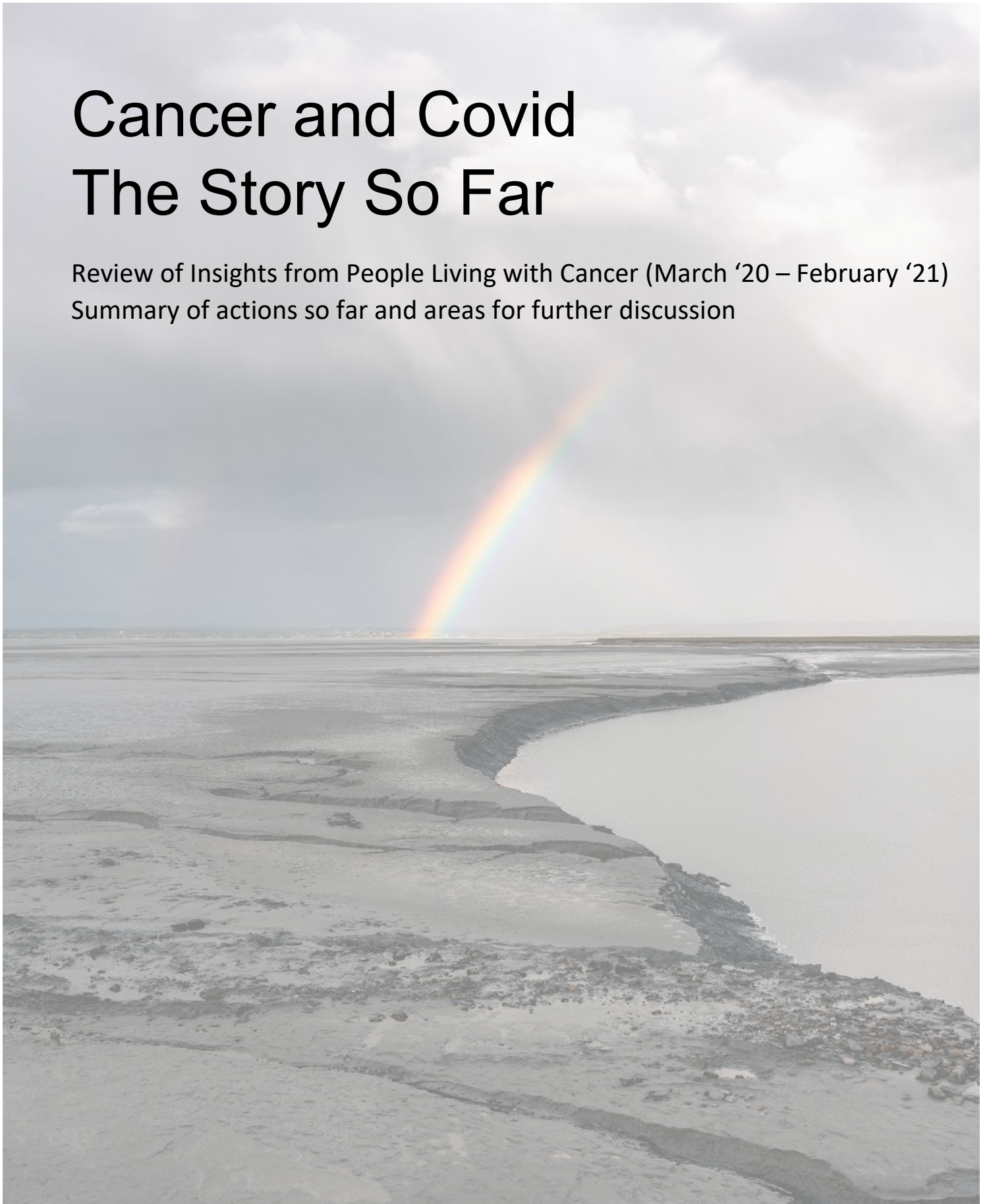


Cancer and Covid The Story So Far

Review of Insights from People Living with Cancer (March '20 – February '21)
Summary of actions so far and areas for further discussion



ACKNOWLEDGMENTS

The Story So Far was written by Helen Davies, Matt Lumsden and Andrea Bushell, with editorial support from Nicole Kirby.

The insights informing this report were gathered by Macmillan Engagement Leads across the UK, drawing on relationships, credibility and trust they have built with individuals, networks, support groups and community partnerships in their areas. The report also reflects insights shared with engagement teams by our Macmillan colleagues, notably volunteering teams, as well as some NHS staff and community organisations in close contact with people living with cancer. We are immensely thankful for the contribution of everyone involved. In particular, we would like to thank the people affected by cancer who took the time to share their lived experiences with Macmillan.

Insights were analysed and themed by a working group from Macmillan's People and Community Engagement teams. Thank you to everyone on the Insight Working Group - Maura McClean, Mark Witcomb, Helen Jarram, Nicole Kirby, Eleanor Ogilvie, Grainne Maginnis, Allan Warnock, Carol Nevison, Andrea Bushell, Helen Davies and Matt Lumsden.

We hope this report is useful to support ongoing discussions within Macmillan; as well as more widely with people living with cancer whose experiences it reflects; and with external NHS and community partners. If you have any questions about the content of the report, or any feedback about its use, please contact Matt Lumsden or Andrea Bushell.



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INTRODUCTION

The Story So Far is a review of six insight reports, produced by the **People and Community Engagement teams** between March 2020 and February 2021, with the aim of supporting and influencing Macmillan's response to the Covid pandemic. This report is primarily based on insights **gathered by Macmillan Engagement Leads (MELs) across the UK** through their direct contact with people affected by cancer. It also reflects insights shared with engagement teams by other Macmillan colleagues, notably volunteering teams; as well as some from NHS staff and community groups closely involved in cancer support.

Our ambition is to accurately report the experiences of people affected by cancer and we include people's own words where relevant. In addition, we are pleased to include **two personal stories** of living with cancer during the pandemic. Our sincere thanks to Michelle and Simon for sharing their experiences.

People's lived experiences are far from uniform. We have attempted to reflect and highlight the **range of experiences and inequalities** in this report. Some differences related to where people lived, particularly from the summer onwards, when restrictions varied by region or country. Others to where people were in their cancer pathways, with Covid taking a higher toll on people with incurable cancer or those facing the end of their lives. Insights demonstrated inequalities in access and poorer experiences for some people from BAME communities; those with language or cultural needs; and people with sensory or physical impairments. Some people told us their experience was worsened by attitudinal and/or practical barriers; the most notable being digital exclusion

Sections One to Four summarise the key themes of lived experience shared with engagement teams:

1. What's working for some – but not for all
2. Covid specific challenges
3. Treatment related issues and concerns
4. Emotional impact of cancer and Covid

A key principle underpinning our approach to connecting with people affected by cancer is to **'listen, understand, and act.'** The Story So Far gives a flavour of how that is happening in practice. Section Five summarises how insights have been used to influence and support action throughout the last year; and how they continue to make a difference.

Engagement teams are sharing this report now as a **basis for ongoing and further discussions** with other Macmillan teams, people with cancer and partners. How do we act on what people have told us? And crucially, what else needs to happen to support and partner with people as emerge from Covid restrictions and start looking ahead to the future?

