



WHARFSIDE PATIENTS' FORUM
AT THE JEFFERISS WING

Reducing Primary Healthcare Inequalities For People With HIV Infection

**A proposal to Primary Care Trusts and
Imperial College Academic Health Science Centre**

February 2009

Reducing Primary Healthcare Inequalities For People With HIV Infection

“All previous experiences with my GP were quite frustrating and I didn't believe I got the appropriate attention or treatment”¹

“I feel he sees me like a monster”²

The core task for primary care trusts (PCTs) is to invest locally to achieve the greatest health gains and reductions in health inequalities, at best value for current and future service users.³

Despite sustained investment and improvement in the NHS over the past ten years, access to primary medical care services and the quality of those services, continues to vary significantly across the country⁴. The position is worse for people from minority communities and anyone with a stigmatising condition like HIV.

We request that an observational research study is set up providing a primary care service within the Wharfside clinic at St. Mary's Hospital, accessible by any patient attending the clinic that chooses to do so, in order to test the hypothesis that health outcomes will be enhanced by creating a primary care service that many patients would trust and be far more likely to make good use of than existing community services.

We suggest this

- on the assumption that such a service would overall provide “high quality care where patients are in control, have effective access to treatment, are safe and where illnesses are not just treated, but prevented”⁵.
- on the basis that patient opposition to other versions of “shared care” is high, that primary healthcare provision for patients with HIV infection is patchy and that many people with HIV infection lack confidence to access primary care.

¹ comments from patients the Imperial College NHS Trust Adult HIV Service Patient Satisfaction Survey, 2008

² comments from patients the Imperial College NHS Trust Adult HIV Service Patient Satisfaction Survey, 2008

³“NHS World Class Commissioning – Competencies” Department of Health, December 2007

⁴ Darzi - NHS Next Stage Review Interim Report, October 2007

⁵ “High Quality Care For All, NHS Next Stage Review Final Report”, Department of Health, June 2008

While it is recognized that this proposal runs counter to current funding arrangements for primary care, i.e., that the patient be registered with, cared for by a General Practitioner based (and funded) in the patient's PCT of residence, it does reflect one of the key themes in the vision set out in Lord Darzi's Next Steps Review Final Report⁶, namely that healthcare be tailored to meet the needs and wants of the individual - especially the most vulnerable and those in greatest need.

London's HIV services and patient outcomes are already amongst the best in the world

Eight of London's HIV providers have a world-class reputation for HIV treatment and care and research, including St. Mary's Hospital / Imperial College Healthcare through the Wharfside Clinic, associated services and the clinical trials centre.

As patients, we feel it incredibly important that commissioners of both primary care and specialised services don't play down the achievements in specialised HIV medicine, or take any actions that alter the way the specialised service is provided until and unless there is evidence to prove that tinkering with an existing world-class exemplar will produce even better results.

In order to prove whether this approach to primary care provision reduces health inequalities and improves outcomes, as patients we feel it important that the construction and operation of such a primary care service is properly researched and evaluated over a medium to longer term timescale, in order to provide credible evidence of what works (and what doesn't).

This is important in order that those who oppose this suggestion, as going against the grain of current thinking in the NHS, can be persuaded that the pragmatic and patient centred approach we are taking in these specific circumstances, is potentially better than other options. The learning should be used where appropriate in other parts of the NHS to improve health outcomes for people with HIV infection.

⁶ "High Quality Care For All, NHS Next Stage Review Final Report", Department of Health, June 2008

“Bring back the one site all services that you used to offer before forcing us to disclose to community GP. It is MY HIV and you took the choice of disclosure away from me.”⁷

“That there would be doctors who would replace our GP, they would know better how to deal with our condition.”⁸

The important issue is that such a scheme has to keep quality at the heart of what is done; to build upon the world renowned achievement in HIV medicine that St. Mary's and other London providers have pioneered. Such a scheme has to allow patient choice⁹ whether to opt into this version of primary care provision or not, and must offer a simple way of registering (perhaps electronically) this choice of GP. We feel this option would also provide a seamless and integrated approach to personal care planning for people with a long term medical condition¹⁰ that is in line with current thinking.

As patients, we assert that this method of primary care provision would ensure that patients with HIV got access to the most effective treatments overall, effectively dealt with issues unrelated to HIV infection, whilst also improving patient safety (in support of “do no harm”)¹¹.

Anecdotal evidence to the patients' forum is that issues of GP continuity are of less importance than those of physical location alongside HIV specialists, thus the attraction of a GP service embedded within an HIV clinic is a far more attractive option than specialised GP practices within wider community settings. However, we suspect that just as patients surveyed are full of praise for their specialist HIV physicians, they would be just as appreciative of high quality primary care physicians: the impression we get is that patients want the support of a GP service and wouldn't start moaning about inconsistency until they got a service to make comment on. At present, many are electing not to take part in primary care at all, even though primary care interventions or preventive check ups may be greatly to their advantage.

