

**Macmillan Living With and Beyond Cancer in Morecambe Bay**

**Final Report**

**A Series of Three Open Space Events Held in 2017**

**For People Affected by Cancer**

**08 February in Barrow**

**06 April in Morecambe**

**24 April in Kendal**

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## Terminology

The phrase '*people living with and beyond cancer*' is used in this report to refer to patients, people affected by cancer, service users and cancer survivors. It is inclusive of carers, though the phrase '*including carers*' has been added in places for extra emphasis. Where attendees at the Open Space event used the term '*patient*' this has been reported verbatim.

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**Acknowledgement: Mary Riches, Project Manager, Macmillan Cancer Support, Doncaster**

# Executive Summary

## ***Background***

NHS and voluntary sector organisations across Morecambe Bay are working together on a two and a half year plan to improve the experiences of people living with and beyond cancer. This plan is the **Macmillan Living With and Beyond Cancer Project 2016-2018** and the organisations involved include:

- Morecambe Bay Clinical Commissioning Group (formerly Lancashire North Clinical Commissioning Group)
- Macmillan Cancer Support
- University Hospitals of Morecambe Bay NHS Foundation Trust
- Cumbria County Council
- Lancashire County Council
- CancerCare
- St John's Hospice, Lancaster
- St Mary's Hospice, Ulverston
- Morecambe Bay Cancer Locality Group

Introducing the **Cancer Recovery Package** is key to the plan and will support partners in their co-design both during and beyond Macmillan's funding of the plan. A key part is the involvement of people to form a **Living With and Beyond Cancer Hub** that will inform and help to shape the plan. The Hub will make recommendations on what should be done to improve the experience of people diagnosed with cancer, their carers, families and friends.

## ***Who came to the events?***

A series of three Open Space events, shaped *by* people affected by cancer *for* people affected by cancer, were held in Morecambe Bay. Those who were currently living with, or have been in recovery from cancer in the last five years were the people we most wanted to hear from. An open invitation was publicised to members of the public who were interested in having their say about cancer services. Thirty One people – 20 female and 11 male - came to the events, along with professionals from the partner

organisations. Attendances showed that no one under 36 years of age and no people from minority ethnic groups were at the events. The events aimed to engage with people affected by all cancers. Attendees said that the primary site of their cancer included breast, prostate, bowel, womb, lymphoma, oesophageal and skin.

Feedback provided by attendees showed that they thought the events were enjoyable and well-organised. Suggestions for improvements to events in neighbouring areas were taken into account paying attention to acoustics in the room, the location of the toilets and availability of parking. Meeting and hearing from other people living with and beyond cancer was highlighted as a positive and it was suggested that the meeting report should be widely shared and more events should be arranged. The lessons learned will be used to make sure that future events are more effective, inclusive and as successful as possible.

### ***What did people say?***

The events began with attendees writing down their thoughts and ideas in response to the Open Question:

*'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? Looking to the future, how do you begin to get the most out of life again? What support might be helpful?'*

These initial thoughts were then grouped into themes for further discussion which took place in small groups over one or two rounds. What people said about each issue was written on flip charts and at the end of the afternoon, attendees were each given three dots to use as votes to show which of the issues raised were most important in their view. The professionals from the NHS, local authority and voluntary sector also voted, but using different coloured dots.

Analysing and grouping together what people living with and beyond cancer said shows that, in order of importance, the key themes are:

- Information
- Clinical and Professional Support
- Shared Decision Making
- Health and Wellbeing

- Peer Support
- Control and Return to Normal

More detail about each of these can be found in the main report including some suggested actions/possible solutions.

### ***What happens next?***

This report will be considered by the **Macmillan Living With and Beyond Cancer in Morecambe Bay Steering Group (LWBCMB)** and the findings used to shape the Framework for Delivery One Year Plan (2017/2018) of the **Morecambe Bay Cancer Locality Group**.

People who came to the Open Space events and said they were interested in being involved further are regularly being invited to get involved in new opportunities planned for 2017 / 2018. There will also be opportunities to join the **Living With and Beyond Cancer Hub** which will review the findings of this report. The Hub will be active in the co-design and co-production of solutions about what implementation of the **Cancer Recovery Package** should include.

Ultimately it is expected that the information gathered at the Open Spaces and the new involvement opportunities in 2017/18, will be used to ensure that longer term initiatives, projects and services are targeted at meeting the needs and issues most important to people living with and beyond cancer (including carers).

## **1. Background and purpose of the events**

Morecambe Bay Clinical Commissioning Group (formerly Lancashire North Clinical Commissioning Group) worked in partnership with Macmillan Cancer Support and other partners to host a series of three listening events for people living with and beyond cancer (including carers) in Morecambe Bay. Taking account of the geography of the area and distance travelled, the events took place in Barrow, Morecambe and Kendal.

In 2008 the National Cancer Survivorship Initiative (NCSI) developed and tested a number of key interventions, together called the Recovery Package. Ensuring that communities joined forces, the views of people were collected about their needs for, and experiences of cancer services.

Reflecting this:

- It has been identified from the National Cancer Patient Experience Survey (NCPES) that there is an important priority of listening to current cancer patient experiences to address any issues within services.
- Morecambe Bay CCG in partnership with Macmillan Cancer Support, Better Care Together, the local strategy to develop new models of care, and University Hospitals of Morecambe Bay NHS Foundation Trust are looking to make changes in the way local services work together for a better patient experience.