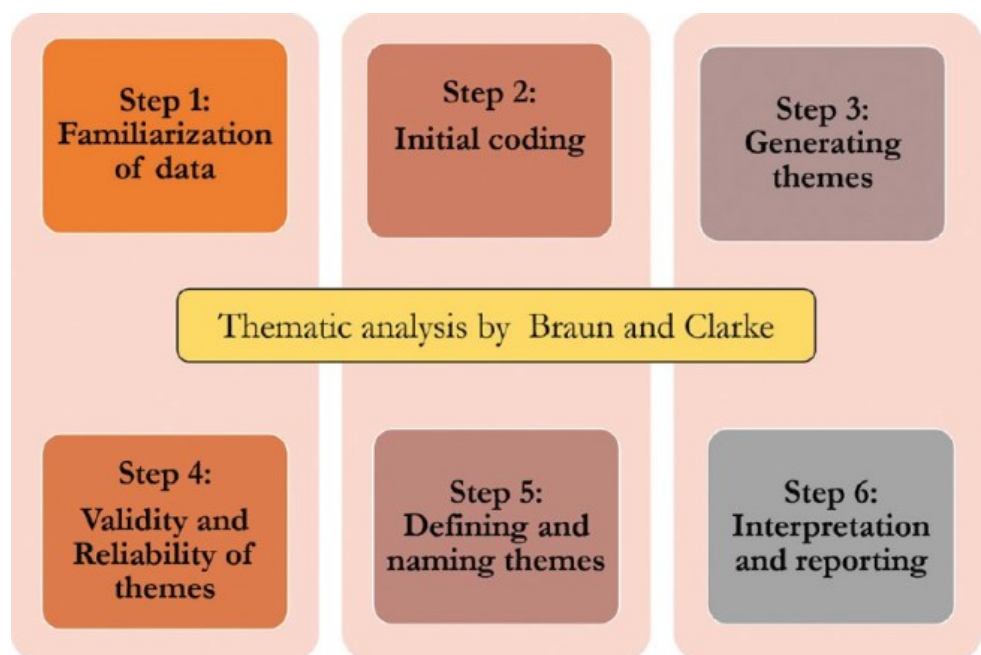
The closing section highlights some implications for action which have already been identified. We encourage everyone to consider **what more can be done** within your own teams and networks.

What we did

In March 2020, as the Covid pandemic took hold in the UK, the Macmillan 'Engagement Community' of engagement leads, managers and advisors from across the regional and national engagement teams, started capturing what we heard from people about their experiences of cancer and Covid. We wanted to share these insights with a wide range of internal colleagues, to inform and influence decisions; and help shape plans in response to Covid, alongside other sources of evidence and insight.

Engagement colleagues across the UK are in regular contact with individuals, networks, community organisations and partner agencies supporting people with cancer. Using a simple 'reflective summary' form, engagement colleagues were asked to summarise key themes, quotes and stories about **people's Covid specific experiences** from conversations, workshops, or any other engagement activity they had carried out in the previous month.

A working group of 6 colleagues with engagement experience met regularly throughout the following 12 months to analyse the completed forms. Free-text comments were grouped thematically, using an inductive approach. Coding involved identification of themes developed by content. Process analysis included identifying similarities in data; searching and comparing data to identify and list patterns (i.e. relationships) and themes. The volume of data was large (between 50-100 individual forms each time), leading the group to adopt the **Braun and Clarke six- steps** thematic analysis:



Six Insight reports were produced and shared by the working group during the 12 months covered by this summary report. The six reports were published in April, May, June, September and October 2020; and February 2021.

Who we heard from

The number of people we heard from varied in each report, depending on the length of time between reports and how many conversations had taken place in that time. Each report summarised the experiences of **30 - 90 people living with and/or affected by cancer** in direct contact with Macmillan Engagement Leads (MELs), including quotes from many. Reports also **reflected the experiences of hundreds more people from across the UK**, as reported to MELs by support group leads; Macmillan colleagues; and external colleagues in direct contact with people living with cancer. In each report we heard from:

- **Between 9 and 52 peer support group or network leads**, most of them also living with or affected by cancer
- **Between 30 and 90 additional people living with or affected by cancer**, including 47 people referred by Macmillan's **Telephone Buddying service** since September
- Several **cancer patient involvement / service improvement partnerships** with over 60 members between them - most with personal experience of cancer; the remainder health care professionals or local support organisations
- Other **Macmillan colleagues and local partners** sharing the experiences of between 80 and 140 people living with cancer, with whom they are in regular contact



PART 1

WHAT WORKS?

Despite significant challenges, insights consistently demonstrated how people succeeded in **looking after themselves and each other**, drawing on life experience and personal resilience, as well as sources of support.

We heard about the importance of **self-management strategies**, including those developed during cancer treatment; as well as peer support from individuals and groups. People told us about the significance of **family, friends, neighbours and local community** responses, which helped them face both practical and emotional challenges. We also heard about the importance of contact with, advice from, and practical support signposted by services, including Macmillan.



"I wait at the beach until everyone else has gone home and then paddle in the sea - it feels like a lifeline"

"I didn't realise how low I was feeling until I had my hair cut and styled – it made me feel like me again"



We also heard about the strain on individual resilience and coping over time, the increased fragility of some support groups, reduction in some community responses, and variable access to sources of support.

Personal resilience, coping skills and self-management

People tapped into their own life experiences and existing coping strategies, as well as developing new ones. Many people who had **experience of cancer treatment** identified this as something that helped them cope with the restrictions and isolation imposed by the pandemic.

"We are experts at self-isolating anyway – we had to do it all through chemo"

"I am in 'chemo mindset' - eating well to stay well and contacting friends by phone"



People developed resilience, coping skills and self-management approaches. **Physical activity** was most often cited as beneficial for its impact on health and emotional well-being. **Contact with other people** was similarly crucial. Other approaches commonly used to stay as well as possible and to help get through periods of isolation and challenge included spending time outdoors and contact with nature; personal faith and spirituality; mindfulness, meditation and yoga; doing things for other people; online exercise, social and fun activities; healthy eating; and local support.



"You can't stop it from happening but you can learn to look after yourself whilst it does"

"Helping others has greatly helped me – it has kept my mind off my own situation and focus on others"

We also heard about a **depletion of resilience** and, in some cases, a **loss of optimism and hope** over time. This was most notable in those who had to remain at home throughout the year; those facing continued treatment delays or uncertainty about cancer; and/or those dealing with other worries to do with finances, family or work issues. For some, this was exacerbated by a reluctance to continue calling on others for support for extended periods of time, adding to the sense that they ‘should’ be able to cope.

“I’ve tried so hard to ‘make do’ but I’m really worried now”

“There is so much going on in the world, my cancer isn’t worth talking about”



Importance of peer support, including support groups

The value of peer support, and the unique **empathy and understanding** people with cancer give and receive through these relationships, was reiterated throughout the pandemic. With extended periods of shielding or self-isolation, coupled with separation from family, anxiety about cancer, and uncertainty about next steps, **contact with ‘someone like me’** was a lifeline for many.



“I can’t believe I am talking about my diagnosis – it is so nice to talk to someone who has been there”

“I can’t talk to my family and friends about cancer. That’s where I really appreciate the support groups - they understand”

“They understand what I am going through my partner is great but doesn’t get it like they do”



We heard how **peer support – individually or in groups** – provided emotional support and reassurance; advice on living with cancer during the pandemic; shared experiences of what was helpful, how to stay as well as possible, where to get more support; practical help, including help with benefit applications and clarity on treatment plans; known and trusted contacts to signpost to other services and support.

“It’s nice to offer encouragement and reassurance and be active in our connection with one another during isolation”

“I still am able to offer a listening ear”



Access to digital platforms was crucial in enabling groups **to stay connected online**, with Zoom preferred by most. Individuals also buddied up to **support each other by phone, messaging services or social media**; staying in contact with isolated members and checking in with those they knew were vulnerable or particularly anxious.

Support groups found **new and creative ways to keep in touch** as restrictions continued – including tailored support sessions (e.g. for newly diagnosed people or for those with incurable cancer), self-help sessions (e.g. managing anxiety seminars, reflexology demonstrations), exercise and yoga sessions, crafting activities, and social activities.



“These Zoom drop-ins have been my lifeline”

“People are so grateful for the hampers and flowers we dropped round – there were tears!”



While some groups have successfully maintained or even increased contact with members, others reported **increasing difficulty remaining active and viable**. Some reported a significant decline in referrals from health professionals or other ‘warm contacts.’ The most recent insights demonstrated the increased fragility of some support groups and patient involvement networks, as they struggled to manage decreasing numbers of actively involved members, with limited external help.

“It’s very unlikely that we will have any future meetings with our aging membership, six months of no meetings and no new members”

Support group leaders, coordinators and chairs, most of them living with cancer themselves, have been leading lights throughout the pandemic, reaching out to their members in many ways. In some areas, group leads also offered each other peer support, sharing ideas and advice on how to keep groups active and connected during the pandemic.

