alone is not sufficient to provide for the service needs of people living with HIV.

For example, people with HIV experience significantly elevated levels of depression, anxiety and suicidal ideation compared with the general population.[3] As stated above, Positive Voices found that 30% of people with HIV also experience depression/anxiety. HIV support services, including counselling, can be low threshold, preventive and cost-saving interventions to avert acute ill-health and crisis.

There are also high levels of social disadvantage amongst people with HIV. There is robust evidence of the impact that such social disadvantage (for example around income, employment and housing) has, in the absence of interventions, on the ability of people with HIV to adhere to their medication and maintain the suppressed viral load necessary for good health and non-infectivity.[4]

HIV specialist support organisations provide a vital service in helping people cope with the experience of stigma. 37% of the UK's 2015 Stigma Index Survey participants who had experienced HIV-related discrimination had relied on support from a local specialist HIV organisation within the last year.

Specialist support services may be the only places where people living with HIV can be open about their status and there is a great danger that, without HIV specialist services, people living with HIV will drop out of the vital support that allow them to achieve optimal health and wellbeing.

Comprehensive HIV support services are agreed to be an essential element in the HIV care pathway

BHIVA Standard 9 recommends a number of services beyond peer support. It indicates that support and information about HIV treatment, healthy living with HIV, diet and lifestyle, and optimisation of general health; support around access to health services; and financial, housing and employment support are all necessary for effective long term condition management.[5]

Moreover, drawing on BHIVA Standards, NHS England has clearly stated in its service specification for adult HIV specialised services that 'the effectiveness of HIV specialised services depends on other elements of the HIV care pathway being in place and effectively coordinated' (NHS England HIV adult service specification 2.2). These other elements include 'Community services provided by third sector and other organisations. These services can provide important support on long-term condition management'. They are later described in the same service specification as 'third sector HIV care and support services for treatment adherence, peer support

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[3] See *Psychology, Health and Medicine* Vol 16 Number 5 October 2011

[4] See Socio-Economic Factors and Virological Rebound: a Prospective UK Cohort Study Burch *et al*, Abstract 560, CROI 2015

[5] Standards of Care for People Living with HIV, British HIV Association, 2013

and self management' as well as 'social care, mental health and community services for rehabilitation, personal care or housing' (section 2.5). In other words, these HIV support services are an integral part of the required care package available to people with HIV.

It is perverse to use good HIV clinical outcomes as an argument that HIV support services are no longer needed. It is precisely the historical combination in England of specialised clinical care and comprehensive, usually community-based, support which has secured such outcomes. Withdrawing specialist counselling, advice and needs assessment/signposting puts such outcomes at risk for a significant proportion of people with HIV.

The Public Health England Positive Voices survey in 2014 found that 35% of people with HIV had accessed HIV support services in the previous 12 months, most commonly:

- information about living with HIV
- treatment advice
- peer support or social contact with other HIV positive people, and
- counselling.

Data from the Stigma Survey UK[6] show similar results for use of HIV support services, but also indicate that certain groups of people living with HIV particularly depend on these services. Among their sample, 46% of those recently diagnosed and 43% of those feeling suicidal had accessed local HIV support organisations.

In other words, LSL are not proposing to end marginal aspects of HIV care, but rather essential elements, both in terms of national guidance and actual use.

Use of generic services

The LSL proposals rely heavily on the recommendation that for advice and counselling people with HIV access instead generic advice and talking therapy services. The public health consultation refers to 'A review of HIV care and support services undertaken by the NHS suggested that many mainstream services would be able to support people living with HIV and that this might be desirable to avoid service duplication and de-stigmatise HIV as a long term condition'. I am unsure which review is being referred to and think it poor practice for there to be no reference to allow consultees to read and assess the review for themselves.

This approach to generic services is itself too generic – there needs to be a distinction between elements of advice and counselling which intrinsically require HIV specialism and those which could be delivered by generic services if they were competent around HIV-related issues.

The consultation indicates that generic services such as Law Centres, CABs, and specialist advice agencies such as Every Pound Counts will provide advice and support around HIV-specific matters such as long term condition management, adherence support, support with disclosing status, dealing with stigma, or advice on how to have sex safely. Even stating the proposition so baldly demonstrates at once

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[6] HIV in the UK: Change and Challenges; Actions and Answers, The People Living With HIV Stigma Survey UK 2015 National findings, 2016

how impossible and inappropriate that would be. More work is needed to distinguish elements of advice, information and counselling which are inherently HIV-specific and those elements which genuinely over time could possibly be delivered by generic providers. It is vital that HIV-specific advice, information and counselling remain in place.

The reason even more generally applicable advice and counselling have historically been provided by specialist providers is of course the prevalence of HIV stigma. This has not gone away. The recently published findings of the Stigma Index show that stigma and discrimination remain common and affect the ability to come to terms with a new diagnosis, contribute to feelings of social isolation (especially around fears of disclosing to friends and family who would otherwise be providing much needed social support) and to difficulties coping.

The same social stigma that increases the demand for HIV support services fuels the need for *specialist* service provision.

HIV specialist providers remain well placed to meet the needs of people living with HIV, having the nuanced and detailed understanding of the condition to deal sensitively with complex HIV issues and, most importantly, secure the trust and confidence of all people with HIV.

