

# **REVIEW OF HIV CARE & SUPPORT PROVISION (LAMBETH SOUTHWARK AND LEWISHAM)**

**November 2011**

## **Executive Summary**

**Background and Rationale:** LSL Commissioners are in the process of reviewing and remodeling the HIV care pathway across prevention, treatment and care. A previous review of local HIV prevention identified normalisation and expansion of HIV testing and linkage to treatment as a local priority. It is now acknowledges that early diagnosis and access to treatment (which reduces onward transmission of HIV) are key components to a HIV prevention strategy. This subsequent project reviews local HIV care and support services to ensure that LSL provision is modernised to reflect the changing needs of HIV positive patients in line with epidemiological changes of HIV and biomedical advances of treatment. This review has involved a review of epidemiology, needs, evidence and local service provision. From this a proposed service model has been developed with identified commissioning intentions. This report presents the findings and proposals from the review for public consultation.

This project is accountable to a project steering group which reports to the LSL Sexual Health & HIV Programme Board. In addition, a Service User Reference Group has been set up to shadow the project steering group to ensure that the 'service user voice' is central to all stages of the review and will ensure co-production of the future landscape of services. Following consultation, final recommendations for future commissioning intentions will be made to Lambeth, Southwark & Lewisham Clinical Commissioning Boards and Local Authority Commissioners across LSL.

**Epidemiology:** Lambeth, Southwark & Lewisham (LSL) have exceptionally high levels of people living with HIV (PLHIV), which together consist of 11% of the national/23% of the London caseload of HIV patients accessing treatment. There are two key routes of infection across LSL, Men who have sex with Men (MSM) which is most common amongst white men and Heterosexual transmission which predominately affects Black African Communities. These populations have very different service usage, residency patterns and needs. MSM populations are the largest proportion of PLHIV in Lambeth and Southwark and predominately reside in the north of the boroughs, two thirds of these patients access care outside of LSL. In contrast, the Black African Heterosexual communities are more dispersed across the three boroughs and are largely congruent with the most deprived areas. Over three quarters of heterosexual PLHIV access care from local LSL treatment providers.

Treatment and biomedical advances have transformed HIV infection from a fatal disease to a chronic condition. Today, people diagnosed and treated in the early phase of HIV infection can expect a near normal life span and experience fewer side effects compared to previous treatment regimes. What this means is that there is a growing population of people living with HIV who are relatively well and likely to live older. There is therefore a drive to develop models of care for HIV in line with other long term conditions. Late diagnosis continues to be the most important factor associated with HIV-related morbidity and mortality and is a significant concern across LSL where just under half of new diagnoses are diagnosed late.

**Review of Evidence & Need:** The review of evidence highlights the paucity in evidence that exists in relation to cost effectiveness of HIV care & support services. However, there is stronger evidence base for interventions focusing on adherence, case management, psychological interventions, and peer led

programmes. Needs of PLHIV also cross the spectrum of generic health and social care needs and specific HIV related needs. It is recognised that the needs of Black African and MSM communities differ and that individual needs change at different points/life events along the disease progression. i.e. diagnosis, start of treatment, pregnancy, development of a morbidity etc. Therefore services need to be targeted and responsive to such significant events.

**Service Review:** The service portfolio reviewed within this project includes a range of statutory and voluntary sector services providing specialist HIV care and support services (not including specialist HIV treatment services which are commissioned by the London Specialist Commissioners and subject to a London wide review). Stakeholder engagement, mapping of services and analysis of current service provision has been completed to inform this service review. This process has identified key themes or issues of concern amongst the current service provision. These include a lack of defined care pathways resulting in difficulty navigating the system and consistency in access to care, lack of clear thresholds of care amongst specialist services, duplication across services and case management functions, and a tendency to rely on specialist services for PLHIV resulting in inequality of access to mainstream health & social care services. In conclusion, a need has been identified for improved access to mainstream services, more effective use of specialist services/resources, better defined care pathways and thresholds of care, and stronger commissioning based on outcomes related to the changing needs associated with varying stages of the disease progression.

**Proposed Service Model:** Taking this forward, commissioners have developed a proposed service model to modernise services to reflect the changing needs of PLHIV and address the issues identified through the service review. This has enabled identification of future commissioning intentions.

