How well do services join up in Camden?

Experiences of local people living with HIV

September 2015

Acknowledgements

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Summary

Local people have told Healthwatch Camden that the different health and social care services in Camden are not always well integrated.

Older residents living with HIV are particularly affected by how well services join up because their needs are often complex and they are more likely than others to be living with multiple conditions. Therefore, they need to use a wide range of different services which span health and social care and which include specialist HIV services and other non-specialist services.

To find out more about how well the different services in Camden link up, we conducted research among local service users who are over the age of 40 and living with HIV. This focus on older People living with HIV (PLWHIV) represents one phase of a broader and ongoing programme of work by Healthwatch Camden on joined up services across different areas of service provision.

We gathered opinions from PLWHIV at community and outreach events and then conducted in-depth semi-structured interviews to better understand the experiences of users of specialist and non-specialist services.

A number of recurring themes emerged. We heard that many services used by PLHIV in Camden are good and highly valued. However, people told us that difficulties often result from a failure of communication and integration between specialist and non-specialist services.

A resounding theme was the “ping pong” effect felt by older PLWHIV who find themselves being sent back and forth between specialist and non-specialist services.

PLWHIV face challenges when using GP services and other health providers who don’t have specialist knowledge of HIV.

Older PLHIV need more easy access to mental health and emotional support services.

Diversity among older PLHIV is not sufficiently recognised by service-providers. For example, there are PLWHIV who are disabled; who are black, minority ethnic; injected-drug users; who are gay, lesbian, bisexual or transgender.

There is insufficient clarity and consistency of information about community based services and a desire for more peer support networks across Camden.

Finally, service-users reported that stigma and discrimination in healthcare settings remains a barrier to accessing the support they are entitled to when using different services in Camden.

This report summarises the interview responses grouped under key theme headings.

Drawing from what local residents told us, Healthwatch Camden makes seven recommendations about the design and delivery of services for older PLWHIV in Camden.

About Healthwatch Camden

Healthwatch Camden is an independent organisation with a remit to make sure that the views of local service users in Camden are heard, responded to, taken seriously, and help to bring about service improvements.

Our duties (which are set out under the Health and Social Care Act 2012) are to support and promote people's involvement in the planning, running and monitoring of services; to gather views and experience and to make reports and recommendations for improvement based on those views; to offer information and advice on access to services and choices people can make in services; and to enable local people to monitor the quality of local services.

Our remit extends across all publically funded health and social care in the borough.

Background

This research focused on older people (40 years old and above) who are living with HIV because their needs are often complex and they are more likely than others to be living with multiple conditions. Therefore, they need to use a wide range of different services which span health and social care and which include specialist HIV services and other non-specialist services. As such, the experiences of this group can shed light on the wider question of how well different services join up.

The population living with HIV in Camden is growing older and this has implications for service design and delivery[1].

[1] Terence Higgins Trust 2013.

HIV prevalence among the population of Camden is higher than among the general population of London and of England[2].

During 2014, Healthwatch Camden hosted an intern who had a specialist interest in HIV services. Juliet McNelly, a Masters student from Goldsmith's College, University of London, conducted this research during her six-month placement.

Methods

The research method combined four different mechanisms for gathering the views of local people who use HIV specialist and non-specialist services in Camden. These were: a) group discussion at forums with a range of PLWHIV; b) conversations with service user representatives; c) consultation with specialist service providers; d) in-depth one-to-one semi-structured interviews with a sample of seven people living with HIV.

The first phase of the research process aimed to identify the key issues affecting older PLWHIV and to ascertain the potential challenges that may be involved in the evidence gathering process and ways that these could be overcome.

Our researcher attended a forum at the Bloomsbury Clinic, Mortimer Market Centre, where she talked to older PLWHIV who are using health services in Camden. Fear of HIV-related stigma and discrimination and lack of spare time emerged as factors which may affect an individual's willingness to speak up regarding their HIV status.

To address this, it was clear that confidentiality and flexibility would be of the utmost importance in selecting research methods. For this reason, we chose to conduct one-to-one semi-structured interviews in private as part of the research.

Our researcher contacted seven organisations in Camden with specialist HIV knowledge for advice and guidance. These were: the Terence Higgins Trust, The FoodChain, Iain Charleston Centre at the Royal Free Hospital, African Health Forum, Open Age at AgeUK, Camden CAB and Positively UK.

Identifying appropriate interview subjects and achieving their consent to be interviewed proved challenging. Many PLWHIV do not feel comfortable sharing their experiences. To overcome this, our researcher spent many months developing relationships of trust with the different organisations and service users before progressing to the interview stage.

[2] Camden Council 2013.

In group meetings and in one-to-one conversations with patient representatives and specialist service providers at these organisations, she introduced the objective of the research. These discussions helped identify the appropriate themes of enquiry. Three patient representatives in the HIV sector helped to formulate the questionnaire that would form the basis for the semi-structured interviews.

