

Living with and beyond cancer follow up focus group

Thursday 28th November 6-8pm Kindle Centre, Hereford.

Wye Valley NHS Trust, Macmillan and Healthwatch Herefordshire held this focus group to feedback to the attendees of two previous focus groups held with the public about LWABC in December 2018 and April 2019 what has happened with the feedback and how the LWABC programme is developing the offer for patients and their families.

8 members of the public attended.

Part One - LW&BC End of Year Review

The LW&BC End of Year Review was given by Stephen Heptinstall, Project Manager for the Programme. Stephen thanked the participants for their input over the last year and stressed how their ideas had helped shape the work the LW&BC team undertook. Stephen outlined each of the projects within the LW&BC Programme and progress made to-date:

Holistic Needs Assessments: The Holistic Needs Assessment (HNA) is undertaken when a person starts their cancer journey, alongside their medical care. It is a conversation with the patient and possibly their family to ensure that physical, practical, emotional, spiritual and social needs are met in a timely and appropriate way. Eight Clinical Teams have introduced or are about to start HNA's in Hereford County Hospital. These will be supported by four new Cancer Support Workers.

Treatment Summaries: A Treatment Summary (TS) relates to the treatment a patient has just received. It is a personalised summary of information given to the patient and the patients GP about their cancer and their future progress. It is to be given at the end of primary treatment in the hospital. Wye Valley NHS Trust are going to trial TS Templates with three Specialties—Lung, Prostatectomy and Haematology patients. The aim is that it will be shared with all relevant people, including patients. It will include self-help information and be in a language that is more understandable to non-medical people.

Cancer Care Review: The Cancer Care Review (CCR) is a discussion between a patient and their GP about their cancer journey. It helps the person affected by cancer to understand what information and support is available to them in their local area, open up about their cancer experience and enable supported self-management. We have teamed up with the Net-work Project Managers at Taurus, Social Prescribing Service and a volunteer GP Practice to trial a new approach to undertaking CCR's in Herefordshire. The project will investigate whether shifting elements of the CCR to the Social Prescribing Service is feasible locally, when supported by a GP.

Health & Wellbeing: We have developed a number of initiatives around improving health & wellbeing opportunities and education to cancer patients in Herefordshire.

In collaboration with Breast Care Haven and Breast Cancer Care the WVT Clinical Breast Team now run the 'Moving Forwards' 4 week Course for those recovering from Breast Cancer. In the summer the Expert Patient Programme ran a six week 'Self Help' Programme for all those living with or after cancer as well as their relatives at the Kindle Centre. It is hoped we can run something similar in 2020. We also ran Health & Well-being Day at the Three Counties Hotel in September. There were 70 participants and over 30 stalls of local services at the event. Feedback was extremely positive, highlighting that such services are vital for people living with and beyond cancer.

Exercise Referral Scheme: In collaboration with Halo Leisure Ltd we are piloting an ERS in Hereford. Patients can be referred by the Breast, Prostate, Colorectal or Haematology teams to a specially trained Exercise Instructor at the Leisure Pool. Teresa Butler completed her CanRehab training in the summer and is now qualified to help people with cancer begin to exercise safely.

Physiotherapy & Dietetics: We have been able to secure funding to trial dedicated Physiotherapy and Dietetic time, specifically to deal with those with cancer. Chartered Physiotherapist, Siobhan Macquillan and Dietician Jo Clutterbuck are joining us in the Macmillan-Renton Unit and will be offering clinics to patients in New Year.

Psychology: The LW&BC team had been successful in securing funding to get two groups of cancer nurses trained in Level 2 Communication Skills. This was led by Consultant Clinical Psychologist Ray Owen. This training will help nurse team's better support their patients with emotional and psychological needs. It is hoped the money will also support a Level 3 Counsellor linked specifically to cancer services.



Pictured: Stephen Heptinstall, LW&BC Project Manager

Part Two - Workshop

We asked the group to feedback on two further questions to shape current work and to make one vote for each of the questions for their most important theme.

1. How can we make attendance at patient & carer support groups more accessible and attractive?

Practical: 7 votes

- Activity, sometimes people don't just want to talk about cancer
- Should be treated more like a medical appointment as patients are good at attending those
- Content needs to be more practical not just website direction
- Practical advice and instructions
- More information beforehand about where the course/group is and what it will cover
- Know what the content will be

Flexibility:

- Range of days/times
- To know it exists - advertise and promote
- Knowing the name of a support group

Venue: 1 vote

- Transport options
- Environment - outside of clinical setting
- Out and about
- More knowledge of less known cancer type groups
- Internet forum local sites especially for rural needs
- Moving location in the county
- Need car parking space that are affordable
- Transport support for those that need it

Specific:

- Identify needs of the group
- Ownership of group by members
- Trust and confidence
- Group agreement
- Empathy and understanding
- Discussions in group stay in the group - confidentiality
- Patient led groups where you go to them
- Buddying so you don't have to turn up to the first one on your own
- Peer support that's productive