⁷ comments from patients the Imperial College NHS Trust Adult HIV Service Patient Satisfaction Survey, 2008

⁸ comments from patients the Imperial College NHS Trust Adult HIV Service Patient Satisfaction Survey, 2008

⁹ “High Quality Care For All, NHS Next Stage Review Final Report”, Department of Health, June 2008

¹⁰ “Refocusing the Care Programme Approach”, Department of Health, March 2008; and “High Quality Care For All, NHS Next Stage Review Final Report”, Department of Health, June 2008

¹¹ “Our NHS, Our Future: Interim Report”, Lord Darzi, Department of Health, October 2007

Audit

We expect that clinical outcomes should improve and should be capable of proof, alongside measurable differences in patient perspective of quality, including quality of life, and their experience of the NHS overall. Thus investment in specialised healthcare and patients' increased lifespan is supported by access to quality primary healthcare provision in a holistic approach that focuses on the patient rather than the convenience to any artificial bureaucracy that the patient has little or no need to have any understanding of.

Rather than use indicators already found in local enhanced service contracts that merely require indicators to be recorded in patient notes, we would prefer that success measures of a more robust nature – instead of looking for a record that a potential intervention has been discussed, we would prefer to see that an action followed that resulted, or potentially resulted, in some life enhancing outcome.

Example: there is no formal process for reviewing the totality of a patient with HIV's medication, yet repeatedly we hear that interventions by different clinicians result in drug interactions that are [potentially] deleterious to the health of the patient.

We would propose that this research compares the health outcomes for patients electing to use the embedded primary care service against an age matched control group from Wharfside Clinic as an observational study rather than a randomised clinical trial.

Potential audit indicators could include:

- Annual medication review and record of potential drug interactions prevented
- Annual outcome of Framingham cardiovascular risk equation score together with -
 - Annual record of current smoking status, except for those who have never smoked where smoking status need only be recorded once; record of any active smoking cessation interventions supported during the year
 - Annual healthy eating assessment and, where appropriate, record of impact of any dietary changes patient is supported to make
 - Annual assessment of patient's physical activities and, where appropriate, record of outcomes of any recommended exercise programme undertaken
 - Annual record of body mass index together with record of any appropriate action taken to correct high or low BMI score
 - Success of lipid management (undertaken by HIV specialist) measures taken where appropriate

- Appropriate vaccinations are given in line with national guidance (influenza, pneumococcal, hepatitis A, hepatitis B, etc.)
- Annual mental health review
- Annual sexual health screen and, where appropriate, cervical smear testing for women 24-65 years old
- Annual plasma glucose test undertaken and steps taken to manage any patients with diabetes
- Patient satisfaction / acceptability rating – applying a questionnaire on perception of primary care, total care satisfaction and quality of life.

Open Access remains important

For the same reasons that HIV services are “open access” (and thus attract patients from across London and beyond) as patients we request that this research into primary healthcare inequality is also conducted on an open access basis. We realise there may be finance issues that are inconvenient to the NHS, but on the basis of a service that wraps around the patient, it would be unacceptable if patients from other Primary Care Trusts, including those from outside London, were excluded.

Patients' choice should be at the heart of what they consider to be the best healthcare solution for them. However, we accept that the issues of linking to the patient's local community based services may be more challenging; patients, particularly those from outside London, should be supported to make an informed choice that factors in potential difficulty of liaison with local services, but for some patients this will be no worse than their current situation if they aren't accessing local primary care provision or other services.

Changing the way the specialised service is provided

HIV is increasingly being seen as a manageable chronic long term condition. This research into primary care provision may also provide indication of where and how the specialised service can be adapted to meet prevailing conditions.

The pragmatic view of primary care provision may well save considerable time for HIV specialists that could result in greater capacity and/or savings whilst retaining a cost and quality effective specialised service.

Of course, embedding a GP service within a specialised service would be both a major challenge and a major change in the operation of the HIV service itself – research should also be able to identify which parts of the holistic service end up “belonging” to the primary or acute service, some parts may be shared and thus offer better value to the overall NHS.

The results of the research could inform the way that HIV services are provided in future in London, potentially taking forward reforms as part of the Healthcare for London framework.

Wharfside Patients' Forum – Health Inequality in Primary Care

A rough calculation of the potential costs indicates that this proposal could be cost neutral, any health benefits could potentially save money in the longer term.

Background to this proposal

Historically a holistic model of care was provided in the HIV Department at St Mary's, patients got used to attending the daily walk in service within Wharfside with any ailment, HIV-related or not.

A number of factors are affecting this approach:

- increased demand for services resulting in pressures on HIV budgets and specialist staff;
- clinical governance concerns over prescribing by HIV specialists;
- a move towards dealing with HIV as a chronic long term condition.

Now patients with HIV infection are directed to seek treatment from GPs, if their presenting complaint is not HIV-related. The difficulty is often deciding what is and what isn't HIV-related, and what sits in the grey area in the middle that might or might not be.

While it would appear entirely appropriate that patients access specialised care from a specialised centre, and primary care closer to home, few patients at Wharfside inform the clinic they are registered with a GP (<40% March 2008). However, patients surveyed by other patients in 2007 and again in 2008, were much more prepared to admit to being registered with a GP (87% in 2007 and 92% in 2008)¹².

A fair proportion of patients refuse to use GP services, and others refuse to disclose their HIV infection to their GP, preferring to avoid using the GP service if at all possible. Some patients resent having been forced to disclose their HIV infection in order to [continue to] get prescriptions for common conditions that may or may not have occurred, but could be related to their HIV infection or their Anti Retroviral Therapy.