Subsequently, in-depth interviews were conducted with a total of seven individuals who are living with HIV.

All the interviewees have been living with HIV for over 20 years. Five out of the seven individuals were diagnosed in the 1990s, and two individuals had been diagnosed with HIV in the 1980s. Three interviewees were patient/ user representatives from HIV clinics and specialist organisations in Camden.

Findings from the interviews were combined with responses gathered during the earlier group consultations and were summarised in topical sections. Several key themes emerged from the data analysis. These formed the basis for the seven recommendations.

A draft of the report and recommendations was circulated to participating organisations and their clients for comment and to ensure that the findings accurately represent the views of the people who participated in the research.

A copy of the questionnaire is attached as an appendix to this report (Appendix A)

What people living with HIV told us:

The different services are not well joined up and communication between different providers is often poor.

> *"PLWHIV who have multiple health issues have to go to many different places to access help, support and advice."*

Several people commented that there has been little progress in joining up services since the 1990s.

"In the 90s, I had a social worker who helped to join up services for me when I was ill, which was very helpful. This is now non-existent, and self-advocacy is different and much more challenging in the light of a person's multiple health needs."

"At the time of my HIV diagnosis in the early 90s there was no referral processes and no collaboration between voluntary community-based services and clinical services. Over 20 years on, the lack of engagement still exists today. It's a foolish and short-sighted gap."

"After being diagnosed HIV positive in 1997, at first, I put all my trust in my doctor to provide me with the right answers to my questions and the best information; I thought 'doctor knows best' and didn't bother reading up. Now I am sure to do all my research before accepting any prescriptions or medication."

Interviewees told us about the frequent lack of communication between different healthcare professionals and departments.

"I went in to see my clinician for my first appointment out of two, but he sent me away, apparently there was no point in me being there since this particular time-slot was meant to be the second appointment, not the first. To me, this mistake implied that there had been no communication between the departments, and that my records hadn't been shared as appropriate. It was a disempowering experience for me."

"When I moved house, I had to register with a new doctor. Despite my information being on record and sharable between GPs, my new GP hadn't looked at my details so I had to repeat everything about my health status. It was too much."

"How can information be best communicated and shared, to give the patient confidence knowing that their healthcare providers are communicating?"

"Patient-centred care, multidisciplinary team-work and communication - a community nurse specialist, a care worker and better technology - would all add to the equation for improved HIV health and social care services."

People living with HIV are sent back and forth between GPs and HIV specialist providers

We heard that there is a lack of understanding about HIV among GPs and among practice staff. People also told us that GPs often made assumptions that symptoms with which patients presented at regular appointments were related to HIV and should therefore be dealt with by HIV-specific services. At the same time, HIV-specialist services are unwilling to provide treatment for non-HIV related symptoms. The result is that patients are sent back and forth between services.

The challenge involved in understanding whether or not different symptoms are HIV-related was raised frequently by interviewees.

> *"A person loses confidence when they are sent back from their GP to their HIV clinic."*
>
> *"Better knowledge of HIV in non-HIV specific health services would have improved my care."*
>
> *"There is little awareness of HIV outside specialist care, and healthcare providers are unconfident in their knowledge about it."*
>
> *"It would be useful if information were available to indicate which GPs have some HIV specialist knowledge."*

Mental health services are not joined up to HIV services.

We heard that PLWHIV need easier access to mental health and emotional support services.

Interviewees said they would like more help finding out about where people with HIV can access support for mental health issues and relevant sources of information on psychological well-being in regards to living with HIV.

> *"There is no support for a medium level of mental health issues. Many service-users come in to access support around their mental well-being, where they will be listened to and not sent away."*
>
> *"Low-level issues of mental health are a real problem too - unrelated to old-age. 50 percent of the Bloomsbury clinic/Mortimer Market Centre service-users are seen about social issues because they can't access help elsewhere."*

"With my increasing mental health issues I have needed to reach appropriate provision to meet my psychological needs which has not been easy. This is because I have only been informed by my health advisors of medical and holistic venues where I am already professionally familiar, but I am not informed of the opportunities which are unfamiliar to me."

We also heard that the requirement to meet a high level "at risk" threshold for entitlement to mental health provision means that many PLWHIV are turned away.

"In June, I went to an on-call psychiatrist in an emergency situation, who, following my assessment, decided that I wasn't an immediate suicide risk, sent me away and told me that he would "get back to me". I felt that this was completely insensitive to my state of being at the time, and was incredibly under-prioritising."

"An individual living with HIV visited a mental health service but were not viewed as being 'at risk' by the professionals on duty. This was an obvious suicide threat which was not identified quick enough, and sadly, this followed with the individual killing himself."

Diversity among People living with HIV is not always recognised and there are not enough services that cater for the needs of people with multiple identities.

