

Commissioning London's HIV Services

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Executive Summary

The number of people living with HIV in the UK is estimated to be 86,500, representing a threefold increase over the past decade. Over half of all cases are in London. The NHS spends around £550 million on HIV treatment per year, with estimated HIV-related lifetime costs for diagnosed patients ranging from £280,000 to £360,000.

This report focuses on the commissioning of HIV services in London, documenting the findings of semi-structured interviews conducted with key stakeholders in late 2010. It carries particular relevance given the intention of government to transfer commissioning responsibility from Primary Care Trusts to clinical commissioning groups.

The report found a fairly broad consensus on how the commissioning of HIV services should be organised in London; and on the future model of HIV care:

- The role of testing seen as a mechanism for preventing advanced cases of HIV, with far more testing done in settings such as general practice and A&E as well as GUM clinics.
- Greater primary care input, with HIV patients registering at general practice, and the development of care pathways stemming from general practice.
- HIV units providing outpatient HIV care for patients with uncomplicated HIV infection.
- Single-site or cluster HIV centres to provide complex outpatient and inpatient care (suggestions ranged from having between three and seven units across London).

This model reflects the changing nature of HIV which, for many people, has become a 'stable', long-term condition.

However, the report uncovered significant, and worrying, gaps between this ideal and the reality: a fragmented, hospital-based service. As one HIV consultant put it: 'if you were going to design services for London, you wouldn't come up with this'.

- There is a lack of coordination in the commissioning of the different types of HIV services; in the strategy and practice of the different bodies doing the commissioning; and the relationship between HIV and mainstream acute commissioners. Patients receive fragmented services.
- Governance both within and across HIV commissioning bodies is poor; lines of accountability are ill-defined; and the quality of leadership has much to be desired. Service specifications fail to follow evidence-based practice; and quality and value for money is inadequately monitored.
- Clinical networks are underdeveloped in many parts of London, particularly the North-West and North-Central regions. Quality is not systematised.

- There are numerous vested interests in the status quo – consultants, hospital trusts, GPs, patients and government – that prevent HIV services moving from a hospital-based model of care, towards the future model (above). Patients receive much of their care in inappropriate high-cost settings.
- Commissioners, for their part, have lacked gumption in taking difficult decisions, particularly around decommissioning services. They have been able to duck decisions due to expanding budgets and have preferred the benign option of another ‘review’ to action. Too many patients continue to go to services that are providing substandard care.

The report makes a number of recommendations to resolve structural, governance and skills issues (p. 16) in the commissioning of HIV services in London.

It also raises concerns on the risk, uncertainty, delay, and possible fragmentation that may result from the shift in commissioning from PCTs to clinical commissioning groups.

The most pertinent observation, however, is that – in the words of one HIV consultant interviewed for this study – commissioners must ‘take some balls’ and start to reconfigure services; a task that must include the decommissioning of those providing poor quality. If they fail to do so, it is patients who will suffer.

Introduction

HIV is a major public health challenge. The number of infected individuals in the UK continues to grow, bringing personal suffering and significant social and economic cost to society. Over half of all reported cases of HIV in the UK are in London. In the current climate in which NHS and social care budgets are under strain, the imperative must be to ensure that services commissioned to meet growing need are both the right ones (i.e. in line with best practice) and offer excellent value for money.

This report sets out to review how effectively HIV services are being commissioned at both a local and regional level in London, focusing on care and treatment, but encompassing all services. It suggests what needs to change both to improve the service for patients and provide greater value for money – particularly as responsibility for commissioning shifts from Primary Care Trusts (PCTs) to clinical commissioning groups under Coalition Government plans announced in the White Paper *Equity and Excellence: Liberating the NHS*.

Background

HIV in the UK

HIV, a lifelong and potentially fatal condition, impacts on lifestyle, relationships, work, income, health, well-being and life expectancy.¹ It carries significant personal and social costs and represents one of the most serious public health challenges facing the UK.