The proposed service model aims to deliver the following principles:

- Ease of navigation across services through clear defined and well published care pathways
- Use of appropriate levels of care in response to the individuals needs during the progression of their disease
- Equality of access to mainstream health & social care services
- Effective and appropriate use of resources
- Shift of care from specialist services into generic provision (with support) where clinically appropriate
- Phased implementation of the new system to ensure continuity of patient care and sustainability of specialist knowledge and skills

The service model has been broken down into four specific components: accessing care, improving access to mainstream services, provision of interim specialist support services to facilitate the mainstreaming of HIV as a long term condition, and specialist services for specific HIV related needs.

These components of the service model have been briefly detailed below:

*i) Accessing Care:*

- *Assessment:* As first point of contact following diagnoses, HIV treatment centres are considered the lead agency for an individual's holistic assessment. The proposed

service model suggests that where possible (and patient consent is given) this assessment should be shared and used by other care & support agencies to minimise the need for duplication of assessments, requiring only service specific further assessment questions. This will require the development of a multi-agency confidentiality and information sharing protocol across all LSL (or potentially London wide) commissioned services.

- *Case management:* There is a need for the development of a clear case management protocol agreed across LSL which clearly defines responsible agencies to lead on case management, it is proposed that GP's should take the default case manager role (unless registration/disclosure is an issue), shifting to either HIV specialist treatment services or other Specialist HIV services (i.e. HIV Community Nursing) where these agencies are more actively involved in an individual's care.

ii) *Access to mainstream services:*

This report proposes that mainstream health and social care services should be considered the primary option for all non-complex care needs of PLHIV. The model specifically identifies access to primary care, mental health, community services, intermediate and palliative care as care needs that should be prioritised for improved access to mainstream services. This will require varying degrees of service redesign across these care pathways which may include raising awareness amongst specialist HIV agencies as referring agents, development of referral protocols, and training and development of the workforce within mainstream health & social care services. Implementation Plans will need to be developed across each care pathway and the development of shared care arrangements across primary care and specialist HIV treatment services will be prioritised within this programme of work

iii) *Provision of interim specialist support services to facilitate the mainstreaming of HIV as a long term condition:*

There is a long term commitment to ensure PLHIV have appropriate and equitable access to mainstream health and social care services in line with other long term conditions. However, it is acknowledged that this change in culture and shift of care pathways will take some time. It is therefore proposed that certain specific care needs will require specialist resources during a development phase but that these services are interim services that will be decommissioned over time as mainstream pathways become embedded. The care needs identified for this specialist resourcing in the development phase include: counselling/low level psychological support for mild and moderate anxiety and depression, specialist mental health services for PLHIV and day care services for physical rehab.

iv) *Specialist services for specific HIV related needs:*

It is recognised that there are specific HIV related needs, specifically at significant points of an individual's disease progression or with complex patients, which require specialist services that cannot be provided within mainstream health & social care. It is therefore proposed that such specialist services remain an essential part of the local service models.

The following services are considered essential services:

- Specialist HIV treatment services (responsible for prescribing of anti-retro viral treatment and other medical interventions)
- Specialist advice & advocacy services for PLHIV (acknowledging the complexity and discrimination involved with PLHIV accessing health & social care services)
- Specialist Peer Led/Mentoring Programmes for PLHIV (commissioned with clear health & social care outcomes such as expert patient programmes, newly diagnosed courses, and positive self management)
- Specialist Family Support for PLHIV (providing support to pregnant women and a holistic family approach to families infected and affected by HIV), Specialist Community Nursing Services for PLHIV (providing intense case management and community nursing services to complex patients)
- Specialist services for HIV related cognitive impairment (providing specialist HIV related cognitive impairment interventions).

In addition to these specific services a number of core standards have been identified as a requirement for all commissioned specialist HIV services, these include adherence, disclosure, discrimination, confidentiality, safer sex and working with cultural and faith specific issues related to HIV.

Implementation of this service model through specific care pathways has been developed for four defined patient pathways 'newly diagnosed', 'stable', 'co-morbid' and 'complex social problems' which identify patient journeys according to service user needs. These pathways identify specific needs for each patient profiles and identification of which services are commissioned to respond to which needs.

It is acknowledged that this service model sits across a number of responsible commissioners including specialist HIV commissioners, local Sexual Health & HIV commissioners, primary care commissioners and generic health and social care commissioners. This has significant implications for implementation and requires effective integrated commissioning across the care pathway. Further work will be required across commissioners to ensure a shared vision for the local service model and specific implementation plans.

