

Survivorship Meeting 12/6/13

- *personal notes taken by DR of Cancer Forum - may contain inaccuracies & definitely didn't get every point discussed, so check anything that seems interesting!*
- convened by Shropshire CCG Cancer Commissioner at Shropshire Education & Conference Centre, RSH;
- **Agenda:** Introductions, Purpose of meeting, Treatment summaries¹, Well-being clinics², Cancer information³, Support for carers, Next steps
- **Invitees:** Fiona Hay (facilitator), David Whiting, Michael Bennett, patient reps from Cancer Forum, TW GP, Tudor Humphries, Jessica Hancox, Severn hospice rep, Jane Blay, Kate Burley, Reps from both public health depts
- **Attendees:** 16 persons, including 1 GP & reps of Telford & Shropshire CCGs, Macmillan, Hamar, SATH, Severn Hospice & an exercise initiative, 2 Cancer Forum reps

Treatment Summary Form

- unanimously endorsed, and can easily be adopted in the "Somerset system" - the IT system in use at SATH;
- agreed that the four sections on symptoms⁴ could be v useful for patients in distinguishing between symptoms due to underlying condition & other new illnesses; in the event of emergency hospital admission or consultation with GP outside of normal home area; & in referral to &/or from other specialist medical services;
- agreed to at least trial it at SATH with at least one patient group - probably breast cancer;
- considered monitoring issues with GPs & patients;
- BUT Jessica (SATH) very doubtful that the format of the summary form could be modified to make it easily understandable by patients what is meant under the four sections on symptoms - can take many months to get any changes made to Somerset IT system;
- would probably be necessary to have summaries explained to patients - don't just send them in the post!

Health & Wellbeing Clinics

- Fiona (GP & new Macmillan rep) keen to trial three H&WB clinics as soon as possible - probably three consecutive evenings in a non-medical setting (football club meeting room mentioned) -possibly focusing on prostate cancer;
- agreed that having someone to help patients understand & negotiate issues covered in the clinics⁵ excellent , BUT:
- concern (*expressed by me*) on how such clinics would be offered to all cancer patients, given the difficulties of scheduling group activities to suit individual needs of patients with quite different disease timings;

¹ [Treatment Summary link](#)

² [Health and Wellbeing Clinics link](#)

³ [Best way to make information available to patients? -Macmillan information manager -Pods in libraries? Cancer information prescriptions?](#)

⁴ [Four sections on symptoms identified as particularly useful for patients: "Possible treatment consequences and/or late effects", "At risk of", "May experience", & "Alert Symptoms that require referral back to specialist team"](#)

⁵ [Health & Wellbeing Clinic topics: Cancer type and symptoms; Health and wellbeing messages \(diet, exercise\); Treatment; Benefits advice; Prognosis ; Return to work; Management of symptoms e.g. fatigue ; Access back into the system post-treatment; Signs and symptoms of recurrence; Complementary therapies; Counselling](#)

- Cancer Coffee Mornings being held by SATH thought to be quite similar - possible duplication? - need to choose one or other or combine in some way?
- could also collaborate with ongoing Exercise initiatives (*didn't get full details here*);
- CCGs have funds for 4 patient events per year - could be used for this

Cancer Information

- agreed that the appointment of a new Macmillan Information Officer needs widespread publicity, & posters about where to find information on cancer issues in GP surgeries, SATH foyer, public libraries endorsed;
- practical issues with keeping information pods stocked discussed - meeting not so much in favor of these(?);
- Health Information week starts soon & good to get cancer info into that;
- 1 in 7 adults nationally deemed functionally illiterate - need strategy for them⁶;
- Information overload for people facing very emotionally charged situations⁷;
- Polish is 2nd most important language in Telford & Wrekin area currently;
- electronic information needs work - SATH website needs better "signposts" to resources like Macmillan;
- Kathryn⁸ (also Cancer Coffee Morning coordinator) currently working on SATH internal & external websites to make such changes;

Support for Carers

- (*I lost attention here - discussion too woolly*)
- general discussion about the fact that carers need support & the sorts of support needed; and that this is also a local authority issue;
- broadly agreed that this is potentially huge area which needs to be scoped further (*i.e. What are the specific needs of cancer patient carers that are different to those of other carers?; What are the most important needs that aren't being met?*)

Next Steps

- DW will prepare notes on the meeting, formulate a set of actions & suggested actors & circulate;
- No need for 2nd meeting until some actions have been taken based on this one - hopefully hold a review meeting to consider results in due course

⁶ face-to-face events like H&WB clinics & Cancer Coffee Mornings etc. useful here

⁷ face-to-face communications may assist with this also

⁸ Kathryn said she'd be delighted to come & talk to cancer forum about the Cancer Coffee Mornings