“As the members’ anxiety increased, they needed a trusted source to turn to”

“During Covid we’ve grown in different ways, skills-wise, and are trusted more by professionals”

“One new member lives on a farm and by joining the virtual group she has met a diverse cross section of people she would never have ordinarily met”



However, we heard about the **increasing toll** this responsibility took over time. For some, the additional burden of feeling responsible for members’ wellbeing was difficult, on top of managing their own health and supporting family members.

Throughout the pandemic we also heard about the importance to people living with cancer of **giving back to others**, as volunteers, peer supporters, or fundraisers; and of offering practical and emotional support when they could. People increasingly felt that living with Covid restrictions was the new normal and they wanted to find new ways to be helpful, support others, and play a part in moving things on. This often included a wish to resume patient involvement work.

Macmillan support, information and advice

People living with cancer and those who support them, particularly family members, really valued **information provided by Macmillan** at every stage of the pandemic. In particular, we heard about the importance of clear, cancer specific Covid information from trusted Macmillan sources; helping people understand how generic government guidance related to them personally at various stages of their cancer experience.



"Macmillan has been there for us all the way - I can't thank you enough for what you do"

"Macmillan has made me feel like I am not alone"

We heard about the crucial value of **signposting to relevant support**, including Macmillan's own services. Throughout the year, people told us about the importance of Macmillan Engagement Leads (MELs) as known contacts for them and trusted sources of advice about where to access information and support. We also heard about the importance of advice and signposting provided by volunteering colleagues and local Information Service staff, who were described as *"absolutely fantastic"*.

"It's wonderful to know there is such a structure in place (Macmillan Cancer and Covid hub). I will indeed be sharing it with our Facebook Group - thank you so much for this vital information"



Support group leads and members also told us about the value of **advice from MELs**, who helped groups to adapt and keep going through the pandemic. MELs supported group leads to move online; helped them access Support Grants to meet the costs of adapting to Covid restrictions; connected support group leads to provide mutual advice to each other; and (re)connected with professionals, encouraging them to refer people to support groups.



"For less than £150 Macmillan has enabled the cancer choir to run online once a week for 12 months"

We also heard how much people valued informal contact from people they already knew in Macmillan – MELs and volunteering colleagues. People told us how important it was to have space and **time to 'just talk' and be heard** – a reminder they have not been forgotten.

"Just being able to talk to you (MEL) about it today has helped - I keep feeling completely overwhelmed"

"The emotional support (from ICJ staff) was literally lifesaving"

"The check-in calls (from a volunteer) are like therapy"



"They stay in contact through phone calls and emails and I'm grateful for this support"

"There is ongoing gratitude and relief for the telephone contact (from VSC)"

From June 2020 onwards, we heard about the value of the new **Telephone Buddying support** provided by Macmillan in response to the pandemic. This service is currently being evaluated, so there will be richer insight about the ways it helped people when those results are available. The quotes below give a flavour of the difference this support made.



"I look forward to it every week. You've given me a new friend really, a telephone friend. We have lots in common. She's absolutely brilliant"

"I am just delighted that someone will be calling me on a regular basis – I didn't think I would be a priority as there are probably people more deserving than me of this service, but I am so grateful"

"The support the volunteer gives is fantastic and I fully appreciate the calls. It has allowed me to talk openly about my cancer and that has put me in a better place"

"They made me feel more included in society. No that's the wrong word - I felt more connected"

Support from Nurse Specialists and health professionals

The **pivotal role of Clinical Nurse Specialists (CNSs)** has been clear throughout the pandemic, although the impact of variable access to their advice and support has also been evident. Contact with CNSs made a real difference to how well people understood, and were able to cope with, treatment delays. Where CNSs were not available, their absence had a noticeable impact on people awaiting news of treatment outcomes, who didn't know who else to contact.

"I feel so grateful to the NHS and Macmillan for everything they have done for me. Without them, I would be dead. Simple as that"



Despite the challenges described in section 3, people did have positive experiences of contact with, and **support from, healthcare professionals**, emphasising the difference this support made to their ability to cope.

"We have been told by the clinical team that we can contact any of them at any time if we are worried about anything. I know they are there for me"

"They showed compassion and consideration by allowing us to be with her during her last hours of her life. They also went out of their way to check on our wellbeing and offer emotional support. We thank you all from the bottom of our hearts."

Community responses and support

From the early days of the pandemic, people with cancer told us how important local community support was to them. The nature of the support available changed over time. **Practical help with immediate needs**, like food shopping, broadened out over time to include other aspects of practical support, as well as **informal emotional support**.



“Neighbourly support has been exceptional - everyone is rallying around and maybe, long term some good will come out of this”

“The local support group posts online about virtual yoga sessions, provides links to Government advice and shares messages from group members to keep us connected”

Notable throughout was the importance of **local, informal responses** to the pandemic, with people stepping up to help in whatever ways they could. We also heard about local businesses stepping in to provide more responsive help than some of the large supermarket chains. Local charities and volunteer services adapted to meet needs in their communities; and people also commented on the value of support from members of faith communities, sports and social clubs. Some people also had support from their local authorities, but we heard little about NHS volunteers or other national offers.

“In our local area volunteers have delivered food parcels to us, pharmacists are delivering medicines, and the young residents are making sure we are alright”

“The local response has been amazing, everyone pulled together and made sure no-one was left out... it’s been a lifesaver for a lot of people”

“My church family is very important to me and they are very supportive”



The **importance of trust** came through strongly, with people more willing to take up offers of support from known contacts. However, as the pandemic continued, people expressed a **reluctance to keep asking for help** from neighbours and friends. Recently, there have been fewer references to informal community support – whether because people have found ways to manage without it, or because it is no longer available, we cannot be certain.

Staying connected to family and friends

Finding ways to stay in touch with family and friends, despite Covid restrictions, was an important aspect of living with cancer. Those who had **family at home or close enough to help**, even if from a distance, were appreciative of the difference this made to their quality of life, particularly when having to stay at home.



"I think myself lucky - at least I have my husband for company, and family, friends and good neighbours to talk to"

Over time, we heard about people developing **new skills and confidence** to access **virtual ways of keeping in touch** and participating in online social activities. Many people reported feeling more comfortable with a range of online platforms – from social media, to messaging services, to video gatherings – and this has been an important way to cope with the isolation imposed by the pandemic.

"Zoom has become normal now that my fear and inhibitions have gone"



"Social media kept me going - the messages I got helped me to keep positive and kept me in touch with friends"

"Facetime and Zoom have meant I can stay in touch with friends and family and can still enjoy reading a bedtime story to my grandchildren"



Michelle's story...

A bit about me

After a short, 5-week illness in October/November 2018, I was diagnosed with Advanced Stage 3b Ampullary Cancer (Pancreatic Duct). I underwent complex Whipple surgery in late November. I am so grateful to the surgical team and expert care that I received, and continue to receive, from the incredible Hepatobiliary unit at the Mater Hospital, Belfast. The surgery involved removal of the pancreas head, lower stomach, gallbladder, common bile duct and lymph nodes.

Like so many, I am now living with advanced cancer. I feel very passionate about support for people like me, who are living with treatable but not curable cancer.

Post-treatment, I had decisions to make about my employment and whether I would apply for medical retirement. The information I received from Macmillan was invaluable in helping me make an informed choice. I opted for medical retirement in April 2020.

Covid and me

At the beginning of the pandemic, when lockdown was announced and I received my shielding letter, my focus was more on the practical side of things, like shopping for what I needed and keeping connected with family and friends. 2020 has been so tough for people living with cancer, particularly for families and friends - watching loved ones go through treatment, hospital appointments and surgery on their own. I understand the logic behind this, but the one thing I would change is to take away the *loneliness* that people with cancer have experienced. It has been so tough watching friends of mine go through treatment, attend appointments and stay in hospital, all without the support of their loved ones. I recently attended hospital for scans, and I missed having my loved ones by my side. But it has to be done and you just have to get on with it. We are in extraordinary times and we have to adhere to these measures to keep everyone safe. But it's so lonely for everyone in this new world and if I could, I would remove this loneliness.