The partners hosting the Open Space listening events are committed to ensuring that people living with and beyond cancer are at the heart of the development of new services and support. This approach is detailed in the Macmillan Living With and Beyond Project Plan – and the intention is for these Open Space events and other involvement activity to feed directly into a Cancer Recovery Programme which is appropriate for the people of Morecambe Bay.

## **2. Event Publicity**

People living with and beyond cancer, their carers, friends and relatives were invited to attend the events via the clinical nurse specialists, support groups, other

health and social care professionals, voluntary sector organisations, local newspaper press releases, Morecambe Bay CCG and Better Care Together Communications, websites and social media.

A breakdown of how people living with and beyond cancer heard about the Open Space events is shown in Fig 2.1 below:

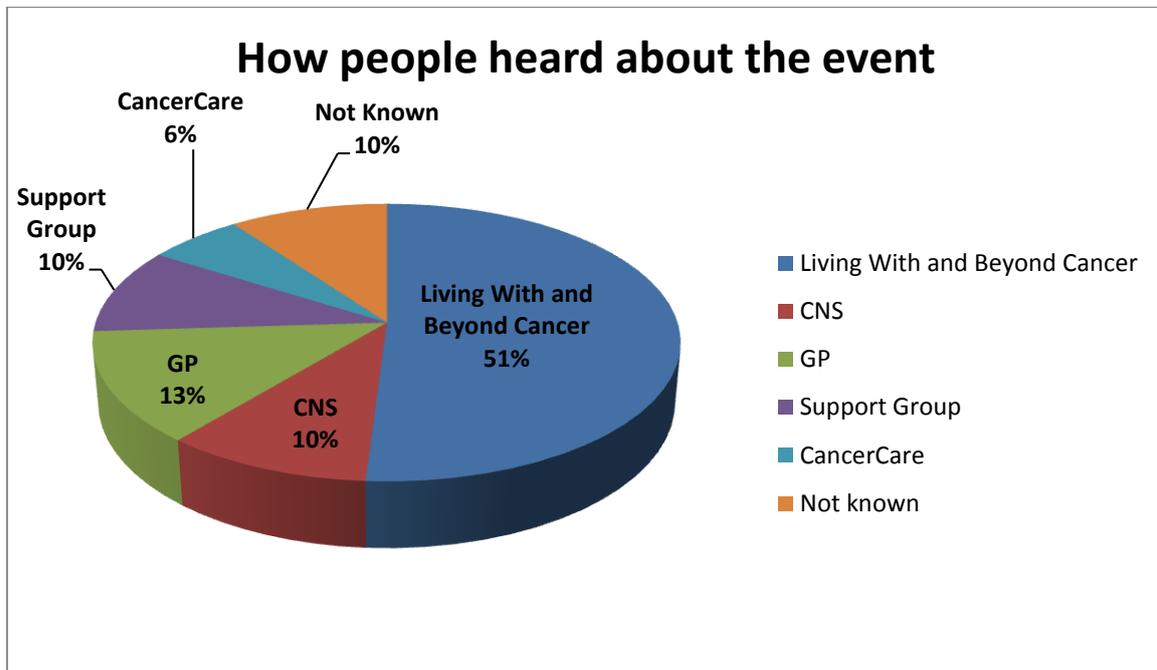


Figure 2.1: How people living with and beyond cancer heard about the event

### ***Learning Point***

*The most effective publicity routes for the event were LWBC face to face contact with individuals, attendance at Support Groups and partners who are members of the project steering group. NHS & Macmillan social media had little impact, reflected in the low attendance by younger people.*

### **3. Approach**

Members of the LWBCMB Steering Group wanted to create an event that covers the issues that are important to people affected by cancer. Deciding to use an 'Open Space' approach - a well-recognised methodology that has been in use for over thirty years<sup>1</sup> - it provides a way for people to talk and so as participants, they create their

<sup>1</sup> <http://openspaceworld.org/wp2/>

own agenda. The format proposes a central question theme around which work takes place in parallel breakout sessions.

The King's Fund<sup>2</sup> describes the objectives of an Open Space session as:

- To enable diverse perspectives to be aired and shared
- To encourage creative thinking
- To support open discussion and collective decisions
- To create ownership over the results
- To be used when we don't already know the answer
- To create new relationships and networks

The King's Fund description of the Guiding Principles for Open Space is:

- 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.

Open Space is highly participative and therefore well-suited to capturing the diverse experiences of people living with and beyond cancer. The format is however resource-intensive, requiring input on the day from a significant number of professionals.

The central question for this Open Space event was:

***'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? Looking to the future, how do you begin to get the most out of life again? What support might be helpful?***