As patient representatives we are well aware of the two major reasons for a low uptake of primary care services:

- Fears and/or experience of discrimination by healthcare providers on grounds of race, sexuality, immigration status and/or HIV status¹³
- Fears and/or experience of breaches of confidentiality by staff in GP surgeries (given credence by first hand experiences related to the Wharfside Patient Forum by patients; further anecdotal evidence is cited in publications like Positive Nation and AIDS Treatment Update). Some patients who do access their GP do not disclose their HIV status for fear of disclosure to a third party e.g. potential employers/insurance

¹² Wharfside annual Patient Satisfaction Survey 2007 (<http://www.wharfside.org.uk/events/Wharfsidepss2007.pdf>)

¹³ "Insider Status – stigma and discrimination experienced by gay men and African people living with HIV", Sigma Research, December 2004

companies,¹⁴ etc., while others deliberately don't use their GP even though they have one, for similar reasons¹⁵.

- Lack of faith in levels of GP knowledge¹⁶ ¹⁷, specifically regarding interactions between medications prescribed for HIV and those prescribed for non-specialist conditions, or because their previous experience has been GP reluctance to treat resulting in the patient being referred back to the HIV specialist for an issue that could have been dealt with in primary care if the GP had sufficient professional confidence to do so.
- Annoyance at being passed from pillar to post to obtain holistic healthcare, in particular with regard to issues in a “grey” area that could/might or might not be HIV related.

“...the GP experience of dealing with HIV is generally very poor. If you go with chest infection they will generally treat economically with antibiotics (not strong enough, not enough days). This means you end up back at the [HIV] clinic anyway.”¹⁸

“I think I should be treated for all medical needs presenting on the day, not just HIV related ones only”¹⁹

As a result Wharfside patients not registered with, not using or not disclosing their HIV status to a GP are not receiving adequate, appropriate or safe primary care service. Such patients run risks of exacerbating conditions that are not taken to a GP at an early stage before getting more complex to manage, or through GP prescribed treatments conflicting with HIV medications (whether or not the GP is aware that the patient is taking ARVs).

This proposed arrangement would assuage patient fears around confidentiality as the service would be provided in an environment covered by The National Health Service (**Venereal Diseases**) **Regulations** 1974

¹⁴ Positive Nation magazine, Issue 120, March 2006

<http://www.positivenation.co.uk/issue120/treatments/treatment1/treatment1.htm>

¹⁵ Wharfside annual Patient Satisfaction Survey 2008 (<http://www.wharfside.org.uk/pss/WSPSS2008.pdf>)

¹⁶ “What Do You Need”, Sigma Research, July 2002

¹⁷ Comprehensive Sexual Health Needs Assessment, Kensington and Chelsea PCT, June 2008

¹⁸ Comments from patients, Wharfside annual Patient Satisfaction Survey 2008

(<http://www.wharfside.org.uk/pss/WSPSS2008.pdf>)

¹⁹ Comments from patients, Wharfside annual Patient Satisfaction Survey 2008

(<http://www.wharfside.org.uk/pss/WSPSS2008.pdf>)

(S.I.1974/29)²⁰ and would also guarantee immediate access to HIV specialist knowledge and provide an opportunity for GPs to acquire training in the management of HIV infection.

Whilst we have found published research that confirms these barriers to primary healthcare, we have found no published research specifically into why patients with HIV infection display such high levels of fear and distrust of general practice. Nevertheless it appears widely accepted as a big issue for some people with HIV.

Positive Nation magazine carried out some national research in late 2006/early 2007 which highlighted high levels of dissatisfaction with both GP and dental services (see [Appendix A](#)). Alongside high levels of dissatisfaction, respondents reported high levels of deliberately not using, and “not needing” to use, GP (and dental) services. Combining the percentages in this survey that report dissatisfaction with those reporting they are not using primary care services perhaps indicates the scale of the problem –

40% of people with HIV responding from London appear to have issues with accessing GPs, and around 50% appear to have difficulties with dental provision.

²⁰ This would require some clarification as to whether the Adult HIV Service, which is part of the Sexual Health and GUM clinic, is actually operating under these additional confidentiality assurances: most patients assume that it does, the reality is less than clear: when it suits staff it does, when it doesn't, it doesn't.

Discrimination by healthcare providers

“staff welcome you like a person with a virus, rather than a person with a health condition”²¹

“... still stigmatised in other clinics and staff outside Jefferiss Wing - using gloves and masks when examining you as they read you are HIV positive”²²

Discrimination, or fear of discrimination, within parts of the healthcare system appear to be major contributing factors. Over time, this should change – younger people, ergo younger healthcare professionals, appear to display less discriminatory attitudes towards HIV.

Surveys of public attitudes appear to show a gradual reduction over time in the percentage of the population at large who agree with the statement that “There is still a great deal of stigma in the UK today around HIV and AIDS”²³. The IPSOS MORI research conducted by the National AIDS Trust (NAT) shows a potential 16% reduction in stigma over the past seven years, but still indicates around 69% of the population believe in HIV stigma at 2007.

Assuming no change to that rate of stigma reduction, the level could still be around 50% in 2015, but this may improve with action by government and others to change public views of HIV.

