

“When frequent hospital visits stop, what sort of support and follow-up care helped, or if it was available, would have helped you and others affected by cancer, begin to feel more like yourself again?”

1. INTRODUCTION

NHS and voluntary sector organisations across Morecambe Bay are working together to improve the experiences of people and their carers living after cancer treatment. This is the Macmillan project Living With and Beyond Cancer 2016-2018. Introducing the Cancer Recovery Package is key and supports partners in their delivery of services both during and beyond Macmillan funding.

2. BACKGROUND

This summary presents the headline themes from a series of Open Space events held across Morecambe Bay in Barrow, Morecambe and Kendal. The meaningful involvement of people affected by cancer in the project is crucial. The Open Spaces were shaped *by* people affected by cancer *for* people affected by cancer. Individuals share the experiences which are most important and relevant to them, while living with and beyond cancer. They provide an insight into what matters in their recovery and can promote well being.

3. PURPOSE

The aim of the Open Spaces is to provide a better understanding and increased awareness of what is important in cancer recovery from the perspective of people affected. The findings act as evidence to co-create improvements in cancer services provided by the local hospitals trust, general practices and a wide range of community partners. They will also inform what the Cancer Recovery Package will look like in Morecambe Bay.

4. APPROACH

Using an ‘Open Space’ approach provided a way for people to talk and as participants, to create their own agenda. A themed, central question around which parallel breakout sessions helped to identify thoughts and ideas. The Guiding Principles for Open Space¹ are:

- Whoever comes are the right people
- Whenever it starts is the right time
- Wherever it happens is the right place
- Whatever happens is the only thing that could have
- When it’s over, it’s over.

Of the 39 expressions of interest, 31 people attended. After the discussion rounds, attendees were asked to use 3 voting stickers to indicate which topics and statements they felt were most important. 12 people pledged their commitment to further involvement in the project following the events.

¹
<http://www.kingsfund.org.uk/sites/files/kf/media/liz-saunders-judy-taylor-kingsfund-clinical-leaders-leaders-front-line-kingsfund-may13.pdf>

5. HEADLINE THEMES

The key points that attendees voted on as being important came together as six broad themes, with an expected degree of cross-over and interconnection between them.

- 1) Information, 2) Clinical and Professional Support, 3) Shared Decision Making 4) Health and Wellbeing, 5) Peer Support, and 6) Control and Return to Normal.

1) **Information;** Attendees wanted a timely way of delivering information using appropriate words;

“It’s information overload”

“There seems to be no standard process for what info you get or how”

2) **Clinical and Professional Support;** Attendees suggested introducing new professional links to continue a conversation;

“We don’t always ask questions at the appointment”

“Can people living with cancer have regular contact with their GP?”

3) **Shared Decision Making;** Attendees said they needed information before an appointment to help to prepare beforehand;

“Being able to create a relationship”

“Establish a good rapport, working 2 ways”

4) **Health and Wellbeing;** Attendees reported they need confidence and reassurance to return to a normal life again;

“I don’t want to get a victim head on”

“I want to be treated as a whole person”

5) **Peer Support;** The experience amongst participants was that they need support over and above that that family and friends can provide;

“I need a buddy to catch me when I step off the cliff”

“I need to know other people are going through the same”

6) **Control and Return to Normal:** Participants stated they need help understanding what is ‘normal’ because what was normal before is not normal afterwards;

“Often the journey is so quick, treatment is finished before you have got your head round it “

“You are dropped out the other side and left”

“When frequent hospital visits stop, what sort of support and follow-up care helped, or if it was available, would have helped you and others affected by cancer, begin to feel more like yourself again?”

6. CONCLUSIONS

People living with and beyond cancer who attended the Open Space events provided a vital insight into their experiences of cancer which will be shared with partner organisations through this report. The rich data generated at the event can now be used as the foundation for further involvement of people living with and beyond cancer. It will also be used for the development of services that will better meet the needs and improve the experience of those affected by cancer in the future.

7. NEXT STEPS

The Morecambe Bay Cancer Locality Group is currently developing its Framework for Delivery, a One Year Plan (2017/2018) which will be reviewed annually. This Plan formally considers the Macmillan Living With and Beyond Cancer Programme and will help to inform and shape implementation of the Cancer Recovery Package in Morecambe Bay. This Locality Group will also include representation of people affected by cancer in its membership.

A key element of Macmillan Living With and Beyond Cancer in Morecambe Bay 2016-2018 that is actively being developed is a Living With and Beyond Cancer Hub. This will ensure that people affected by cancer are involved at the heart of cancer service development and delivery. The Hub will be made up of local patients and carers living with and beyond cancer.

The learning gained is being applied to the creation and development of ongoing involvement opportunities for people affected by cancer. Key lessons are that to maintain involvement, a wide range of opportunities need to reflect what people have already shared about their experiences, need to be relevant and meaningful.

Information gathered at the Open Spaces and additional data collection activities, will be used to ensure that new initiatives, work streams and services are targeted at addressing the needs and issues raised by people living with and beyond cancer, including carers, themselves.

8. THE CANCER RECOVERY PACKAGE

A practical guide made up of four elements to support living with and beyond cancer.

- 1) Holistic Needs Assessment and Care Planning
- 2) Treatment Summary
- 3) Health and Wellbeing Event
- 4) Cancer Care Review

9. PROGRESS

Putting into place the four elements of the Cancer Recovery Package in Morecambe Bay focuses initially on the breast, prostate and colorectal cancer care pathways. Since the project started in 2016:

- A holistic needs assessment is offered in writing to all people newly diagnosed with breast, prostate or colorectal cancer
- An agreed format for treatment summaries so that people affected by cancer know what to expect once their treatment finishes, is under development by the healthcare teams
- Three co-design meetings have taken place to consider Health and Wellbeing events. An event format of market stalls with space for presentations has been agreed.
- Living With and Beyond Cancer education & development sessions are arranged for Practice Nurses and GPs. Training includes use of the Cancer Care Review so that they will either be able to help people affected by cancer themselves or they can find someone who can.
- Opportunities to get involved and have a voice include:
 - The co design of HWB events
 - Involvement in an information work stream
 - Telling your cancer story
 - Developing the Service User Hub
 - Developing a potential model of peer support

10. THANK YOU

Thank you for reading