**Impact on Current Service Provision & Future Commissioning Intentions:** Following the development of the above proposed service model a detailed options appraisal was conducted on the current service provision to identify commissioning intentions for each of the existing commissioned providers. The options appraisal considered the risks and benefits of three options for each of the existing services within the reviewed portfolio; maintain status quo/no service change, remodel & redesign, decommission/re-commission. These options were discussed and preferred options endorsed by both the Project Service User Reference Group and Project Steering Group.

The table below summaries the endorsed recommendations for each of the current commissioned services reviewed within this project.

Summary of options appraisal of current service provision	
Current Service (Provider)	Recommendations for future commissioning:
CASCAID (SLAM)	<b>Remodel &amp; respecify</b> to provide an interim service which support shift to & capacity building within mainstream services. Release efficiencies from immediate shift/decommissioning and plan for <b>phased reduction in service/contract value</b> . Future direction of travel to explore need for specialist service to provide HIV specific Mental Health Services not delivered in mainstream mental health services such as HIV related cognitive impairment services
HIV CNS (GSTT Community Services)	<b>Remodel &amp; Respecify</b> to ensure delivers to most complex services focusing on hospital discharge planning, provision of step down community nursing packages, case management of co-morbid and complex social issues, complex adherence programmes. Review case mix and required capacity for services in line with remodelling, <b>potential reduction in contract value</b> .
Family Support (Positive Parenting & Children)	<b>Remodel &amp; Respecify</b> , maintain contract value but respecify to improve outcomes and focus existing service.
Mildmay Residential & Day Care (Mildmay)	<u>Inpatient HIV related neuro-cognitive impairment (HNCI):</u> <b>maintain status quo</b> of cost & volume arrangements and placement panels. <u>Outpatient HNCI:</u> <b>maintain status quo</b> of cost & volume arrangements and placement panels. <b>Potential to reduce activity</b> levels through shift to CASCAID/existing community physical rehab services. <u>Inpatient Physical Rehab:</u> <b>maintain status quo</b> of cost & volume arrangements and placement panels. <b>Immediate Reduction in activity</b> levels through shift to intermediate care services with intention to <b>decommission</b> over time <u>Outpatient Physical Rehab:</u> <b>maintain status quo</b> of cost & volume arrangements and placement panels. <b>Immediate reduction in activity</b> levels through shift to community rehab services/CNS with intention to <b>decommission</b> over time
Muslin Peer Support (AAF)	<b>Decommission</b> existing provision, consolidate with other peer support, <b>Recommission:</b> design and tender for new peer led/mentoring programme.
Christian/Faith Based Per Support (LEAT)	<b>Decommission</b> existing provision, consolidate with other peer support, <b>Recommission:</b> design and tender for new peer led/mentoring programme.
First Point (Metro- SLHIVP)*	<b>Decommission</b> , mainstream assessment & referral service in Specialist HIV treatment services.
Advice & Advocacy (THT- SLHIVP)*	<b>Decommission &amp; recommission</b> advice & advocacy service
Counselling (THT- SLHIVP)*	<b>Decommission &amp; recommission</b> interim service with <b>phased reduction</b> and <b>intention to decommission</b> over time
Health Trainer (THT-SLHIVP)*	<b>Decommission</b> , mainstream provision through specialist HIV treatment agencies/Health Advisors/Peer led newly diagnosed programmes
Peer Support (THT- SLHIVP)	<b>Decommission</b> existing provision, consolidate with other peer support, <b>Recommission:</b> design and tender for new peer led/mentoring programme.

Recommendations for service developments and commissioning intentions have been highlighted throughout the report. The table below summaries how the proposed service model will be implemented under the three key components of the model: Improving Access to Mainstream Services, Provision of Interim Specialist support services to facilitate mainstreaming HIV as a long term condition, and Specialist services for specific HIV related needs.