Plenty of research confirms discrimination on the grounds of HIV status and/or sexuality by healthcare providers and it is borne out by patient comments in the Wharfside Patient Satisfaction Survey, 2008.^{24 25 26 27}

In 2007, the [then] patient forums for Ealing, Hounslow and Hillingdon PCTs conducted some research with dentists in those boroughs which proved discriminatory and potentially dangerous practices by dentists refusing to treat patients with HIV, or treating them differently to other patients who didn't disclose an HIV positive status. Despite the British Dental Association

21 Comments from patients, Wharfside annual Patient Satisfaction Survey 2008, <http://www.wharfside.org.uk/pss/WSPSS2008.pdf>

22 Comments from patients, Wharfside annual Patient Satisfaction Survey 2008, <http://www.wharfside.org.uk/pss/WSPSS2008.pdf>

23 “Public Attitudes Towards HIV” National AIDS Trust, January 2008

24 “Tackling HIV stigma and discrimination - Department of Health implementation plan”, May 2007

25 “What Do You Need”, Sigma Research, July 2002

26 “HIV related stigma and discrimination” National AIDS Trust, Impact 9, 2004

27 “HIV-related stigma and discrimination” proposals from the national aids trust for the government action plan, National AIDS Trust, undated

reminding all dentists that denying treatment to people with HIV was unethical, we are aware that such discriminatory behaviour persists and that it is only the minority of cases where an aggrieved person is prepared to run the gauntlet of publicity in taking forward complaints or using the law against dentists behaving like this.

The presumption we make is that any action we might take now to improve primary healthcare provision to people with HIV infection would not remain set in stone forever, but could be a medium to long term issue that will eventually resolve in the mainstream.

GP Confidence / Clinical Competence

GPs have similar fears to patients over a relatively new disease area that is fast changing^{28 29 30 31 32}, yet little appears to have changed since the first quoted publication on this subject in 1994 to the latest available research on HIV and primary care cited from 2008. This appears to indicate that what little has been done over the past 14 years has had limited impact on the clinical confidence of the majority of GPs working with patients with HIV.

The Sexual Health Department of St. Mary's and the Wharfside Patient Forum have attempted to address the above via educational events for patients, running training events for Westminster GPs (two expressions of interest in attending) and by attempting to elicit a Locally Enhanced Service (LES) contract for Westminster GPs, all without success.

Kensington & Chelsea PCT conducted a consultation in late 2007/early 2008 on a shared care proposal, an approach which was abandoned when it was realised that most patients were opposed to the proposals³³.

For a GP, gaining experience and confidence in the care of patients with HIV is not as easy as for other long term conditions like diabetes. About 2.3 million people in the UK have diabetes³⁴, around 90 for every GP³⁵, whereas there are only around 75,000 people with diagnosed HIV infection³⁶. That

²⁸ BMJ 1994;308:2 (1 January)

²⁹ "Optimizing Care for Persons with HIV Infection", Annals of Internal Medicine, 20 July 1999 | Volume 131 Issue 2, Frederick M. Hecht, MD; Ira B. Wilson, MD, MSc; Albert W. Wu, MD; Robert L. Cook, MD, MPH; Barbara J. Turner, MD,

³⁰ Kennedy M et al. Understanding the barriers to GP involvement in the care of patients with HIV. Fourteenth BHIVA Conference, Belfast: abstract O6, 2008.

³¹ Benn PD et al. Is best practice to devolve statin prescribing to primary care in patients on HAART? Fourteenth BHIVA Conference, Belfast: abstract P126, 2008.

³² Comprehensive Sexual Health Needs Assessment, Kensington and Chelsea PCT, June 2008

³³ "HIV Shared Care Scheme -Kensington and Chelsea PCT Full Equality Impact Assessment, 30 July 2008

³⁴ Source – Diabetes UK website www.diabetes.org.uk

³⁵ Using numbers of GPs from the British Medical Association, June 2008

³⁶ Health Protection Agency, New HIV Diagnoses Surveillance Tables, December 2007

gives a potential of two people with HIV per GP across the UK, but there will obviously be more in areas (like London) where prevalence is higher.

On this basis alone, we assert that the best value may be found in supporting the professional and clinical development of a small number of specialist GPs who would gain the confidence, competence and, most importantly, the trust of patients with HIV to deal with their primary care needs in close partnership with specialists continuing to address the specifics of HIV medicine.

The HIV epidemic in the UK is not fast growing compared to some other parts of the world, and is potentially affected by a variety of issues including HIV prevention activity, availability and effectiveness of treatments, the economic situation, political and economic turmoil in higher prevalence countries. Additional to this is the fact that around a third (perhaps 40%) of HIV infections in the UK remain undiagnosed.

Of note is that in other countries, specialised HIV treatment and care is provided in what we might consider as a community or primary care setting in the UK. However, that is the way that health care has developed in those countries, we have no evidence to say that it is better or worse, only that the way the UK has approached HIV treatment and care has produced world class results.

Plenty of research proves that doctors' levels of experience in treating patients with HIV is directly linked to outcomes^{37 38 39 40 41 42 43 44 45 46 47 48 49}

37 The HIV Specialist Improves Quality of Care and Outcomes, William M. Valenti, MD

38 Shapiro M, Morton SC, McCaffrey DF, et al. Variations in the care of HIV-infected adults in the United States: results from the HIV Cost and Services Utilization Study. JAMA. 1999;281:2305-2315.

39 US Department of Health and Human Services. Guidelines for the use of antiretroviral agents in HIV-infected adults and adolescents. Revised February 4, 2002. Available at: <http://www.hivatis.org>.