PLWHIV stressed that, in addition to their HIV status, they often identify with different user groups that have different needs (for example, older people, disabled, BME and LGBT.)

"Where does an individual living with HIV, who identifies with BME and LGBT groups, go for support and advice in the Camden and their own community, without fear of facing triple discrimination?"

"There is a definitive difference between the needs of a PLWHIV who is in their late 40s and a PLWHIV who is in their mid-60s. Being 'old' clumps together all these ages into one category, disregarding the personal needs attached."

"What services are there for different age groups of older people who are living with HIV?"

We heard that services need to recognise the different cultural perceptions and behaviours of different user groups.

> *"In African communities in African countries, you have to be very ill to use health services. So individuals who are positive are late to be diagnosed and to disclose. Individuals bring this cultural norm with them when migrating to the UK."*

> *"African communities often choose to manage their own issues with close families and friends."*

We also heard that separate needs such as physical and learning disabilities and special needs are not being addressed in HIV-specific organisations.

> *"In significant HIV organisations which do largely address the needs of PLWHIV in a range of ethnic communities, alternative needs such as physical and learning disabilities and special needs are not being met. Where are PLWHIV who are also living with a physical and/or learning disability meant to go instead?"*

People living with HIV need help to access to both specialist and peer support.

We heard that support networks are available but people are not always finding them, particularly when English is not their first language.

> *"As a specialist professional in HIV healthcare, I was already aware of the support networks and information available to me. However, for an individual not in my position, the experience is different – the information can be hard to find if you don't know who to approach and where to start looking".*

People told us that they need specialist support to understand complex and technical information regarding their HIV diagnosis in order to be able to care for themselves.

> *"Electronic consultation, like emailing patients and suggesting use of the internet following an HIV diagnosis, is not helpful. The information is often deemed useless and difficult to take in by an individual, if they are not supported in understanding the information at hand by a specialist."*

"Language becomes a barrier to understanding information, if a PLWHIV has come to the UK from another country and English isn't their first language."

People told us that being able to discuss their health issues (both HIV related and other) with another individual who has been through similar circumstances is very helpful:

"I am more likely to trust someone who can relate to my own experiences."

"There needs to be a PAL service specifically for PLWHIV in which individuals can come to terms with the information in front of them, whether this is following their diagnosis or filling out documentation regarding benefits etc."

"Peer support is important in primary care, as much as it is in secondary care."

People value support groups which are informal and feel safe:

"If I am attending a peer support group I want it to be somewhere I can relax, a group where therapies are available, there is a cooked meal and I can talk about what I choose, instead of being in a completely HIV focused conversation or session."

"I need a safe space where I can be myself, make friends, and not feel pressured about thinking of HIV all the time."

Stigma and discrimination against People living with HIV is common in healthcare settings.

Interviewees told us that they feel stigma and discrimination from their HIV providers and others in the community. This can affect self-confidence and deter people from accessing the services to which they are entitled.

"In one venue, I had to file a discrimination complaint twice because I felt that the behaviour of the junior doctor and nurse was prejudice towards me."

"In worst case scenarios people won't visit their health provider because they fear being stigmatised in an institute which isn't HIV friendly."

"I have found a dentist in Soho which is HIV friendly, and where the staff has been kind and non-judgemental."

"At a dentist, seven years ago, the staff insisted my appointment should be the last one of the day, so staff could sterilise the dentistry equipment following been used on me. I was expected to sit on a chair covered with tissue too."

Several people expressed unhappiness at having to disclose their status to reception staff at a GP surgery and with lack of attention to confidentiality.

"I went to the GP with my daughter, on arrival, the receptionist had my details up on the computer screen and my daughter read 'HIV' off the screen, and asked me "what is HIV?". I haven't told her about my status yet. The staff member should have known better, anyone in the waiting room could have seen my details on the computer screen or heard my daughter speak."

"There is anxiety around open disclosure in one's community, especially in local practices where you are more likely to know someone in the area or to be recognised."

"We should not be subjected to a forced outing at a GP surgery."

Many services in Camden area good and highly valued.

People living with HIV told us that many HIV services in Camden are good and highly valued by service-users. Our interviewees had lots of good experiences to report:

"Bloomsbury Clinic, Mortimer Market Centre has kept me alive because of their enquiring, teaching and diagnostic nature. They discover things that your GP has missed."

"Couple-counselling at the Bloomsbury clinic, Mortimer Market Centre and at PACE has been excellent."

"In regards to addressing psychological needs at the Bloomsbury clinic, Mortimer Market Centre, despite a long waiting list, referrals have been fantastic since patients' issues are dealt with quickly, easily and with little problems."

"The Margaret Pyke Centre is brilliant, and I have never had any problems using their services. The people are very polite, it is a first-class service."

Recommendations

Recommendation 1

Specialist HIV services and non-specialist services (including Camden's GPs) should improve integration in both service design and communication so that PLWHIV can benefit from care that is joined up.

