



Notes from the meeting held 9th April 2013 at The Hamar Centre, 14.30-16.30

Present: Sian Hallewell (Chair), David Reece, Geoff Searson, Colin Stegeman, Helen Kipling, Greg Haywood, Rob Gough, Ray Dowling (notes), Roger Fallon, Eileen Anderson.

1. Apologies: Marilyn Meade-Brown, David Whiting, Sue Wreglesworth, Linda Bentick, Eileen Lewis, Richard Davis, Alan Morrison

Introductions: David (Rare Cancer), Rob (Prostate, Carer, Bowel & LD), Geoff (Prostate), Colin (Carer), Helen (Breast), Gregg (Exercise H&W), Ray (ex CHC Wales), Sian (Breast), Roger (Prostate).

2. Previous Notes: These were passed as a true record of the afternoons meeting of 12th March 2013

3. Objectives for 2013:

David Whiting has taken our individual thoughts on objectives for the forum and produced a chart of our collective objectives for 2013 and we were all asked as to which objectives we may be able to progress on both a collective and individual basis. Sian and Rob cannot cope with the increased workload, but will help with many aspects. It was indicated the need to drive some forward and a greater push may be needed in these areas.

The allocation and individual input on the various objectives were tabled and interested members of the group selected objectives that they felt they could contribute to the progress of the action, the following is a list of actions of a particular interest to a member or members for advancement.

David R indicated he was willing to help in; - 1.1, 1.5, 1.7, 1.9, 2.1 and 2.2. He would also reassess 1.9 and bring a modified version back to the forum.

Action:

David R

Roger indicated his willingness to help in; - 1.4, 1.5, and 1.8.

Geoff indicated his willingness to help in; - 1.1 and 1.3.

Colin would give support in as many areas as he could.

Gregg would support 2.1 and enable a workshop to promote health and has had 100 active people on 'Get Active Feel Good' programme since June 2012. He had some reservations as he

had had an influx of people but sustainability would only be forthcoming if GAFG was incorporated in referral pathways. The users of the course of exercise had experienced a 'kick start' from post cancer diagnosis concerns into individual design of physical activities to strengthen bodies and minds. Colin supported the programme as his wife had taken part in it and her self-esteem and improved movement at home was the evidence of a successful outcome. Colin did say that cancer has no boundaries but having Gregg gives more impetus to exercise but that mixed messages are a problem.

Moray Hayman to be contacted again to invite her to attend the forum. **Action: Sian**

Helen, previously treated at Christies in Manchester, gave an indication of her discharge summary in which she was given a comprehensive file on post condition awareness's and the route to answers, so ensuring that she had ownership of any direction she wished to take.

Eileen, although Eileen was absent it is believed that she will help in;- 1.1, 1.3, 1.4, 2.1 and 3.1.

Sian indicated her willingness to help in; - 1.2, (in hand meets 22nd April), 1.6 (Aide Memoir), 2.3 (Sian and Rob).

It was suggested that 1.1, 1.3 and 1.4 could all be served by holding an AGM covering these aspects. And that some of 1.4 was already progressing in larger bodies (Health and Wellbeing)

It was considered that 1.7 may be better served by time groups or split into half.

Rob stated, but we all support the need for the forum to grow and if we could find useful links then Sian could promote them along with 1.8.????? what was this sentence meant to mean????

2.2 is to be put to David Whiting and commissioners. A very important aspect of treatment physical, mental and social is the **Treatment Summary** and some concerns are being raised as to whether doctors are issuing them and do we have equal access to leaflets affecting our condition. Symptoms are often missing on consultation discharges

3.3 Sian and Rob to see Marilyn Owens this week on 'Cancer Survival and Programmes'.

3.1 Sian and Rob to look at new streams of funding.

(Please note that the Objective and Action chart will supplement these notes and will also be updated to take into account the above discussion and updates 1.1 – 3.1)

4. Matters Arising

- a) Free prescription post cards for breast team have been successful (an improvement from 43% to 77% in the National Cancer Patient Experience survey) and 500 new postcards have been delivered to the breast team
- b) No update as Dr O' Connor is on holiday.

- c) Confidentiality form agreed to use the template supplied by David Whiting. Sian to add forum's logo
- d) Exercise workshop- following some discussion in which the benefits of holding a one off workshop were discussed. A workshop would meet the need of one group but would not solve the problem of ongoing referrals. It was agreed that Sian would find out when the next exercise working group was to meet to see what was planned by the working group.
- e) Rare cancers, this is still with David Whiting
- f) David R expressed concern that it had been 3 months since the low compliance score of the Upper GI team had been raised. It was agreed that if David W had not received a response the forum would write directly to the lead clinician.
- g) No further information on merger of wards 21 and 23.
- h) List of cancer services delivered by SATH to be drawn up by Sian and sent to David Whiting for confirmation

5. Feedback from other meetings

The Patient Experience & Involvement Panel (PEIP) - Eileen attended and her first impressions were read out, which included:-

It's a generic patient experience group managed by SaTH.

It aims to cover a wide range of patient experiences and offers examples of patient stories

Eileen would value another member also attending.

Sian to produce a feedback form template, which may standardise our feed back information and provide some suggestions on what to consider when representing the forum at a meeting.

6. Feedback from the hospital/Commissioner:

David Whiting was not present to give any hospital/commissioner feedback.

7. Treasurers Report: Allan was not available to the treasurer's report.

8. AOB:

Rob reported he is presently progressing the issue of improving the health of those with learning difficulties/disabilities with the Shropshire Clinical Commissioning Group (CCG)

The meeting closed at 4.30pm.

NEXT MEETING: Tuesday 14th May 2013 at 2:30pm, The Hamar Centre, Royal Shrewsbury Hospital, SY3 8XQ