Cancer Voices Event: Stronger Together

Wednesday 26 May 2021

Q&A with Eve Byrne, Head of Campaigns and Public Affairs

(unanswered questions collated by theme)

Theme 1: Covid

1. What main issues will Macmillan be campaigning on over the next 12 months as we hopefully emerge from the pandemic?

Coronavirus is continuing to deliver a devastating blow to a cancer care system that was already over-stretched. Chronic staff shortages mean an exhausted workforce is struggling to deliver vital care. People living with cancer are caught in the maze of health and care services – unable to access critical help and trying to navigate their worries alone. This is why, over the coming 12 months, we will be campaigning to make sure that Governments across the UK invest in the cancer workforce, to ensure people with cancer get the high-quality support and care they deserve.

2. How are Macmillan continuing to influence around the backlogs due to Covid in diagnosis and treatment? And what measures are Macmillan planning to ensure that the care and treatment of cancer patients (diagnosis and treatment) is given a high priority at Government level and within the NHS as we emerge from the pandemic?

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 understand the extent to which Covid impacted the lives of people living with cancer. You told us what mattered to you and we shared this insight with colleagues across Macmillan, so that it could be turned to action.

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.

Macmillan has been campaigning throughout the pandemic to ensure cancer doesn't become the Forgotten 'C'. Cancer voices sat on the campaign advisory group, contributed to planning, featured in the national Forgotten C Campaign and led on an Open Letter to UK governments.

The UK is slowly emerging from the third wave of the coronavirus pandemic. We know that hardworking cancer professionals are still doing their absolute best to protect services, but the NHS is under strain. Sadly, in early 2021 we saw evidence of cancer operations being cancelled, sometimes in cases where urgent surgery was required.

Our behind-the-scenes influencing work is continuing at pace to make sure decision-makers are doing everything in their power to allow cancer care to continue and to catch up with the backlog. We published a policy report setting out what each Government across the UK needs to do, which you can read here.

If you are interested in learning more about how to become a Macmillan campaigner, you can find more information here. Together we'll make sure that cancer isn't forgotten during or after this pandemic.

3. What do you think the NHS and Macmillan can learn from the pandemic in providing cancer services going forward? (e.g. telephone / video consultations have been helpful for many patients, but I haven't seen my oncologist face to face for more than a year and worry about getting bad news by phone. Should there be a maximum period of time without a physical meeting?)

Many people with cancer have been anxious about the impact of coronavirus (COVID-19) on their treatment and care. Whilst virtual appointments have allowed clinicians to see as many people as possible, we hear from people who would prefer to see their clinician face-to face; especially if they are receiving difficult or complex news, or are worried that signs and symptoms are being missed because of online or telephone appointments.

Over time, people have become more used to virtual consultations and have reported some real benefits, particularly around reduced travel and waiting times. It may be that such benefits could result in real improvements in people's experiences of treatment and recovery, providing virtual appointments are combined with more traditional face-to-face consultations. During the first lockdown, most accepted the need for virtual consultations to reduce risks to themselves and others. However, as the pandemic continued, there was a growing sense that virtual consultations were not always necessary or acceptable.

Some people experience practical difficulties with virtual consultations. Many are not offered (or able to access) video calls, so only have telephone contact with clinicians. We heard about variable quality in how staff arranged and managed virtual consultations, and concerns that needs were more likely to be missed when communication was less good and there was no personal contact.

There is increasing frustration with 'one size fits all' regulations and restrictions to service delivery. The need for, and expectation of, more nuanced approaches has been clearly expressed over time. The necessity of recognising different needs at different stages of the cancer pathway - as well as the diverse needs of people living with cancer - highlights the vital importance of more personalised approaches.

Doctors should continue to consider each person's individual situation and your healthcare team should talk with you about the options for your treatment and appointments. People from the cancer voices community have been in early conversations about influencing professionals around virtual consultations. Work continues on this, but in the meantime, Macmillan established some top tips to support patients through their virtual appointments, which you can find here:

- Patient 10 Top Tips for virtual consultations in Primary Care
- Patient 10 Top Tips for virtual consultations in Secondary Care

If it would help to talk through your worries, our support line specialist are available 7 days a week, 8am-8pm on 0808 808 00 00.

