

Looking back and celebrating 2021

We know 2021 has been another year of uncertainty. The pandemic continues to affect diagnosis and treatment, as well as our ability to see loved ones. The rising cost of living, combined with the financial impact of cancer, remains a difficult reality for many.

Despite this, the cancer voices community has grown not only in numbers but in strength. More of you than ever before have been directly involved in Macmillan's work - bringing an unbeatable combination of passion, energy, authenticity and humour, which really gets to the heart of what matters to, and for, people living with cancer. Together, we make a great team!

The numbers and stories on the following pages speak for themselves, but they can never fully represent all that you have brought to Macmillan, and one another, this year. We have loved learning from you, laughing with you, and figuring out some stuff with your help and advice. We look forward to more of this in 2022.

With our thanks and warm wishes

Holly, Andrea, Helen and Matt - the People and Community Engagement Team



Looking after yourself

As always, for anyone who needs practical advice, or simply a listening ear, Macmillan is here for you. Our support line is open 7 days a week, 8am to 8pm, 0808 808 0000, and our<u>website</u> lists all of the ways you and the people around you can get information and support.







28 new projects involving cancer voices

14 consultations, workshops, interviews

- **S** online surveys
- 9 advisory group meetings
- **3** Macmillan staff recruitment panels
- **3** Macmillan staff onboarding sessions
- **3** speaking events
- **117** participants

Stronger Together Event, May 2021







cancer voices holding the mic

During 2021, cancer voices have held the mic at various events:

- In March, Genevieve was a keynote panelist at Macmillan Live, an online event for all Macmillan Staff
- In April, Michelle led the launch of the new Macmillan Values for all Macmillan staff



- In May, Sabrina and Natasha hosted the Stronger Together cancer voices event
- Eammon, Laurine and Donna facilitated break-out sessions at the same event
- In October, the <u>cancer voices film</u> went live on our website. In the film Mikki, Gabhan, Caryn and Sabrina talk about some of the projects they have been involved in with Macmillan
- In November, Sarah was a keynote panelist at the Macmillan Professionals Conference in Manchester
- In December, James, Sabrina and Donna spoke in conversation with one another and with new staff members as part of induction sessions for all new Macmillan colleagues (see the following page for further details)

cancer voices impact and influence

The Macmillan teams and departments you have worked with and influenced this year:

- Advocacy and Communications Learning and Development Professional Development and Knowledge Media and Public Relations Marketing Corporate Partnerships Content Information Development Talent Acquisition
- Cancer Support Operations
- Chief of Staff
- Executive Strategy Team
- Strategic Events Team
- Chief Medical Officer's Team
- Volunteering
- Human Resources
- Strategy Development

Outside of Macmillan, you have influenced or worked with:

- The Department for Work and Pensions NHS England The 4 UK Governments Researchers at various universities
- The national Patient Experience Network





DECEMBER LOUDHAILER

Cancer Voices inspiring and motivating new Macmillan colleagues



Back in August, colleagues in our People Development Team asked us to think about how we could involve people living with cancer in welcoming new staff into Macmillan. The brief was to "Inspire, Connect and Empower" new starters to feel ready to roll up their sleeves and join Macmillan in giving everything we've got to people living with cancer.

Sabrina, James and Donna from the cancer voices community agreed to help us plan, deliver and test three pilot sessions. The first two sessions

took place earlier this month. New Macmillan staff joined our three brave pioneers online in a conversation about what life was like for them going through diagnosis, treatment and beyond; what has helped them – as well as what hasn't; and what is the one thing they think all new Macmillan staff should know about life with cancer.

This project has had such a positive impact on everyone involved so far. 100% of the 23 new starters who attended the sessions said it had exceeded their expectations. Let's hear what people are saying in their own words!

"For me, sharing my cancer experience is like leaving little drops of reality with people. So, I jumped at the chance to be involved. Starting a new job is an exciting time; establishing a connection to your organisation and its cause is essential to fostering a sense of belonging and feeling empowered in your role. It was great to be able to provide some context for how Macmillan has made a difference to me and my family, as well as the realities of living with cancer. There is no substitute for hearing someone's experience directly from the source!" Sabrina

"Taking part was so empowering for me, so immersive and great for my self-esteem. It felt so authentic, hearing the reality of people's lives. Even though I was there talking about my own cancer experience, it was also so moving for me to hear about Sabrina and James's experiences. These sessions really felt like the beginning of something great. It has been my absolute privilege to work again with cancer voices and the Macmillan team." Donna

I was honoured to take part. I think the cancer voices approach really works - finding the right ways for people to connect, meet others, get involved in what matters to them. When I got diagnosed, I didn't know anyone with cancer, but the people I've got to know are great, upbeat, funny despite it. We're just normal people who want to be heard and understood. It was good to have the opportunity to share this with the new starters, as well as to remind them to have fun with their job. It's not all bad and they are all making a difference." James

And feedback from colleagues who are new to Macmillan:

"I feel really grateful that they shared their personal experiences with us. Hearing from them about what they would say to us as new starters at Macmillan too was really powerful and motivating."

