



MRS Awards 2021

Public Policy/Social Research

Liz Nelson Grand Prix for Social Impact

Winner

Macmillan

Covid-19 and The Forgotten C

SUMMARY

Over the last year the Covid pandemic has dealt a huge blow to cancer services across the UK, disrupting screening, diagnosis, treatment and holistic support services. Less visibly but no less profoundly, it has also massively added to the emotional trauma and anxiety typically experienced by people living with cancer.

Macmillan's Covid-19 and The Forgotten C research played a key role in informing our strategic response to the pandemic, ensuring that we could continue to be there for the people who need us most. As well as providing a robust evidence base for organisational decision-making, the findings underpinned a highly-effective campaign to draw attention to the challenges faced by people living with cancer during the pandemic.

Insights from the research have been used extensively in national and local media, appearing in headlines, sound bites and parliamentary debate. The urgency of the situation prompted Macmillan to innovate and adopt highly agile and collaborative new ways of working, drawing on a wide range of expertise both within and outside the organisation. We feel that this project is a strong contender for the award both for its use of multiple research methodologies and its tangible impact on an issue of national importance.

SYNOPSIS

Covid-19 represents the biggest disruption to the healthcare system in a generation. As the full extent of the pandemic started to become apparent, Macmillan quickly mobilised a multi-disciplinary team of researchers, data scientists and healthcare specialists to understand its impact on people living with cancer, the NHS and Macmillan as an organisation. We were briefed to quickly gather robust intelligence to inform our organisational response.

An initial desk research exercise pinpointed key information sources that would shed light on the emerging situation. In parallel, a series of working groups were set-up to identify the most pressing business questions posed by the pandemic. These scoping exercises helped to prioritise and co-ordinate activity, allocate responsibilities and establish oversight of the various workstreams.

The insight project was comprised of a series of distinct but complementary research activities that happened over the space of around 2 months:

- We commissioned a large-scale quantitative survey of 2100 people living with cancer to understand their lived experience during the pandemic. The survey explored how their daily lives were being affected by the national lockdown and shielding measures and the impact it was having on their experience of cancer care.
- We used internal Macmillan service data to track how uptake of support had been affected during the pandemic and the barriers faced by people living with cancer because of lockdown restrictions.
- We conducted more than 25 depth interviews and workshops with healthcare professionals and experts across Macmillan to understand the scale of disruption, implications for the cancer pathway and the innovative ways that frontline services were adapting.
- We analysed NHS reports & data to quantify the impact of the pandemic on cancer-related hospital appointments, screening programmes and diagnostic pathways. This enabled us to build projections of the size of the cancer backlog in terms of how many people were not being diagnosed or missing out on vital cancer treatment.

Findings from the research (published in Macmillan's landmark report "The Forgotten C?") painted a deeply concerning picture. As of October 2020, there were 50,000 'missing cancer diagnoses' across the UK due to missed or cancelled appointments, and there was anxiety amongst people with cancer about visiting their GP or hospital due to Covid. This was causing an increase a backlog of undiagnosed people which would take at least 20 months to clear. There was an appreciable increase in anxiety and worries among people living with cancer and some were facing financial difficulties, with the most vulnerable groups often being impacted the most.

As well as providing crucial operational insights into the types of need that people living with cancer experienced during lockdown, the research provided a powerful platform for engaging with external stakeholders and led to a number of influencing successes. To highlight the human impact of the pandemic and the scale of the challenge facing the NHS, we used the research findings as a central part of our 'Forgotten C' campaign. Its objectives were to highlight the risk to cancer services as result of Covid-19 and to ensure that cancer services were prioritised in long-term recovery plans.

The research insights achieved editorial cut-through during an incredibly busy and ever-changing news agenda helping to raise awareness of the impact of Covid-19 on cancer care and sending a clear message that – despite the disruption – Macmillan continued to be there for people living with cancer.

The message resonated and we were able to secure a series of high-profile media coverage:

- Between April and December 2020 our national, devolved nations and regional PR teams secured over 4,600 pieces of PR coverage related to Covid-19 from April – December 2020. Subsequent research revealed that this coverage reached almost four in five people affected by cancer in the UK (78%) and the same proportion of Macmillan supporters (78%).
- It reached 83% of decision makers, with Matt Hancock commenting; 'I strongly support Macmillan and what they're saying' during Question Time in the House of Parliament, and live on LBC Breakfast. The PR coverage played a key role in securing a meeting between Matt Hancock and Macmillan's Chief Executive. This led to commitments from the government to create a cancer taskforce and a cancer-specific recovery plan to help get cancer care back on track.
- The Scottish Government's cancer recovery plan included Macmillan's key 'Forgotten C' influencing calls.
- Awareness of Macmillan among the public increased at a time when people living with cancer needed reassurance that we were open and were fighting for them. A study by nfpSynergy in June 2020 placed Macmillan in the top ten charities associated with responding to the crisis and 29% of the UK public saw or heard about the 'Forgotten C' campaign.
- Key pieces of our national 'Forgotten C' PR activity were also associated with notable increases in calls to Macmillan's telephone support line
- We increased the public's consideration to support Macmillan at a time when our income was under great threat, with nfpSynergy reporting that willingness to support cancer charities grew 8% during the first months of the pandemic. By the end of June, our emergency fundraising appeal had received over £800,000

In January 2021 the campaign received front page coverage in The Telegraph, with Prince Charles warning that cancer was in danger of becoming "the Forgotten C". By the end of summer 2020, NHS England had publicly acknowledged the need for a national cancer recovery plan and had invited Macmillan to sit on a new taskforce to oversee the restoration of cancer care services following the pandemic. Shortly after, the government announced £3billion additional funding to help NHS England tackle the cancer treatment backlog.