Coming out of shielding was quite a big thing for me. I was OK but felt very nervous and apprehensive. I am asking myself the question now, "Should I be shielding?" There has been no communication since my last letter, notifying me that I can come out of shielding at the end of July.

There is a lack of knowledge/understanding about the impact of Covid on cancer patients and are there certain cancers that are more vulnerable. I have been out of chemo for one year. What will the impact be for me if I contract the virus? Are there things that I can do to build up my immune system? I am just researching it myself, but in the meantime, I am keeping my bubble as tight as I can.

What has helped me cope

Lots of things helped me and got me through the last 8 months, including:

Staying connected with friends and family, particularly when I was shielding and the last few months; whether it was a telephone call, online or just getting out for a walk. I am a great believer that when you are going through treatment or living with advanced cancer, keep doing things that ignite your well-being; and for me that is staying connected with family, friends, loved ones and great cancer support organisations, such as Macmillan Cancer Support

I have a brilliant relationship with my GP practice, and I would encourage other people with cancer to build and keep connected to their GP during these difficult times. My GP was superb and so proactive throughout my treatment. They have continued to be an incredible support to me during this past period. I can't sing their praises enough and I am so grateful for the support that I have received.

Taking up new hobbies has helped me during the pandemic. I am learning the tin whistle online and it has been great. Suffice to say I have a long way to go before I can play a decent tune, but I am getting there!

I have recently become involved in a Macmillan Advisory Group working with the communications and campaigns teams, inputting into the 'Forgotten C' campaign. I have thoroughly enjoyed meeting up online with other people with cancer from the four devolved nations and it's been great to feel that I am making a real difference. I would encourage other people with cancer to get involved with Macmillan campaigning groups or local engagement groups

What matters to me right now

Maintaining contact with my GP and medical teams who have been excellent throughout the pandemic.

Building resilience and working on my mental and physical health is critical going forward. Cancer is not just a physical illness; it affects you mentally too. At times, it is a battle against yourself, and I try to work on my emotional well-being all the time, and to build resilience. I took up mindfulness over the last year and it has been great. I have continued this through the pandemic, via online training.

Peer support is also critical, and I get that in bucket loads from friends who I have met on my cancer journey; through fellow patients in the hospital; and friends who I have met through Macmillan Move More programmes. I believe that we are all on this earth to see each other through. I had people who helped me on my journey and now I am doing this for others in my community. It's hard to explain, but through adversity, I got hope, fortitude and an inner strength that I didn't realise I had. This has channelled itself by me helping and hopefully inspiring others the way I was inspired. It's like a virtuous circle - a family who all help each other out - and Macmillan, for me, is the broker of that. They have been there, supporting me through my journey, providing that valuable information and advice at key points, and helping me staying connected and strong throughout the process.

PART 2

COVID SPECIFIC CHALLENGES

Covid and Cancer Interface

Like everyone, people living with cancer have had to face, and cope with, Covid-related anxieties, fears and uncertainties throughout the last year. But unlike many, these challenges have been amplified by concerns about **how Covid might impact on cancer, and vice versa** – both in relation to health consequences and access to treatment. This was reported by people living with cancer; those still living with the consequences of cancer and its treatment; and those who care for them.

“My consultant told me if I get Covid I’ll probably die”



In the early months of the pandemic, some people were informed, and many others speculated from what they’d heard, that they **would not be offered treatment for Covid** because of their cancer status. Throughout the year, we heard about insensitive communications regarding ‘Do Not Resuscitate’ statuses. Many felt a responsibility to **reduce the pressure on health services** and did not seek help or advice with cancer-related concerns.

In later months, as further lockdowns were introduced and cancer services were again disrupted, there was an increasing sense of people feeling **forgotten, de-prioritised and side-lined**. Many felt they were viewed as **less important than people with Covid**.



“My one message would be: Why are non-Covid patients less of a priority for the NHS? One person is going in with Covid and one has cancer that needs rigorous and thorough treatment. The Covid patient is getting priority, but they need to do both”

Uncertainty about Covid guidance

People consistently told us about the impact of **unclear government guidance** on Covid, and difficulties seeking clarification about how generic guidelines related to their personal health situations. Another concern was **how frequently guidance seemed to change** and a perceived lack of clarity about why it was safe to reduce restrictions / necessary to increase them at specific points in time.

“It worried a lot of people and felt like it had put me back to where I was at the end of treatment” (on people who weren’t on the shielding list, now being added to it)



The importance of trusted sources of advice and support has remained prominent throughout the pandemic. Exasperation at unclear government advice was particularly marked during periods of divergence between or within the countries of the UK.



"I fully appreciate that we are a devolved nation – but as someone (with treatable but not curable cancer) who is told she must shield; I would appreciate updates that are relevant to me on the 'national' update. There is so much information...but it's surprising when you delve just a little bit deeper, how much of it relates to England only."

The need for **cancer-specific Covid advice** has been a recurring and persistent issue, especially whenever government advice changed, as well as during the roll-out of the **vaccination programme**. Uncertainty about added vulnerability, including compromised immunity, following previous cancer treatment was reported throughout the year. The need to **balance Covid and cancer risks**, in the absence of sufficiently detailed or individualised advice, was a challenge for people with cancer and those caring for them. This issue is also referenced in the treatment section.

"You just don't know who or what to believe - there's so much conflicting information out there"



Guidance on shielding and self-isolating

Whether shielding or self-isolating, on medical advice or by choice, the **impact on people living with cancer** was marked. The most frequently referenced isolation issues were loneliness; physical inactivity and associated health problems; mental health concerns; and worries about family members being impacted by restrictions. From the summer, some people told us they were **starting to come out of isolation**, concluding for themselves that the problems associated with staying in outweighed the risks of leaving home. Some felt, when shielding was paused, that it was safer, and they were now 'allowed' to come out. For most people, however, it was more about reducing the impact on themselves and their families; and/or practical reasons they needed to leave their houses.

By the winter, the **increasing emotional toll** felt as a result of successive lockdowns was clear. The loneliness of isolation impacted people heavily. People missed contact with, and support from, family, friends and others living with cancer. We saw frequent reports of continuing and growing anxiety about the risks of exposure to Covid; cancer returning or progressing; or a combination of the two.

"I don't know whether I am dying through loneliness or my cancer, but I can't cope on my own"



Barriers to following government guidance

Throughout the year people told us about the challenges of following government advice and the **need to balance practicalities with relative risks**. In some cases, the lack of practical and/or financial support made it impossible for people to fully comply with government guidelines. This included people who were unable to follow advice to shield and/or self-isolate.

We heard about people having to leave their homes to buy food, collect prescriptions and deal with other practical issues. From the start, people faced **problems getting food and other essential shopping**. This was very difficult or impossible for many in the early weeks; eased somewhat as local community responses stepped up; but increased again as friends, family and neighbours returned to work or school. Practical, technical and/or financial barriers prevented some from accessing online food deliveries; while others were reluctant to keep asking people for help over an extended period. As a result, many had to venture out against advice.



"I'm running out of food. The Government told me I am not allowed to go out – so what am I supposed to do? I've tried so hard to 'make do' but I'm really worried now. What am I going to eat?"

A significant concern as the year progressed was the increasing impact of restrictions on health and well-being. Over time there were more references to the **physical health consequences** of inactivity - both cancer-related and more broadly - including weight gain; increased experience of pain; and loss of mobility. This particularly worried those who had been advised to be physically active and maintain a healthy weight to promote recovery from cancer treatment and reduce the risk of recurrence. **Emotional and mental health consequences** also increased over time. Section 4 provides more information about this.

Risk from other people's behaviour

Concern that people were at risk of exposure due to other people's behaviour was flagged throughout the year and continues to be an issue. In some cases, the risks felt unavoidable - notably for those **living with family members or housemates** who needed to work or attend school; or to leave the house to buy food and other essentials. In turn, family members who had to work shared their concerns about exposing loved ones to risk.



"We were all very fearful – this return to normality could mean that any one of them could bring it into the house"

We frequently heard frustration about **people who chose not to follow Covid guidance** putting people with cancer at greater risk. This often related to people ignoring social distancing guidelines and restrictions on people gathering together. Several felt their fears were heightened because their cancer-related vulnerability was not visible, so other people were not aware of the need to be more considerate.



