



Shropshire & Mid Wales
Cancer Forum

Notes of Meeting 13th June 2017

Attendance: Sian, Sally, Mandy (H&N CNS), Clare, Irene, Colin,

Apologies: Jan, Pete, Sue, Roger, Rob, Jean, Adelle, Yula

Statistics/ information for chemotherapy patients—Angie not in attendance. Sian will contact for update for next meeting

Pre Treatment chemotherapy information session- Angie not in attendance, Sian will contact for update for next meeting. Clare recently spent a day with the chemo unit and saw the video. Clare advised that no volunteers remained in the room to answer any questions. While patients could ask any questions at their 1 2 1 with a chemo nurse appointment everyone felt someone should be in the room to answer questions that arose.

Lymphoedema – no update from the commissioners, will chase for an update for next meeting. Clare has a months wait for an appointment.

Sian reminded everyone that Yula is holding her first a support group meeting for lymphoedema patients, this month at the Hamar centre.

Hospital food – Sian had emailed Helen offering for members of the group to meet with the housekeepers and Health Care Assistants, ward by ward if necessary to raise awareness of the importance of food and the difficulties we had encountered and the availability of involvement from the kitchens for patients with multiple food needs. Helen had offered to come back with some dates, but these still hadn't been received. Sian will chase.

Stoma friendly toilets- Irene advised that Hannah Roy had not been in contact regarding her offer to make the toilets at Royal Shrewsbury stoma friendly. Sally and Irene will contact Hannah again. Sian confirmed that Telford Patients First, (Telford patient group) will be officially launching this month and will be issuing a letter introducing themselves and setting out the stoma friendly toilet campaign in Telford. Sian will forward letter to Irene when it is issued.

Prostate cancer- Sally advised that the Lingen Davies cancer fund had been successful in raising funds for an MRI guided Prostate Biopsy Machine. The machine merges MRI images with live CT scanning to provide pinpoint accuracy for prostate biopsies. The aim is to have this working by December 2017.

Digital Health- Sally advised that funding for the digital health – (chemo and prostate) app runs out shortly and nurses working as part of this app will return to their substantive posts at the end of July. It also appears that SaTH have no intellectual rights on the app and the provider is looking to work with other interested hospitals. There is a bid into Macmillan for the development of a different app, which would be part of the Macmillan living with and beyond cancer survivorship agenda.

National Cancer Patients Experience Survey –Not discussed.

Head and neck patients. Mandy shared with the group the information they provide to a patient on first diagnosis. The group commended the head and neck team on the information. There was a suggestion that at the next edit the wording of the get fit advisor is reworded, it was felt the description of an exercise specialist may put people off. The group were particularly pleased with the letter offering patients an invitation to a holistic needs assessment clinic and reassurance that this was available to patients at any time in their pathway.

Vulnerable patients feedback Sian has not received any further feedback on how/if the Trust plan to capture feedback from patients. There was discussion where it was agreed (and people had evidence) that many patients did not like to give negative feedback as they felt this would affect their care. Sally made the point that sometimes people do not realize how their words/actions have come over and would want to know. Mandy confirmed that they like having feedback, that it is very useful to them. It was suggested that the head and neck team add a few sentences to their main leaflet letting patients know that they value feedback. Mandy agreed to do this.

Details of two forthcoming events were shared:

Observe and act patient experience conference at Shrewsbury football club 5th July

West Midlands clinical network patient engagement event, Birmingham 11th July

NEXT MEETING: TUESDAY 11th July 2017 HAMAR CENTRE, ROYAL SHREWSBURY HOSPITAL, SHREWSBURY