Evidence: Patients who are living with HIV experience a "ping pong effect" as they are bounced back and forth between specialist and non-specialist services. This can result in poor care and poor health outcomes. It causes the patient to lose confidence in services and results in stress and distress. Different funding streams for the commissioning of specialist HIV services and of the primary care services provided by GPs should not be allowed to prevent better links between the two.

Recommendation 2

Education and training should be provided for GPs and other non-HIV specialist service providers to ensure a better understanding of HIV and of the needs of patients who are PLWHIV. Healthcare professionals who are not HIV specialists should be provided with guidance on likely HIV-related symptoms and helped to distinguish these from symptoms that are non-HIV related. Where there is limited understanding of HIV among non-HIV specialist services providers, an expert link could be provided by HIV specialist nurses.

Evidence: Lack of consensus or agreed protocols as to which and whether specific symptoms are HIV-related contributes to the "ping pong effect".

Recommendation 3

Links between mental health service providers and specialist HIV health care providers should be strengthened through improvements in system design and better communication, information sharing and signposting.

Evidence: PLWHIV told us that they would find it helpful if support for their mental health needs could be accessed in a well-coordinated way through their HIV care provider. The fact that PLWHIV may be physically well can obscure the extent to which their mental health needs may be associated with their HIV status and leave them with insufficient support from non-specialist providers.

Recommendation 4

The information and advice provided for PLWHIV about the range of services available in Camden should be centralised and be clearer, more consistent and more easily available. Up to date and consistent information about community services and peer support networks should be easily accessible for GPs and other providers who perform a signposting role.

Evidence: PLWHIV told us there are many good services in Camden but that they are often unaware of what is available for them and that the path by which they might access different services is disjointed and ad hoc. PLWHIV value peer support networks and would like more opportunities to access peer support in Camden.

Recommendation 5

There should be increased provision of mental health services in the community for medium to low risk patients who are PLWHIV.

Evidence: PLWHIV have a high likelihood of experiencing mental health issues. However, those who do not reach the "high risk" needs assessment threshold cannot get appropriate support.

Recommendation 6

HIV service providers should work to address the other co-existing barriers that may prevent some PLWHIV who have multiple identities from accessing services, for example, where PLWHIV are also older people, disabled, injected-drug users, BME and LGBT.

***Evidence*:** Service providers tend to focus on a person's HIV status as a primary identity. This can mean that other coexisting identities, needs and sensitivities get ignored.

Recommendation 7

Existing anti-stigma and discrimination regulations and guidance must be upheld throughout all healthcare settings. Procedures to ensure confidentiality around HIV status should also be more strictly followed, particularly in GP practices.

Management should ensure all staff are sensitized to different forms of stigma and discriminatory behaviour and adopt a zero-tolerance approach.

Evidence: People who are living with HIV and using services in Camden have reported prejudice, discriminatory treatment and being stigmatised by staff in primary and secondary health care settings. GP practice staff members do not always recognise the sensitivity accompanying HIV disclosure and sometimes fail to adhere to best practice guidelines around confidentiality.

Thank you!

References

Camden Council (2013) *Joint Strategic Needs Assessment 2013/4: Chapter 1*. Available at: http://www.camden.gov.uk/linear/ccm/content/social-care-and-health/health-in-camden/joint-strategic-needs-assessment-2012/chapter-1-demographic-chapter.en?page=2. (Accessed: 28/10/2014).

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Terence Higgins Trust (2013) Ageing: *50 plus*. Available at: http://www.tht.org.uk/myhiv/Your-rights/Ageing/50-plus. (Accessed: 28/10/2014).

Terence Higgins Trust (2014a) *What are HIV and AIDS?*. Available at: http://www.tht.org.uk/sexual-health/About-HIV/What-are-HIV-and-AIDS_qm_ (Accessed: 12th September 2014).

Definition: What is HIV?

The Human-Immunodeficiency Virus (HIV) affects the immune system in a way that destroys CD4 immunity cells so that an individual becomes less able to overcome illness, making them very vulnerable to other conditions. HIV is transmitted only via inner bodily contact with semen, urine, blood and breast milk. This can develop into Acquired Immune Deficiency Syndrome (AIDS) which is 'a collection of diseases' in the body[3]. AIDS is non-communicable meaning that it can only be acquired following an advanced HIV diagnosis.

[3] Terence Higgins Trust 2014.

Appendix: RESPONSES TO THE RECOMMENDATIONS

Healthwatch Camden has statutory powers to make recommendations to those bodies that are responsible for policy or for commissioning or providing health and social care services across Camden. In accordance with regulations, those bodies are required to respond formally and in public to any recommendations made by Healthwatch Camden.