"I feel very anxious now (after lockdown) and feel I have less control"

"I wish I could wear a badge that says, 'I've been shielding - please give me space.' Perhaps people would stay away from me"

During periods when restrictions were eased, **people living in tourist areas** shared concerns that increased numbers of visitors were putting them at risk by making it harder to maintain social distancing. In addition, this had practical knock-on effects as demand for local services increased, for example by reducing locals' access to online food deliveries.



Other practical challenges

Finding **safe transport options** has been particularly challenging for those without access to private vehicles. Most community transport schemes have been paused and demand for those continuing has increased significantly. People with cancer have been reluctant to accept lifts from friends because of the associated Covid risk. As a result, some people have had to use public transport, against medical advice, to access services, including NHS appointments; or have had to miss out on services altogether.

Accessibility issues were particularly marked for people with **physical or sensory impairments** who required practical help to use transport or services. Some reported that their need for patience and understanding from others was not always forthcoming (e.g. difficulty following social distancing guidance or wearing masks).



"I previously used public transport every day but haven't used it since all this. I've relied on friends to get me back and fro for appointments but sooner or later, I'm going to have to go back onto it. I know that but if I need help, will anyone help me? Some stations have provided guards with gloves and sanitiser so that they can push wheelchairs on or off trains – but not all of them have this available"

Working age people with cancer experienced a range of **work-related concerns**, including worries about loss of income because they are not able to work safely; the risk, or reality, of losing work; and concerns about health risks associated with returning to the workplace.

“It has been very hard for me to face early retirement. They tried to make adjustments for me, but it just wouldn’t work, so they offered to make me medically retired and I took them up on that”



Simon's story...

A bit about me

I have neurofibromatosis (NF) which means I have a number of benign tumours all over my body. I have been a wheelchair user since 2003. I was fit and well when I was younger, but the NF has got progressively worse as I've got older.

I also have a malignant brain tumour, which they think is part of NF. It was found during a routine scan on my back in 2018. I had two operations and things improved, but it came back last year and has gone from a grade 1 to grade 3 malignant tumour in a short space of time.

Covid and me

In February 2020, I went to my GP because my head felt weird and I was feeling very dizzy. I knew I had a problem, but he just shrugged me off and gave me tablets for the dizziness. I didn't feel too worried as I was being scanned every three months following my previous surgery and the next one was due on 12 March. But then that was cancelled because of the crisis. I received a letter the day before the scan, saying all non-urgent scans were cancelled. No new date was given. I phoned them straight away to say the scan WAS urgent. It took two and a half months, and about 12 phone calls, for them to listen to me and for me to have a scan, by which time the tumour had grown. The day after the scan, I received a phone call to say, "Sorry. It seems you were right. You do have a brain tumour, but it's inoperable. You'll have to have treatment at the local cancer centre" (which is 20 miles away). Initially, they said I'd hear more within 4 weeks, but I told them that wasn't good enough and spoke to the cancer centre, who said I'd hear within a week. It's lucky I'm so persistent, otherwise I don't know when I would have been seen. I really had to fight. It was so frustrating.

During the whole experience, I just wish I could have been seen straight away. I knew things weren't right and I asked to be seen. I didn't mind having to wait for the scan, or the chemotherapy, or radiotherapy. I can't fault the treatment I've had – I just think I should have been seen a lot earlier. The patient should be listened to more.

My friends have been great, taking me to have my treatment. But it is difficult because they can't come in with me; they have to sit in the car, sometimes for up to 3 hours. It would have been nice if they could have come in and sat next to me. That was very hard.

I have had some appointments over the phone, and some over Zoom. The Zoom meetings are great because, if they are explaining an exercise to me, they can show me and then see if I do it properly.

I am a fighter. If I'm told that I can't do something, I just think, "I WILL do it". I used to compete in marathons in my wheelchair – but I can't at the moment, because they are not being held. However, I did do the London Marathon last October. It took over 7 hours in the most awful weather. My hands and arms were in a terrible state for days, but it made me feel so good when I finished it. The date for it came at just the right time too. If it had been a few weeks later, I wouldn't have been well enough.

Before the crisis, I would often go out and see people. I'd never sit around the house on my own. I would meet people for lunch, or they would call to see me. If I was unwell, they would visit, we'd watch a DVD, have some food and a bottle of wine and they would stay overnight. But we can't do that – we can't do normal stuff. I spend a lot of time on my own at home. When I have been feeling unwell lately, I wonder if it is because I am staying home all day and doing nothing. I feel better if I have a Zoom meeting or pop out to the shop. I don't know if I am unwell because of the tumour or because life is not normal.

I like normality. I like going to disability ceremonies, events and meetings but so many things have been cancelled. I love to go to the rugby with my mates - but I can't even do that. I like to keep myself busy. It's hard not to think negatively when you are sat in the house on your own all day. I have had bad diagnoses over the years, but I've always been able to keep positive.

What has helped me cope

My family and friends. I like positivity. And the little things that make such a difference, like someone phoning and saying, "How are you? What are you going to cook tonight?"

It's been important to have help to go to appointments too. I am so grateful to those who have given me lifts to and from hospital. I really would have struggled without them.

Exercise and keeping fit are very important to me. I would go out to the local park when the weather was good. I'm lucky because I have some good places nearby. Since the weather got bad, a friend dropped over some weights. I'm using them to keep the strength in my arms up.

What matters to me right now

Normality. If we all stay at home, if we all listen to the rules, then we'll get out of this quicker. Every day lost to Covid is a day you don't get back. I want to be active. I want to be fit. I want to be doing stuff and I want normality back, especially as I have a shorter time to live. I just want to see people.

If you are given two years, you want them to be two good years. I'm hoping that we can all get back to normal soon and I will keep as fit and active for as long as I can. Some people are given a bad diagnosis and seem to give up – but that's not me.

PART 3

TREATMENT RELATED ISSUES AND CONCERNS

Cancelled and delayed treatment

Cancer treatment cancellations, delays and changes have been major sources of concern throughout the pandemic, with anxiety about the impact on survival and recovery an ongoing feature of people's experiences. While people living with cancer understood the need to be protected from Covid, the ways they perceived and felt about health services changed over time. Communication and quality issues became more frequent; and there was increasing frustration at the 'one size fits all' restrictions and their impact on people. Many of these issues were magnified and particularly distressing for people with incurable or terminal cancer and those who cared for them.

Initially the most prevalent concerns reported were about the impact of **cancellations and delays**, and uncertainty about what would happen next. These fears were particularly acute for people with incurable cancer and those awaiting initial treatment. Delays caused considerable anxiety for people to whom the importance of prompt action had been emphasised pre-pandemic.

"It [cancelled chemotherapy] feels like signing a death warrant; as though chucked out and the door has been closed"

From early in the pandemic, increasing numbers of people told us about their **fear of cancer progressing or returning undetected**. Initial fears about exposure to Covid quickly became outweighed for some by their fear of what would happen if cancer was left untreated.

"Feeling like my cancer is spreading or getting worse. I lie awake wondering, 'is it back?'"



From April, people reported concerns about being denied treatment to make space for Covid. Before long, we were hearing about people feeling **forgotten and abandoned** by health services. This sense of abandonment continued throughout the year, although for some this was eased significantly by increased contact with health services in the second half of the year.

"We feel abandoned since my husband's diagnosis two weeks before lockdown – and all through it"



Over time, anxiety turned to frustration and an increasing sense of it being **unfair and unacceptable** that cancer was no longer a priority. Being unable to contact members of the cancer team and not knowing where else to take concerns or to get advice only added to this.



"My cancer surgery was cancelled, and I was told cancer patients no longer had any say in their treatment"

"Covid has pushed the cancer patient voice to the bottom of the agenda in trusts"

Lack of information and advice about what to expect and next steps

Treatment-related fears and frustrations were worsened by a **lack of communication and updates** from health services. Many people reported they had no information about next steps following delayed or cancelled treatment. Delayed or non-existent feedback about the outcomes of previous treatments or the results of tests was an ongoing source of worry and frustration for many.