40 Centers for Disease Control and Prevention. Report of the NIH panel to define principles of therapy of HIV infection. Department of Health and Human Services and Henry J. Kaiser Family Foundation. MMWR. 1998;47(RR-5):1-41.

41 Centers for Disease Control and Prevention. Guidelines for the use of antiretroviral agents in HIV-infected adults and adolescents. Department of Health and Human Services and Henry J. Kaiser Family Foundation. MMWR. 1998;47(RR-5): 43-82

42 Kitahata MM, Koepsell TD, Deyo RA, et al. Physicians' experience with the acquired immunodeficiency syndrome as a factor in patients' survival. N Engl J Med. 1996;334:701-706.

43 Brosgart CL. Community patterns of care for HIV disease: experience makes a difference. In: Program and abstracts of the 12th World AIDS Conference; June 28-July 3, 1998; Geneva. Abstract 60779.

44 Brosgart CL, Mitchell, TF, Coleman RL, et al. Clinical experience and choice of drug therapy for human immunodeficiency virus disease. Clin Infect Dis. 1999;28: 14-22.

45 Kitahata MM, Van Rompaey SE, Shields AW. Physician experience in the care of HIV-infected persons is associated with earlier adoption of new antiretroviral therapy. J Acquir Immune Defic Syndr. 2000;24:106-114.

⁵⁰. Much of this research was conducted in what would be considered as primary care, it also appears that many of the primary care outcomes were improved alongside the HIV medical outcomes.

Health Inequality

There is a stark relationship between HIV and health inequalities in the UK. Around 75% of HIV infections occurring in the UK were (are) amongst gay or bisexual men. The vast majority of people diagnosed with HIV in the UK are gay or bisexual men, or men and women from migrant African communities. A proportion of people with HIV from African communities are refugees and/or asylum seekers. All these groups are marginalised, albeit in different ways; people from these groups are then further marginalised by HIV infection.

The report of the National Improvement Team for Primary Care Access and Responsiveness⁵¹ highlights that Black and minority ethnic (BME) patients, especially Bangladeshi patients, show far higher levels of dissatisfaction: almost half of Wharfside patients are from BME backgrounds. We assert that our proposed approach is in line with the confidentiality and quality expectations expressed in particular by BME patients.

Pragmatic Solution

The pragmatic solution to this inequity in healthcare provision has consistently been suggested by patients with HIV as the need to shift their primary care into the acute setting, a location patients trust, a location where primary care staff would have immediate support from their specialised colleagues.

This would also appear to be a far more cost and clinically effective approach than attempting to improve the clinical competence and patient acceptability of every GP practice in North West London (and, bearing in mind that HIV is

46 Bach PB, Calhoun EA, Bennett CL. The relation between physician experience and patterns of care for patients with AIDS-related *Pneumocystis carinii* pneumonia: results from a survey of 1,500 physicians in the United States. *Chest*. 1999;115: 1563-1569.

47 Markson LE, Houchens R, Fanning TR, Turner BJ. Repeated emergency department use by HIV-infected persons: effect of clinic accessibility and expertise in HIV care. *J Acquir Immune Defic Syndr Hum Retrovirol*. 1998;17:35-41.

48 New York State Department of Health AIDS Institute. HIV specialist. Available at: <http://www.hivguidelines.org>.

49 HIV Medicine Association/Infectious Diseases Society of America Web site. Available at: <http://www.idsociety.org/HIV/HIVMA/CALetterFeb2002.html>.

50 The American Academy of HIV Medicine Web site. Available at: <http://www.aahivm.org/new/index.html>.

50 "Report of the National Improvement Team for Primary Care Access and Responsiveness", Department of Health, May 2008

an open access service, Wharfside Clinic attracts patients from across London, the Home Counties and beyond).

Whilst this approach does little to address either the stigmatisation or lack of clinical understanding of the management of HIV infected patients in primary care, at least in the short to medium term, we assert that over the longer term, the professional development opportunities of a structured and evidence-based approach like this should result in potential to look again at whether the primary care needs of patients with HIV would continue to be best served by this kind of quasi-“ghetto” arrangement.

The issue of access to GP care has been discussed repeatedly at Wharfside Patients' Forum meetings. During 2007/8 Wharfside and Kobler/Victoria/Nkosi Johnson clinic forums shared the debate on access to primary care services and attitudes and expectations were identical. Participants included the director of primary care commissioning from K+C PCT at a meeting at the Chelsea and Westminster Hospital, and the Director of London's HIV Programme at that and a further meeting held at St. Mary's, along with the K+C PCT Sexual Health Lead.

Patients do not favour the provision of specialised HIV services in community settings. The overwhelming preference is for patient-centred holistic healthcare based around the HIV clinic, and there is minimal interest in concepts like Locally Enhanced Service contracts with interested practices. Many patients prefer the reassurance that a general physician could operate with immediate access to any HIV related support required; there seems less insistence on access to the same general physician than there is in fondness for seeing the same HIV consultant.

On the issue of cost and clinical effectiveness, during a discussion with K+C PCT on the potential for Locally Enhanced Service contracts with GP practices, Wharfside Patients' Forum did some “back of envelope” calculations using the published costs of the Brighton and Hove LES for HIV services:

Brighton and Hove LES03 pricing from 2006/7 applied to Wharfside-

If half of Wharfside's patients took up the ability to register with a GP based in Wharfside, it could actually save on the cost of LES contracts with an unknown number of separate practices and would entail much less bureaucracy, monitoring and management costs. 1000 patients attracting an LES payment of £102 per year, plus each practice attracting an LES payment of £1032.25⁵², is actually greater than a salaried GP on £75k a year (if you could find one to work for that amount).