- Available for social interaction

Involve professionals:

- Involve the cancer nurse specialist over the border to help spread word
- Opportunity for 1-2-1 if a sensitive issue arises
- Sell it via social media, share information with other health boards over border

Online:

- Does it have to be face to face?
- Group mailing list
- Telehealth - people dial in to help reduce travel time. Could use community hub locations

2. What would you want included in your discharge letter (treatment summary) from the consultant?

Specific information:

- Information about useful apps, access to test results and GP records
- Details of the information which has been provided to me

Contacts: 3 votes

- Who to contact for new symptoms or signs of recurrence?
- How to Fastrack in if symptoms recur
- Out of Hours contacts
- List of people/contacts for professionals involved in all aspects of my care
- What health professionals will be involved in the future
- List of contact for questions or concerns about recurrence

Medication:

- Interactions of meds
- Quicker meds on discharge day
- Summary of meds start/finish date
- Interaction with other existing conditions

Care Plan:

- Secondary care ongoing management plan
- Integrated care plan

Transport:

- Plans for cross border/county transport

- Eligibility for non-emergency patient transport

Monitor:

- Ongoing tests, type and frequency
- Reference and cross check to the holistic needs' assessment
- Timeline of what happens next to me, surveillance and cancer care review
- Treatment breaks documented
- What other considerations do I need to think about?

Support services:

- Identify what support services there are available
- Appointments for support services

Lifestyle Information:

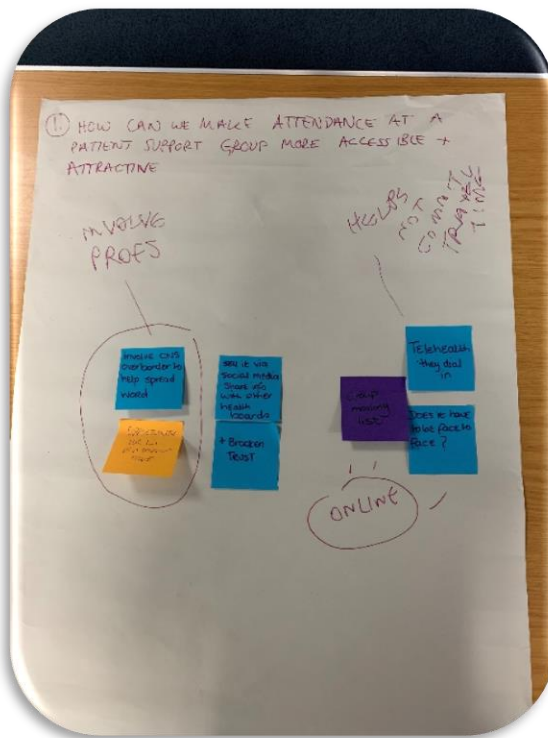
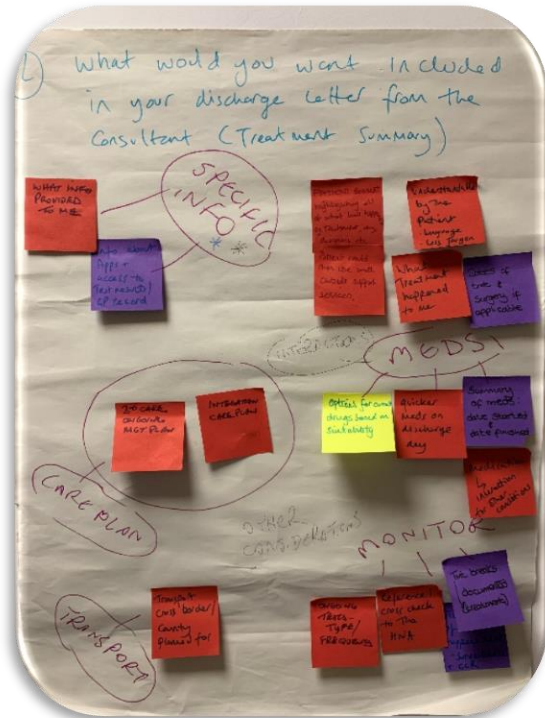
- Lifestyle support advice
- Dietitian
- What should the patient do regarding exercise?
- What to avoid in activity/diet relevant to specific cancer

Follow up: 4 votes

- When is the next follow up appointment?
- Follow up plan and commitments
- Identifying specific medical, mental, physical, social needs
- Accurate and complete record of diagnosis and treatment side effects
- Clear concise follow up care instructions
- What are the things to look out for signs of recurrence?
- Clear follow up regime

List side effects:

- Were there any complications in treatment/surgery to keep an eye on?
- Detail what side effects patient had to drugs/treatment
- Potential side effects to treatment & drugs
- Drugs and side effects of comorbidities



Pictured: Three posters with labels created during the evening