"This session was really moving, honest and made me really proud to work for Macmillan."

"The session puts everything into perspective about why we're all here at Macmillan and do the job we do."

We'd like to say a huge thank you to James, Donna and Sabrina for helping shape and deliver this project and making such a powerful difference for new Macmillan colleagues.

Next Steps

We have one more session planned with James, Donna and Sabrina in January, but we would like to invite more of you to be part of future sessions. If you would like to get involved, we will share further information about how to take part in January's newsletter.





Each month, we invite your thoughts on topical issues, sometimes linked to upcoming pieces of work, always with an eye to the things you have told us matter to you.

Many thanks to everyone who took the time to reply to November's Question of the Month. Your thoughts about the one thing you think all new employees at Macmillan should know about life with cancer helped to inform Sabrina, James and Donna's sessions with new starters earlier this month.

December's Cancer Voices Question of the Month is:

"This time next year, what are the things you hope will have been achieved or improved for people living with cancer?"

We'd love to hear your thoughts on this question! It's easy to tell us what you think. You can email us at <u>cancervoices@macmillan.org.uk</u> or you can text or leave a voicemail on 07710 308055.

And, as always, if you have any ideas for future questions of the month, please get in touch and let us know at <u>cancervoices@macmillan.org.uk</u>

Thank you for reading and, as ever, please let us know if you have any feedback or questions by emailing <u>cancervoices@macmillan.org.uk</u>

With best wishes from the People and Community Engagement Team - Holly, Andrea, Helen and Matt





Highlights from November's Newsletter

Sarah's visit to the Macmillan Professionals Conference



Sarah has been a member of the cancer voices community since May. On 3 November, Sarah was part of a panel for one of the keynote sessions at the Macmillan Professionals Conference in Manchester. The conference brought together Macmillan professionals from around the UK to connect, share best practice and reflect on learnings from the pandemic.

The panel's focus was the increasing use of digital solutions in health care. Sarah spoke from her perspective as a woman living with cancer and disability. She emphasised how small changes can make such a difference. In Sarah's case, her cancer nurse specialists

learned how to use the screen-reading apps that Sarah uses, so they could share cancer information with her that was not accessible in leaflet form. This is what Sarah had to say about her involvement in the event:

"It was so good to be there and talk about that positive experience and be proud of my nurses. I also wanted to represent what I have achieved as a disabled woman who is living with cancer. And it's so important that cancer voices are there as part of an event aimed at professionals. These sessions should be patient-led and it's important that we talk about the work cancer voices are doing with Macmillan to make life better for communities and other people living with cancer.

Travelling and being at a large event with lots of other people felt safe. It was a big room, very wellspaced out and well-organised. I felt very confident on the Covid side of things.

The event was also an opportunity to remind people that accessibility should not be taken for granted. Most people just don't notice until you really spell it out to them that there might be three steps here, or a pale-coloured step without a handrail there. Technically everything can be on the same floor, but for people like me who have access needs, just that one step can be a huge barrier. And I did notice that in one of the breakout sessions, professionals talked about printed packs still being handed out to patients. These are not accessible to everyone.

I would say to other cancer voices considering taking part in a project, definitely go for it. If you see an opportunity and you think it's not for you because it's working with professionals, or people high up in the organisation, or people you haven't met before, don't be put off. Just get involved. You'll be made so welcome. You will be listened to and you'll get all the support you need - before, during and after. I happened to sit next to Lynda, the CEO, over lunch and she held Nelly's lead whilst I ate. We chatted about her running and my tandem skydive. We're all just people at the end of the day, and cancer voices need to be there to tell it like it is.

The one thing I would like healthcare professionals to take away from my involvement in the event is to continue to educate themselves about accessibility. Take time to learn about what apps people are using, what support and training people might need to access services. Talking to people and communities about what they need is so important. And please remember that emails, texts, WhatsApp are all technology that people widely use already. You don't always need something cutting edge."