⁵² Brighton and Hove PCT, Enhanced Services LES03, 2008 – see [Appendix B](#) of this document

Of course there are other costs on top of salary, but as there are ingredients of the Brighton LES that Wharfside are already undertaking (certain aspects of health screening more appropriate to primary care), and certain costs that could be shared with the existing HIV service (premises and other facilities), it would seem likely that any LES payment in NW London should be lower than the Brighton figure (and thus less of an inducement).

As 1000 patients appears around half the national average list size for a full time GP in England (not that it is easy to quantify a list size by GP since the GMS contract was introduced in 2004, so the data available is potentially unreliable), it doesn't look as though this would be a full time post, so the salary cost could be less than the arbitrary £75k used above unless opportunity was taken to create a new position. Thus it looks even more likely that employing a GP within the largest HIV clinics would be more cost effective than LES contracts, and these calculations are made without including the per capita allocation.

When you factor in that the back of envelope calculation only covers the enhanced costs, and does not include the per capita allocation for primary care services, it begins to make more financial sense than any other option. It remains to be seen if it would satisfy Quality and Outcomes Framework measures, but then it wouldn't be a GMS practice.

How would the PCTs like to pay less for better outcomes?

In terms of Patient and Public Engagement, as patients we challenge the PCTs to end their malign neglect of patients with HIV who cannot bring themselves to use existing community based primary care services, and set up to the challenge by rectifying the health inequality faced by people whose health and lives are damaged by fear of disclosure that they have a long term medical condition.

Appendix A

My Life With HIV is

In late 2006, Positive Nation magazine surveyed readers nationally, one question related to satisfaction levels with General Practitioners within the previous 12 months:

	<u>National (n=849)</u>		<u>London (n=372)</u>	
Very dissatisfied	8%	} 22%	9%	} 21%
Dissatisfied	14%		12%	
Not needed / not used	17%		19%	
Satisfied	29%	} 58%	26%	} 56%
Very satisfied	29%		30%	

The same question was asked regarding use of dentists within the previous 12 months:

	<u>National (n=825)</u>		<u>London (n=366)</u>	
Very dissatisfied	9%	} 18%	9%	} 18%
Dissatisfied	9%		9%	
Not needed / not used	24%		24%	
Satisfied	26%	} 53%	24%	} 51%
Very satisfied	27%		27%	

Appendix B

New General Medical Services Contract

Specification for the provision of an Enhanced Services

SERVICE	REFERENCE
HIV in Primary Care	LES 03
	Updated June 08

1. Background

- Brighton & Hove has a high number of people living with HIV. There are approximately 900 Brighton and Hove residents accessing the Lawson clinic. Of these 699 are registered with a GP with consent for the GP to be aware. This is a high level of registration compared with London clinics. The figures will increase with new diagnoses, and also as patients overcome their barriers to GP involvement. The number of people living with HIV is increasing by approximately 10-15% per annum. Unlike some health conditions there are marked differences in HIV prevalence between different areas and Brighton is one of the four geographical areas (along with London, Manchester and Birmingham) with the highest HIV prevalence in the UK (Terrence Higgins Trust 2002). It is also known that there remains a large body of undiagnosed HIV infection.
- HIV for many people has become a chronic manageable condition akin to diabetes or CHD. Patients are living longer with HIV infection due to effective treatments. Drug treatment and monitoring are complex and constantly evolving and remain the role of secondary care services. However, these services often find themselves providing much of the primary care of their patients. It is recognised that a patient's primary care needs may be better managed by their GP, than by a consultant in HIV/GUM. The Medical Foundation for AIDS and Sexual Health have recommended that all people with HIV should have access to good quality primary care encompassing prevention, diagnosis, treatment and care.
- Local experience in Brighton and Hove has identified barriers to GP involvement in HIV care. These include; a lack of confidence by some GPs, a lack of confidence by some HIV patients in their GPs, and a lack of knowledge around HIV care. Policy Guidance on Developing HIV in Primary Care produced by the Terrence Higgins Trust in 2002 suggests caution in treating HIV as a chronic condition which can routinely be managed in primary care. The local HIV-

Wharfside Patients' Forum – Health Inequality in Primary Care

educational course has been developed to address training needs of GPs and Practice nurses. It aims to equip participants with the basic knowledge, skills, attitudes and confidence for the effective discussion of HIV and its testing in primary care, and the management of patients with HIV.

- **Clinical Issues.** Patients often have co-existing physical problems which GPs are experienced in managing. Awareness of long term drug toxicities is very important with the increasing number of patients on antiretroviral treatment. These include hyperlipidaemia, glucose intolerance and cardiovascular disease. There is also potential for drug interactions and overlapping toxicities which can make co-prescribing complex. Adherence to treatment is of great importance as resistant virus can emerge if doses are missed. Patients who are not on treatment or where treatment has failed still require symptom control and palliative care. HIV patients also often have complex psychological and social problems.

In summary there is scope to expand the role of primary care in delivering care to HIV patients, but this needs to be supported by training and education to enable this to happen.