The number of people living with HIV in the UK is estimated to be 86,500, representing a threefold increase over the past decade.² If such rates continue, there could be as many as 150,000 infected individuals by 2015.³ As things stand, just over a quarter of people currently infected with HIV (22,200) are thought to be unaware of their infection. In 2008, fifty-five per cent of people who were diagnosed with HIV were diagnosed late, a factor associated with poorer prognosis and higher costs in both the short and long-term.⁴ In total, the NHS spends around £550 million on HIV treatment per year, with estimated HIV-related lifetime costs for diagnosed patients ranging from £280,000 to £360,000. Had all the UK-acquired infections newly diagnosed in 2008 been prevented, there would have been a saving of approximately £1 billion in direct healthcare costs.⁵

Although overall prevalence is low (1.4 per 1,000, 15-59 years), two groups – men who have sex with men and Black Africans – are disproportionately affected. Geographical variation in the prevalence of diagnosed HIV infection is substantial. London, Brighton and Manchester are the cities with the greatest number of infected individuals, but over half of all cases are in London (overall diagnosed prevalence of 5 per 1,000, 15-59 years). Within London, diagnosed prevalence varies between 1.2 per 1,000 in Havering PCT and 12.9 per 1,000 in Lambeth PCT (both 15-59 years).⁶ It is on London that this study focuses.

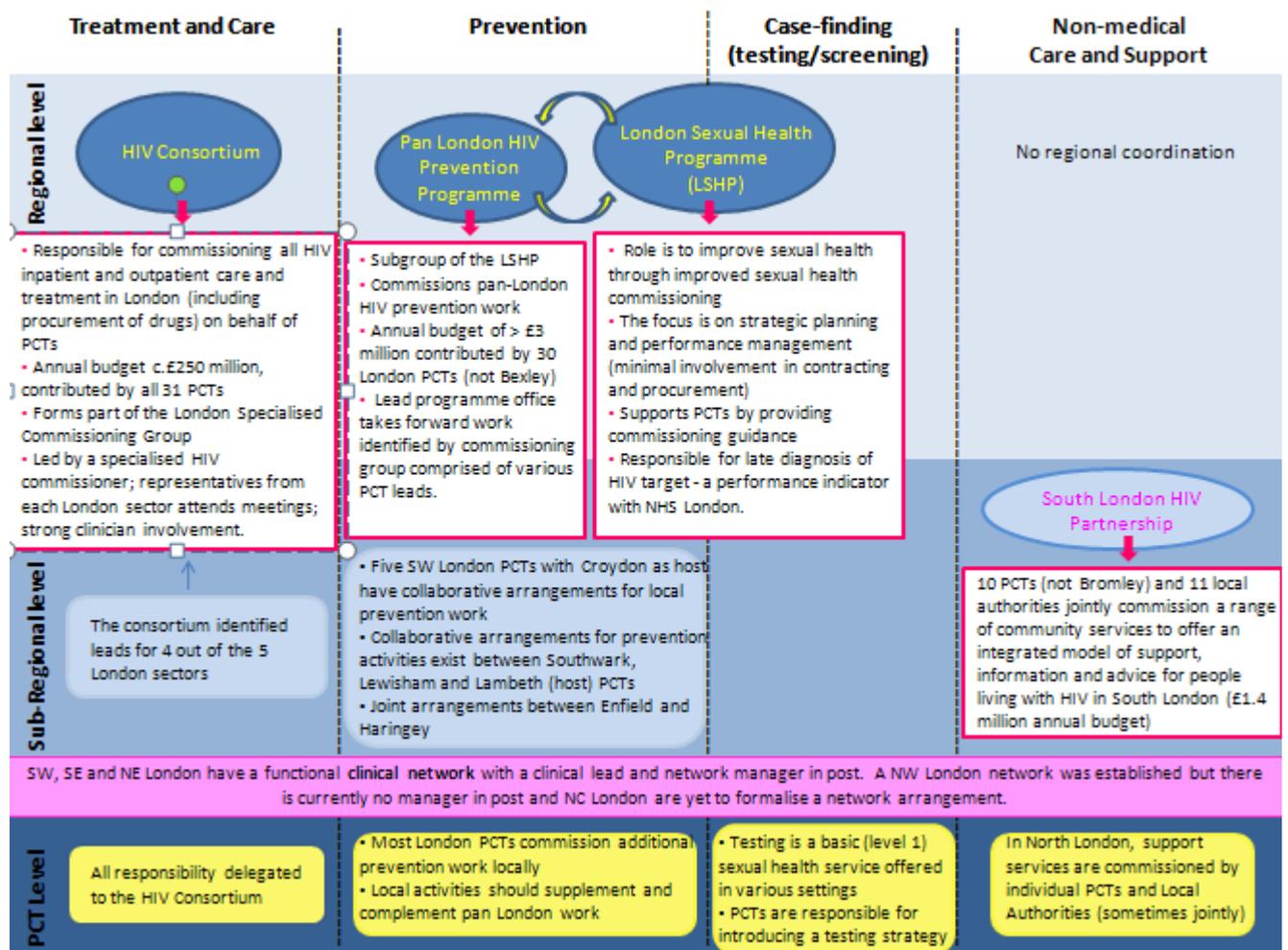
Commissioning arrangements for HIV services in London

