



ethnic, gender and age diversity of people affected by cancer, and to make sure that it can be a strong force for ensuring that patients' and carers' voices are heard loudly within Macmillan.

Cancer Voices were given the opportunity to hear from Macmillan's new CEO and from experts in user involvement speaking from a variety of perspectives (i.e. from a patient, a medical and - perhaps surprisingly - a criminal justice system viewpoint, chosen to give a broader perspective on user involvement). Attendees came together to write material to form the basis of Macmillan's new Principles of Involvement – a draft statement of how people affected by cancer would like to be involved in the work that Macmillan does. They also had the opportunity to explore and develop their skills in a choice of 9 skills workshops. Cancer Voices give their time to Macmillan in so many different ways and are an integral part of helping Macmillan to inspire millions by ensuring that it speaks from lived experience.

The objectives/aims for the conference were:

- 1) To provide a space for Cancer Voices to gain practical and emotional support both from their peers (experts by experience) and from experts by profession
- 2) To explore the skills and knowledge that people affected by cancer have about user involvement and support them to use their experiences to drive change
- 3) To test methods and tools for involving people affected by cancer in wider decision-making
- 4) To raise awareness among Macmillan Cancer Voices and staff of the barriers to and opportunities for user involvement, as well as of useful tools and techniques to promote involvement.
- 5) To give people affected by cancer a better understanding of how they can use their experiences to influence decisions and shape the future of cancer care at various levels (individual/community, organisational, national)
- 6) To start to develop some Macmillan 'Principles of Involvement': a vision, plus values and practical principles of good user involvement to inform how Macmillan engages with people affected by cancer.

**Key Conference Statistics:**

<b>Total number of Cancer Voices attending</b>	<b>138</b>
<b>Overall event rating (respondents rating 'very good' and 'good')</b>	<b>91%</b>
<b>Overall customer experience rating (respondents rating experience as 'very good' and 'good')</b>	<b>91%</b>
<b>Evaluation response rate</b>	<b>84%</b>

<b>As a result of attending do you agree with the following statements:</b>	<b>Results - either 'strongly agree' or 'agree'</b>
The conference was a good use of my time	92%
My expectations of the conference were met	89%
My input and opinions were valued by Macmillan	84%
I am more aware of why user involvement is important	84%

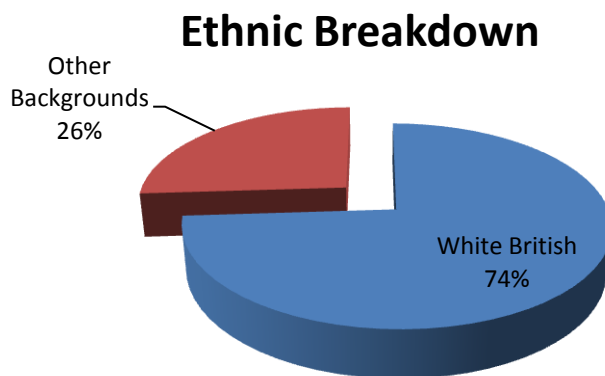
Diversity of views as to whether the conference outcomes were met is reflected in these contrasting quotes:

- a) *“I really liked the change to the conference running order and workshops this year. I've been attending for years and enjoy it each time, but this really felt like we were actually producing something. Thanks for another fantastic conference and to a great team!”*
- b) *“I hate the expression 'user involvement'. So detached and impersonal. Seemed different this year. Less successful, satisfying and effective. Missed the Macmillan stand, which had useful information.”*

**Delegates were asked about the specific actions or ‘pledges’ they would take as a result of attending the conference.** Not many delegates shared their ‘pledge card’, but of those that did, many said that they would promote membership of the Cancer Voices network. Others said they would start a support group, attend a course, or engage more people from diverse ethnic groups in their voluntary work.

### Positive Outcomes of the Conference:

1. A more diverse group of people attended the conference this year, including **36%** of new people affected by cancer who were not yet registered with the Cancer Voices network:



This compares well to the **19%** of non-white British people we have signed up as current Cancer Voices. We hope that these more diverse delegates will sign up to become Cancer Voices now or in the future.

2. The new format, with a panel of speakers on user involvement who took questions from the floor was generally popular, with the speakers mostly going down well with the audience.

*“Well facilitated. Inspiring speakers that really made me think and want to do more myself”*  
*“It was refreshing for it not just to be about cancer”*

3. Principles of Involvement for Macmillan Cancer Support were drafted based on delegates’ input throughout the two days. Although still requiring further input from people affected by cancer, these Principles will allow Macmillan to start to embed meaningful involvement of patients and carers in all its teams and practices, as involvement levels are currently variable across the organisation.

*“I’ve been attending for years and enjoy it each time, but this really felt like we were actually producing something. It wasn’t just about Macmillan giving information on new initiatives and projects, it felt like we were a real part of a future process which in my opinion is vitally important”*

4. Many delegates really appreciated hearing from Macmillan’s new Chief Executive, Lynda Thomas

*“Enthusiastic, energetic....I loved the personal touch – photos, stories etc”*

5. A planning group of 8 Cancer Voices has been recruited to help plan the 2016 conference.
6. Using the same venue allowed Macmillan to keep costs down. Money was saved on various aspects of the conference, totalling **£6,400**. Additionally, all external speakers waived their fees, allowing us to spend more on external workshop providers in order to build delegates’ skills in 9 chosen areas.