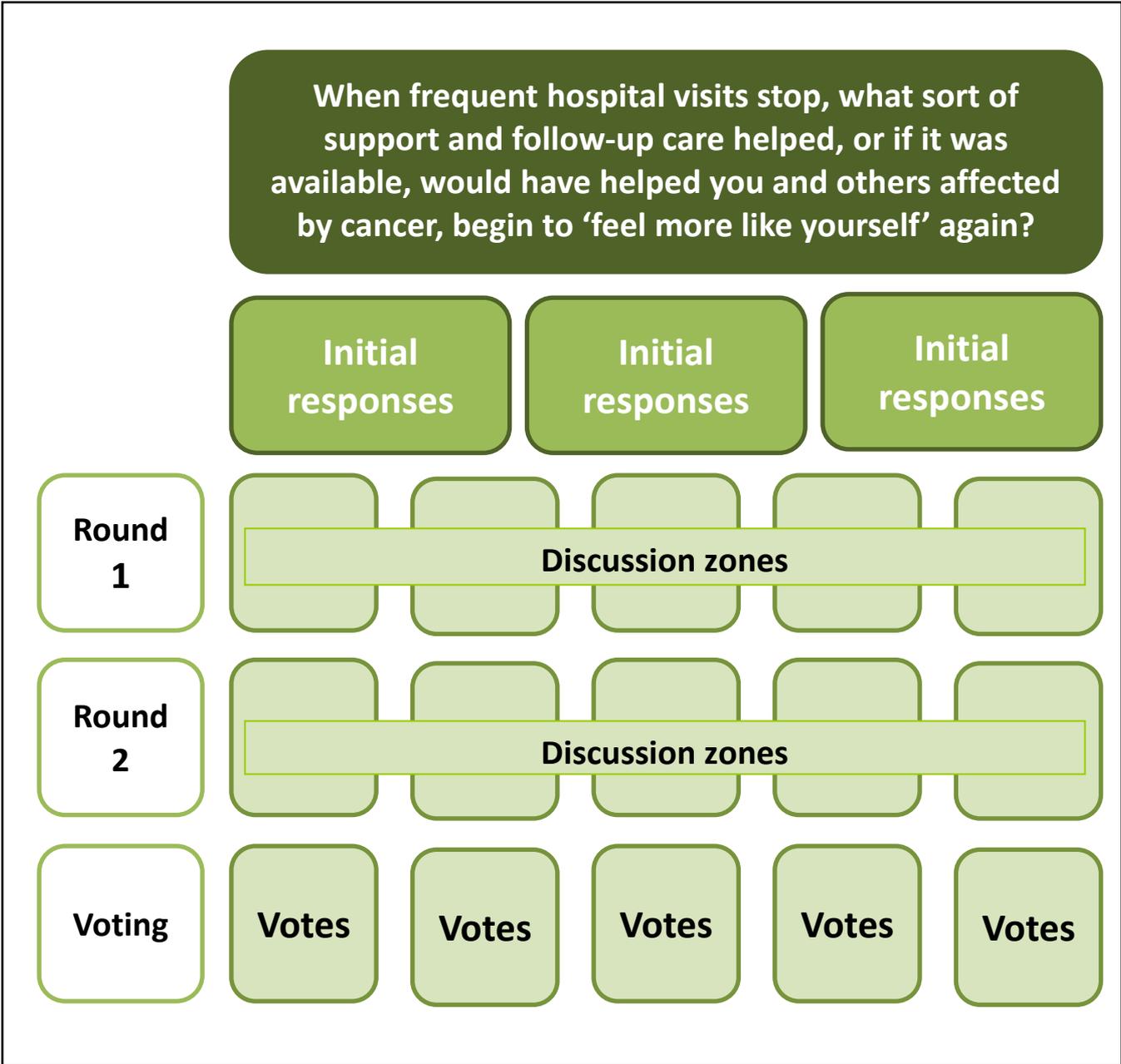
The key event activities were:

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<sup>2</sup> <http://www.kingsfund.org.uk/sites/files/kf/media/liz-saunders-judy-taylor-kingsfund-clinical-leaders-leaders-front-line-kingsfund-may13.pdf>

- Attendees were asked to write their initial responses / ideas / questions on large sheets of paper
- With the help of attendees, these initial thoughts were then grouped into common themes
- The themes were in turn divided over two rounds, creating an agenda for the afternoon
- Each theme was then allocated to a discussion zone in the room, each with a flip chart to record key points from the conversation
- Attendees moved to and between the topics being discussed, spending as much time as they wished to contribute, ask questions or observe
- After two rounds, attendees were asked to view the flipcharts and use three voting stickers to indicate which topics and statements they felt were most important
- Professionals attending the event were invited to vote in the same way using different coloured stickers.

**Figure 3.1** below outlines the process for the Open Space:



**Figure 3.1: Open space process**

The events were facilitated by a range of colleagues from Macmillan, Morecambe Bay Clinical Commissioning Group, University Hospitals of Morecambe Bay NHS Foundation Trust, Cumbria Partnership NHS Foundation Trust, voluntary sector partners, CancerCare, Citizen’s Advice Bureau and St. Mary’s Hospice. Communication and Engagement colleagues from the CCG attended the events to take photographs and interview people living with and beyond cancer during the event.

Healthwatch Lancashire and Cumbria attended the events to offer people their support and there was also a clinical psychologist or counsellor at each event to support any

attendees experiencing distress or becoming upset. The Barrow and Kendal events were led by Jez Such, Macmillan Development Manager. The Morecambe event was led by Neil Wynne, Morecambe Bay CCG, Service Improvement Lead for the Macmillan Living With and Beyond Cancer in Morecambe Bay.

#### 4. Recruitment process

People living with and beyond cancer, their carers, friends and relatives were invited to attend the event via members of the LWBCMB Steering Group, the breast, prostate and colorectal Cancer Nurse Specialists, support groups, other health and social care professionals, voluntary sector organisations, local newspaper contacts, CCG communications websites and social media.