2. Service Outline

Practices participating in this enhanced service will be expected to provide the following service on at least an annual basis.

1. A register of HIV positive patients
2. A record of drugs prescribed including anti retroviral drugs
3. Routine Primary Care and management of co-morbidity.
4. Monitoring adherence to treatment
5. Monitoring cardiovascular risks
 - Family history
 - Smoking
 - Lipids
 - Glucose intolerance
 - Blood pressure
6. Monitoring mental health
 - Depression
 - Anxiety
 - Psychotic illnesses
7. Advice specifically in relation to
 - Drugs
 - Alcohol
 - Safer Sex
 - Regular sexual health checks

8. Women's health

- Contraception (see appendix 3)
- Annual smears

9. Vaccinations

- Influenza
- Pneumococcal
- Travel vaccines

10. Awareness of, and liaison with, local HIV services; statutory and voluntary. E.g. Lawson unit, Elton John Centre, HIV integrated team, Sussex Beacon, Terence Higgins Trust south, and Brighton Body Positive.

3. Eligibility to provide the service

There are three eligibility criteria:

i. Training

Given the need for regular updates in clinical knowledge, all participating practices need to ensure that at least one GP **and preferably** one practice nurse attends the HIV Educational course "The diagnosis and management in primary care of people with HIV" before a practice will be eligible to provide the service. It is also recommended that staff from the participating practices attend the Sexually Transmitted Infectious Disease (STIF) Course.

ii. Patient Numbers

Participating practices should have at least five HIV patients registered on their patient list.

iii. Competence

In addition, all participating practices will be required to demonstrate they meet the competencies in the RCGP Sex, Drugs and HIV task groups "*Minimum standards of care for HIV in general practice* (2003) which are detailed in appendix 2.

On-going Requirements

Two educational meetings for practices participating in this LES will be organised twice a year by Dr Anna Cressey, (GP working at the Lawson Unit) and it is a requirement for ongoing participating in this LES **that either a GP or Practice Nurse from each practice attends at least one of these meetings.**

4. Setting up the Register

1. Search for all patients already coded

5 Byte Codes

A788% **HIV infection**
A789% HIV infection resulting in other disease

43C3 **HIV positive**
ZV01A Asymptomatic HIV infection status
ei% Antiviral drugs (chapterBNF)
Eu024 Acquired immune deficiency syndrome dementia complex
R109 [D]Laboratory evidence of human immunodeficiency virus [HIV]
AyuC [X]Human immunodeficiency virus disease

CTV3 Codes

43C3 **HIV positive**
X70M6% Human immunodeficiency virus infection
R109. **[D]Laboratory evidence of human immunodeficiency virus [HIV]**

ei% Antiviral drugs

2. Assign one of the following codes to all patients found in the search with patient's consent.

5 Byte Read Codes

A788-1 Human Immunodeficiency Virus Disease. This may not be available to all systems
A7881 Asymptomatic human immunodeficiency virus disease
43C3 HTLV3 positive. This is a laboratory result code and not ideal as a diagnosis code but is already being used by some practices.

CTv3 Codes

A7881 Asymptomatic human immunodeficiency virus infection

X70M6 Human immunodeficiency virus infection

43C3 HIV positive. This is a laboratory result code and not ideal as a diagnosis code but is already being used by some practices.

3. All patients who agree to be included in the register should be offered the care as detailed in the service outline. . Some practices may choose to offer opportunistic monitoring whereas others may wish to set up a formal recall system with an annual review appointment with a nurse or doctor.

5. Audit

In 2008-09 the audit has been divided into two stages. Please refer to the audit schedule that accompanies this specification for further details.

Stage 1

All practices will be required to produce the following information:

1. The number of patients with HIV aged 18 years and over included on the practice register (with patient consent)
2. Name of GP/ nurse co-ordinator
3. Name of GP and/or Practice Nurse attending the HIV education course.
4. Name of GP and/or Practice Nurse carrying out HIV reviews.

Stage 2.

For each patient review the following indicators should be recorded

1. Medication review recorded in the last 12 months
2. Smoking status recorded in the past 12 months, except those who have never smoked where smoking status need only be recorded once
3. If the patient smokes, whether appropriate advice has been given in the last 12 months.
4. Blood Pressure recorded in the last 12 months
5. Whether the latest recorded blood pressure is 150/90 or less

6. Plasma glucose recorded in the last 12 months
7. Cholesterol or cholesterol:HDL recorded in the last 12 months
8. Whether the latest recorded total cholesterol is 5mmol/l or less
9. CVD risk calculated in the last 12 months
10. Lifestyle advice to reduce CVD risk recorded in the last 12 months.
11. Flu vaccination given in the last 12 months
12. Pneumococcal vaccination given in line with national guidance
13. Mental health reviewed in the last 12 months
14. Advice on safer sex and sexual health given in the last 12 months
15. If a patient is a woman aged 24-65 years whether a cervical smear been offered in the last 12 months.
16. If a patient is on anti-retroviral therapy whether the notes record a discussion concerning adherence to drug regimes in the last 12 months.

6. Pricing

The fee for the service is divided in to two parts. In the first year a practice participates in the LES a **one-off retainer of £1,032** to reflect training and set-up costs. In addition there is a **fee of £120** for each patient that attends the practice's surgery for a review. As one of the aims of the enhanced service is to transfer some of the work undertaken in secondary care, the fee per patient will only be made to practices that undertake the annual review in order to help facilitate this shift. Practices that achieve at least 11 out of the 16 indicators for each patient (See details of the Stage 2 audit above) will be eligible for the patient review fee.