As the consultation document on the NHS White Paper *Liberating the NHS: Commissioning for Patients* recognises, ‘one of the most fundamental responsibilities in the NHS is to decide what services will best meet the needs of patients and local communities and to commission these services in ways that ensure high-quality outcomes, maximise patient choice and secure efficient use of NHS resources’.⁷ The actions of commissioners in monitoring providers and changing patterns of service provision should have a profound impact on patient care. This report focuses on the *commissioning*^a of HIV services in London, focusing on care and treatment, but encompassing all services.

Commissioning structures for HIV services in London (2010) are shown in Fig. 1.

^a Commissioning is generally defined in the NHS as the process of ensuring that the health and care services provided effectively meet the needs of the population. The Department of Health describe it as ‘a complex process with responsibilities ranging from assessing population needs, prioritising health outcomes, procuring products and services, and managing service providers’. We adopt this definition in this paper.

Fig.1. Commissioning structure for HIV services in London (compiled by authors)



Paediatric HIV care and HIV inpatient care are classified nationally as ‘specialised’ services; by default they are commissioned at a regional level. However, in London, outpatient HIV services are also commissioned at a regional level (although, here, PCTs hold statutory responsibility). This work is carried out by the London HIV Consortium. A large amount of prevention work, too, is commissioned at a pan-London level, but this time by the London Sexual Health Programme and Pan-London HIV Prevention Programme (though, again, PCTs hold statutory responsibility). This is supplemented by prevention work, screening and non-medical care and support commissioned directly by PCTs and groups of PCTs (and local authorities in the case of non-medical care and support) at a local level. Exact arrangements, however, do vary across London.

Under plans laid out in the NHS White Paper, *Equity and Excellence: Liberating the NHS*, PCTs will be abolished and replaced by clinical commissioning groups. Paediatric HIV care and HIV inpatient care, being designated ‘specialised’ services, will be commissioned at a national level by the NHS Commissioning Board. The commissioning of all other HIV services, including outpatient, will be the responsibility of clinical commissioning groups, with local authorities taking over much responsibility for prevention.⁸

'Best practice' in commissioning of HIV services

The National Strategy for Sexual Health and HIV (2001) sets the overarching goals for tackling HIV in England.⁹ These are to: reduce the transmission of HIV; reduce the prevalence of undiagnosed HIV; improve health and social care for people living with HIV; and reduce the stigma associated with HIV.

Supporting these goals are a number of key documents outlining best practice in the commissioning of HIV services. The most prominent are: the Department of Health (DH) toolkit for the effective commissioning of sexual health and HIV services (2003); the MedFASH recommended standards for HIV services (2003); and the BHIVA Standards for HIV Clinical Care (2007).¹⁰

However, reports consistently have found a disjuncture between the national strategy agenda and the realities of commissioning practice. Common themes include: variable and insufficient capacity, expertise and skills on the part of HIV/sexual health commissioners; a lack of needs-led commissioning, with a preference for maintaining the status quo; a lack of monitoring and evaluation of services; inadequate use of evidence-based service specifications; a lack of joint commissioning; poor understanding of the role of service networks in integrating services across pathways; inadequate involvement of service-users; and a lack of attention to accountability arrangements.¹¹ The London Sexual Health Needs Assessment and Service Mapping project (2009), carried out by MedFASH, concluded: 'the lack of consistent use of commissioning best practice, in particular the development, implementation and monitoring of service specifications, would suggest that PCTs in London are not always maximising value for money in terms of investment and outcomes'.¹² Service provision and outcomes vary widely; higher spending does not equate to better outcomes.

Aims and objectives

Most of the work looking at HIV commissioning has been done through surveys. The aim of this study was to obtain the views of key stakeholders as to the state of HIV commissioning in London, delve into reasons for any substandard performance, and inform the debate on what needs to change to improve the quality of commissioning and, by implication, quality of care for patients. The latter points were considered particularly pertinent in light of the reforms to commissioning proposed in the Coalition Government's White Paper *Equity and Excellence: Liberating the NHS*.

