

# AIREDALE CANCER USER PARTNERSHIP GROUP

## *Minutes of the meeting held in the boardroom AGH*

**16<sup>th</sup> September 2008, 12 noon to 2pm**

**Present:** Marion Allinson (Chair), Peter Sale (Vice Chair), Janet Duerden (Lead Cancer Nurse for Trust), Pat Dyminski (CNS Chemotherapy, Haematology & Manager HODU), Nick Carter, Barbara Shuttleworth, Betty Wandsworth, Mary Brennan, Dr Jane Hornsey, Peter Allen (CAB), Marjorie Stewart, Chris Whale, Aidan Henry (UGI Cancer CNS AGH), Philip Turner (General Manager for Medicine AGH), Colin Sloane (YCN), Pam Whitaker.

**Apologies:** Gwen Moore, Lesley Conti, Bridget Fletcher (Director of Nursing, AGH), Dr Georgina Haslam (Cancer Lead).

**Minutes of the last meeting:** PW asked to be included as present at the July meeting, the minutes were then accepted as a true record of the meeting.

### **Matters Arising:-**

**Managing the Stress of Cancer Booklet:** JD is expecting delivery of 5000 copies on 17.09.08. MA to write and thank the printers who did this work free of charge.

**Cancer Information Booklet:** Now ready to be sent to printers, Reva Underwood to organise and liaise with Pat Dyminski who will take delivery and store.

**Cancer Nutrition:** As suggested by PD, Lesley C has now written-up her story that will be available to other patients in HODU. MA has emailed this to PD.

**Website:** had been updated in July and August, by NC, PW & MA

## **1 User Involvement Update**

**Lesley Sterling-Baxter,  
Head of Patient Engagement, Bradford & Airedale Teaching PCT**

LS-B told us that the need for the 'User Voice' was now embedded in commissioning health services and there was a need to find a way of engaging users more. Two Project Leaders had now been appointed by the PCT. The first of these would be in post on 3<sup>rd</sup> November and would have the User Partnership in her remit, to act as a facilitator, take minutes etc and would be liaising with MA to get up-to-date information about the development of cancer services. Colin Sloane, now User Involvement Facilitator at the Yorkshire Cancer Network, but prior to this UI facilitator to both the Bradford and Airedale UPGs, offered to meet up with the new person when she was in post.

MA asked about payment for Users out-of-pocket expenses; LS-B is looking into this. CW brought up the case for the people of East Lancs, who feel they have no voice, MA said that this would be covered later in the meeting.

LS-B said that a district wide approach would be taken (we were one of 7 local User Groups, all reporting to YCN, MA) and we would be a forum for issues to be voiced and she would be prepared to approach other PCTs, if required, to raise issues brought to the meeting. CS said that this would be an ideal opportunity to re-assess the structure of the group to be an efficient and effective voice for the views of patients and carers.

The need to increase the membership of the UPG, especially to include those newly out of treatment was raised. Recruiting new members would be part of the new project leader's remit. MA remarked that this stated intent by the Board to improve services and user involvement should be celebrated and was most welcome.

## 2 Reports & Feedback

**Cancer in the Community event:** report now in its final draft and would be available for the next UPG meeting.

**Patient & Carer panel:** PS, PW & CN were members of this panel and would report back any relevant issues to the UPG.

**Cancer Reform Strategy:** MA handed round a précis of the strategy focussing on what it means for patients. The full document: Cancer Reform Strategy, NHS Crown Copyright 2007 can be ordered from: **Quote: 283524/Cancer Reform Strategy**

DH Publications Orderline, PO Box 777, London SE1 6XH Tel: 08701 555 455

Email: [dh@prolog.uk.com](mailto:dh@prolog.uk.com)

Document can be downloaded from; [www.dh.gov.uk/publications](http://www.dh.gov.uk/publications)

**Oncology Collaboration with BRI:** This has been a contentious issue, often fractious and difficult from the start. The decision was made to implement the changes on 31<sup>st</sup> March with the understanding that patients from HODU would be given the choice of place of care (BRI or AGH) when requiring out-of-hours emergency treatment. The accompanying extension to HODU hours has been successful.

MA has been informed by the PCT that 'Patient Quality Indicators' are now being included in all of their contracts with service providers to demonstrate quality in:

1. Access to services and waiting times
2. Better information and more choice
3. Building closer relationships between staff and patients
4. Clean, safe and welcoming environment
5. Integrated and co-ordinated packages of care.

It will be interesting to see how this can be reconciled within the Oncology Collaboration. With the service spread across two sites, it has been difficult provide a single service and many patients are not happy. A patient audit of patient experience since 31<sup>st</sup> March was set up (by Stephanie Loveridge, who has since moved on). Philip Turner (General Manager for Medicine) said this was only a numbers audit – how many patients & where they went – and that this autumn it was intended to carry out a more detailed audit, again on patient numbers. JH suggested that the name of the consultant involved be included as some consultants appeared to give patients biased choice. PD said that she had a book of more detailed, personal experiences (anonymous), from which the numbers had been extracted. LS-B said she would be interested in looking at the patient experience data as it would assist her department. NC wondered if this information could be more widely available. Between 31st March

– 13<sup>th</sup> August, there had been 55 admissions to AGH and 21 admissions to BRI. It seems that most out-of-hours patients prefer to stay at AGH.