“Communication is so vital in normal times but even more so at the moment”

The **pivotal role of Cancer Nurse Specialists** was clear. They fulfilled a vital role, helping people to understand and cope with treatment delays. However, access to Cancer Nurse Specialists was variable and more limited than many had previously experienced pre-Covid.



People with cancer and family members felt an **increased burden of care**. This was particularly noticeable towards the end of 2020 and into 2021. Many reported that staff who were usually their main point of contact and advice were less available, particularly when Covid patient numbers were high; and people did not know who to contact in their absence. This resulted in patients or their families having to do more to access health advice and support and take more responsibility for knowing when and how to get help.



“I’m fed up having to be so proactive to get care”

“I feel like I have so many teams involved, I’m sitting here so confused and I would much rather be face to face. I don’t feel as though I have been cared for, I feel as though I have been rushed through and I am the one who is co-ordinating everything and holding everything together”

Changes to treatment delivery

As well as delays to treatment, changes to the way services were provided caused difficulties and distress. At the time of writing, this continues to be the case for many. The need to **attend appointments alone** ‘*at the most awful time in our lives*’ was particularly difficult. We heard about the experience of being alone at diagnosis and not being told about, or able to access, help and support at this crucial time. People told us it was stressful not having someone with them when there was a lot of information to take in, or choices to be made, especially when the news was not good.

“Felt very frightened and alone at diagnosis - I really wanted my husband to be present, and didn’t feel able to take everything thing in”



A significant change has been the move to **virtual consultations**, with people often not able to meet with clinical or support staff face-to-face. Over time, people have become more used to virtual consultations and have reported some real benefits, particularly around reduced travel and waiting times. During the first lockdown, most accepted the need for virtual consultations to reduce risks to themselves and others. However, views appeared to shift as the pandemic continued, with a growing sense that virtual consultations were not always necessary or acceptable.



"I don't see how attending an outpatient appointment is any riskier than going shopping"

Several people experienced practical difficulties with virtual consultations. Many were not offered (or able to access) video calls, so only had 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.

"I feel like I'm in limbo now as I can't remember my results. The whole conversation was lost on me. And I can't get through as everyone is busy on the phone."



There was increasing frustration with '**one size fits all**' regulations and restrictions to service delivery. The need for, and expectation of, more nuanced approaches was 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; highlighted the vital importance of more personalised approaches.

Quality and communication issues

Over time, there were increased reports of people experiencing **poor quality interactions with health staff**. We heard about rushed consultations; blunt sharing of diagnosis and prognosis news; people told over the phone they were '*now terminal*' or there was '*no more that could be done*', with no advice about palliative options; as well as little emphasis on ensuring people were able to access support.



"I had no calls or emails to follow up and show compassion, even though they couldn't treat my cancer"

Most people were aware of, and concerned about, the pressure on health systems and staff, but several were upset by **insensitive communication** and a lack of empathy when they did seek support. This was particularly distressing at diagnosis, and for those being told there were few or no further treatment options available for them.



"In March everything went over to telephone. I haven't seen anyone from haematology since Feb. They ring once a month for five minutes to check on my medication. Quality doesn't come into it."

Return to services



From the summer, people able to return to services reported **some positive experiences**, including follow-up scans and consultations; people offered choices of scan timings – whether to go ahead or postpone; hospital clinics feeling quieter, less crowded and less rushed; someone who was allowed to continue taking medication previously accessed through a clinical trial (which had been stopped) on compassionate grounds.

Throughout the year, people have told us their concerns about **whether, and how, they could safely attend treatment settings**. A feature of people's experiences in earlier months was uncertainty about what to expect from NHS staff, particularly around the wearing of PPE. There was such emphasis on the importance of PPE in the media at the time, but some staff were not wearing masks when seeing people. As more services resumed, this became a concern for many more people, who felt NHS communications emphasised the precautions patients should take to keep others safe, more than the precautions services were taking to keep them safe.

"People are still very confused about the rules about Covid – should you go to a hospital or not go to a hospital?"



From the Autumn, we also heard about **practical challenges following guidance** about staying safe and/or complying with Covid-safe requirements to return to treatment settings. Some people struggled to understand what was required of them in order to access services safely; had difficulty complying with Covid-safe procedures, notably self-isolation prior to treatment (e.g. when living with others who had returned to work or school); and experienced difficulty accessing transport to and from appointments.

With Covid cases increasing towards the end of 2020, and another lockdown imposed in early 2021, increased concern about the impact of delays to treatment and the lack of routine follow-up and monitoring were evident.



"The waiting is horrible. I felt very anxious, I'm nervous for my appointment tomorrow. I understand why they had to cancel but you can't help worry."

People with treatable but not curable or terminal cancer

Throughout the year, we heard about the increased impact of the pandemic on those living with incurable cancer, people facing the end of life, and those who love and care for them – family, friends and peers. Treatment and quality issues **impacted even more profoundly** on people with incurable cancer: delayed or cancelled treatment; limited or insensitive communications; loss of choice about treatment; and lack of contact with teams which had previously supported them.



“My daughter came out of hospital because she wasn’t allowed any visitors. And she died 3 days later”

Family members were deeply impacted, worrying about those they loved and having to do more to meet their practical and emotional needs. Insensitive communication about bad news; limited advice about where to get support when facing incurable cancer; and reduced contact with support groups and other networks left people with cancer and their families significantly less supported than they should be at this time.

A prevalent concern for people with incurable cancer and their families were insensitive communications around **‘Do not resuscitate’ decisions**. In the early months, these tended to be written statements included in letters from health services. Later, they also became a feature of conversations with health professionals.

“As the doctors were leaving the room, one turned back and asked, ‘By the way, have you had the DNR conversation with your consultant?’ ‘Um, no.’ ‘Well you probably should”



We also heard about the impact of **clinical trials being cancelled or delayed**, and the loss of hope often associated with that.