Any move to generic services needs to be gradual and planned – if done well it could be a model nationally of how to provide appropriate generic support for people living with HIV. I suspect, however, that these same generic services are themselves short of resources and ill-prepared for new service users and fresh competencies. It does not go down well among people with HIV for the move to generic services to be presented airily as 'de-stigmatising' when in fact it may mean nothing more than exposure to stigma.

Both consultations promise that generic services will be knowledgeable, competent and welcoming, in line with BHIVA's standard 9 on long term condition management, which states that "Services should be delivered by providers with appropriate expertise and competencies." However there is no information provided on how staff will be trained; what arrangements will be made to ensure that provision is appropriately private; or how confidentiality will be assured.

More detail and thought is needed from LSL on how generic services will be trained to support people with HIV, how access of people with HIV will be measured and monitored, what outcome measures would be agreed to demonstrate success of generic services in meeting the needs of people with HIV, and how experiences of people with HIV will be assessed.

The sudden end of key HIV services without any real vision for HIV-competent generic provision is not reassuring. And it is a missed opportunity to bring people with HIV and the HIV sector along with LSL in genuine service development and innovation.

Short term cuts do not relieve long term financial pressures

Specialised support services not only help to improve the well-being of people living with HIV, they can also promote adherence to HIV treatment and encourage partner notification and partner testing, with consequent public health benefits and savings in relation to treatment costs.

These support services have an important role in preventing needs for more expensive assessed care and support the work of clinics in encouraging adherence to treatment which is important for people to stay well and to reduce transmission, maintaining an undetectable viral load.

NAT is very conscious of the financial pressures currently facing local authorities and know that savings are required. I do not, however, believe that the proposed cuts to key service elements of HIV support can be justified. I also strongly believe it is a false economy which will end up placing increased costs on local services. The costs of such action will be felt -

- in increased serious ill-health as people with HIV fail to engage as effectively with healthcare or adhere to medication,
- in greater local rates of HIV transmission as people with HIV remain infectious (not achieving a suppressed viral load) and have difficulty maintaining safer sex,
- in increased unemployment as they lack the support to remain in work or the expert advice to prepare for and apply for jobs,
- in poorer mental health as they lack the counselling to deal with depression and anxiety, and
- in social isolation and family/relationship breakdown as issues of stigma and disclosure remain unresolved.

Consultation process

I have significant concerns about the consultation process. In the consultation specifically dealing with HIV support services, you have asked for responses only from people who have used services provided by Metro, Positive Parenting and Children, or Terrence Higgins Trust. In so doing you have actively excluded responses from those who have as yet chosen not to use these services, or those who are not service users but whose lives may be affected by the proposed changes to services (such as a family member of an HIV specialist support service user), or indeed people who were unaware of such services but are nevertheless local residents living with HIV.

Further, the initial survey questions strongly imply that respondents should be people who have used these services within the last 12 months (if these are simply identifying questions they should be at the end of the survey along with the other identifying questions). This implication is a barrier to inclusion of people who have not accessed services within the last year. We know that many people living with HIV only need to access support services at key moments in their lives, rather than routinely.

By effectively excluding these groups from your survey you will not receive complete information on the full impact of the service cuts that you are proposing.

A consultation survey such as this (especially given the limitations I have cited) cannot substitute for the councils' legal obligation to undertake a needs assessment of local people living with HIV which can feed into, or be part of, the Joint Strategic

Needs Assessment (JSNA). I am not clear that such a needs assessment has been done. It would involve close liaison with the HIV clinics which local residents attend, both to get detailed evidence around psychosocial needs, for example, as well as appropriate means to contact the wide range of LSL residents being seen for HIV care.

Before any changes to services are made, a full evidence based assessment should be made of the needs of people living with HIV who use the services in Lambeth, Southwark and Lewisham.

Furthermore, HIV is a disability (under the Equality Act 2010) and people with HIV are disproportionately from gay and African communities. There is an equalities dimension to these services, linked to the Council's public sector equality duty, which needs to be taken into account before any decision on the future of these services is made. I am not aware whether as yet an Equality Impact Assessment has been done on these proposals, but it is vitally important that it is done and fully consulted on and discussed before any final decisions are reached.

There is no reference in either consultation to the fact that in Lewisham and Southwark the commissioner responsible for funding the HIV support services is, I understand, the local Clinical Commissioning Group. This is in my view entirely appropriate given how much of HIV support is in effect long-term condition management. I know that NHS budgets are themselves under immense strain but the argument around public health budget cuts made in the Lambeth consultation does not apply to NHS funding which is increasing in real terms. Lambeth needs to consider sharing of commissioning responsibility with Lambeth CCG as one way forward.

I am very conscious of the financial challenges facing Lambeth, Southwark and Lewisham, and I am not resisting any and every reduction in expenditure. However, the LSL proposals go beyond 'savings' to the total end of core elements of HIV support, and seem to make the case for such decommissioning on the basis that the services are either not needed or can be replicated by generic provision. I challenge both those two assumptions, and believe LSL need instead to model how, even in a time of financial strain, necessary provision can be maintained. A decision to end key HIV support services in the local authorities with the highest HIV prevalence in the country will send a profoundly harmful national message and I urge you to think again and work with people with HIV locally, clinicians and the HIV voluntary sector to achieve innovative solutions.

I look forward to hearing from you.

Yours sincerely

Deborah Gold
Chief Executive