Cancer Voices Event: Stronger Together

Wednesday 26 May 2021

Event report

Dear cancer voices

Thank you again to everyone who registered their interest in the recent Cancer Voices Event: Stronger Together. To those of you who were able to join us on the day, thank you for taking part so fully. For those who couldn't, a recording of the main session, including the Question & Answer session with Eve Byrne, Head of Campaigns and Public Affairs at Macmillan, is available to watch here.

This was the second time cancer voices from across the UK have come together online. The event was an opportunity to welcome new people, catch up on the contribution cancer voices have made to Macmillan's work and what we have achieved together since we last met in July 2020, and look forward to what's next.

In response to your feedback from last summer's webinar, this event was planned as an opportunity for people to connect with one another, as well as with Macmillan. Last year, you told us there was a lot of being talked at and that you would have preferred more interactive elements. As a result, the Stronger Together Event included a Q&A session hosted by cancer voices; as well as a number of small breakout sessions, some facilitated by cancer voices, enabling people to discuss a variety of issues that you told us really matter to you.

Valerie, a member of the cancer voices community, drew these incredible visual minutes during the event. We are sure you will be as blown away by them as we are!

We hope you agree that involving people from the cancer voices community in the planning and delivery of this event was a positive step. We are keen to build on this in the future, to involve people earlier and more frequently in planning cancer voices events. With this in mind, we came out to you recently with an invitation to help us plan future events, and the first meeting of interested people will be happening soon.

Our heartfelt thanks to Sabrina and Natasha for hosting the Q&A with Eve Byrne; to Eamonn, Donna and Laurine for facilitating the breakout sessions; to Caryn, Gabhan, Sabrina and Mikki for appearing in the video; and to Valerie for producing the visual minutes.

Delegate Feedback

140 people registered for the event, with 81 able to attend on the day. Over half of those registered were new to cancer voices. It was lovely to welcome so many people who had not worked with Macmillan in this way before.

Thank you to everyone who took the time to complete the post event questionnaire. We were delighted that over 70% of delegates completed the survey – a significant increase on previous events (for example, 24% of delegates completed the post-event questionnaire after the webinar in 2020.)

Feedback from delegates was overwhelmingly positive, with 85% of attendees rating the event as either 'Very good' or 'Good'; and 100% of delegates saying they would encourage others to join a cancer voices event.

> *I really enjoyed the conference. It was good to air our views and also learn from others too.*

> *I learned so much and feel much more a part of something wider now.*

> *It was great to get the opportunity to voice our opinions. It is lovely to be heard and know that you are taking these forward.*

Outcomes

To what extent do you agree with the following:	% responses either 'strongly agree' or 'agree'
I feel more connected to fellow cancer voices	78%
I feel there was the right balance between listening and having the chance to contribute	81%
I feel I know more about how my and other people living with cancer's experience has been heard, valued, and acted on within Macmillan	80%
I feel reassured that Macmillan is planning to continue to hear what matters to people living with cancer	93%
I feel committed to Macmillan and continuing to use my experience to help Macmillan improve services for people living with cancer	90%
I feel that Macmillan is offering a good range of opportunities for people living with cancer to share their experiences and make change happen	88%

Some people expressed frustration with the limitations of an online event. While appreciative of efforts to make the event more interactive and provide space for delegates to connect with one another, some found it difficult to chat informally and others experienced technical issues with Microsoft Teams. We share your frustrations and very much look forward to a time when we can meet up in person once again. As one delegate said, "There is always room for improvement." 😊

Video, Q&A, Breakout Sessions

When asked what people found most valuable, 63% of respondents selected the breakout sessions. While comments suggested people valued them all and found it difficult to select just one; the consensus was that people really valued the opportunity to connect with a smaller group of people and share their experiences in the breakout sessions:

> *[The breakout sessions] opened up ideas and options and inspired me to get more involved.*

> *I think this was a really good idea as it isn't always easy to contribute to the conversations in a large group setting.*

> *Great to 'meet' new cancer voices. Enjoyed being able to contribute. Lovely to see people I have worked with before.*

> *The breakout session gave everyone a chance to talk and express their views*

> *I liked that the breakout discussions were facilitated by people from the cancer voices community. Hearing from Eve was good. There were so many wonderful questions and great answers.*

> *I could have chosen any, they all are valuable choices*

> *The video was great. I loved how it highlighted Macmillan cancer voices roles and updates. The breakout session*

> *It was all great, but the Q&A was most interesting for the questions as much as the responses.*

When asked how delegates felt after attending the event, over half selected 'connected,' with the remaining respondents choosing 'inspired' or 'heard.' In future, we will aim to make this an open question from the start, as some felt limited by the options provided.

