



CENTRE FOR SEXUAL HEALTH

THE JEFFERISS WING

Wharfside Patients Forum

Adult HIV Service

Patient Satisfaction Survey 2008

October 2008

Adult HIV Service - Patient Satisfaction Survey 2008

Wharfside Patients' Forum again played a major role in design and delivery of the annual satisfaction survey. Forum members reviewed the survey questions based on the 2007 survey and the use made of the results. Where collected data had not been used, questions were dropped. Some new questions were added including some in support of the London HIV Consortium's PPI Audit Tool.

Forum volunteers handed out the survey to patients waiting in Wharfside during the week of 15th to 19th September 2008, and staff encouraged Family Clinic patients in paediatric outpatients over a similar period. All patients attending clinics during the survey week were eligible for inclusion; four forms were requested for Almroth Wright Ward patients.

201 questionnaires were completed or partially completed; 32 patients (22 men, 10 women) declined the questionnaire giving reasons such as "not interested" (9) "not feeling well enough" (4), "too busy" or "no time" (4). Two questionnaires were returned blank.

Percentages below reflect the proportion of people answering each particular question; where available, results are provided from the 2007 PSS.

Demographics of Survey Respondents

Gender

	2008		2007
Female	47	24%	20%
Male	151	76%	80%
	198		

Sexual orientation

	2008		2007
Bisexual	8	4%	9%
Heterosexual	60	30%	25%
Homosexual	115	58%	67%
No Answer	15	8%	4%
	198		

Those choosing not to answer this question were predominantly African women.

Ethnicity

	2008		2007
Arabic	2	1%	1%
Asian	5	3%	2%
Black African	47	24%	16%
Black Caribbean	9	5%	3%
Black Other	6	3%	2%
Oriental	3	2%	1%
White British	64	33%	40%
White Irish	7	4%	7%
White Other	51	26%	20%
Other or mixed race	2	1%	8%
	189		

One patient refused to complete the survey as there was no option for “Latino”

Age of patients

The age bands in this question were amended for the 2008 survey

Under 20	3	2%	1%
20 to 29	27	14%	11%
30 to 39	57	29%	31%
40 to 49	71	36%	
50 to 59	24	12%	
Over 60	16	8%	
	195		

Access to Primary Care

Patients registered with a GP

	2008		2007
Yes	182	92%	88%
no	15	8%	12%
No Answer	1		
	198		

There was no difference in the proportion of patients from different ethnic backgrounds answering yes to this question.

Patients using GP within past year

	2008	
Yes	152	77%
No	35	18%
N/A	4	2%
No answer	7	4%
	198	

Patients answering “No” were asked for their reasons

The vast majority (20 of 35) cited having no need to visit their GP during the previous year. Six patients gave reasons relating to the quality of past experience

White British	All previous experiences with my GP were quite frustrating and I didn't believe I got the appropriate attention or treatment
White British	Because I feel he see me like monster
White Irish	Too difficult to make appointment
Black African	When I moved house surgery said I was not in the catchment area, I was taken off the register and have not been able to register with another GP, I had a lot of difficulty trying to register
Black African	not been unwell, GP constantly changing due to changes in practice
White Other	don't like

Three patients reported the reason they didn't use their GP as being **the hospital disclosed their HIV status without their consent.**

To have found three patients in such a small sample reporting this breach of confidentiality suggests it is a frequent occurrence; applied across the whole Wharfside patient cohort, it suggests that this could have happened to around 36 patients. In some of these cases the consequences for the individual can damage their career prospects.

The Trust is at risk of legal action for breach of confidentiality – in July 2008 the European Court of Human Rights ordered a health authority in Finland to pay a patient with HIV €14,000 in damages and €20,000 costs, for failing to protect the confidentiality of patient information (HIV status of patient).

Patient disclosure of HIV status to GP

Yes	130	72%
No	51	28%
	181	

Is GP kept informed about patient's HIV care

Yes	98
no	70
No answer	22
N/A	8
	198

- patient has disclosed status to GP

Yes	94	72%
No	25	19%
No answer	11	8%
	130	

Note: 3 patients answered they had disclosed but also said they currently did not have a GP

- patient hasn't disclosed status to GP

Yes	4	8%
no	42	82%
N/A	2	4%
No answer	3	6%
	51	

Is this because you don't want them to be?

