

NOTES OF BRADFORD USER PARTNERSHIP GROUP MEETING
27th June 2007 6.30 p.m.

Present: Margaret Dalgety; Mehmoodah Hadi; Tracey Hiley (lung cancer nurse specialist); Sue Hodgson; Brian Magson; Jane Margerum; Linda McAlroy (in the chair); Alan Perfit; Peter Sale and Colin Sloane.

Apologies for absence were received from David Bland; Stanley Shepherd; Jools Symonds and Liz & Ronnie Sykes.

- 1) **Minutes** of the meeting on 18th May were approved with one small matter arising – the letter to Rose Stephens has not yet been sent as there are other matters to bring to her attention.
- 2) **West Yorkshire Universities Service User Involvement Project** – Jools is unable to attend this meeting but will come to the next lunchtime meeting on 20th July. However, Sue, Alan and Linda were involved in the project and spoke about it. People tell their stories of ill health (not just cancer patients) sharing with a view to possibly helping to train nurses and junior doctors. The universities involved are Bradford, Huddersfield, Leeds and East Lancs in Preston. Information has been circulated which Linda passed round and the motto is “**the best people to educate health professionals are patients**”. Jane Priestley of Bradford University’s Department of Rehabilitation hopes to make a virtual community of people with health problems or carers, also linked with East Lancs. A physiotherapist is also involved who will speak at Huddersfield and a link with sick children will be formed. There is also some role playing as an alternative to people telling their own story. Very interesting comments have been received. Where it is not possible for students to speak to people a “live” video will be used. Our members will also be involved in the consultation process and have found the whole experience very interesting and worthwhile. Reports will be presented to future meetings.
- 3) **Membership of the Group** – Linda and Colin had met with Cancer Nurse Specialists this morning to talk about user involvement and mentioned the lack of representation at these meetings. Tracey has volunteered to take on the role of attending our meetings and feeding back to CNSs until a replacement for June Toovey (Lead Cancer Nurse) is found. Peter said that Rose had assured him that an appointment has been put in motion and they are now considering a part-time appointment though this has not yet been advertised. Linda will bring up this issue when writing to Rose including our concern that it may be only a two-day post instead of a full time post. Peter asked that a copy should be sent to Jenny Scott, Chair of the Hospital Trust PPI and Tracey will also approach Rose regarding a Lead Cancer Nurse and will try to encourage more CNSs to attend. There have been some communication problems though she is now on the mailing list. Peter said that it would be good to see a consultant occasionally. Tracey holds a respiratory clinic on Fridays which usually imparts bad news and would

like the timing to be changed as the weekend is a long time to wait when bad news has just been given. She will take the views of our group back to the outpatients matron and Peter will bring the matter to the attention of the next PPI Forum and it will be added to our letter to Rose. The question of attendance at meetings will also be brought to the attention of the Cancer Local Area Network group along with others who receive our notes and agendas.

It is also some time since new service user group members had attended and Colin feels it is time to look at ways to attract new members. PALS have been contacted to ask if people would like to be involved in the future and Colin will invite people to attend a short meeting. Jackie Morris, the membership manager of Trust members could identify people interested in cancer services and may talk to her superiors with a view to inviting people to an afternoon session. Peter suggested that she be asked to organise a morning talking to people about cancer services at which we could take part.

4) **Work Plan Update** - Colour-coded work plans (enclosed) were passed round and Colin talked through it. (a) News re car parking – a slight improvement – in the near future concessionary parking permits will be available at the PALS office in the main hospital entrance and it is hoped that the system can be changed so that a ward manager can countersign the ward sister's signature instead of a level three manager. It has been agreed to raise awareness of concessions by including it on the website. A meeting is planned between Maria Nearey, Rose Stephens, Colin, Reva and another group member to look into the question of making information about concessions more available to patients, possibly when admitting patients. Peter suggested a leaflet explaining the criteria for permits would be a good idea. Mrs. Hadi will mention this at the PPI Forum but we particularly want to target cancer patients and carers. Tracey felt that a notice could be put on the boards in the cancer wards. However, some cancer patients are accommodated on other wards. It may be possible to start with cancer wards and move to other areas though it may be difficult to persuade the Trust to agree to this. If/when a meeting takes place Linda and Peter will represent this group. (b) – Ian Hammond, Director of Pharmacy, will attend the July meeting. © Engagement with Primary Care Trust – the Health Improvement Team may be interested in running an event and a steering group would need to be recruited from this group. (d) – The Website Project is under reconstruction but it is working. It is being changed to the same package as used by the hospital. (e) – Link with Yorkshire Cancer Network – a good event was held, a report to follow later.

5) **Reports and Feedback** – YCN Local user groups get-together – a very nice day and interesting to see what other groups are doing and how many similarities exist.

6) **Any other Business** (a) Peter regarding policy in hospital whereby people aged 77 or over are admitted to the care of the elderly ward – is this the right place for people admitted with a cancer diagnosis? Tracey said that if they are admitted under an oncologist they will go toward 15 or Haematology Ward 7 irrespective of age. However, other patients with a cancer diagnosis may go to the elderly medical unit or medical assessment unit but would then be referred to the relevant doctor, not just the geriatric doctor. There are not enough beds

to see all cancer patients on cancer wards. Peter feels this should be taken into account when the new cancer wing is opened and we can feed this in as we have representation on the planning committee.

(b) Peter, having read a press report on the discharge of an elderly lady from hospital, is worried about lack of communication and whether enough thought is being given to people being looked after following discharge. Could cancer nurses/social services visit to assess before the operation in preparation for discharge from hospital? The carer should also be given information regarding the care of the patient after discharge. Tracey said teams are in place to deal with discharge and look at all the issues but Peter feels that this is too late. Colin suggested that Peter take up this matter with the PPI Forum.

© Colin passed round Travel Insurance information notes from two sources and asked members to read and comment.

(d) Sue Hodgson suggested that we consider inviting speakers to the meetings, to talk about different roles of health professionals. This is something we used to do in the past and worked very well. Bosom Friends had recently invited the Breast Care nurses to come and talk to their group and they felt it had been really useful to learn more about the nurses' role within breast cancer services. This suggestion will be put to the main group at the July meeting.

Next meeting Friday 20th July 11.30 a.m. to 1.30 p.m.