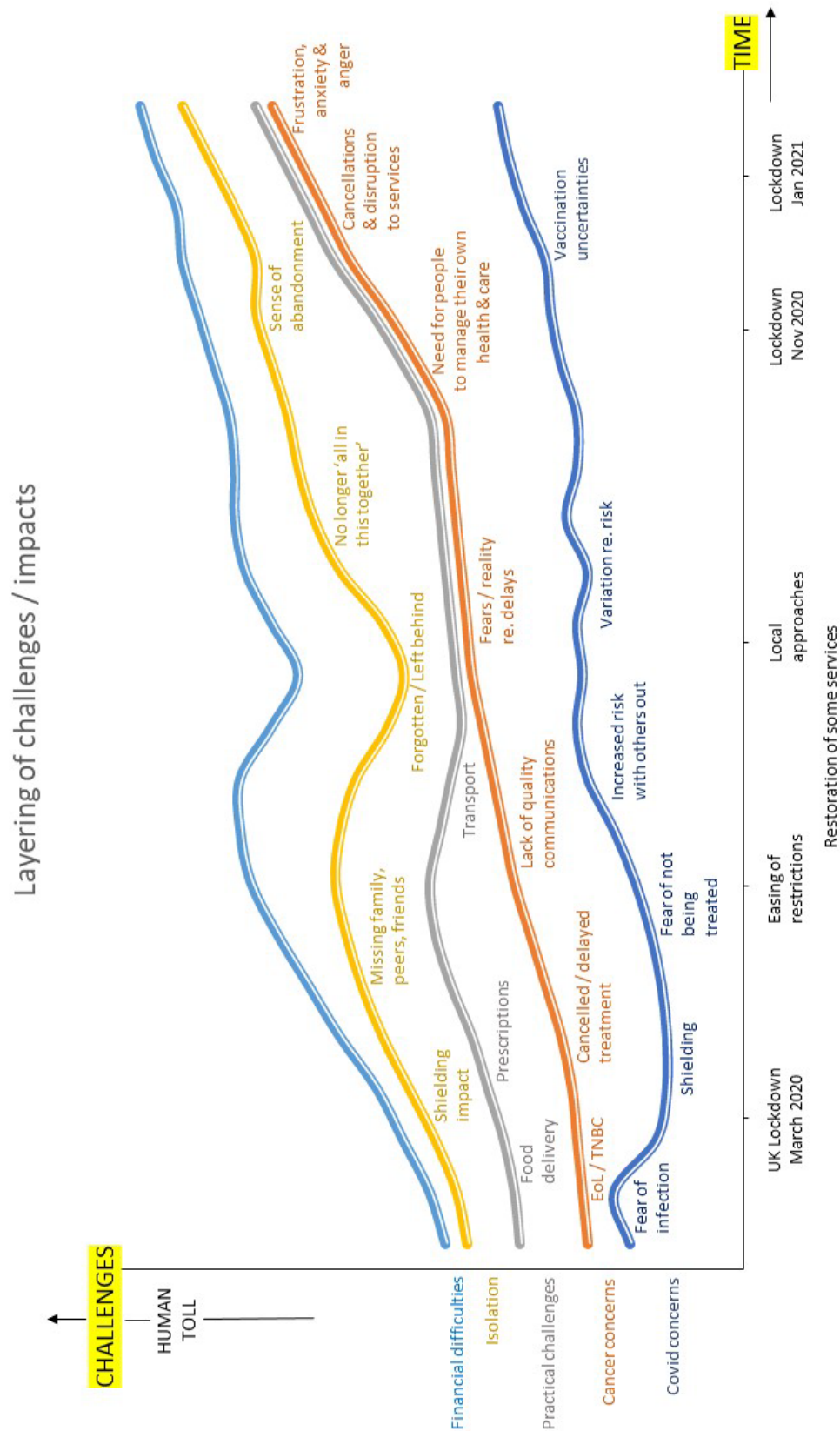


“The trials had given a glimmer of hope and something to aim towards – this has now been taken away”

PART 4

EMOTIONAL IMPACT OF CANCER AND COVID

The visual below seeks to summarise the increasing emotional toll felt by people affected by cancer as the year progressed. The prolonged period of living with Covid-related challenges; as well as the cumulative impact of cancer and its consequences, the pandemic, and other personal and practical life challenges, had a significant impact on people's emotional wellbeing.



Anxiety and fear

Over time, the prevailing mood reported by people living with or affected by cancer has shifted in response to changing circumstances. **Anxiety and fear**, however, have remained consistent features. In the early days of the pandemic, people reported feeling anxious primarily about the possibility of **treatments being cancelled or postponed**, as well as fear of infection and the risk of catching Covid. However, people's fears began to shift relatively quickly. As treatments were delayed, people feared the **consequences of those delays**, specifically the risk of cancers growing or returning. Many people reported feeling distressed at the **perception they were being 'denied' cancer treatment** which they had previously been told was necessary.

"Fear has taken over my life"

People living with cancer who were either shielding or choosing to self-isolate reported feeling a rising sense that they were being **'left behind'** as others in their communities and around the country returned to work and school. By the summer, it was clear that many people were living with an **increased sense of generalised anxiety** – not specific to individual issues, but a more pervasive feeling related to multiple causes and, therefore, harder to address.

"I'm struggling; anxious; worried about what future holds"



As the first lockdown eased, fears about exposure to Covid increased and many expressed concerns about the **risks of coming out of isolation** and uncertainty about what to expect and how to stay safe. This was especially acute for those who had to go out to attend appointments.

As 2020 drew to a close and Covid cases began to rise once again, the reality of another lockdown and worries about the impact that might have on cancer services were a significant feature of the insights we gathered.



"My mental health has really been affected, it's so tough, as it has been for a lot of people. The support bubble makes it better, but all the other support has gone."

Isolation and loneliness

Social isolation has been a key challenge for many people with cancer during the pandemic. Isolation affected not only those shielding, but also people concerned about the risks of leaving their homes and those not able to go out alone. For some this has been exacerbated by physical isolation in rural areas; and for others by limited digital access or a lack of confidence connecting with others online. Several insights reflect an increased sense of feeling alone with cancer and its consequences.

Separation from family and friends has had a major impact on people's quality of life. This is felt particularly keenly by those facing the end of life and their loved ones.



"The lengthy period of shielding has meant more time to think about illness, and feelings of extreme loneliness"

Peer support and **contact with others living with similar challenges** is highly valued by many, and the loss of this has exacerbated the sense of being alone with cancer. Recently, reports have highlighted the increasing fragility of support groups, many of whom have far fewer referrals. The burden on support group leads is keenly felt.

"We have continued to have Zoom committee meetings, but I must admit I do feel very weary and disheartened by it all at times"



Loss of contact with community, notably faith groups, has added to the sense of isolation and in some cases contributed to feelings of lost identity and purpose. **Lack of human contact** came through ever more strongly as the year progressed. While this started to ease for some in the autumn, the lack of close interactions with friends and family became a significant issue again as the country entered another lockdown in January.



"Touch is such a big part of life for people, it brings comfort, and now there is a loss of that"

Feeling forgotten

Throughout the year, there was a growing sense of people feeling **forgotten, abandoned or excluded**. Initially, this was in relation to health services; but over time it extended to other support services and communities. As life appeared to return to normal for some in the summer months, people living with cancer increasingly felt removed from others in their neighbourhoods and workplaces.



"I just sat there with my video off and tears in my eyes. I've never felt so excluded" (on work call about returning to office – June/July)

In latter months, the sense of exclusion was exacerbated by a growing feeling that people were no longer 'all in this together'. People's experiences of the pandemic became more divergent across different parts of the UK, for different communities, and for those with specific needs. The solidarity that had helped to carry people through the early months diminished as people's experiences varied.

*"I just feel so left out of everything"
"Left on the shelf"*



Depletion of resilience and hope

Over time, a growing sense of **weariness and depletion of resilience** was reported by people. The initial belief that Covid would impact on people's lives for a limited time, gave way to a growing understanding that Covid measures were likely to be in place for a prolonged period and that these might impact disproportionately on people living with, and affected by, cancer.

From the summer, a strong theme was the increasing emotional toll that the **combined impact of cancer and Covid** was taking – both on people living with cancer and those who care about them. For some, hope and optimism were being depleted. This was particularly the case for those with incurable cancer. Some people told us they felt at the limits of their resilience and coping skills.

I've asked God to speed it up because I've had enough

People also reported experiencing an increased **sense of withdrawing** over time: disengaging from media; feeling less connected to, and less trustful of, others; feeling increasingly isolated. Loss of contact, confidence and identity were all frequently reported.



"Becoming withdrawn and lethargic, giving up on life. There is nothing to look forward to anymore"

Worry and guilt about others

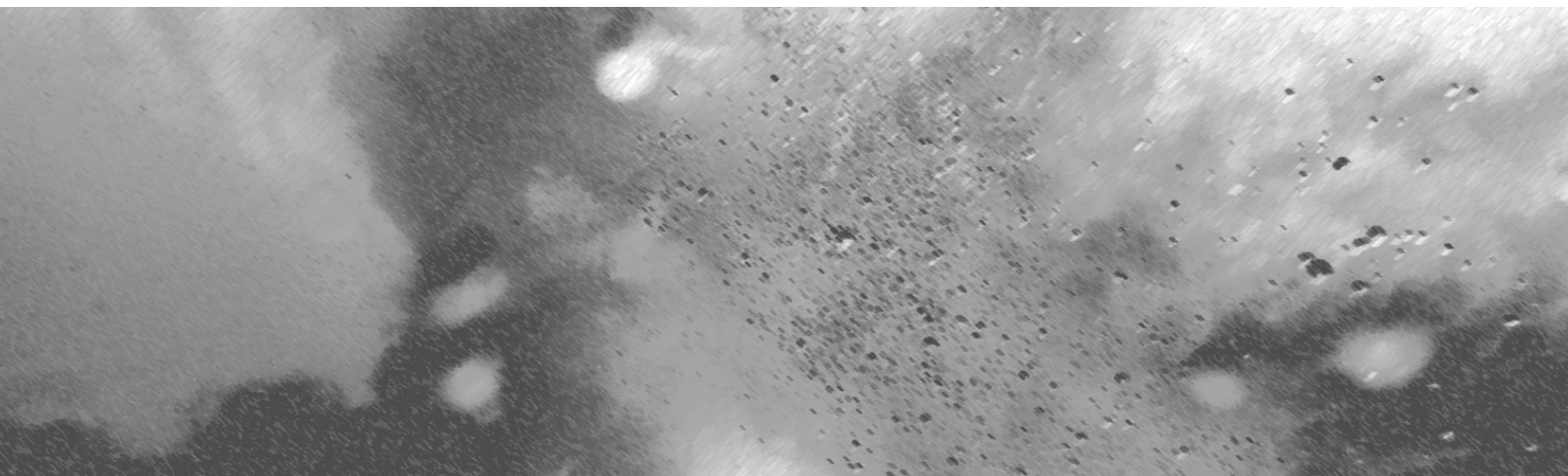
A recurring theme throughout the year was the **responsibility people felt for others** and the **pervasive feelings of worry and guilt** felt by people living with cancer; their loved ones; carers; and support group workers. Support Group leads told us they worried about lack of capacity and their struggles to continue to try and support others. These included financial difficulties, as well as a lack of resources and knowledge to move support online.