#### 5. Who attended the Open Space Events?

A total of 39 expressions of interests were submitted to attend the series of events. 31 individuals attended. The demographics of the people living with and beyond cancer who attended the events are shown below:

##### Gender

Male – 11                      Female – 20

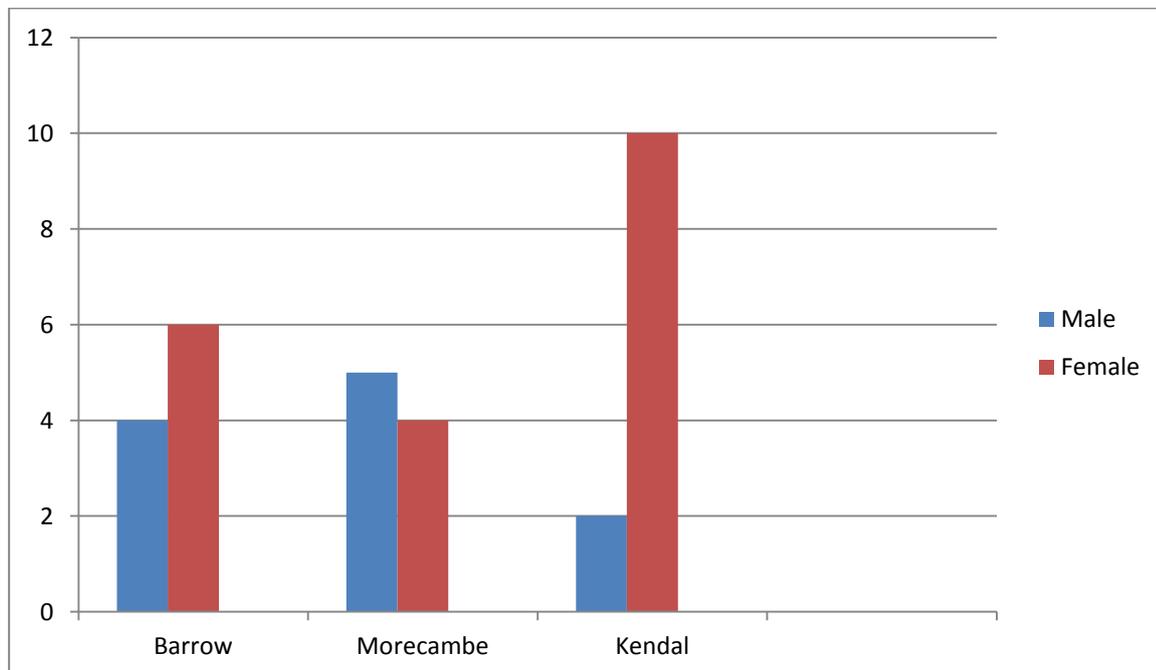


Figure 5.1 Who attended the Open Space events

## **Ethnicity**

Attendees living with and beyond cancer were not given the opportunity to record their ethnicity so this data is unknown. A recommendation, therefore, is made for future events to collect robust data on ethnicity. An apparent lack of diversity was noted at the events with attendees described mostly as white British / British / English.

## **Age and Number attending**

Attendees living with and beyond cancer were not given the opportunity to record their age so this data is unknown. A recommendation therefore is made for future events to collect robust data on age. An apparent lack of diversity was noted at the events with attendees described mostly as 50+ years of age.

## **Site of cancer**

Those attending the event were not asked to record the primary site of their cancer and so this data is unknown. A recommendation therefore is made for future events to collect robust data on site of cancer. An apparent range of diversity was noted at the events with attendees describing themselves as affected by a range of cancers.

Breast	Prostate	Bladder	Bowel	Womb	Lymphoma	Oesophageal	Skin
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These include friends, relatives and carers of people who have had a cancer diagnosis in these categories. For some attendees, the primary site was not disclosed or noted.

### ***Learning Points***

***A recommendation is made when planning future events to collect robust data on ethnicity, age and site of cancer. The lack of diversity – particularly with regard to age and ethnicity - of the attendees suggests that attention should be paid to these characteristics. Reason for non- attendance at the events should be followed up and an offer made of alternative involvement opportunities as appropriate.***

## 6. Event feedback

Evaluation forms were distributed at the events and 29 were returned. Satisfaction with the event arrangements is shown in Table 6.1 below:

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
<b>Content</b>					
The experience gained on this event was as I expected	14	13	2		
The event was organised and kept to time	20	8	1		
The event structure helped me to be involved	18	11			
<b>Facilitators</b>					
The facilitators were sufficiently supportive and listened attentively	25	4			
The facilitators used a range of styles to suit everyone's preferred level of involvement	16	13			
<b>Logistics</b>					
The venue and refreshments were satisfactory	18	10	1		
I was satisfied with the information and admin support I received prior to the event	17	9	3		
<b>Networking</b>					
I would recommend this event to others	24	5			
I found the opportunity to be involved and share experiences with other people useful	22	6	1		

**Table 6.1: Satisfaction with the events**

No attendees recorded their disagreement or strong disagreement with the questions asked. Learning from similar events was taken into account to avoid issues with acoustics of a venue, the closeness of toilet facilities and access for people who may have schoolchildren to collect or be working; for example, the Kendal event took place between 16:15 – 20:30.

When asked to provide an overall rating for the event (excellent, good, average, poor, very poor) 24 attendees rated the event 'excellent' and 5 rated it 'good'. 2 attendees did not complete an evaluation.