Yes	58	73%
No	21	27%
	79	

13 patients who answered that they had disclosed their HIV status to their GP also stated they did not want their GP informed about their HIV care.

About our Services

Why do patients choose this clinic over other centres ...

Patients were given a selection of possible answers, selecting any that applied, or give additional reasons . 187 patients gave 276 reasons for choosing the service

	2008		2007
Diagnosed at St. Mary's	103	37%	42%
Convenient	56	20%	17%
Reputation	56	20%	16%
Personal recommendation	43	16%	11%
Referred by GP	18	7%	7%
	276		

There appears to be an increase in the number of people choosing our services due to personal recommendation.

12 patients gave additional reasons none of which are different from the options already given :

- Been seeing Sean Waldron for 15 years and very happy to carry on
- Fantastic first class treatment by consultants
- Had health checks whenever I changed my partner and liked the service received
- Recommended by Freedom Health
- Referral from Chelsea and Westminster
- referred by St George's Tooting for a clinical trial
- Referred by private GP, Freedom Health
- referred by Prof Gazzard
- Registered as a patient here before my diagnosis
- The staff are really good in every way, Friendly and helpful, they always point people to the right direction
- was already a patient at the Praed Street Clinic
- Was an inpatient, staff excellent & also Dr Greene, also better location
- working close by

Does the service meet patients' needs ?

This was a "yes" or "no" choice with an invitation to elaborate if the answer was "no".

	2008		2007
Yes	172	95%	91%
No	10	5%	9%

182

Some patients wanted to answer yes and no, or "sometimes". It may be more use in future surveys if a range of qualitative options are available rather than a yes/no selection.

19 respondents gave reasons where they saw the service as falling short of their needs.

Ten of the identified shortfalls related to **primary care** provision :

- Yes and No - 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 clinic anyway.
- 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.
- That there would be doctors who would replace our GP, they would know better how to deal with our condition
- There should be a once a year skin check to check for moles for long term infected people
- Pain medication via the clinic would help
- I think I should be treated for all medical needs presenting on the day, not just HIV related ones only
- GP services in clinic more convenient, backup of HIV doctors if necessary
- Dental treatment as my dentist became private patients only and I cannot find an NHS dentist
- Urgent need of HIV dentists
- dental care

Nine comments related to perceived shortfalls in the HIV service:

- See a noticeable decline in "friendliness" of day ward during the year, this seems to be getting better
- Some services such as phoning for blood results is quite confusing - called several times and got no reply, then found they are changing the format. Called the new number according to info sheet and got the HR Dept. Confusing
- Shorter waiting lists for appointments - longer gaps between appts and more time with doctor
- More late evening appointments

- Better communication to working people, ie not informed about cancelled appointment
- PEP clinic only on Fridays - another day would be useful
- Most of the time Yes
- better sexual dysfunction service needed
- Dr Linda Greene is a miracle worker + Dr Jane Ashby

Members of Staff

This question asked for a yes/no response to whether staff were (1) helpful and pleasant, (2) make you feel at ease, and (3) maintain your confidentiality.

Due to some poor formatting of the printed questionnaire, there was some confusion which generally resulted in some patients not providing an answer for nursing staff. Some respondents wrote “sometimes” or “yes and no” on the forms, therefore “sometimes” was added as a potential response. In future it may be more useful to give a selection of qualitative options instead of “yes/no”.

There is a 10% drop in how helpful doctors are viewed by patients from 2007 to 2008, and a 6% drop for nurses.

Receptionists

	Helpful		2007	Make Patients Feel At Ease		2007	Maintain patient confidentiality		2007
Yes	188	96%	96%	182	95%	93%	188	98%	98%
No	5	3%		8	4%		2	1%	
Sometimes	2	1%		2	1%		2	1%	
	195			192			192		

Doctors

	Helpful		2007	Make Patients Feel At Ease		2007	Maintain patient confidentiality		2007
Yes	177	90%	100%	173	97%	98%	172	97%	100%
No	4	2%		6	3%		6	3%	
Sometimes	15	8%		0	0%		0	0%	
	196			179			178		

Nurses

	Helpful		2007	Make Patients Feel At Ease		2007	Maintain patient confidentiality		2007
Yes	156	93%	99%	157	94%	98%	156	95%	99%
No	11	7%		10	6%		9	5%	
Sometimes	0	0%		0	0%		0	0%	
	167			167			165		

Pharmacists

This was a new category added this year

	Helpful		Make Patients Feel At Ease		Maintain patient confidentiality	
Yes	176	93%	165	91%	174	95%
No	11	6%	17	9%	8	4%
Sometimes	2	1%	0	0%	1	1%
	189		182		183	

Some patients didn't answer the pharmacist question but put question marks by it – the assumption is they were not on treatment and thus not using pharmacy.

