

Notes of Meeting 11th April 2017

Attendance: Sian, Sally, Gina (H&N CNS), Jan, Pete, Sue Clare, Irene, Adelle, Yula Apologies: Colin, Roger Rob, Jean, Julia, Angie

Statistics/ information for chemotherapy patients- Update from Angie (not in attendance), , "in principle I think they (consultants) will be happy to add CRUK to our list of information sources handed out and discussed at preassessment, so patients can be signposted to CRUK if they wish to do further research. At the next consultant meeting we plan to discuss the statistical side again once each consultant has looked at where they get their individual figures.

Pre Treatment chemotherapy information session- Update from Angie (not in attendance), "Audit of preassessment - just completed the gathering of the info, data needs to be examined. No significant issues on first glance. There is a plan to discuss and utilise any aspects to improve the sessions

Cancer Wellbeing event- Sian advised the group that due to personal reasons she was unable to participate in this event, but the group were welcome to continue. After some discussion it was agreed to defer an event until next year and possibly tie it in with the cancer survivors day, 1st Sunday in June.

Lymphoedema – patient update from Clare who has having had an appointment, now has to wait until after Easter for the lymphoedema massage. Telford & Wrekin CCG commissioners confirmed that the contract is still not complete, but the plan is still for services to be available in Telford hospice.

Yula advised the group that she is planning on starting a support group for lymphoedema patients, which will be on the third Wednesday of the month. First meeting 17th May in Telford. Yula will share her poster, so everyone can share with their networks.

Action Yula

Hospital food – It seems the problem is ongoing with Jan and Sian having problems with the hospital food, either in person or witnessed. Adelle advised that Healthwatch can only follow up on trends and suggested if we let people know to contact Healthwatch if appropriate they will follow up.

Healthwatch – Adelle explained the role of Healthwatch to the group. There was discussion on how to let patients know that Healthwatch is there to support patients. Gina invited Adelle to meet her head and neck patients.

Stoma friendly toilets- Irene advised that Oswestry has been recognized as a stoma friendly town, only the second in the UK. Irene is also working with Hannah Roy to make the toilets at Royal Shrewsbury stoma friendly. Sian advised that she is working with Telford Patients First, (Telford patient group) who are going to campaign for stoma friendly toilets. They have created a task and finish group and the aim is to convert 75% of the organizations we approach into stoma friendly toilets. The Telford & Wrekin CCG have agreed to work with us and will be approaching all the GP surgeries. We are planning to meet with the local authority to find out what toilets they have and ask them to make them stoma friendly. Sian also advised that she has recently been made aware of men have incontinence needs as a result of prostate surgery. Roger has contacted Prostate UK to see if they have a campaign to get suitable bins in gents toilets

Prostate cancer- Roger (not in attendance), confirmed he was waiting on a reply from Dr Elves to see if he would attend the group to discuss.

Digital Health- Unfortunately SATH failed to get the grant they applied for to continue working on developing the app. Rachel is still working with the app.

National Cancer Patients Experience Survey – Sian highlighted a few areas for improvement from the survey. As a general note prostate and urology were generally showing need to improve, having lower scores in many areas.

A few specific questions where SaTH had a low overall score were discussed briefly. These included

Q15 55% Patient definitely told about side effects that could affect them in future.

Q22 53% Hospital staff gave information on getting financial help

Q45 41% patient given understandable information about whether radiotherapy was working

Q48 63% patient given understandable information about whether chemotherapy was working.

Gina advised that Head and neck patients get a letter from their consultant detailing diagnosis and treatment. They have also recently implemented Holistic needs assessment clinic, which are receiving excellent feedback.

Sally advised that patients finishing chemo will now receive an end of treatment discharge summary. (This is due to the new e prescribing system going live). Sally will share a sample.

NEXT MEETING: TUESDAY 9th May 2017 HAMAR CENTRE, ROYAL SHREWSBURY HOSPITAL, SHREWSBURY