Overall I would rate this event as... (please circle)	Excellent 24	Good 5	Average	Poor	Very poor
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**Table 6.2 Overall rating of the event**

Further comments/suggestions provided by attendees (see Appendix 4 for full record) focused on:

- Found it hugely helpful
- First time have had an opportunity to use experiences in a way that might be of benefit to other people.
- Nice for people to talk
- Was so much better than expected.

**Pledges to become further involved**

At each event, future plans for the LWBC project were explained and attendees were invited to complete a ‘pledge’ if they were willing to be further involved in project developments. The number of pledges received at each event is shown below.

Open Space	Barrow	Morecambe	Kendal
Number of pledges received	5	3	6

**Learning Points**

*The event was well-organised and proved to be an enjoyable and positive experience for the people living with and beyond cancer who attended.*

*For future events, attention should be paid to attracting individuals who are not members of groups.*

**7. Initial responses generated by attendees and common themes**

In response to the central question

*‘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? Looking to the future, how do you begin to get the most out of life again? What support might be helpful?*

People living with and beyond cancer attending the event generated 68 initial issues. These were then grouped into common themes by the participants and host facilitators and used as headings for two rounds of discussion groups held in different parts of the venue. 17 themes were created. These can be seen at Appendix 2.

The results of the discussions were captured on flipcharts and can be seen at Appendix 6.

## 8. Voting on the results of the discussions

After all the initial responses raised had been discussed, the resulting flip chart notes showing key points from the discussion were displayed at the end of the afternoon. Attendees were asked to vote using three coloured dots to indicate which of the key points they felt were most important to them. Different coloured dots were used to distinguish between votes placed by people living with and beyond cancer and those from professionals. No restriction was put on how the votes were used meaning all three dots could be used to emphasise the importance of a single key point if the participant so wished.

**Table 8.1:** shows the key points voted for by people affected by cancer and professionals, where 2+ votes were cast and listed in priority order. Some key points were voted for both by people living with and beyond cancer and by professionals.

**Table 8.1** provides a visual comparison of voting preferences for the key points:

● Vote cast by person living with and beyond cancer      ● Vote cast by professional

Table 8.1: Key points voted for by people affected by cancer and professionals, where 2+ votes were cast and listed in priority order	Number of votes
Would be really helpful to have a medical professional within support groups <ul style="list-style-type: none"> <li>○ Helps stop you being in limbo between appointments</li> <li>○ As an individual you don't know what is important or not – the medical professionals do</li> </ul>	★ ★ ★ ★ ★
Patient Advocate, Patient volunteers – Buddy phone numbers, email	★ ★ ★ ●
Clinic letter to GP <ul style="list-style-type: none"> <li>● Copy to patient</li> <li>● Access to letters with patient consent</li> <li>● Can make complete notes</li> </ul>	★ ★ ★ ●

Table 8.1: Key points voted for by people affected by cancer and professionals, where 2+ votes were cast and listed in priority order	Number of votes
You need someone with you to hear what you miss - <ul style="list-style-type: none"> <li>○ To take notes</li> <li>○ To prepare questions</li> </ul>	***●
Clinical support good when told going to be given treatment, given information <ul style="list-style-type: none"> <li>● Included in care</li> <li>● Length of treatment</li> <li>● Side effects</li> <li>● What treatment (name)</li> </ul>	***
GP – good / bad e.g. <ul style="list-style-type: none"> <li>● Suggest possible diagnosis to GP, GP says no, months later, patient right</li> <li>● Consultant said if it hadn't been for my GP, I'd be dead</li> </ul>	***
Need help understanding what is 'normal'? What was normal before is not normal afterwards. <ul style="list-style-type: none"> <li>○ <u>Need help to adjust to a new normal</u> and to regain confidence in your body</li> </ul>	**●●●●
One booklet showing what's available to cancer patients	**●●●
Psychological referrals? Terminal diagnosis as standard	**●●
Opt in annual cancer care review like asthma clinic. Option of an annual health check	**●●
Medics assumptions caused grief. Poor communication. Attitude, tone, content.	**●●
A timely way of delivering information using appropriate words	●●●●
Realisation hits you at home, no practical information given at all <ul style="list-style-type: none"> <li>○ What changes are likely to occur</li> <li>○ How long will it last</li> <li>○ Will it change again</li> <li>○ Told to take pads – no explanation as to why (bowel surgery)?</li> </ul>	**●
Being able to create a relationship <ul style="list-style-type: none"> <li>● I saw same one every time over 2 years. Helped my recovery. Trust</li> <li>● I saw someone different every time</li> <li>● Important they know your story</li> </ul>	**●
Helpful to have someone who's been through it to talk about what to expect "buddy"	*●●
Appointments are not just for doctors to give information – it is an opportunity for patient / family to feedback re symptoms, worries etc.	*●●
Need to know that GP is 'first port of call' other than consultant	**●
MY BODY: MY TREATMENT: MY LIFE	*●●