Methods

Semi-structured interviews were conducted with key stakeholders (n=9), including: lead commissioners for both pan-London, sub-regional and local commissioning groups; prominent HIV consultants; and managers of clinical networks. Interviews were recorded with consent and transcribed within three days of being conducted. The transcripts were read through several times in order to become familiar with the data and subsequently coded. The results are presented according to themes that arose from the data.

Results

The 'ideal' model

Interviews with stakeholders revealed a fairly broad consensus on how things *should* be done, or *could* be done better, in terms of HIV commissioning structures and HIV services commissioned in London.

HIV commissioning structures

There is a basic understanding that HIV commissioning does not lend itself to a 'one-size-fits-all approach'. Some services – namely specialist care and treatment, and some prevention and case-finding services – are pan-London or regional in their scope, and hence thought to require pan-London or regionally-based commissioning.

'I think it would be a mistake not to have things organised on a pan-London basis. Treatment and care should be done by specialised commissioners. There is so much money involved and so much risk. I think you need to manage that risk across a large group of people.'

Particularly pertinent here is the additional bargaining power a pan-London approach confers in the procurement of anti-retroviral drugs; and the ability to effectively manage the public health nature of HIV.

Other services – namely more locally targeted prevention, case-finding services and non-medical care and support – are more local in their scope, and hence considered more appropriately commissioned at a local level by PCTs and/or local authorities. One lead commissioner said:

'It makes absolutely no sense from a transaction point of view for each individual PCT to try to deliver what pan-London does... but I think it [prevention work] will always need to have a local flavour... [for example] targeting African communities particularly is quite difficult to do on a pan-London basis- 1) because of the huge number of African communities we have and 2) there are greater proportion of certain African populations within different boroughs. From that point of view I think testing is the same.'

A programme manager summarised:

'Ideally in a place like London you need to be thinking about commissioning at a range of levels... that are fit for purpose depending on the planning population, issues around equity of access, equitable provision and equitable cost.'

The 'ideal' structure described is not dissimilar to that which currently exists (see Fig.1, p.3), although a few made the case for integrating the pan-London bodies: the HIV Consortium, pan-London HIV Prevention Programme and London Sexual Health Partnership.

The more important point made by interviewees, though, is that there needs to be effective coordination between regional and local commissioners, in order to link pathways of care in the continuum from prevention, to testing, to treatment, and non-medical care and support – perhaps through merged budgets and ‘whole pathway’ commissioning. Many interviewees drew a clear link between fragmented commissioning and fragmented service provision. One lead commissioner suggested the use of an assessment framework to inform this:

‘There should be a service specification that may well include, and certainly describe, the interface [of treatment and care] with prevention services, social care and voluntary sector support.’

The commissioning of HIV services

There was a consensus among respondents that HIV services should be judged against core standards in the care of HIV, in particular the British HIV Association’s published ‘Standards for HIV Clinical Care’ – written by health professionals with patient input.

Most perceived this, also, as leading towards a system based on:

1. The role of testing seen as a mechanism for preventing advanced cases of HIV, with a real need for greater testing in settings such as general practice and A&E as well as GUM clinics.
2. Greater primary care input, with HIV patients registering at general practice, and the development of care pathways stemming from general practice.
3. HIV units providing outpatient HIV care for patients with uncomplicated HIV infection.
4. Single-site or cluster HIV centres to provide complex outpatient and inpatient care (suggestions ranged from having between three and seven units across London).

The reasoning behind this was firstly that, for many people, HIV has become a stable, long-term condition, not typically requiring specialist consultant input on a regular basis. As one HIV consultant said:

‘I think ultimately it should be a GP model... [particularly] with the ageing cohort who need to see their GP for their hypertension, diabetes, asthma or whatever; we should migrate to their HIV care becoming part of all the other reasons they need to access healthcare.’

Secondly, that the complexity around inpatient and some outpatient HIV care demands the specialisation and concentration of services in centres of excellence. As one HIV consultant argued:

‘It’s not pleasant for somebody to say “your unit is not admitting inpatients. You will see somebody, assess them and then you will transfer.” Nobody wants to hear that but if you are not on call at night, you have to. You can’t hope that the foundation year doctor will have a go overnight and keep them alive until you pop in again in the morning... It is specialised and there are so few patients, you don’t need them scattered all over London.’

Supporting such configuration of services, interviewees highlighted the need for: benchmarking against agreed standards; closing services that consistently failed to meet agreed standards; and clear care pathways with managed clinical networks linking aspects of care together, defined by geography. As one commissioner argued:

'The vision is to have a model of care which meets the required standards, is forward looking in terms of the current and emerging evidence base for how you can treat patients.'