Information

These questions were added because they are included in the London HIV Consortium's audit tool for patient and public involvement.

Does the service provide useful up to date information via leaflets and/or the web?

yes	162	88%
no	23	12%
	185	

Comments on what people wanted written information about were:

- Would like to have copies of letters sent about his care
- where to meet straight catholic groups for socialising
- web access to own records (CD4 etc) email automatically after blood tests etc
- Tend to receive most info from consultant who also gave me leaflets
- Staff always have information
- Side effects of medication; new medication/treatments available
- Phoning for blood results
- Only if I remember to get Positive Nation or similar
- new concerns which arise about possible harmful side effects of HIV drugs (eg Abacavir)
- I registered my email address with you - why have I never received any info with regards to service updates, trials or the range of services you offer?
- GUM Clinic; Opening times; what to do if I run out of medication
- for long term patient at the clinic since 1991 more info about the diminution of services available at Wharfside
- drug combinations

- Don't know
- Diet
- not used web for here or taken leaflets
- Never received anything from here

Copying letters to patients

Does your doctor offer you copies of letters about your care ?

Yes	89	47%
No	100	53%
	189	

This appears to indicate that the policy of copying letters to patients is not being followed by all clinicians, but there may be reasons for this which a yes/no question couldn't indicate (eg, patient has already indicated a preference for no communication).

Patient involvement in their own care

Do you feel as involved as you would like to be in decisions about your care?

Yes		164	89%
No		20	11%
		184	

Other services

Would OneStop@Wharfside be of interest to you?

			2007
yes	122	66%	64%
no	62	34%	
	184		

Appears to indicate that the OneStop concept of nurse led clinics is an acceptable way to manage a large proportion of patients, thus creating capacity for doctors to deal with new patients within the 2 week target, as well as focus more on patients with more complex needs.

Would P4P (Patients4Patients) peer support be of interest to you?

			2007
yes	103	55%	58%
no	84	45%	
	187		

The consistent high stated interest in this kind of service is not matched by the number of referrals.

Awareness of Home Delivery Service

yes	127	66%
no	66	34%
	193	

Question presupposes the respondents on treatment should have a higher level of awareness ... but we didn't ask if they were on treatment and the earlier indications about pharmacy are that some weren't.

There is a fair level of awareness of the Home Delivery Service.

Use of other services within St. Mary's

Patients were asked if they had used other services at St. Mary's not provided either at the Jefferiss Wing or Family Clinic

			2007
yes	93	50%	57%
no	54	29%	43%
not sure	38	21%	*

185

*"not sure" was not an option in the 2007 PSS

Patients were asked for comments on these other services – far fewer were received than last year : 17 showed other services favourably, 13 were critical. Some of the favourable comments related to the HIV in-patient service.

Favourable comments

- Using services of Wharfside for some time. I feel honoured to be a "Wharfsider" From reception staff to Pharmacy Dispensing medication I have best care, support, love and respect.
- since 1994 and as recently as last summer the service and care has been extremely good and beneficial to my HIV related treatment both in outpatient department and Almroth Wright ward, I have no complaints!
- Rodney Porter Feb 2008; fantastic, clean and well presented. Most nurses friendly, sometimes feel like I have no clue about the treatment, tests,etc. be great if doctors gave info rather than have to ask.
- Western Eye is excellent as I'm in A+E there regularly. Dermatology and General Surgery are satisfactory.
- That is been very good services, I'm very pleased with St. Mary's services
- Pain clinic = am quite happy with service
- Outpatients and A+E facilities standard of services is excellent and care provided is of supreme calibre
- Good Ante Natal care
- I have always received a good and friendly service by the staff of St Mary's

- OK
- Virology excellent
- Good services
- Excellent care
- Excellent
- ENT OK
- Day surgery was very good