Appendix 1

Suggested 5 Byte codes for computer template

Diagnosis

- A788-1** **Human Immunodeficiency Virus Disease.** This may not be available to all systems
- A7881** **Asymptomatic human immunodeficiency virus disease**
- 43C3** **HTLV3 positive. This is a laboratory result code and not ideal as a diagnosis code but is already being used by some practices.**

Medication

- 8Biq** Drug compliance checked
- 8B3V** **or 8B3S** **Medication review done**

Smoking

- 1371** Never smoked
- 137R etc** **See CHD template/Read code formulary**

Alcohol

- 136%** Alcohol consumption

Drug misuse

- Eu1%** **[x] Mental and behaviour disturbances due to use of psychoactive substances** (see sub codes for different drugs)

CHD Risk

2469	Systolic blood pressure
246A	Diastolic blood pressure
44P	serum cholesterol
44PF	Chol:HDL
44g1	Fasting plasma glucose level
44g	Plasma glucose level

Women's health

611	General contraceptive advice (see appendix 3)
671J	Pre-conception advice

Sexual Health

679K	Health education – sexual health
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1B1C **Sexual symptom**

E2273 **Erectile dysfunction**

Mental Health

6A6	Mental health review (could have sub template for psychiatric diagnoses or code separately)
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Health promotion

65E	Influenza vaccination
68NE	No consent – flu vaccine
6572	Pneumococcal vaccination
68NX	No consent – pneumococcal vaccination

Suggested CTv3 codes for computer template

Diagnosis

A7881	Asymptomatic human immunodeficiency virus infection
X70M6	Human immunodeficiency virus infection

43C3 HIV positive. This is a laboratory result code and not ideal as a diagnosis code but is already being used by some practices.

Medication

XaJKn **Drug compliance checked**

8B314 Medication review

XaF8d **Medication review done**

Smoking

XE0oh Never smoked tobacco

Ub1na Ex-smoker

137R% Current smoker

Alcohol

136% Alcohol consumption

Drug misuse

Eu1% **[x] Mental and behaviour disturbances due to use of psychoactive substances** (see subcodes for different drugs)

CHD Risk

2469 Systolic blood pressure

246A Diastolic blood pressure

XE2eD% Serum cholesterol level

XaEil High density lipoprotein/total cholesterol ratio

44g1 Fasting plasma glucose level

XM0ly Plasma glucose level

Women's health

611 General contraceptive advice **(see appendix 4)**

Xalwm Pre-conception advice

Sexual Health

XalyP Health education - sexual health

1B1C Sexual symptom

E2273 Erectile dysfunction

Mental Health

XalyU Mental health review (could have sub-template for psychiatric diagnoses or code separately)

Health promotion

65E Influenza vaccination

68NE No consent – flu vaccine

6572 Pneumococcal vaccination

68NX No consent – pneumococcal vaccination

Appendix 2

Minimum standards RCGP Sex, Drugs and HIV task group

GENERAL/ETHICS

1. All primary care workers should be non-judgemental and respect patients' dignity, integrity, personal beliefs, sexual orientation, life style, cultural background and socio-economic status
2. They should respect the right of patients to be fully involved in decisions about HIV and prevention and care – and be able to respect the decisions that they make.
3. Confidential information should be respected and protected. Any access to this information or other situations where information may be divulged to others (including within the team) should be explicit from the start of any interactions.
4. Professionals should be able to recognise their own limitations in providing help and care to people affected by HIV and deal with these in an appropriate way.
5. The team should be motivated to keep up to date their professional knowledge and skills on relevant developments in HIV care, appropriate to their level of commitment.

SKILLS FOR THE CLINICAL TEAM

1. All members of the clinical team should be able to talk to people about their individual lifestyle including sexual and drug taking behaviour.
2. They should be able to answer and discuss basic questions about the HIV and HIV disease.
3. They should be able to identify patients at risk of HIV infection, even if they are not in traditional high risk groups.
4. People at risk, and those already infected, should be supported to reach and sustain safer behaviour with individually tailored advice.
5. The team should be able to carry out HIV testing, including appropriate pre and post-test discussions with all patients.
6. Patients found to be HIV positive should continue to receive primary care from the team and to have their care with other services co-ordinated if necessary.
7. Partners, family and caregivers of those affected should also be able to receive support from the primary care team.

KNOWLEDGE OF THE CLINICAL TEAM

1. Members of the team should understand all modes of HIV transmission (including vertical) and be able to identify people at risk Ways to prevent HIV transmission should be understood.
2. They should understand HIV tests and their implications, both beneficial and adverse.
3. They should understand the course, early symptoms, and psychosocial implications of HIV infection.
4. Appropriate members of the team should understand clinical management options and the implications for patients in broad terms.
5. The team should be aware of appropriate local HIV related services.

Contraception

- Antiretroviral drugs, mainly protease inhibitors and non nucleosides may interact with some OCPs and POPs reducing their effectiveness (check with pharmacy). IUDs and implants are not contra indicated.
- Emergency contraception: no contra indications, but if on nevirapine, ritonavir or nelfinavir increase dose to 3 tablets.