Future events

Looking ahead to future events, a majority said you would prefer to attend in-person events. However, a sizable minority remain unsure about meeting up face-to-face and some would prefer to continue attending events online.

In addition, people expressed a variety of views on the sort of events they would prefer to see in the future. The vast majority would like the opportunity to attend smaller events with fewer people, to focus on particular themes or pieces of work. But many would also enjoy coming to larger events, with the opportunity for lots of people to hear about what's been happening and about future opportunities. Similarly, a majority of people are keen to see specific events for people with similar backgrounds or interests.

With these comments in mind, we are considering the possibility of hosting a hybrid cancer voices conference in 2022; with the aim of speaking to the wishes of as many people as possible. A hybrid event would combine a number of smaller events around the country, in a variety of locations and communities, enabling people to focus on particular themes or pieces of work; with the ability for everyone to come together online – either from their homes or direct from the smaller events – to hear about what's been happening across the country and about future opportunities. This is something we hope to discuss in more detail as part of the events planning opportunity mentioned earlier in this report.

A number of key themes emerged strongly from people's comments when asked about the topics you would like to discuss at future cancer voices events:

- Holistic treatment and advice: coping with cancer / cancer and family / building understanding between people living with cancer and clinicians
- Equity, Diversity & Inclusion: vulnerable / minority groups / diverse communities
- Covid backlog and recovery
- More on advocacy
- The creation and provision of cancer information – from the NHS and Macmillan

Other feedback we will be taking forward includes:

- Keeping the peer-to-peer aspects and the small breakout rooms
- Considering holding events that happen out of office hours
- Illustrating how the topics talked about at the event are put into practice
- Focusing more on new opportunities. Sharing ideas for things people can do now

Diversity of attendees

Survey responses showed a more diverse group of delegates than at previous cancer voices events. Increased numbers of younger delegates and people of colour completed the evaluation than for previous cancer voices events and surveys. We have welcomed over 70 new members to the cancer voices community over the last 12 months and the profile of membership is more reflective of the general population than ever before. It's great to have that mix of those who have been with us for some time - and the value you bring through that long-term relationship - and the different perspectives that come with people who are new to cancer voices events and the community.

- **80% of respondents were people living with cancer** (as a current or former patient); 12% were people affected by cancer (e.g. caring for a loved one); 8% were both living with, and affected by, cancer.
- **63% of respondents identified as women**; 37% as men.
- 61.6% of delegates were over the age of 55; 25.8% were aged 45 to 55; and **11.6% were between the ages of 25 and 44**. This is likely to reflect the fact that the event took place during standard working hours. Nonetheless these figures mark a significant shift from previous events: responses following last year's webinar indicated more than 80% of delegates were over the age of 55.
- **13.79% of respondents identified as people of colour** (mixed / Asian / Indian / African / Black Caribbean), slightly below the current National average of 14%.
- **12% of respondents considered themselves to have additional physical and / or sensory impairments or disabilities** which would mean they would need additional support to work with us in the future.

Q&A with Eve Byrne

Sabrina and Natasha did a wonderful job of hosting the Q&A session with Eve Byrne, Macmillan's Head of Campaigns and Public Affairs. You can revisit the session by watching the recording from around the 11min 30s mark here. A total of 38 questions were submitted via the pre-event survey, with a further 13 questions asked during the event. Eve answered as many of these as possible, on a range of topics - from her own role within Macmillan, to how, what and why Macmillan influences Governments across the UK; from how we plan to address inequalities in access to support and treatment around the country, to how Macmillan ensures people from marginalised communities get the help they need; from treatment backlogs as a result of covid, to gender inequality.

We collated and themed all the remaining questions, enabling Eve to respond to those there wasn't time to address on the day. Eve's responses can be found here.

For the cancer voices team, all the questions you asked are as interesting to us as the discussions we had in the breakout sessions, because they tell us what's on your mind. There were a number of questions which weren't directly relevant to the work of Eve's team. Everything you raised in these questions is valuable and shows us what matters to you right now. We will continue to share such insight with other teams within Macmillan, to inform their work.

Cancer Voices Video

We were delighted to launch our new cancer voices video at the event. Our thanks once again to Caryn, Gabhan, Sabrina and Mikki for appearing in the film and for sharing their experiences of working with Macmillan.

Breakout Sessions

The breakout sessions were designed so the cancer voices community could discuss a variety of issues you have told us matter to you. Smaller groups ensured people felt as comfortable as possible contributing to discussions and sharing their thoughts and ideas.

Facilitators from each of the three sessions came together after the event to look at the main themes from the discussions and next steps, as summarised below:

What Does it Mean to be a Cancer Voice?