Barriers to change

The problem in London is that despite the broad consensus among stakeholders over a model for the HIV commissioning structure and configuration of services, there was equal consensus that the current situation in the capital is far from this ideal, resulting in substandard care for too many patients. As one HIV consultant wryly put it:

'If you were going to design services for London you wouldn't come up with this.'

Currently – in contrast to the 'ideal' model described by many interviewees – 23 hospital trusts deliver HIV outpatient services in London; ranging from small units that see 200 patients to larger ones catering for up to 6,000 patients. While nine hospital trusts are commissioned by the HIV Consortium for HIV inpatient care, others still provide this but bill on a case-by-case basis. Commissioners recognise that there is oversupply and variable quality; and that services are commissioned more on the basis of historic precedent than quality.

Headline problems and barriers to change include:

Integration of commissioning

Three related problems were raised around the integration of the commissioning of HIV services. Firstly, interviewees identified a lack of coordination between the commissioning of different types of HIV services: care and treatment, prevention and case-finding, and non-medical. One lead commissioner commented:

'I think the models that work within themselves are good but... there is a lot of isolation in terms of the agendas. Treatment and care sits very much around just treatment and care. HIV prevention sits very much around just HIV prevention. Although we've tried to break down some of the barriers between the health and social care element there are massive gaps between health and social care; prevention; and treatment and care. Certain commissioners sit on the same commissioning boards but with very different hats.'

Consequences of this, described by participants, include waste and negative impacts on continuity of care. One HIV consultant reported:

'We don't link to prevention at all really... We used to have much stronger relationships with the council– that would be five to seven years ago. As they've mainstreamed HIV care into adult social care the links have been weakened. We use... our local NGO [non-government

organisation]. They are only a mile down the road so we signpost people there for advice and support.'

The underuse of the South London HIV Partnership for non-medical care and support is a good illustration of such problems: there is duplication of services and only one-fifth of diagnosed patients in South London access the facility, despite reports of better quality and annual savings of two-thirds compared with other models. A lead commissioner said:

'One missed opportunity was being very clear about having commissioned this programme in South London, translating that into a contractual requirement for the care and treatment providers that they facilitated access of patients to that.'

Secondly, and causally related to the disconnection in the commissioning of HIV services, is the lack of integration between the strategies and commissioning activities of pan-London, regional and local commissioners (PCTs and local authorities). Particular challenges included the number of PCTs and local authorities (31 each) to coordinate and the different pathways each PCT has in place to commission 'across'. One lead commissioner commented:

'It gets complicated when you look at the nitty gritty. Let me reflect on the social care element. X and Y PCT have a CNS [Community Nurse Specialist], we don't... The care pathway in each borough is very different and bringing it together efficiently and getting consensus about what you provide would be a huge piece of work.'

A programme director reasoned:

'There are all sorts of locally enhanced services around chlamydia screening and HIV testing. They are all separate, they are all developed locally and they all have different financial incentives for remuneration... we need the consistency of a framework for how the services can be procured.'

Many reported particular difficulties for greater collaboration in commissioning (and, in turn, services) when funding streams are coming from different places. One lead commissioner reported:

'The HIV consortium sits within specialised commissioning and it deals with very, very big amounts of money. Whereas the prevention budget very much sits within PCTs. It's at their behest really. Non-medical care and support is a borough responsibility—so there is local authority and PCT funding that contributes. The different funding [streams] might have led to the way things have taken place or the way structures have become.'

Thirdly, there are issues in terms of the coordination of acute commissioning and HIV services. Many HIV inpatient and outpatient service specifications sit within acute contracts administered by non-specialist commissioners which HIV commissioners must seek to influence. Engagement between the two, with the possible exception of the Lambeth, Southwark and Lewisham Commissioning Alliance, is typically poor. As one lead commissioner said:

'I can't influence the acute contracting because I don't commission the acute hospitals. It is done on our behalf.'

Another described:

'We need to have some frame of engagement around how we influence expansion of HIV testing in a service that we don't directly commission. The way we would influence that is through quality work... lobby a yearly CQUIN^b around HIV testing... you need a high level of liaison and communication to be able to influence that.'

Governance, accountability and leadership skills

A significant part of the disconnection between HIV commissioning structures can be explained by poor governance, ill-defined lines of accountability and the quality of leadership. This applies particularly to the relationship between PCTs and pan-London HIV commissioning bodies; and most specifically to the pan-London HIV Prevention Programme, considered by most to be inefficient and failing to deliver value for money. As one lead commissioner said:

'I think one of the areas that have resulted in a lack of efficiency in the pan-London PP is we've never quite got our governance structures right... I feel it would be much better if the programme had a lead... and decisions are devolved to that lead. Clearly there needs to be a dialogue between that person and the PCTs.'