**HODU patient information:** PD described the out-of-hours procedure at the Consent Clinic with the patient. A card with out-of-hours telephone number and a leaflet detailing the procedure was given to each new patient, together with numerous booklets. A patient-held record is given to each patient. These accompany the patient to each consultation or transfer to BRI. However, few doctors write in these, though nurses, A&E dept and St Luke's all seem to use them well. Copies of the leaflet were shown to UPG members at the meeting. JH thought that the wording was a little misleading/unclear and required amendment. PT to look into

PD also said that the problems arising were not about the care received on transferring to the BRI, but were issues regarding travelling distance/unfamiliarity of BRI, this set against the location of AGH, where the patient and their history of care were known influenced their choice. Also, on transfer, patient records requested by BRI would be sent AGH by taxi, which seemed an unsafe and expensive way to transport the only paper record of a patient's treatment. MA suggested that now with 2 full-time oncologists based at AGH and with what appeared to be a cumbersome, time-consuming and costly OOH emergency oncology pathway that patients patently don't want it might be an appropriate time to re-visit this issue.

Dr Crawford's recent leaflet was also discussed. It was proposed that patients would be given this on admission to AGH when HODU is closed, to re-enforce the information already given to them at the consent clinic. NC and several others thought this was insulting and unnecessary. PD asked if it should be scrapped. There was an overwhelming vote to get rid of it.

PS. Since this collaboration scheme had been developed we have heard that the situation at AGH has altered. We now have two oncologists in post as well as extra staff offering an extended service in HODU as well as the services of three oncologists from Bradford.. During the past six months on twenty-one occasions patients had opted to go to Bradford. PD has already described the problems when this happens. It is becoming obvious that the system is not popular with the patient, is continually creating worries and is becoming a means of bad feeling towards improving patients' experience as well as being a hindrance to the public's opinion of the hospital. In my opinion the time has come to review the situation with a view to discontinuing it

UPG members from east Lancashire who belong to **Bosom Friends** have collected over a thousand signatures on a petition about OOH oncology services. People from this area are unhappy with the current situation; they do not want to go to Bradford for treatment. Cancer patients who have their treatment at AGH understandably want to go back there when they feel unwell. Burnley Hospital now has no A&E so their nearest hospital is Blackburn. These patients and their carers feel disenfranchised, they have no voice. They hope that their petition will get them heard. There was some discussion on appropriate treatment and choices. JD said that clinicians always tried to make the pathway work in the best interests of the patients.

PT suggested that our comments should be taken back for discussion at the next business meeting with consultants and senior staff. He informed the UPG that a new strategic group the Cancer Board was being set up, chaired by Adam Cairns (CEO AGH) MA would be regularly invited and the first meeting (where membership and terms of reference would be discussed) would be end of September. (MA will be on

holiday so vice-chair PS will be attending). JH asked whether GPs would be invited. PT explained that there were other forums where GPs had input. There is also to be a Cancer Business Group looking at how treatment/service development was managed within the hospital. A service-user representative would sit on this group.

Site Specific Groups which meet quarterly would also invite a patient/carer representative to meetings.

### **Reports & Feedback**

**CLAN:** Equity of service had again been raised regarding the availability of reconstructive surgery after mastectomy. A was asked to look at the Breast Cancer Pathway at AGH and report back to CLAN on 10<sup>th</sup> October. PT is attending CLAN so will have information available.

**Lymphoedema Service:** Since Martine Huit (Macmillan Lymphoedema CNS) left in December 2006, there has been no proper service, currently there is an interim service at Leeds (St James). MA had been telephoned by Lorraine Macdonald (Macmillan Development Manager) to ask what was happening about lymphoedema services at AGH. PT (with Dr Georgina Haslam) reported that the specification for a Lymphoedema service was now ready to be put out to tender. AGH will look into the viability and decide whether to put in a bid. Whoever takes this on should realise that demand will escalate and that the funding must be adequate. The timescale is such that a service would not be in place until the new financial year.

### **Any Other Business**

**JD, Palliative Care:** Les Dory (National Lead for Preferred Care) will give a presentation on 17<sup>th</sup> September in the Education Centre, AGH. There would be room for a couple of people from the Usergroup. PA and JH volunteered to attend.

**CS:** thanked MA for her efficiency and energy in doing all the work that he used to do as facilitator in preparation for the Usergroup meetings. This was echoed by all present.

**Next meeting: Tuesday 4<sup>th</sup> November, 2008  
Boardroom, Education Centre, Airedale General Hospital,**