## Things to improve on

You Said	We Listen
<b><i>'The travel booking process was complicated'</i></b>	This year for the first time we outsourced travel booking to an external company, to save time and money, as it is very time consuming to make personal bookings for everyone within our small team. Delegates could book train travel online via a website and be given a phone number to call for flight booking, or in case of difficulty. <i>Moving forward, we will analyse the cost/benefit of outsourcing, as well as listening to and using the feedback received about the kinds of issues that arose to improve this process whether this is outsourced again or not.</i>
<b><i>'London is a long way to travel for a lot of delegates – it is very tiring; consider a more central UK venue, or change the conference timings'</i></b>	Many people had to travel long distances to attend and were tired, despite the offer of accommodation the night before for those travelling over 4hrs, the late morning start on day 1 and the lunchtime finish on day 2. <i>We will consider carefully the best location and timings for the conference next year. We get a very good rate from the London Gatwick Hilton because we have a well established relationship with them, plus it is difficult to find a venue that meets all our space and accessibility requirements. We will analyse transport routes to see if a more central UK location would make a significant difference to average travel time and cost. Planning further ahead, we will consider the possibility of holding several smaller regional events, rather than one big national conference</i>
<b><i>'Dietary requirements were not well catered for at dinner.'</i></b>	While requirements were provided to the venue, many with particular dietary requirements were not well served with various problems identified by delegates and staff. <i>The Hilton London Gatwick has been given detailed feedback and the Events Team will raise this issue specifically with whatever venue is used next year. We will also look at whether offering more menu options for dinner is possible.</i>
<b><i>'We missed having an exhibition stand or 'market place' with details of different projects across Macmillan'</i></b>	The exhibition space was not included this year to allow more free time for rest, refreshment and networking and because it was less relevant to the theme of this year's conference. <i>We will consult with Cancer Voices on whether to reintroduce an exhibition space at next year's conference.</i>
<b><i>'The Principles of Involvement written up by staff at the conference did not reflect the language used by delegates on their table templates. They were too wordy and full of jargon.'</i></b>	The current Principles of Involvement are a first draft and need development to ensure they make sense and are relevant to different parts of the UK. <i>We are planning regional events in 2016 for people affected by cancer to view the feedback on the Principles and to input further into them, also agreeing how to put them into practice locally. We will keep you posted on how you can get involved.</i>



You Said	We Listen
<p><b><i>‘Make sure everybody can see and hear’</i></b></p>	<p>Acoustics presented a problem for some, with speakers playing music close to the tables, ambient noise, or distance from the stage making hearing the presentations difficult for a few delegates. Some people were seated behind pillars blocking their view. <i>Next year we will ensure that nobody asks a question without using a roving microphone, and that the Chairs repeat the question. We will raise the issue of speakers/music and obstructed views when setting up the venue, planning seating so that the environment is as comfortable as possible.</i></p>
<p><b><i>‘Make it easier to network with people from similar regions during sessions as well as in the hotel the night before the conference’</i></b></p>	<p>This year, we seated people at tables by region with (where possible) their local Macmillan Involvement Coordinator. Some regions were less well represented, so had to share with staff or delegates from a different region. Owing to last minute cancellations, a couple of tables and regions had very few delegates, so these people had fewer networking opportunities. <i>Next year, we will consider delegate suggestions such as coloured stickers for staff and Macmillan stickers to be given to delegates the night before the conference starts. From 2017 onwards we will scope the possibility of holding smaller regional events, rather than one big national conference, making regional networking easier.</i></p>
<p><b><i>‘Some workshops were dominated by individuals who spoke for too long off the session topic’</i></b></p>	<p>Workshops varied in size and larger groups tended to have poorer feedback, including on facilitation. <i>Moving forward, we will brief facilitators on sensitive closing of interjections, try to reduce group size, and introduce group agreements for delegates to follow.</i></p>
<p><b><i>‘The new format was (for some) confusing and disappointing’</i></b></p>	<p>This year we chose a theme of ‘user involvement’ to reflect the energy we hope to generate in the Cancer Voices Network for enabling members to increase opportunities to shape Macmillan’s work. Writing our ‘Principles of Involvement’ was an important step in setting the standard for involvement of people affected by cancer across the organisation. However, some people did not agree with or understand the reasons for this change and were unsure what was meant by ‘user involvement’. <i>Moving forward, we will communicate with Cancer Voices to explain how the Principles of Involvement can support meaningful participation, providing examples and promoting the support available to facilitate this kind of meaningful participation.</i></p>
<p><b><i>‘Feed back to us all about what happens to the work we put in at the conference.’</i></b></p>	<p><i>You should have received our email update containing the first draft of the Principles of Involvement, plus a summary of the feedback on them. We will keep you posted on regional events to further develop the Principles, and will share their outcomes. Workshop leaders have been asked, where appropriate, to keep delegates informed of developments with work they were involved in.</i></p>

***“I should have got involved ten years ago. I had no idea how rewarding this work could be.”***