Table 8.1: Key points voted for by people affected by cancer and professionals, where 2+ votes were cast and listed in priority order	Number of votes
Wait until got treatment package to tell family (CNS) <ul style="list-style-type: none"> <li>• Helpful info</li> </ul>	**
I had a nurse who said contact me anytime	**
Moving Forward (Breast Cancer Care) course was a ‘turning point’ <ul style="list-style-type: none"> <li>○ 4 weeks</li> <li>○ Nutrition, exercise, breast checks, symptoms, relaxation techniques</li> <li>○ Different ages, symptoms, treatment</li> <li>○ Time to chat, to compare + contextualise</li> <li>○ Links with other places</li> </ul>	**
Support <ul style="list-style-type: none"> <li>○ Future – Joining Paddlers for Life + meeting other ‘survivors’. Makes you realise that lots make it, 20 years and beyond. Helps you to see a future as well as enjoying ‘living in the moment’</li> <li>○ Meeting and being in contact with LOCAL people who have been through cancer</li> <li>○ Support from people with the same/similar experience</li> <li>○ Need a buddy to catch me when I step off the cliff. Totally dependent on voluntary support groups. Support to mentally meet the challenge to be physically active again.</li> </ul>	**
BE HONEST	*●
TRUST – Help, caring, know genuine concern, compassionate, attitude needs to be good	*●
CancerCare provided us with a support group in Lancaster. In Kendal there wasn’t a support group but I was able to find the support even though I didn’t have a specialist nurse. The group had a proactive approach to finding support	*●
GP has a letter about diagnosis so that they can let you know what to expect – chemo etc.- it would be low key, familiar environment. Coming back to the GP	*●
Need the information before an appointment. Helps to prepare prior to this	*●
I did complain that it should never have been done that way and the words that were used shouldn’t have been used	*●
Being treated as a whole person	●●
Diagnosis through post <ul style="list-style-type: none"> <li>• No support</li> <li>• Not personal</li> <li>• Not able to talk about it</li> <li>• Not informed choice for care</li> </ul>	●●
Open with family. Include family <ul style="list-style-type: none"> <li>• Important that family member knows what to expect</li> </ul>	●●

Table 8.1: Key points voted for by people affected by cancer and professionals, where 2+ votes were cast and listed in priority order	Number of votes
<ul style="list-style-type: none"> <li>• Different people take in different info</li> <li>• Together, better info</li> </ul>	
Role of the GP – not knowledgeable – even aware of diagnosis	●●
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.	●●
Regardless of personality type you need accurate information and time to process – seems medical process takes over – often at the expense of psychological support	●●
From a practical point – had no idea what to expect on a daily basis, down to toilet habits and dietary needs	●●
Timing – Information needs to be given at the right time	●●
Would be lovely for each cancer patient to have an individual mentor – realistically never going to happen. Therefore, GP surgery next best thing – should have a trained professional as a point of contact at the practice who knows or can access the information from trusted sources to stop isolation	●●

**Table 8.1: Key points voted for by people affected by cancer and professionals, where 2+ votes were cast and listed in priority order.**

**Appendix 3 shows individual key points voted for by people affected by cancer and professionals, where all votes were cast and listed in priority order.**

### ***Learning Points***

*Presenting raw data, as shown in Table 8.1 and in Appendix 3 illustrates that there is a common, shared importance of some of the key points raised. However, the single votes cast highlight personal points which are most important to specific individuals. The raw data serves to ensure that people living with and beyond cancer who attended the event can recognise their own words in what has been captured and therefore feel that their contributions have been listened to and valued.*

## **9. Headline Themes**

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

The emerging themes, placed in priority order according to votes cast by attendees, are:

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

The issues voted on can be further sub-divided into the following categories:

- Headline issues
- Specific concerns
- Suggested actions / possible solutions

The six themes and the issues, concerns and suggested actions associated with each are shown in **Tables 9.1- 9.6** below.

1.INFORMATION	
<b>Headline Issues</b>	A timely way of delivering information using appropriate words
	Open with family. Include family <ul style="list-style-type: none"> <li>• Important that family member knows what to expect</li> <li>• Different people take in different info</li> <li>• Together, better info</li> </ul>
	Regardless of personality type you need accurate information and time to process – seems medical process takes over – often at the expense of psychological support
	Timing – Information needs to be given at the right time
	Online web pages can scare you to death <ul style="list-style-type: none"> <li>o How old is it</li> <li>o How reliable?</li> </ul>
	Information overload
	There seems to be no standard process for what info you get or how

<b>Specific concerns</b>	Realisation hits you at home, no practical information given at all <ul style="list-style-type: none"> <li>o What changes are likely to occur</li> <li>o How long will it last</li> <li>o Will it change again</li> <li>o Told to take pads – no explanation as to why (bowel surgery)?</li> </ul>
	Pass on information to support groups
	Don't get told enough. No information given. Had to search internet
	I was asked to make a choice without the info to do so
	When the oncologist discharges you, do you go back to the GP? I don't know
	Other questions asked, not answered
	Wasn't told I could contact the department directly if I thought I had a recurrence
	From a practical point – had no idea what to expect on a daily basis, down to toilet habits and dietary needs
<b>Suggested actions/possible solutions</b>	Clinic letter to GP <ul style="list-style-type: none"> <li>• Copy to patient</li> <li>• Access to letters with patient consent</li> <li>• Can make complete notes</li> </ul>
	Clinical support good when told going to be given treatment, given information <ul style="list-style-type: none"> <li>• Included in care</li> <li>• Length of treatment</li> <li>• Side effects</li> <li>• What treatment (name)</li> </ul>
	One booklet showing what's available to cancer patients
	Need to know that GP is 'first port of call' other than consultant
	Wait until got treatment package to tell family (CNS) <ul style="list-style-type: none"> <li>• Helpful info</li> </ul>
	Proactive contact from professionals <ul style="list-style-type: none"> <li>o Information about what's available locally</li> </ul>
	Clarifying information on more than one occasion