Aside from the very tangible impact on our influencing activities, insights from the project have been used across the organisation to set strategic priorities, inform service development and inspire fundraising innovation, thereby ensuring that people living with cancer continue to receive the support they need throughout and beyond the pandemic.

STAKEHOLDER ENDORSEMENT

Steven McIntosh: Executive Director of Advocacy & Communications

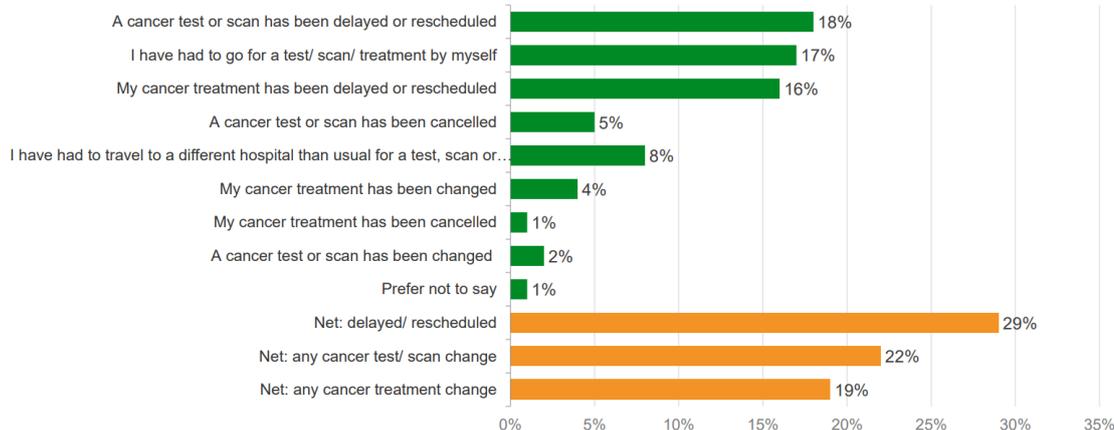
"The Insight & Performance team's rapid analysis to assess the scale of the backlog in cancer care was a critical factor in establishing cancer as one of the highest profile and most serious areas of collateral damage for healthcare as a result of the pandemic. This led to Macmillan securing major government commitments on prioritising cancer care during the most severe NHS pressures over the winter of 2021-22 and in plans for long-term service recovery.

The backlog figures enabled Macmillan to make an authoritative and high-profile case for change – they drove some highest profile national media coverage of any health condition during the pandemic, and have frequently been referred to in parliamentary scrutiny. Unusually the analysis continues to be regularly used in parliament and the media six months after publication, to assess whether governments across the UK have put in place sufficient measures to respond to the scale of the challenge.

As well as assessing the scale of 'the problem', the analysis assessed the implications for the capacity cancer services would need to catch up on cancer diagnosis and treatment. So, as well as enabling Macmillan to push disruption to cancer services to the top of the political priority list as one of the biggest knock-on consequences of the pandemic, it enabled us to make tangible proposals on the solutions needed. This focus on solutions resulted in Macmillan securing political access to top healthcare decision-makers and extracting increasingly strategic national responses on cancer service restoration – including securing government U-turns in all four nations on the need for specific cancer service recovery plans, and acknowledgement that returning services to 'pre-pandemic levels' would be insufficient to catch up on missed diagnosis and disrupted treatment."

Three in ten of those currently receiving anti-cancer treatment have experienced a delay to or rescheduling of cancer treatments or tests

C16. Which, if any, of the following have you experienced as a result of coronavirus or the associated lockdown?

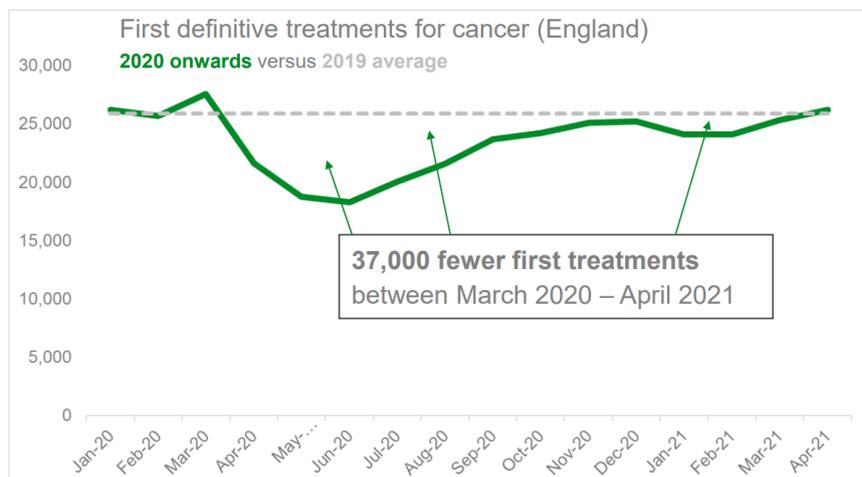


Base: All PLWC undergoing treatment at time of survey (166)

37k fewer first cancer treatments in England since the start of the pandemic

NHS England Cancer Waiting Times reporting shows:

- 37k fewer first cancer treatments reported between March 2020 and April 2021 (10% below pre-pandemic levels)
- Urology (19%) and breast (17%) saw the largest drops of the cancer types reported.
- Devolved nations show broadly similar trends in first treatments for cancer, with significant drops observed across the measures they report.



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