Another, speaking from the PCT perspective, detailed the consequences, documenting failures to follow evidence-based and outcome-focused service specifications and knock-on effects on the quality of prevention facilities available to the public:

'The programme hasn't given us practical things that we can use. It gets back to how the specification was set, how it was managed and that you have a three-year programme and when you don't have the right people in place at the beginning, the contract is not monitored properly, the contract is not discussed and renegotiated properly. If these things are not working you need to sit down with the provider and say what can we do to change and make this work? Those practical things didn't happen.'

Problems, however, are not confined to the pan-London HIV Prevention Programme. The original intention of all three pan-London commissioning organisations (the HIV Consortium, the London HIV Prevention Programme and the London Sexual Health Partnership) was to have a governance structure based on a lead commissioner from each of the five London sectors (NE, NW, NC, SW and SE) sitting on the commissioning board and carrying the vote of that sector. In reality, this does not appear to have happened. The HIV Consortium, for example, was unable to identify any representative for one area of London; some commissioning leads on the board described themselves as representing a single PCT or areas smaller than that of a sector; and decisions made in

^b CQUIN is a scheme by which a proportion of a secondary care provider's income is dependent on meeting particular quality standards.

absence of certain (usually clinical) members would often be changed on their return. One interviewee commented:

'If [certain] clinicians aren't at the meeting [of commissioners] and don't approve of what you have decided then it will get changed at the next one.'

The make-up of the London HIV Prevention Programme's board, too, was described by one interviewee as 'a bit messy', with some lead commissioners only having the authority to vote on behalf of their PCT. Interviewees also described battles between those tending towards representation based on an equal geographic spread and those tending towards representation based on prevalence.

Clinical networks

There are clinical networks in operation (with both a network manager and clinical lead in post) in three sectors of London, encouraging collaboration across care pathways and the spreading of good practice. However, two sectors, North-West and North-Central London, are distinctly behind in this area. This was explained by interviewees in terms of: a lack of funding from PCTs; an inability of clinicians to work together; and the recruitment of an unsuitable network manager. One HIV consultant compared the situation in their patch with North-West and North-Central London:

'The advantage here is that there is only one teaching hospital. We don't have the turf wars that you get in West or North Central London. And we've got a medical training rotation in the sector... so you've already got those looser networking arrangements which helps... there is a kind of fraternity. The network works in terms of clinical pathways.'

However, even where clinical networks existed, most felt they could be more effective, either by reaching more into primary care and public health; or by having greater input from commissioners. One network manager argued:

'World Class Commissioning was very clear that you had to engage with your providers and some people didn't like to hear that. Within the network we think commissioning is incredibly important... we wanted a commissioner/provider group to talk about the way forward... but it never happened.'

There was a feeling that the wider inability of commissioners and providers to have an effective dialogue with each other contributed to fragmented services and more difficult decision-making.

5.2.3 Interests in the status quo

Questions of commissioning structures alone do not, however, explain why service models for delivering HIV care in London have not changed significantly since the 1980s when treatments for HIV/AIDS emerged.

Despite recognising the need for change – and talking significantly of an 'ideal' model for delivering HIV services – nearly all interviewees acknowledged powerful vested interests in the status quo.

Four parties were identified by interviewees: specialist consultants and the hospital trusts they work for; primary care; patients; and government. Each will be taken in turn.

Firstly, as HIV care has shifted further towards the domain of evidence-based or 'precision' medicine, the need for consultant specialist input in the routine management of HIV has decreased. Interviewees told how consultants have tended to resist the logical consequence of this: shifts in care out of hospitals to less specialist settings. One HIV consultant reported:

'I think stable patients, which is probably 50-70% of most cohorts, are pretty simple after one year. Loads of that care can be very remotely delivered... They need to get a blood test somewhere, someone needs to review the result, someone needs to communicate that to them and they need to get their resupply of meds. That can all happen without coming to hospital... [However] I think there is reluctance amongst clinicians to lose their cohort because it is easy and satisfying work to do. Turkeys don't vote for Christmas do they?'