<b>Commissioning Intentions associated with the proposed service model</b>		
<b>Services</b>	<b>Delivery Mechanism</b>	<b>Financial Implications/ funding source</b>
<b>i) Improving access to mainstream services</b>		
Primary Care	Pilots of 'shared management' to: <ul style="list-style-type: none"> <li>Improve access to primary care services</li> <li>Develop involvement in case management</li> </ul>	<ul style="list-style-type: none"> <li>Cost neutral</li> <li>Potential need for pump priming</li> </ul>
Mental Health	Shift of activity from specialised services to: <ul style="list-style-type: none"> <li>IAPT</li> <li>Community Mental Health Services</li> </ul>	Potential need for transfer of resources from specialist HIV services to mainstream services
Community Services	Access to mainstream services	Potential need for transfer of resources from specialist HIV services to mainstream services
Intermediate Care	Access to mainstream services	Potential need for transfer of resources from specialist HIV services to mainstream services
Palliative Care	Access to mainstream services	Minimal activity hence expected to have no significant cost pressure
<b>ii) Provision of interim specialist support services to facilitate mainstreaming HIV as a long term condition</b>		
Counselling	Potential renegotiation of existing provider/Tender for new service	Reduction in existing contract value
Specialist Mental Health Services for PLHIV*	Redesign/Respecify	Reduction in existing contract value
Day care for physical rehab	Maintain cost & volume arrangements with reduction in activity	Potential for reduction in existing contract value
<b>• Specialist services for specific HIV related needs</b>		
HIV Treatment Services	Service Improvement through specialised commissioning	To be included in costs under national tariff, potential for short term funding
Advice & Advocacy	Potential renegotiation with existing provider/Tender for new service	Within existing contract value
Peer Led/Mentoring Programme	Tender for new service	Need to cost up new service, shift of £86k from existing peer support provision
Family Support	Redesign/Respecify	Maintain existing contract value
HIV Community Nursing Services	Redesign/Respecify	Potential for reduction in existing contract value
Community & Inpatient HNCI	Maintain cost & Volume contracting arrangements	Within existing contract value

\* Future work is required on assessing the need for community services for HIV specific Mental Health needs ie. HNCI long term

**Financial Implications:** It is not yet possible to ascertain accurate financial implications of the proposed service model and this is further work which will be undertaken during the consultation process. No additional cost pressures are envisaged as a result of the proposed recommended service changes. The initial financial assumptions regarding the proposed service changes have been highlighted in the table above outlining the proposed commissioning intentions.

Key areas that require immediate further work include:

- Scoping of potential efficiencies to be released from shift of activity over three years
- Efficiencies released from decommissioning and redesign of services
- Cost of shifted activity in mainstream services
- Costs of re-tendered service provision

It is recognised that there is potential to release productivity and efficiency savings from the proposed service changes. Such efficiencies will be prioritised in the following areas:

- Reinvestment in the expansion of HIV testing as the key HIV prevention strategy across LSL
- Investment in mainstream services to increase capacity required to manage with shift from specialist HIV services to mainstream services
- Reinvestment into the HIV care pathway to manage growth in new infections
- Efficiencies required as a reduction to the Comprehensive Spending Review

**Consultation Process:** The service model and commissioning intentions proposed in this report are open for three months public consultation from the 7<sup>th</sup> November 2011 until 6<sup>th</sup> February 2012. A list of consultation questions can be found in the report which stakeholders are invited to comment on. As part of the consultation process six public events targeted at stakeholders, patients and public are being held across LSL on the following dates:

- 9<sup>th</sup> December 2011, 9.30am-12.30pm, Guys Hospital, Robens Suite, 29th Floor, Tower Wing, SE1 9RT
- 12<sup>th</sup> December 2011, 2-5pm, Assembly Rooms, Lambeth Town Hall, Brixton Hill, SW2 1RW
- 13<sup>th</sup> December 2011, 9.30am-12.30pm, Committee rooms 1 & 2, Civic Suite Lewisham Town Hall, Catford, SE6 4RU
- 5<sup>th</sup> January 2012, 6-9pm, , Guys Hospital, Robens Suite, 29th Floor, Tower Wing, SE1 9RT
- 9<sup>th</sup> January 2012, 6-9pm, Assembly Rooms, Lambeth Town Hall, Brixton Hill, SW2 1RW
- 10<sup>th</sup> January 2012, 6-9pm, Committee rooms 1 & 2, Civic Suite Lewisham Town Hall, Catford, SE6 4RU

In addition, focus groups are currently being arranged across LSL to ensure effective engagement with PLHIV. An initial Equality & Equity Impact Assessment Screening has been completed which will be expanded on in more detail during the consultation phase.

A list of consultation questions can be found in section 6 of this report. All consultation responses should be emailed to [Patricia.Riley@lambethpct.nhs.uk](mailto:Patricia.Riley@lambethpct.nhs.uk) by 5pm on 6<sup>th</sup> February 2012.