4. A few delegates said they had felt very disconnected from Macmillan during the pandemic; or they weren't aware of Macmillan's campaigns. Some felt Macmillan was not visible in rural communities. How are you planning to reconnect with users?

I'm sorry to hear of people feeling disconnected from Macmillan during the pandemic. Sadly, much of our in-person community support was suspended last year, for the protection of Macmillan users, volunteers, and staff. However, many people affected by cancer really valued the clear, cancer specific covid information from trusted Macmillan sources during the pandemic. They told us that signposting to relevant support, including Macmillan's own services, was crucial. We also heard from people about the importance of Macmillan Engagement Leads as known contacts and trusted sources of advice about where to access information and support; as well as advice and signposting provided by volunteering colleagues and local Information Service staff, who were described as "absolutely fantastic."

We want to be there for as many people as we can. We know that some people don't know how Macmillan can help them when they are first diagnosed, throughout treatment and recovery, as well as at the end of life. Sometimes healthcare professionals involved in the diagnosis aren't aware of the support we can provide. This means people are missing out on vital information and support when they find out they have cancer. We've made it one of our main priorities to work to ensure that everyone with cancer knows they can turn to Macmillan and how we can help from the moment they are diagnosed. We have committed to:

- Make sure our information and support is available when people need it, easy to find and personalised.
- Reach more people recently diagnosed with cancer through targeted marketing so they know about Macmillan's services and come to us for support earlier.
- Work with the 80,000 doctors, nurses and other professionals who support people living with cancer so that they understand how Macmillan can help the people they are caring for.

From 1st September, Macmillan began reopening face-to-face support at various venues around the UK - providing cancer information, someone to talk to and support around the non-clinical aspects of a cancer diagnosis, including referrals to local organisations, such as Macmillan benefits advice.

If you are unable to attend a face-to-face appointment, there are lots of different ways Macmillan can support you, including through our free support line, our online community, and our telephone buddying service. The Online Community understands what it's like to have cancer – it has 90,000 members who have all been there. Support is available 24 hours a day, in a safe environment. Alternatively, our free Telephone Buddy service will match you with someone who understands what you're going through, and they'll give you a weekly call.

You can find out more about all these services here.

Theme 2: Variations in the quality of care and treatment across the country

5. How is Macmillan working to tackle inequalities in access to care and services?

We are concerned by the unacceptable variation and inequalities in access and experience of cancer care and treatment and have been pushing decision makers to put forward plans to tackle it. Some of this variation is geographical, with some Cancer Alliance areas performing better than others on key metrics like first treatments; some of this is variation in relation to different cancer types, for example recovery for some types of cancer is slower than others; and some of this is inequalities in care and experience for people from different communities.

Macmillan has just published our new Equity, Diversity and Inclusion Strategy which sets out how over the next four years Macmillan will develop our leadership and culture and improve our services, advocacy and how we look and communicate so everyone with cancer can get the support they need from us. We will improve our services to ensure they are accessible for everyone and we will play our part in addressing healthcare inequalities in cancer care through our influencing work.

6. Is Macmillan working to ensure it provides the same level of service throughout the UK? Should every hospital have a Macmillan nurse, for example? There are many fantastic projects up and down the country, but there's a fear that the learning from these is not always shared across the country and doesn't always feed through to NHS business as usual when the Macmillan funding comes to a close.

Macmillan recently launched the next phase of our Forgotten 'C' campaign, calling for urgent investment for cancer nurses across the UK. You can find out more about the campaign here.

Dedicated cancer nurses provide vital care. Time and time again, people living with cancer tell us that their nurse was a 'lifeline'. The worsening crisis facing the cancer workforce means there are far too few nurses. And many people living with cancer are unable to access the critical help they need.

We've released a new research report, which sets out that, across the UK, a total investment of around £170 million is needed. This would be to fund the training costs of creating nearly 4,000 specialist cancer nurses required in 2030 to provide the care people need.

7. What is being done to standardise routes to diagnosis and make sure there's a more consistent approach to cancer care and cancer support across the whole of the UK?