A lead commissioner made a similar point:

'It isn't necessarily the case anymore that it's necessary or indeed affordable for patients that are fine and have been on their meds for 20 years and take them religiously to see a consultant for 20 minutes, four times a year so they can sit there and say how are you? I'm fine etc. It's not a good use of resources. There are more complications, new complications emerging and we need to be focussing our specialists on being able to respond to those things rather than making patients that are well feel ok.'

Hospital trusts, too, have tended to support consultants, due to the income streams that HIV care and treatment tends to bring – income streams that in some cases cover up wider inefficiencies in management and practice across the hospital. An HIV consultant reported:

'Trusts have learned to depend on the surpluses that those departments [HIV] make.'

Secondly, where HIV consultants are reluctant to give up 'routine' work, primary care is often equally reluctant to take it on. GPs tend to see HIV as the domain of the specialist and do not feel confident that they possess the skills to manage patients with HIV. Indeed, most interviewees felt that for care to move in this direction there would need to be significant investment in the training of primary care clinicians (GPs or nurses) to ensure they reach required levels of competency. One HIV consultant said:

'I think there is an issue around skilling up the nursing workforce. You do need band 6 or 7 nurses. There needs to be nursing leadership and there needs to be medical support to give people the confidence.'

Other interviewees focused on the 'stigma' associated with HIV and the impact of this on primary care. A lead commissioner commented:

'Should it be normalised? Yes it should. Is there a lot of stigma? Yes there is. Does that mean it should remain specialised? I'm not sure. Because in a sense it's a vicious cycle. People say

there is a lot of stigma so you should treat it as special. The longer you treat it as special, however, you won't normalise it... Historically patients haven't had a good relationship with their GPs; they are not involved. But we are only going to crack that as long as we do some work to crack that. So long as HIV services continue to do everything for HIV patients, primary care will remain on the periphery.'

Thirdly, and perhaps because of the lack of training in primary care, interviewees reported patients to be reluctant to see their care shifted away from the hospital-setting and their specialist consultant. One lead commissioner reported:

'I think what worries people with HIV is that they won't know who is responsible for them'.

An HIV consultant said:

'We have a patients forum here... what the patients said was if on the wall of the waiting room it said "This general practice is approved by, and is working with, and is trained by X hospital", and they knew that if the GP had a problem they could phone us; the patient would be happy.'

The fourth interest that tends to pull service models toward the status quo is that of government. Most importantly, many interviewees drew attention to the lack of support afforded to commissioners to take difficult decisions around service reconfiguration. Political rhetoric remains focused on institutions, not services, and politicians are reluctant to see services closed. As one HIV consultant asserted:

'The system failed [at commissioning the most effective services]. I don't want to blame people who are commissioners because some of them... are really genuine but they are working in an environment where they were never given the status to do the work.'

Related to this was the belief on the part of some interviewees that government struggles with anything that is not 'local' – in this case centralising inpatient HIV services in centres of excellence – and is seen to reduce 'patient choice'. As one lead commissioner said:

'Those issues about "you have to have something local" I don't think hold up in the same way for HIV [inpatient treatment].'

Another interviewee reported:

'For me, there is a conflict. The NHS agenda is saying you want local care for local patients so actually if you live in X and suddenly you have to go to Y—you are not providing that.'

Interviewees, too, felt that – although reducing late diagnosis of HIV has been included as a 'proposed indicator' in the new Public Health Outcomes Framework – it is disappointing the Department of Health only described the BHIVA HIV standards, which could have been used as a driving force to change, as '*really good*', rather than officially endorsing them as standards for clinical care. One consultant described the political backdrop:

'This was at a time within the NHS... of the whole Darzi distraction. That created the feeling that, well, if a group of hospital doctors have done something... it can't be right. We don't want ivory towers; we want to move into these community visions of loveliness... so if it is written by hospital-based clinicians by definition there must be something wrong with it.'

Gumption and skills in commissioning

For all the lack of political support commissioners have enjoyed, and problems with structure and governance, one of the biggest problems referred to by interviewees of HIV commissioning in London is unwillingness on the part of commissioners to take difficult decisions – or have the skills to do so.