**Table 9.1: Information**

2. CLINICAL AND PROFESSIONAL SUPPORT	
<b>Headline issues</b>	<p>Would be really helpful to have a medical professional within support groups</p> <ul style="list-style-type: none"> <li>o Helps stop you being in limbo between appointments</li> <li>o As an individual you don't know what is important or not – the medical professionals do</li> </ul>
	Psychological referrals? Terminal diagnosis as standard
	Medics assumptions caused grief. Poor communication. Attitude, tone, content
	Role of the GP – not knowledgeable – even aware of diagnosis
	<p>Patients are complex = several conditions</p> <ul style="list-style-type: none"> <li>o Better link across specialities = whole person</li> </ul>
	Communicating a diagnosis
	<p>Can people living with cancer have regular contact with their GP? A general chat –</p> <ul style="list-style-type: none"> <li>o How are you</li> <li>o How is it going?</li> </ul>
	<b>Specific concerns</b>
BE HONEST	
I did complain that it should never have been done that way and the words that were used shouldn't have been used	
<p>Diagnosis through post</p> <ul style="list-style-type: none"> <li>• No support</li> <li>• Not personal</li> <li>• Not able to talk about it</li> <li>• Not informed choice for care</li> </ul>	
There is a lack of follow up from the nurses and I would have liked them to make contact to provide reassurance	
GP unaware of diagnosis – shocking to discover – If I can't get help from a GP Practice, where do I get it from?	
Waiting time between tests and results – lack of support	
We don't always ask questions at the appointment	
Sometimes feel like medics opt out – need ongoing medical oversight to bounce ideas off	
<b>Suggested actions/possible solutions</b>	GP has a letter about diagnosis so that they can let you know what to expect – chemo etc.- it would be low key, familiar environment. Coming back to the GP
	Would be lovely for each cancer patient to have an individual mentor – realistically never going to happen. Therefore, GP surgery next best thing – should have a trained professional as a point of contact at the practice who knows or can access the information from trusted sources to stop isolation
	Info and links between different centres to improve

	Ideal scenario – support group overseen by professional to aide those who are unwell, supporting those with recurrence
	Introduce new professional links to continue a conversation
	GPs need more guidance about what to do and when to do it

**Table 9.2: Clinical and Professional Support**

<b>3. SHARED DECISION MAKING</b>	
<b>Headline issues</b>	Being able to create a relationship <ul style="list-style-type: none"> <li>• I saw same one every time over 2 years. Helped my recovery, trust</li> <li>• I saw someone different every time</li> <li>• Important they know your story</li> </ul>
	Appointments are not just for doctors to give information – it is an opportunity for patient / family to feedback re symptoms, worries etc.
	TRUST – Help, caring, know genuine concern, compassionate, attitude needs to be good
	Not knowing
<b>Specific concerns</b>	GP – bad / good e.g. <ul style="list-style-type: none"> <li>• Suggest possible diagnosis to GP, GP says no, months later, patient right</li> <li>• Consultant said if it hadn't been for my GP, I'd be dead</li> </ul>
	MY BODY: MY TREATMENT: MY LIFE
	Following diagnosis I had to ask what my options were. I had to ask those questions ... the consultant didn't say ...
	Need help to be involved in the process before being pushed down the medical route
	How do we empower people to share in their treatment and create independence?
	I'd like to be told about what the GP is doing? Are they just making contact? Anyway, told I can't go back to work until 3 months after treatment. We never really discussed how I was feeling
<b>Suggested actions/possible solutions</b>	You need someone with you to hear what you miss - <ul style="list-style-type: none"> <li>• To take notes</li> <li>• To prepare questions</li> </ul>
	Need the information before an appointment. Helps to prepare prior to this
	It should happen automatically, being given, proactive support
	TRUST – Establish a good rapport, working 2 ways
	Right type of follow-up

**Table 9.3: Shared decision making**

4. HEALTH AND WELLBEING	
<b>Headline issues</b>	Opt in annual cancer care review like asthma clinic. Option of an annual health check
	Being treated as a whole person
	No links to anybody when treatment stops
	Review Process <ul style="list-style-type: none"> <li>• Attended a Breast Cancer Care ‘Moving Forward’ course, 4 weeks, seminars, shared experiences, hugely informative + helpful to meet others in similar situation</li> <li>• Exit interview with my Breast Cancer Nurse. I thought I was OK but filled in a check list and realised I was just getting through the days. She then asked me to take part in a Moving Forward course</li> </ul>
<b>Specific concerns</b>	Everything geared towards breast cancer but not bladder
	Don't want to get a victim head on / negative
	Because I am deemed ‘fit and healthy’, I feel abandoned, unsupported and alone
<b>Suggested actions/possible solutions</b>	Times even after diagnosis to speak to someone
	Peripatetic adviser is needed in GPs
	Support groups – Pizza Express, hydrotherapy pool session. Nice knowing that you're with people in the same boat
	CancerCare provided us with a support group in Lancaster. In Kendal there wasn't a support group but I was able to find the support even though I didn't have a specialist nurse. The group had a proactive approach to finding support.

