

Wharfside Patients' Forum

Notes of meeting held on Wednesday Sept 24th 2008

Present: Bernard Forbes co-chair
Philippe B, Frank, Fotios.

Garry Wall co-chair

Caroline Hart, Sexual Health Pathways and Implementations Manager

Apologies: Martin S, David M, Michael W.

The following issues were dealt with at this meeting:

1. Notes from last meeting
2. PSS-Patient Satisfaction Survey
3. GP Access
4. Phoning for Blood Results
5. P4P
6. CRS-Computerised Records Service
7. Other Business

1 Notes from last meeting

Agreed

2 PSS-Patient Satisfaction Survey

This years Patient Satisfaction Survey was carried out at Wharfside from 15-19th Sept and the survey at the Family Clinic will run over a four week period due to there being only two clinics per week. 190 survey forms were handed out and 180 returned completed or partially completed. Bernard Forbes and Fotios will create a database and collate the information gathered so we shall have the results of the survey available soon and these will be posted on the notice board above the sink in Wharfside as well as on the forum website.

The Forum would like to thank the volunteers who gave their free time to facilitate with this survey.

3 GP Access

Kensington & Chelsea PCT (Primary Care Trust) endeavoured to place a GP in THT Lighthouse in West London but refrained when patients reacted strongly against the idea of visiting a GP anywhere other than at a practise or in their HIV clinic. K&C PCT will now run a patient consultation on a new potential primary care service, but still provided away from the HIV clinic(s). The Wharfside paper on moving primary care provision into the clinic is being

refined and when finished will be passed to Dr Walsh and also Professor Azeem Majid, in charge of primary care research and development at Imperial College, to try to get a research backed programme of primary care provision within the HIV clinic (in line with patients' preferred option) in a way that proved what worked and what didn't.

4 Phoning for Blood Results

The new phone line for blood results is in place and is due to be running by the end of October. Patients will no longer be able to call the nurses station at random to request blood results but will call on a new number of 020 7886 6783 at the specific times of Monday : 11-1pm and Wednesday: 12-2pm. Concern was expressed to the forum that this new information is not well advertised in Wharfside for patients and Garry will speak with Zoe to improve this. The plasma screen needs updating with this information.

5 P4P-Patients for Patient

THT (Terence Higgins Trust) are launching a new health advisor service similar to P4P at Wharfside. The health advisors are HIV aware and can advise on how to adapt HIV into patients lives such as medication adherence, lifestyle changes, psychological concerns etc. This new service may mean disbanding P4P so as not to confuse patients and Philippe B will speak to Verity Morehead from THT to see if this is a duplicated service or a complementary one.

6 CRS-Computerised Records Service

CRS will not take effect until the end of January '09. The forum will organise an event for patients to air their concerns and to learn more about CRS. However a facilitator from Wharfside needs to assist the forum with this event and we are waiting to learn who may be available to help. Concerns are felt regarding the confidentiality of Wharfside patients' records after a problem in Finland where confidential records of HIV patients were breached and a health provider fined a considerable amount.

7 Other Business

HAVE YOUR SAY: Westminster HIV Service User Forum are having two consultation meetings about voluntary sector support services and what services Westminster PCT should commission for people living with or affected by HIV. They will be held at the Soho centre for Health and Care, 1 Frith Street, London W1D 3QS. The first one will be on Saturday Oct 11th and starts with lunch at 1.30 followed by meeting from 2-5pm and the second will be on the Tuesday 14th Oct 6.30-8.30pm, refreshments served at 6pm.

Should you wish to attend RSVP to: Claire McGing – clare.mcging@westminster-pct.nhs.uk or Tel: 020 7150 8008

Suggestion Box:

- a. A patient complained of having to wait for a long period on two occasions for an emergency prescription. Garry discussed this at the September HIV Service Meeting and Brett from Pharmacy agreed to contact the patient to discuss the trust policy on emergency prescriptions.
- b. There was a complaint about the plants at Wharfside looking very tired and dry. Half dead plants in a hospital waiting area does not inspire confidence in patients and at the next HIV Service Meeting in October this will be addressed to see if a member of Wharfside staff can take responsibility for keeping them fresh.

HIV Consortium: The London HIV Commissioners will be holding two meetings for Patient and Public Engagement (PPE) in North and South London. Times and dates to be confirmed but the South London meeting will be held at Positive Place and we are hoping to have the North London meeting at St. Mary's.

Recently a patient was admitted to the Zachary Cope ward from the Kobler Centre and was denied allowance of self medicating his HIV meds. Pharmacists were called and the patient informed that it is NOT trust policy to allow self medication. The patient stood firm as he has established times for taking his meds but not without considerable stress and upset. Most HIV patients have an established routine for taking their anti-retrovirals and when admitted to hospital is required to hand over their meds to be dispensed on ward drug rounds which are often done at erratic times.

The next Wharfside Patients' Forum meeting will be on Wednesday Oct 29th 6-8pm in the Macrae Room in the QEQM Building (beside Canal Restaurant)