By nature of the subject matter, the recommendations in this report speak to a range of different commissioning bodies and service providers in Camden. We shared our seven recommendations with all the relevant bodies but in each case we asked for a formal response only to those recommendations that are specifically relevant to the organisation concerned.

a) Response from Camden and Islington Public Health

Camden and Islington Public Health is the commissioner of sexual health services in Camden. Healthwatch Camden therefore asked for a specific response to Recommendation 4; Recommendation 6; and Recommendation 7.

Camden and Islington Public Health responded to our recommendations as follows:

This report by Healthwatch Camden is welcome and timely. It provides a helpful insight into some of the challenges for people living with HIV, particularly as they age. It echoes national reports about the experiences of being older and living with HIV, including the increasing prevalence of other long term conditions (both physical and mental health). There are a number of local recommendations as to how support can be commissioned and provided in a more joined-up and person-centred way.

There are a number of messages coming out of this report.

- *People feel that support services for PLWHIV could work in a more joined-up way.*
- *There is a need to improve the links between HIV specialist and non-specialist services, particularly highlighting links within the health service including other secondary care services and primary care.*
- *Support should be genuinely person-centred, recognising the multiple cultural, gender, sexual and other identities that make up the individual.*
- *People want to be able to access peer support, and specialist support where necessary.*

- *There are concerns about and examples of lack of confidentiality about HIV status and stigmatising behaviour that affect the confidence and experience of use of health services.*
- *It is positive to hear accounts about how high quality services in Camden can make a difference, create confidence and can empower PLWHIV.*

Public health and joint commissioning will be working together across Camden and Islington during 2015/16 to commission a range of sexual health services, where ***Recommendations 4 and 6*** *are particularly relevant. This includes psycho-social and other services to support PLWHIV, including peer support. The principles of integration, clarity and consistency will be at the heart of this process, and we will work with PLWHIV and professionals to design a pathway of services which is easy to use.*

A number of other recommendations relate more specifically to the commissioning responsibilities of NHS England (for example with regard to HIV treatment and care services and primary care) or Camden CCG (for example, general hospital, community health and mental health services), as well as directly to providers of services, but it is important that commissioners and services work together to improve the quality and experience of services and how they link together. We will work with those in other services to help bring down the barriers described in this report.

Sexual health contracts commissioned by the council will stipulate guidance around confidentiality, anti-discrimination and stigma in support of ***Recommendation 7****, including in those services commissioned directly from GP practices.*

Jonathan O'Sullivan

Camden and Islington Public Health

b) Response from the Camden and Islington Mental Health Foundation Trust

The Camden and Islington Mental Health Foundation Trust is the provider of mental health services in Camden. Healthwatch Camden therefore asked for a specific response to Recommendation 3, Recommendation 5 and Recommendation 7.

Camden and Islington Mental Health Foundation Trust responded to our recommendations as follows:

Thank you for sharing this report with the Trust in advance of its publication. The Trust welcomes the report and I thought it would be helpful to summarise the services we provide and the well-established links in Camden, which is relevant to Recommendation 3 or the report as well as the section on Mental Health which starts at page 8.

In Camden Substance Misuse Services, there is a long tradition of working closely with HIV services. We have a lead worker for blood borne viruses who offers testing to all new drug users who start treatment with our service. This worker has developed close links with local HIV services, in particular with Mortimer Market. This includes accompanying clients to appointments, liaising with HIV specialists around a client's management, and regular meetings with clinicians at Mortimer Market. Mortimer Market hold HIV assessment and follow-up clinics at the GP practice (SHIP) which is based at the Margarete Centre. These services are provided to both patients with new diagnosis as well as patients who have had HIV for many years. We have a small but significant cohort of clients who have been living with HIV since the 1980s and 90s. Doctors can liaise directly with the lead consultant at Mortimer Market – Dr Patrick French. The service also holds regular training events for our staff on blood borne viruses.

The specific reference in the report to the sad death of a service user is noted. All incidents of this kind are subject to a serious incident investigation, which seeks to establish the root cause of the incident and make recommendations for improvement.

*With regards **Recommendation 5**, which calls for an increase in provision of mental health services in the community for medium to low risk patients who are living with HIV, there are possible opportunities to examine this further with the development of primary care mental health teams, which are currently being commissioned in Camden.*

*You have also drawn my attention to **Recommendation 7** in relation to upholding anti-stigma and discrimination regulations and guidance. Whilst the report highlights this as a particular issue for GP practices, of course the Trust takes this very seriously and fully supports this recommendation.*

I hope you find these comments helpful and we look forward to discussing the findings of the report in more detail in due course.

Wendy Wallace

Chief Executive

Camden and Islington Mental Health Foundation Trust

c) Response from NHS England

NHS England is responsible for commissioning specialist HIV services and also commissions primary care services in Camden. Healthwatch Camden therefore asked for a specific response to Recommendation 1, Recommendation 2, Recommendation 3, Recommendation 6 and Recommendation 7.