These sessions focused on our identity as cancer voices and our expectations when we belong to the cancer voices community. Sessions were facilitated by Holly Swinckels, Macmillan's National Engagement Lead; alongside cancer voices Eamonn and Laurine.

You told us that the cancer voices community is seen as the place to bring together what matters to people living with cancer; that cancer voices events are helpful in supporting people to be part of the community; that cancer voices opportunities help people find their voice again; and that the cancer voices community feels important because it means people get what they actually need, rather than what others think they need. Being a cancer voice and getting involved in the range of opportunities on offer feels meaningful and that Macmillan staff and cancer voices are together. Cancer voices provides not only a space to be valued and heard, but also to give something back

We heard that many people self-identify as being a cancer voice and that it feels important to have that description and title, it gives shape to what people are doing, through sharing experiences for influence. There was a strong sense that cancer voices is not just about Macmillan: it's about ensuring the voices of people living with cancer are represented and embedded in lots of different organisations; and individual cancer voices can make that happen in a variety of ways.

Cancer voices feel that their role is valued within and outside of Macmillan; and they feel able to challenge and have honest conversations. However, some people felt that they were coming across cancer voices by accident, or later than they would have liked. People felt that having a collective identity and identifying how to engage people with lived experience beyond the cancer voices community needed some thought and development; many cancer voices have relationships with peers and networks where more insight and experience could be heard, and where the voices that Macmillan does not always hear from could be represented.

Delegates suggested a number of steps which they felt would strengthen the community. Suggestions included a planned programme of activities around connecting with people in existing networks on what to bring back into Macmillan; and creating stronger links between local voices and groups. People would like something, such as a logo and/or a badge, to mark the collective identity of cancer voices. There was a strong feeling that cancer voices should play a part in supporting people who have finished treatment, and that the cancer voices community should be part of the pathway to meeting other people and getting peer support.

Delegates felt that in the past, Macmillan had taken a Top Down approach, but that there was now a change in approach to Bottom Up. There was a general feeling that it has taken a while for Macmillan to "get" this approach, but it is starting to do it well. However, many perceive a postcode lottery, meaning voices are heard loud and clear in some areas, but in others, they are not represented at all. It should be made the norm that everyone can expect excellent treatment – and everyone should expect to have their voices heard.

"It's important that it's not only our voices that matter, but the people that we speak to – other people with cancer who are new to the journey or haven't really heard of Macmillan or cancer voices – their voices matter too"

"You have the staff voice and the cancer voice and it's about the two coming together."

"Before my welcome call and coming to this event, I wasn't confident I had anything to offer, it had all been heard before. Now, I want to go out and start conversations, I no longer want to be the wallflower"

"Cancer voices is where a thousand whispers become a shout."

Insight to Action

Our conversations with you, and our engagement work across the UK, help us understand what matters to you. We share this insight with colleagues across Macmillan, so that it can be turned to action. 'Insights' are the stories, experiences and views that you talk to us about in relation to your personal experience of cancer, or the experience of someone close to you.

During the pandemic, your lived experience played a vital role in informing Macmillan's response to Covid. Our conversations with you, and our engagement work across the UK, helped us to understand the extent to which Covid impacted the lives of people living with cancer.

Members of the cancer voices community contributed to six insight reports, produced by the People and Community Engagement teams, between March 2020 and February 2021. These reports were intended to support and influence Macmillan's response to the pandemic. The Story So Far, published in May this year, was a review of these insight reports, a summary of actions so far, and highlighted areas for further discussion. The Story So Far can be read here.

What struck us was how the pandemic not only impacted people living with cancer in new ways, such as treatment delays and shielding; but also how it amplified some issues that affected you before Covid.

These sessions were intended as an opportunity for delegates to consider next steps on a number of issues people living with cancer raised with us during the pandemic. These included how to ensure people know about Macmillan's support offer; how we might better connect people living with cancer to 'someone like me'; and how Macmillan can better reach out to communities and become more relevant to diverse groups.

We heard that when trying to ensure people know about Macmillan's offer, human contact and one-to-one conversations are essential. A visible Macmillan presence in the right places is important. However, information doesn't have to be Macmillan specific, but about accessing support more broadly – it's important to approach it as a good conversation, not just a script.

People spoke about support groups being invaluable in helping connect people with each other. Similarly, support group events for family members enable people to talk to others with similar experiences who appreciate how difficult it can be supporting someone you love through cancer, knowing you can't fully understand what they're going through. Many delegates shared positive experiences of Telephone Buddying, while others spoke of the effectiveness of the peer support available through the Online Community.

We heard there is too much reliance on leaflets as the answer to reaching out at point of diagnosis.