Thank you to everyone who completed our recent survey, telling us how you were feeling about winter and the festive season this year. Your responses will help to ensure Macmillan's messaging accurately reflects the ways people with cancer are feeling.

Lyndsey White, Media & PR Manager at Macmillan told us:

"We are planning a news story to land before Christmas which will aim to highlight the major themes that came through from the survey, in order to direct people affected by cancer towards our support services and to reassure them that Macmillan is here to help."

We are working with colleagues in the Strategic Communications team to publish an internal media story which will be shared with Macmillan employees across the organisation. We will share a summary of the survey findings and ask colleagues to consider what we can all do as individuals in response to what you have told us.

The Media and PR team are also planning a media moment in December focusing on the rising financial costs of living with cancer. This was a strong theme of the survey responses. Many of you told us you were concerned about the rising cost of heating, increased living costs generally and the reduction in Universal Credit. We also heard that some of you were worried about the financial impact of the festive period.

Other themes that came through strongly were the acute sense of loss felt by many people affected by cancer, especially at this time of year; the continuing impact of covid on people's lives; concern about pressures on the NHS generally and the cancer backlog specifically; consensus that winter significantly affects people's ability to look after themselves – you told us the shorter days and cold wet weather really impact your ability to get outside as often as you'd like.

What also came through was an incredible sense of resilience – the various ways people continue to keep themselves buoyant and feeling positive. You told us about the importance of peer support and the support of friends and family; the comfort taken from doing things you love; the contentment found in nature; and the power of giving back and helping others.

It's clear that your responses are already influencing both internal and external Macmillan stories. This is a great illustration of the value of the cancer voices community and the impact sharing your experiences has on the work of Macmillan teams.

As ever, Macmillan is here for you. If you're affected by any of the issues highlighted in the survey and would like support or just a listening ear, we can help.

- Our Telephone support line <u>0808 808 00 00</u> is open 7 days a week, 8am 8pm
- Chat online 7 days a week, 8am 8pm
- <u>The Online Community</u> is there 24/7 to connect to other people living with cancer

More information about ways we can support you can be found on our website: Emotional, financial and physical help for people with cancer - Macmillan Cancer Support





As part of Macmillan's response to a Government consultation on reforming health and disability benefits, we recently shared an opportunity for cancer voices to help the Department for Work and Pensions (DWP) understand more about the experiences of people living with cancer and claiming benefits. We had an incredible response and would like to thank everyone who expressed interest in taking part.

Last month, seven members of the cancer voices community met with representatives from the DWP, alongside colleagues from Macmillan's Policy Team. James Thorneycroft, Senior Policy Advisor at Macmillan, shared the following update after the event:

"Members of the cancer voices community provided valuable testimony and insight into what it's like to claim benefits and how the system can be improved. Many in the room told a similar story of feeling frustrated and worn out by their experience of claiming benefits. There was also a sense of optimism among participants that their experience can help inform changes to make the system work better for others. The Macmillan policy team continues to present evidence and recommendations to shape the system as the Government develop more fully formed proposals, some of which will be presented before Parliament as legislation next year."

Holly was also there and said:

"As ever, people from the cancer voices community not only shared their time and experiences but also got to the heart of how things could be done differently and better. People fed back that a more personalised process is needed, delivered by someone trained in the impact of cancer. There was also an emphasis on much earlier conversations to support people to stay in work, rather than entering the benefits system in the first place, and to acknowledge people's ambition and existing work. The conversation was so helpful not only for the DWP but also to enable Macmillan to think about what most matters to people on this, and we will be sharing this insight with colleagues across the organisation. Thank you to everyone who took part."

A further opportunity to influence the DWP's work to improve health assessments can be found in the New Macmillan Involvement Opportunities section on the following page.

The Online Community



The <u>Online Community</u> is a forum, hosted on Macmillan's website, with over 90,000 members who all understand what it is like to have cancer.

We know from the cancer voices community how much you value connecting to other people living with cancer - at our events and working together on cancer voices projects. And many of you mention in your welcome call that connecting to people with similar experiences is part of what motivated you to join us.

The online community is another place where you can connect to people living with cancer, ask questions, start a blog to share your own experiences, hear about other people's experiences, and so much more. If you're thinking of joining or would like to know more, you can head over to the online <u>Community Help pages</u> and check out a <u>new video</u> which tells you more about what's on there, and how to use it.