Interviewees argued that the significant increases in the NHS's budget over the past decade have enabled commissioners to duck difficult decisions on service reconfiguration and continue paying for poor quality – despite a 'review' always being in the offing. One HIV consultant argued:

*'For about a decade there has been a plan to reduce the number of inpatient centres [in London] but nobody has had the wherewithal to do it. There's always another **review** coming on. There is always something people wait for... It might just be that good things come out of the NHS/public sector recession. Where people have to say-ok we can't put this off any longer. We should have done this years ago, we didn't do it because we didn't have to... because it's not pleasant... but now we have to.'*

A lead commissioner referred to one such review:

*'At the moment we haven't decommissioned services... however, we are doing an HIV service **review** in London because there are 23 providers of HIV services when as a result of drugs HIV can effectively be managed as a long-term condition.'*

Other interviewees felt the reluctance of commissioners to benchmark, reconfigure and decommission services reflects a simple lack of skills and gumption. One HIV consultant reported:

'I think everybody agrees it is a disgrace that commissioners have not designated [HIV centres against a standard of care that would be paid for]... It was the one job they were given. These guys have had four to five years in their new "we are the commissioners role" and haven't... The PCTs are always looking over the shoulder saying "oh well you [the HIV Consortium] can do that but I wouldn't want to upset our local hospital"... [Particularly with the payment-by-results framework] you have to designate against the standard of care you are going to get before you pay.'

Another argued:

'I think they need to just take some balls around the whole network designation thing and write a spec, do some peer review and say "you're there, you're not and we are going to decommission you". Or "we are going to give you a year to get your house in order and then we are going to come back and visit you [and decommission you if you haven't]".'

Discussion

There are widely-agreed standards against which the quality of HIV care and treatment should be benchmarked. Interviews conducted for this study also revealed a fairly broad consensus over the 'ideal' models of commissioning and service configuration that would optimally deliver this in London.

Commissioning needs to take place at pan-London, sub-regional and local levels, dependant on the population scope of services, but there must be effective coordination, governance and clear lines of accountability between them.

Service models need to reflect the fact that, for many people, HIV has become a stable, long-term condition, not typically requiring specialist consultant input on a regular basis; but that for others highly specialist input is required. This means greater testing outside of GUM clinics; greater primary care input, with GP and nurse-led care pathways; routine services shifting out of the hospital setting to dedicated HIV units; and single-site or cluster HIV centres of excellence to provide complex outpatient and inpatient care. Overlaying this, all HIV services must be benchmarked against agreed standards; the number of hospital sites providing HIV care must fall; services that consistently fail to meet agreed standards should be closed; and clear care pathways with managed clinical networks should link the continuum of HIV care from treatment to prevention to case-finding to non-medical care together.

Despite this broad consensus, for the most part, models of delivering HIV care in London remain substantially unchanged since the 1980s, when treatments for the condition first emerged and HIV was typically an acute condition appropriately placed in the hospital-setting. Hospital trusts providing substandard care remain open; too often patients are not receiving high-quality, integrated, care; and value for money is not being secured.

Interviewees pointed to a number of key reasons for this: a lack of integration across pan-London, sub-regional and local commissioning structures; inadequate governance, ill-defined accountability and poor leadership across commissioning groups, with services not benchmarked against recommended standards; underdeveloped clinical networks; significant vested interests in the status quo, particularly on the part of hospital-based consultants and government; and a lack of skills, but more importantly gumption, on the part of commissioners. 'Reviews' are preferred to 'action'.

To improve the situation and address these issues – at a minimum – the following must occur:

- Much improved inter-agency coordination, with effective governance structures in place both within and between organisations, defining roles, responsibility and what each party is being held to account against.
- A much stronger focus on outcomes (most particularly late diagnosis), written into contracts and monitored as standard.
- Greater and more effective use of incentives – including financial and the threat of service withdrawal – to support the provision of high quality care and value for money. CQUIN offers obvious potential.

- The development of NICE Quality Standards, based on MedFash and BHIVA standards, for HIV care, thereby lending profile to, and providing a framework for, standards in local contracts.
- Increased involvement of primary care, supported by high quality training in HIV care for general practice. Kitemarks could be introduced for those practices trained in HIV care to provide reassurance for patients.
- More generally, profile and government support must be given to commissioners as impartial agents, charged with securing the services that best meet the needs of patients and the public and deliver the best possible outcomes and value for money (i.e. not protecting existing services regardless of quality and value).

Over and above this, however, the observation of one HIV consultant is pertinent and decisive: commissioners, whether PCTs or the new clinical commissioning groups, must *'take some balls'* and be prepared to take the difficult decisions they have thus far ducked away from: to reconfigure and decommission services. If they fail to do so, or if, in the transition from PCTs to clinical commissioning groups, attention is distracted, commissioning structures are further fragmented, expertise is lost or decision-making is delayed (all very real possibilities), the outcome in the current financial climate facing the NHS is simple: standards of care will fall.

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