**Table 9.4: Health and wellbeing**

<b>5. PEER SUPPORT</b>	
<b>Headline issues</b>	Patient Advocate, Patient volunteers – Buddy phone numbers, email
<b>Specific concerns</b>	Need support over and above that that family and friends can provide
<b>Suggested actions/possible solutions</b>	Helpful to have someone who's been through it to talk about what to expect "buddy"
	Support <ul style="list-style-type: none"> <li>• Future – Joining Paddlers for Life + meeting other 'survivors'. Makes you realise that lots make it, 20 years and beyond. Helps you to see a future as well as enjoying 'living in the moment'</li> <li>• Meeting and being in contact with LOCAL people who have been through cancer</li> <li>• Support from people with the same/similar experience</li> <li>• Need a buddy to catch me when I step off the cliff. Totally dependent on voluntary support groups. Support to mentally meet the challenge to be physically active again</li> </ul>
	Need to know other people going through the same
	Shared experience – doesn't have to be the same type of cancer

**Table 9.5: Peer Support**

<b>6. CONTROL &amp; RETURN TO NORMAL</b>	
<b>Headline issues</b>	Need help understanding what is 'normal'? What was normal before is not normal afterwards. <ul style="list-style-type: none"> <li>• Need help to adjust to a new normal and to regain confidence in your body</li> </ul>
<b>Specific concerns</b>	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
	Should never ever be told things are fine if there is the slightest chance it is not, over confidence causes false hope
<b>Suggested actions/possible solutions</b>	Moving Forward (Breast Cancer Care) course was a 'turning point' <ul style="list-style-type: none"> <li>• 4 weeks</li> <li>• Nutrition, exercise, breast checks, symptoms, relaxation techniques</li> <li>• Different ages, symptoms, treatment</li> <li>• Time to chat, to compare + contextualise</li> </ul> Links with other places

**Table 9.6: Control and Return to Normal**

### **Learning Points**

*The richness of the data collected at the events reflects the complexity of the lives of some people living with and beyond a cancer diagnosis. Analysing and categorising the data is essential and provides a framework for future action but the original context remains vital and we should not lose sight of the issues faced by individuals.*

## **10. Conclusions**

The Open Spaces were enjoyable, successful, well-organised and provided groups of local people living with and beyond cancer (including carers) with an opportunity to have their voices heard.

Lessons learned about the days will be used to ensure that future events will build on this positive start. They will address diversity matters raised. In this way future events will be as effective and successful as possible.

People living with and beyond cancer who attended the Open Space event 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 with people living with and beyond cancer and for the development of services that will meet the needs and improve the experience of those affected by cancer in the future.

## **11. 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 make recommendations for future activity including representation of people affected by cancer in its membership.

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

people living with and beyond cancer, including many who attended and expressed an interest in further involvement at the Open Space events.

This Report will be formally considered at the first meeting of the **Living With and Beyond Cancer Hub**, giving members the opportunity to help direct how the report findings are used and make recommendations for other future work.

Follow up involvement opportunities are currently taking place and future activities are being developed by the LWBC project and partner service providers during 2017 / 2018. Many of those invited to the series of Open Space events, along with other people living with and beyond cancer and members of the public, are invited to get involved. The detail of some of these opportunities are building upon the feedback from the Open Space events, while others are yet to be determined but will be directed by the recommendations of both the **LWBC Steering Group** and, crucially, the **Living With and Beyond Cancer Hub**.

Ultimately it is expected that the information gathered at the Open Spaces and additional data collection activities, will be used to ensure that new initiatives, projects and services are targeted at meeting the needs and issues raised by people living with and beyond cancer (including carers) themselves.

## 12. Appendices

### Appendix 1: Macmillan Living With and Beyond Cancer in Morecambe Bay Governance Framework

#### Recovery Package – Sharing Good Practice



Recovery-Package-Sharing-Good-Practice.pdf

### Appendix 2: Initial Responses and Common Themes Generated by Attendees



Initial\_Responses\_&Common\_Themes.doc

### Appendix 3: Individual key points voted for by people affected by cancer and professionals, where all votes were cast and listed in priority order



Individual\_keypoints\_ALL\_votes.docx

### Appendix 4: Event Feedback

<b>For participants not fully satisfied with any of the aspects of the Open Space events other comments explained more:</b>
Most participants are from existing support groups / medical, charity, professionals. Unfortunately, many more people feel alone and isolated than are represented here. Needs to be a way of attracting individuals who are not members of groups.
A shorter refreshment break at start, to enable involvement in more than two discussions.
It would be good to reach patients who are living well and beyond cancer for their input.

## Appendix 5: Other Comments or Suggestions

For participants fully satisfied with aspects of the Open Space events other comments explained more:
A pity that others from CARDS were unable to attend. Past members could have had a positive input on the days' timetable.
Nice for people to talk.
Well organised and informative.
Very well organised.
It felt non-threatening and relaxed. It was handled sensitively, with openness and non-judgemental facilitation. Good interaction allowed.
Was so much better than expected.
Well-presented and very interesting.
First time have had an opportunity to use experiences in a way that might be of benefit to other people.
Very useful event.

## Appendix 6: Flip Charts from Rounds 1&2

### Barrow



FINAL\_Flipcharts\_BAR  
ROW.docx

### Morecambe



FINAL\_Flipcharts\_MO  
RECAMBE.docx

### Kendal



FINAL\_Flipcharts\_KEN  
DAL.docx