We received two responses from NHS England — one from one of the Medical Directors for the London Region and another from the Regional Director of Specialised Commissioning for the London Region. Both responses are reported below:

i. Response from Regional Director of Specialised Commissioning for London Region

It was very helpful to receive the report, and to read your summary of the experience of people in Camden living with HIV.

As the lead commissioner for HIV treatment and Care within NHS England's Specialised Commissioning function in London I have sought to provide a response to recommendations: 1,3, 6 and 7 that were highlighted as being pertinent to NHS England. NHS England commissions HIV services from 19 Hospital Trusts in London and commissions against a national service specification, developed by the national HIV Clinical Reference Group (CRG).

NHS England endorses the ***Recommendations 1 and 2*** *fully, and we agree that the management of long term treatable conditions requires joined up care.*

- *This is recognised in the National Service specification where interdependencies are identified between HIV Treatment and care services and a range of specialist and no- specialist services (including sexual health and contraception services, mental health services, peer support services and primary care) in acknowledgement that robust care pathways need to developed and maintained across organisations.*

- *In acknowledgement of the need for integrated pathways, formalised networks are a key requirement of the National HIV service specification against which all HIV services are commissioned. London has 5 formalised HIV networks. As the networks continue to evolve the role of non-specialist services in these networks needs to be championed and a key objective to achieve.*

- *The BHIVA standards of care for people living with HIV (2013) cited in the specification also identifies the importance of networks as collaborations between service providers to ensure that people living with HIV have equity of access to appropriate care.*

- *The key objective of the London HIV service review has been to develop a service model of care that will enable the management of HIV as a long term condition. It has brought together stakeholders across the whole health economy and has included primary care as a key stakeholder. The primary care steering group has sought to gain consensus on the role of primary care in managing the non HIV needs of patients. This work has built on the foundation of GP registration and disclosure which remains at ~90% across London.*

- *There has been a key development that could enable improved primary care management of people with HIV. This is a GP / patient mobile phone application developed by our HIV provider in Camden at the Mortimer Market centre. The app is supported by 'decision trees' that enable primary care to work collaboratively with the HIV service in the optimal management of the patient. Such developments and technology offer great opportunities in co- management in going forward.*

- *The NHS England strategy 'The Five Year Forward View' identified organisational barriers as a key block in facilitating integrated care for patients. The future direction of travel for the majority of specialised services will be co-commissioning to address some of these key blocks and the piloting of some of the new care provider models that include combining general practice and hospital care into Primary and Acute Care Systems; or bringing general practice together with specialists into Multispecialty Community Providers.*

  Some of these will be going live nationally and London needs to review their applicability for HIV.

- *In London there has been a strong culture of collaboration between HIV and Sexual Health Commissioners born out of the HIV pathway that crosses multiple commissioning organisations.*
  - *The guide to system commissioning developed by PHE in collaboration with NHS England 'Making it Work' is a key commissioner's tool to work towards the avoidance of fragmentation of pathways.*

  https://www.gov.uk/government/publications/commissioning-sexual-healthreproductive-health-and-hiv-services

— *There are commissioning networks in London and in England enable commissioners to share best practice and raise areas of concern early in the piece with regards to pathway fragmentation as access to primary care services is essential.*

- *The non HIV needs of people living with HIV need to be addressed through the expertise of generalists and GP are essential stakeholders.*

- *NHS England continues to Support initiatives that drive GP interest and awareness of HIV as a long term condition.*

In response to ***Recommendation 3***

- *The BHIVA standards of Care for people living with HIV are referenced within the National Service specification against which all providers are commissioned.*

- *Standard 6: Psychological care sets out the requirement for care and support which promotes mental, emotional and cognitive well-being whilst sensitive to the unique aspects of HIV in acknowledgement of the higher rates of depression and other psychological problems in people living with HIV than the general population.*

- *The standard states that people with HIV should have access to services that assess emotional and psychological well-being, detect potential psychological problems and plan appropriate interventions and that these services should be provided by appropriately qualified providers. The key point being that the expertise that the clients require for their psychological care will not always be directly available within the HIV service and will require onwards referrals for appropriate assessment.*

- *Providers need to provide the assurance that they are managing the diverse needs of the patient optimally and where they do not have the specific expertise they need to provide access to that expertise.*

- *The work that commissioners do collaboratively across the pathways of care is essential here to ensure that the services commissioned by CCGs and Local authorities can meet the needs of all service users.*

In response to ***Recommendation 6***

- *HIV providers of Care and support should be in a position to identify the needs of the client through the needs assessments they undertake.*

- *However, as specialist providers of HIV treatment and care the management of some of the more individual needs of the patient could be*

out of the professional remit of the services and hence the requirement for onward referrals to other more appropriate services.