Health care is devolved to the different Governments across the UK, meaning different approaches are taken according to the needs of local communities. You can read more about plans Governments across the UK are making to improve routes to diagnosis here:

- For England: https://www.longtermplan.nhs.uk/online-version/chapter-3-further-progress-on-care-quality-and-outcomes/better-care-for-major-health-conditions/cancer/
- For Scotland: https://www.gov.scot/publications/beating-cancer-ambition-action-2016-update-achievements-new-action-testing-change/

- For Northern Ireland: https://www.health-ni.gov.uk/news/minister-publishes-detailed-recovery-plan-cancer-services
- For Wales: https://gov.wales/quality-statement-cancer-html

If you're worried about cancer, you can read more about the information and support Macmillan offers here. If you are looking for help and advice in relation to diagnosis, you can find more here.

8. How does Macmillan work with GPs to encourage them to be more alert to cancer signs? Should GPs be more involved in people's treatment plans as a whole?

Macmillan Cancer Support has funded GP positions from the early 1990's. We recognised that there was a need to support the medical care of patients based at home who were being cared for by (GPs) and primary care teams. Today, all GP posts supported or developed by Macmillan are referred to as Macmillan GPs. Whilst different models of Macmillan GPs have emerged over time and to suit the differing health and social care structures across the UK, the overall aim of all Macmillan GPs is to produce a recognisable improvement in the quality of cancer provided by primary health care teams within a local area.

Alongside recognising the important role primary care professionals play in supporting people living with cancer we also do a great deal of work with non-Macmillan GPs and Practice Nurses to improve their understanding of the needs of people living with cancer and to provide them with education, tools and support in this area. This work involves supporting professionals with early diagnosis of cancer through the development of tools, resources, and quality improvement activities. You can find more information about this work here.

Theme 3: Post treatment

9. What is Macmillan's current position nationally on support for patients after treatment? How can we reduce the regional variation that currently exists and 'level-up' provision? What plans for further support for people wanting to rebuild their lives after a cancer experience? Support post-treatment is incredibly patchy up and down the country.

It is very important that people who have finished their cancer treatment have access to the right support to help them live well. We know that too many people in the UK are not getting the support they need when treatment ends, and this needs to change. Just because cancer treatment has ended and less time is spent attending hospital appointments, doesn't mean life automatically goes back to the way it was before a cancer diagnosis. Living with physical or emotional problems for months – or even years – after treatment ends is all too common.

People often don't know what to expect or where to turn for help after treatment ends. They can feel abandoned at a time when they need support to get back on their feet.

We believe everyone should have access to the support they need to live well after cancer treatment ends. This means:

- The different ways cancer has affected someone's life should be talked about from diagnosis, through treatment and beyond so that any needs people have can be identified and addressed, and a plan can be made for their ongoing care.

- Communication between the hospital, GP practice and person with cancer should be improved, so that people feel that they still have a support network after treatment, and they and their GP know what problems to look out for.
- People should be able to access the support available in their local community to help them adjust to life after treatment and feel less isolated.

To make sure this happens, we are calling for the right care and support – including a personalised care plan and tailored follow up care - to be made available to everyone with cancer, regardless of where they live.

Theme 4: Use of language

10. Does Macmillan have any plans to address unhelpful language that often surrounds cancer? (e.g. battling with / you have to fight this / lost her fight / stay positive etc)

We have published research looking at the language people with cancer prefer to use. You can read more here. The results show just how divisive and 'Marmite' simple words and descriptions can be. Cancer throws all kinds of things your way. Struggling to find the words, and the emotional turmoil caused when our friends and family don't get it 'right' can make things even more difficult. We know there is no such thing as a 'typical' person with cancer, so it follows that people will prefer different ways of talking about cancer. By drawing attention to this, we want to encourage more people to talk about the words they prefer to hear and stop the damage that can be caused to people's wellbeing and relationships. Our support line, information services and Macmillan professionals are right there to make sure that everyone with cancer gets the support they need.

We also offer support on our dedicated 'Talking about Cancer' webpage. Please see here for more information.