Critical comments

- normally pretty incompetent and slipshod, particularly the wards in QEQM. Staff turnover seems v high since last October. Why do they keep trying to force [in] patients to hand over their HIV medication? We CAN and WILL self medicate on the wards!
- It was a nightmare - I didn't know who would disclose my status first : endoscopy, Grafton or when I had bowel cancer
- HIV still stigmatised in other clinics and staff outside Jefferiss Wing - using gloves and masks when examining you/taking blood as they read you are HIV positive
- Bloody awful
- A+E very slow and looked very dirty.
- chaotic due to understaffing
- I am not comfortable with these services at all
- Long queue at ultrasound
- Urology was satisfactory but as of this week MOST UNSATISFACTORY
- There does appear at times to be a great deal of miscommunication between departments
- staff attitudes have changed a lot in terms of welcoming, showing genuine concern over well being of patients' health needs. EG when sent for blood sample, staff welcome you like a person with a virus, rather than a person with a health condition
- Problems with notes because I have been seen by Hepatitis C, clinical psychology, etc
- Private care is OK, NHS incredibly long wait
- Physiotherapist - wasn't too helpful

Future Improvements

“What do you like most about the clinic?”

Keywords in responses were collated in order to show the most frequently used words in answers to this question.

Friendly	37
Helpful	21
Caring	14
Efficient	8
Good Service	8
Confidential	7
Relationship with doctor	7
The Staff	7
Relaxed	6
Professional	5
Respect	4
Welcoming	4
Quick service	4
Comfortable	4

What do you like least about the clinic?

Keywords in responses were collated in order to show the most frequently used words in answers to this question.

Pharmacy waiting times	14
Waiting times	6
OneStop - not getting results by email	4
Waiting for Walk-in	4
Bloods taken in full view of other patients	3
Waiting for my doctor	3
State of the toilets	3
Difficulty getting an appointment	3
Waiting on phone for reception to answer	2
Waiting for blood tests to be done	2
Bureaucracy	2
Factory approach to processing patients	2

Waiting times in general were highest on the list last year. However, the number of times that waiting was mentioned in 2007 was 21 compared to 31 this year, with waits in Pharmacy raised most often.

Changes to the Wharfside reception waiting area appear to have worked – the only references to the waiting room were regarding the high temperature, lack of ventilation and in respect of the open nature of the reception desk.

Suggestions as to how the service could be improved

Evening/weekend appointment	6
More pharmacists to shorten the wait	4
Online access to results etc	4
GP service	3
CD4 tests after 1pm on Fridays	2
Bloods area needs expanding	2
More use of web and IT	2
PEP - 24/7 support line	
Walk in service for children	
PEP - not just Fridays	
Incentives to staff	
More senior nurses	
More appts with Dr Smith	
Online booking of appts	
Reorganise reception area	
Less frequent visits	
Make the OneStop email results system work	
Email contact with my doctor	
Use the TV for entertainment	
Water the plants	
Weekly or monthly support group	

Notable quotes -

- As far as I am concerned the clinic is the best among those I have visited, therefore unless otherwise, everything is OK
- Keep doing the same excellent job that you are currently doing
- Your staff is excellent
- STOP changing the doctors
- Pharmacy is way too slow

Comments on the clinic environment, cleanliness, etc.

The toilets were an issue raised in 2007, despite efforts since the 2007 PSS, little has happened and patients are highlighting the toilets as in need of attention in even greater numbers. There seems little point in asking patients for their views if the things they raise cannot be addressed.

Toilets	11
Very clean	4
Waiting area is a vast improvement	3
Better ventilation in reception -air conditioning perhaps?	3
Thanks for the drinks machine (Family clinic ?)	2
More reading materials	2
Access to more websites other than HIV	
Always clean	
Feels good to be there	
Fridge for the milk	
Make reception desk more private	
Pleasant and relaxing environment	
Shabby environment	
Tidy clean and refreshing	
Toilets good (Family clinic)	
Update facilities and the decor	
Water Cooler	

To assuage the patient asking for a water cooler, perhaps we should put a notice on the water cooler that says something like “water cooler”.

Notable quotes:

- Please do your best to keep the same staff, they are great
- Nearly no one uses the hand gel at the entrance, you shouldn't be afraid to tell them off - I caught super bug at St. Mary's
- I've seen nicer hospitals in the third world!
- It's all pretty grim with lots of windowless rooms
- Excellent all round, a warm friendly place
- Absolutely marvellous

Wharfside Patients' Forum

32 patients indicated that they were interested in getting involved with the forum. Only one left contact details by writing them on the form – the survey form should include space for this in future.