- *HIV Networks are key here to benchmark pathways across a geographical area.*

- *Case management has been discussed and is cited in the service specification as a mechanism to address these key issues.*

In response to ***Recommendation 7***

- *The NHS Constitution sets out standards and expectations on a wide range of issues, including anti-stigma and discrimination. This applies to NHS England in both its direct commissioning role and in its role of assuring CCGs. NHS England would strongly agree that anti stigma and discrimination regulations must be upheld.*

- *Standard 10 'Participation of people with HIV in their care' is a key resource in relation to this point.*

- *People living with HIV should not be exposed to stigma and have a right to discrimination free care.*

- *From a specialised commissioning perspective, we will raise this issue with our primary care colleagues within the organisation to address this issue directly.*

- *The option that patients should have in terms of choice of GP from 2015 onward will enable patients to take greater control over their primary care needs. However, commissioners and providers need to remain cognisant of the support patients/ service users may require to be empowered sufficiently to make these active choices and self-manage their condition effectively.*

Yours sincerely
Will Huxter
Regional Director of Specialised Commissioning (London Region)

ii. Response from Medical Director – NHSE London Region

Thank you very much for sending this report through. It makes very interesting reading. I have responded to each of your recommendations in turn.

Response to ***Recommendation 1***

I agree that improved communication between primary and secondary providers (with appropriate patient consent) can make an enormous difference to providing

a holistic service for all patients including PLWHIV. This is particularly important when co existing long term conditions increase complexity.

*Response to **Recommendation 2***

Educational modules are available either on line or at courses such as BASSH. Guidance documents have been produced by MedFash and by the Terence Higgins Foundation. Individual clinicians develop personal development plans and are encouraged to use PUNs and DENS (Patient unmet need and Doctors Educational Need) diaries to improve on areas identified during consultations. Annually this information is reviewed at the GP appraisal leading to a 5 yearly cycle of Revalidation.

*Response to **Recommendation 3***

In General Practice patients can be referred for IAPTs, an evidence based talking therapy. In addition self-referral is available. For more complex emotional or mental health concerns referral can be made to the Community Mental Health Team.

*Response to **Recommendation 4***

The excellent Camden CCG website has information for professionals and service users regarding referral pathways and external links

http://www.camdenccg.nhs.uk/gps/hiv-services

*Response to **Recommendation 5***

Please see response to recommendation 3

*Response to **Recommendation 6***

I agree that for all patients a tailored approach is necessary. Primary care services are well place to do this as there is often better continuity of care and an opportunity to build lasting relationships between the patient and the clinical team.

*Response to **Recommendation 7***

Confidentiality is a key part of Good Medical Practice, the GMC document which informs and guides all doctor's practice. The organisational aspects of General Practice including staff training and maintaining confidentiality in all parts of the practice is key. It is very important if PLWHIV have experienced discrimination or breaches of confidentiality that they are able to feed this back to the practice in order that this can be recognised and remedied.

Dr Henrietta Hughes

Medical Director NC/E Area Team (London Region)

d) Response from the Central and North West London NHS Foundation Trust

The Central and North West London NHS Foundation Trust provides HIV treatment and care services in Camden. Healthwatch Camden therefore asked for a response to Recommendations 1-7.

*Response to **Recommendation 1***

Determining what is HIV and what is not HIV-related is complex. The Bloomsbury clinic has strived to improve communication with primary care. The content of GP letters from the HIV service are very comprehensive and contain all diagnoses, allergies, medications and key blood tests and other investigations. In 2014, the service visited our top 10 local General Practices, and was congratulated on our communication. In addition the letters to General Practice now contain details of our direct phone line to speak to an HIV Consultant and a generic email address in which queries are dealt with within 3 working days. We have a telephone line for queries for patients and we also have a daily walk in service and out of hour's advice line.

CNWL are not commissioned to manage non HIV related medical problems and neither are we commissioned to make onward referral for non HIV related problems. Therefore asking patients to go back to their GP is part of the way that non HIV care is delivered.

We have a Patient Representative service that can help deal with patient anxieties and queries about how to access appropriate health care.

We acknowledge that the system may result in poor experience for some patients but the pathway is designed to deliver better health care and better health outcomes as the appropriately qualified healthcare practitioner deals with the issues within their area of competence. The Bloomsbury Clinic has systems in place to support both patient and GP management of HIV and to receive rapid advice on the HIV aspect of care.

Our psychology service offers a full assessment at referral, to establish whether psychological needs are specifically HIV related or best met by local mental health providers. In the event that patients agree to referral on, a full assessment

report is offered to facilitate a smooth transfer of care. Access to local psychological services is now available mainly through the IAPT (Increasing Access to Psychological Therapies) services within each borough. The majority of these are self-referral, making this much more accessible than in the past.

*Response to **Recommendation 2***

We contribute to the SHIP project. We gave talks at multiple GP Practices last year and at UCH departmental meetings. Whilst education is helpful it is often more helpful to be readily available to provide expert advice to anyone who needs it which we are committed to doing.