> *"There needs to be something more human, not just handing out leaflets. you need someone who will come and sit with you, calm you down, have a chat, and offer you a number for a follow-up conversation."*

Many felt there is insufficient awareness amongst people living with cancer of what's on offer after treatment. There is a strong feeling that people need to be their own advocates and know how to navigate the system in order to access the help and services they need. Many spoke about "only getting help by pushing and shouting" and expressed concern for those "who can't do that for themselves and don't have family to do it for them."

People felt there was a lack of information about local support groups. People also raised concerns about some of the safeguarding rules in place for Telephone Buddying preventing people from supporting others as well as they would like: "emotional support is about being available when it's most needed."

Many wanted to see a better understanding from professionals and organisations that peer support is different from volunteering, and the ways it's provided and supported needs to reflect that. Macmillan's role in providing emotional support through peer support is not visible enough to people with cancer.

We heard about a lack of peer support for people living with incurable cancer, and for people who have finished treatment, but who are having to make big life changes as a result of their cancer and/or the effects of treatment.

> *"I needed someone who knew what I was going through who could cheer me on, someone who was in my corner."*

When discussing how to better reach out to communities and become more relevant to diverse groups, people told us that Macmillan is often seen as a "stand-alone structure" which is not good at partnering or working with other groups.

Delegates in these sessions suggested a number of steps, including more actively marketing Macmillan's offer – making it clearer that it's ok to need help at any stage and encouraging people to ask for help; focusing more on promoting good conversations, rather than formal processes; promoting what's available after treatment.

We heard that people would like Macmillan to explore the differences between peer support and volunteering and identify ways of providing more access to peer-led support, signposting and/or services. People would like to see Macmillan explore with people living with cancer ways of "creating space – both real and virtual" for people to informally connect, share ideas and support each other. People felt there was a role for Macmillan to coordinate small groups of people for peer support; as well as for Macmillan to support self-organised support groups in an enabling and encouraging role, rather than a leadership role. Delegates would like to see Macmillan explore ways people living with cancer can support others learning to live well following treatment – as a "life coach."

We heard that more work is needed to explore different ways of partnering with communities. Macmillan should focus on smaller groups and charities, who have the connections with their communities, but not the resources to support them in the same way that Macmillan can. You told us that Macmillan should invest in cultural competence – supporting staff and volunteers to be more confident reaching out to diverse groups and doing it well.

> *"Spending time finding out how **we** do things, not just telling us how **you** do things."*

People would like to see Macmillan do more to address language issues and provide additional support; as well encourage people living with cancer to share their skills, including language, as well as their cancer experience.

There was a lot of emphasis in these sessions on the importance of emotional support – for people living with cancer and their families; after treatment, as well as during it.

Advocacy

The advocacy breakout sessions, facilitated by colleagues in our Campaigns team, were an opportunity for people to find out about the work we are doing to involve people living with cancer in Macmillan's advocacy and campaigns work. The sessions built on previous conversations with cancer voices and were intended to help shape Macmillan's advocacy strategy. Delegates talked about who and where they would like to influence, how they would like to work with Macmillan to influence change, and what people need from Macmillan.

The Campaigns team subsequently shared their proposed approach to involving people living with cancer in Advocacy at Macmillan. This was sent via email to everyone who took part in the Advocacy breakout sessions. This approach was put together after lots of conversations with people living with cancer who are close to our Advocacy work, as well as those who haven't ever done Advocacy work, and of course your own feedback from the breakout sessions.

Delegates were invited to provide feedback on how this would work as an approach, based on their own experiences. We would like to thank everyone who took the time to respond. We know our Advocacy colleagues found all your comments invaluable in helping to shape Macmillan's advocacy policy.

The Campaigns team are currently in the process of finalising Macmillan's advocacy strategy, with a view to sharing this in the Autumn. In the meantime, we will be coming out to everyone shortly to let you know about the next phase of Macmillan's Forgotten C Campaign.

Next steps

Feedback from both delegates and facilitators was very positive. People liked the format and the content of the sessions. Other feedback was that many delegates would have liked to attend more than one session or have had more time to discuss each topic in greater depth. That said, some very rich insight was generated through the discussions on the day, as you can see from the earlier sections in this report.

In response to your feedback, and the observations and perspectives gained at the event, we will shortly be inviting you to a number of follow-on sessions; with the intention of progressing some of the discussions and achieving that greater depth. These sessions will enable some of you who couldn't make it to the event to still be involved.

As mentioned earlier in this report, since the event we have also come out to you with an invitation to help us plan future events, and the first meeting of interested people will be happening soon.

Finally, we would like to thank all of you who attended the event for making it such an enjoyable and productive time together.

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