Our psychology service staff provides training through multiple pan London training programmes for psychological, medical and nursing colleagues. Where psychological assessment recommends referral into non-specialist service providers, consultation around HIV specific issues is offered, if required. In some cases, where specialist knowledge is required from both in-house psychology services and community mental health services, joint working can be considered (e.g. with local drugs services).

*Response to **Recommendation 3***

We have a well-established in-house psychology service and heath advisor team, working as part of our MDT. We have mental health guidelines for the care of PLwHIV, which recognise the importance of identifying psychological needs, even in our physically well patients, who may be seen less often within the clinic. We actively screen for psychological difficulties and when these are identified, offer a full assessment and appropriate referral. We also have drug and alcohol drop in services on site for patients with these specific concerns.

We also have three paid Patient Representatives, who offer individual support and signposting into a range of psychosocial services, including our in house teams. Our Patient Representatives are part of a more extensive service user network who offer a range of workshops, forums and courses which support psychological health and well-being.

All of these services are also promoted to patients through the newly diagnosed packs, information leaflets within the waiting areas and the Bloomsbury Patient Network.

We have an in house counselling and psychology team. We have up to date guidelines on how to refer to appropriate mental health services. We have given a grand round afternoon to CNWL psychiatry trainees and we have strong links with

recreational drug rehabilitation services. We have on-going in house training on mental health issues.

*Response to **Recommendation 4***

We have three trained Patient Representatives. One of their key roles is to signpost patients to appropriate services in Camden. Our health advisor team also have a significant role in identifying wider psychosocial needs and signposting into other services.

*Response to **Recommendation 5***

We offer a 'stepped care' approach to screening, assessing and managing psychological needs within the clinic, with interventions ranging from peer support, counselling to formal psychological therapy, depending on the level of need. Where needs are identified that do not require specialist HIV input from our in-house teams, we can refer into local mental health services. As detailed above, the majority of boroughs now have local IAPT services which were developed to provide support to individuals who have concerns but do not meet the threshold for the 'severe and enduring' mental health service. These are mainly self-referral, with relatively short waiting lists, therefore very accessible.

*Response to **Recommendation 6***

Our medical, health advisor and psychology assessments include questions about a patient's wider psychosocial context. Care plans are individually tailored to take into account personal needs. This may include access to interpreters, assistance attending appointments, easy read information or recommendations to MDT colleagues about any adjustments needs (e.g. for cognitive impairment). Shared care between services can be considered if appropriate (e.g. with rehab services, or palliative care) and we have a Community Matron in HIV who can visit patients in the community who require additional support. Regular contact with a patient's GP also ensures GPs co-ordinate with other services providing care.

In addition to this, we have developed some specialist services catering to specific populations, such as the Bridge Clinic for people with learning difficulties, the NCAT Service, for patients with neuro-cognitive impairments and outreach / in-reach clinics with our local substance misuse services.

We are mindful that our largest patient cohorts are men who have sex with men (MSM and BME communities, with an increasing proportion of patients over 50 and our services are designed and selectively promoted with this in mind. Our

extensive patient network runs workshops and forums on areas requested by the patients themselves, which cover topics from Growing Older with HIV to HIV and Spirituality. Our Patient Representatives have links with spiritual leaders from the main religious groups and can signpost patients if needed. Our three paid Patient Representatives themselves represent different demographic groups, from an Eastern European younger bisexual man, to an older white British gay man to a Black African mother of two.

We carry out regular audits of our patient group to enable us to compare trends in attendance from different populations and selectively target certain patient groups in future service developments.

*Response to **Recommendation 7***

Although issue is beyond the control of the HIV service but we do try and educate (see above) and facilitate good care of patients through communication with GPs. Within our own service we have clear trust policies around zero tolerance of any discriminatory or inappropriate behaviour and a culture which encourages staff and patients to report any concerns that they may have. Confidentiality is key to our services and discussed with every patient. Training around HIV stigma and other kinds of discrimination (e.g. LGBTQI) is provided regularly to our in-house staff and many of our staff provides training to non-specialist providers around the same issues.

e) Response from Health Education North Central and East London (HENCEL)

HENCEL is the provider of health education programmes in Camden. Healthwatch Camden therefore asked for a specific response to Recommendation 2 and Recommendation 7.

HENCEL did not make a response to our recommendations.

f) Response from the Camden Clinical Commissioning Group (CCG)

The CCG is a group of General Practices that work together to plan and design the local health services. The CCG commissions many of Camden's NHS health and care services, (although not the HIV services). Healthwatch Camden therefore asked for a specific response to Recommendation 1, Recommendation 2, Recommendation 4 and Recommendation 7.

The Camden Clinical Commissioning Group did not make a formal response to our recommendations. However, CCG Chair, Caz Sayer, responded to say:

I think it is a good and helpful report. As you are aware the CCG does not commission HIV services nor do we hold GP contracts but that does not need to stop us disseminating the recommendations and looking to see how we might assist in implementing them, particularly some of those that are more general (lack of integration etc.)