People living with cancer reported feeling distressed that, as a result of shielding and/or self-isolating, they were **not able to support other people affected by cancer**. Support Groups are no longer meeting in person and people have frequently struggled to access online groups. In addition to missing the support and companionship offered by such groups themselves, people reported feeling guilty that they couldn't offer support to others.

There was also a strong feeling that an **increased burden of care** was being borne by people living with cancer and their families. As the year progressed and Covid continued to impact heavily, people felt **increasingly reluctant to keep asking others for help**.

Mounting losses / particular issues for people with incurable cancer

Over time, insights demonstrated an increasing awareness of how much people have lost as a direct result of Covid. Some losses feel likely to be long-term or permanent. Some are cancer specific, including **lost hope** for future recovery and **lost plans** to live life as fully as possible, however much time may be left. Others are broader than cancer, such as **loss of work** and/or financial security. Some people reported struggling to make ends meet, while others saw their savings dwindle. Some losses are more practical, such as the **loss of support** and help with day-to-day life and **lost opportunities** to socialise. All have a significant emotional impact on people.



PART 5

ACTING ON WHAT WE HEARD

What has been done so far

Since March 2020, the six Cancer and Covid Insight Reports have been used by a range of teams within Macmillan, to inform their work. This includes Executive Leaders across the organisation, Strategy Development, the Chief Medical Officer, Advocacy and Communications, Fundraising Marketing and Communications teams, and Geography-based partnership teams. In this way, people's lived experiences have impacted a range of Macmillan work during the pandemic. For example:

- Informing strategic decisions by the Executive Leadership Team about Macmillan's immediate Covid response, as well as feeding into longer-term strategy discussions.
- Making improvements to Macmillan's public Coronavirus Information Hub webpages, to reflect what people living with cancer told us they needed more advice on; and to update and add information as people's concerns changed throughout the year.
- Through Macmillan's 'Get Support' campaign, encouraging people to come forward for cancer specific advice and support during the pandemic, addressing their reluctance to 'burden' the NHS and providing practical advice to address their concerns about returning to services safely.
- Informing the creative brief for the 'Get Support' campaign; Macmillan's 'Give Support' appeals; and other fundraising initiatives.
- Supporting local discussions with NHS and community partners about people's concerns; and influencing use of support grants to tackle digital exclusion as a result of Covid restrictions

Our UK Engagement team worked closely with the Advocacy division and Communications colleagues throughout the pandemic, to ensure insights on lived experience were relevant and useful to their advocacy work. The Advocacy division used insights to inform policy positions; and to shape products for external use, including reports and public campaigns. They also used the insight reports internally, alongside other sources of data, to add depth and more person-centred understanding of the most pressing needs of people affected by cancer during different stages of the pandemic.



Influencing and Advocacy work

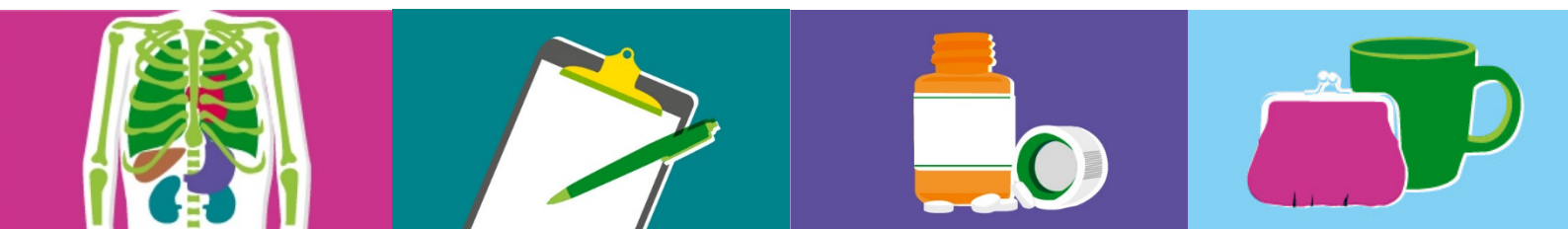
Specific examples of how insight reports have been used for influencing and advocacy work throughout the year include:

- Helping to instigate Macmillan's **policy response on shielding**. The Cancer and Covid insight reports highlighted confusion about the meaning of shielding; the difference between shielding and self-isolation; and about how long people should be shielding. As a result, Macmillan led a joint letter to the Cabinet Office, based on our policy asks and signed by 48 charities - bringing together several separate shielding initiatives within the sector (May 2020).
- Improving understanding of some poor practice around **Do Not Resuscitate (DNR) conversations and decisions** during the pandemic, most notably in the first wave. The need for good practice concerning DNR orders was emphasised in Macmillan's End Of Life policy positions and raised in the organisation's policy submission to the Women and Equalities Select Committee inquiry into the unequal impact of Covid-19 on those with protected characteristics (April 2020).
- Shaping Macmillan's influencing work with the Department of the Environment, Food and Rural Affairs (DEFRA) to highlight **difficulties in accessing food**. Macmillan joined a sector-wide letter to DEFRA ensuring people shielding were assured of prioritised supermarket deliveries as well as government food parcels (May 2020).
- Using intelligence, quotes and individuals' lived experience to help tell the story of how delayed or disrupted health services were affecting people living with cancer in the **Forgotten C report** (October 2020) to influence NHS policy and practice.
<https://www.macmillan.org.uk/assets/forgotten-c-impact-of-covid-19-on-cancer-care.pdf>
- Informing Macmillan's successful '**Forgotten C**' **advocacy campaign** to ensure that cancer services were being prioritised by Governments and to mitigate against the disruption to care caused by the pandemic.
- Using intelligence as part of Macmillan's growing internal evidence base informing **end of life care (EOLC) policy** during the pandemic; and feeding into influencing activity around the need for guidance allowing people to visit loved ones in the final days of their lives.
- Informing Macmillan's policy position and practical advice on **virtual consultations**, working with the Chief Medical Officer's team, professionals, people with cancer and the National Voices coalition of charities to develop top tips for health and social care professionals.

Implications for action and further discussion

Some of the actions summarised above were relevant to particular points in time during the first year of the pandemic. Others represent **areas of ongoing action**, helping to ensure Macmillan continues to provide relevant advice and support as people and services begin to emerge from Covid restrictions. Teams across the organisation continue to reflect the lived experiences of people affected by cancer in their ongoing work:

- Meeting the need for cancer specific Covid information and advice, adding to and amending this as needed, to ensure it remains current.
- Helping to improve the quality of telephone, video and other virtual consultations; working closely with people affected by cancer, other charities and professionals to identify and support best practice.
- Influencing work to address the impact of Covid restrictions and disruption to services on people with incurable cancer or who are at end of life, including playing an active role in lobbying government to provide clearer guidance for people visiting loved ones; and continuing to influence other activity to improve end of life care across the UK.
- Raising awareness of available Macmillan advice and support and encouraging people to seek help from us and the NHS to meet their cancer-related needs.
- Working with the NHS and other partners to improve local services and support restoration of cancer provision to address the backlog.



Areas for further discussion

There is **still more to do to fill gaps and meet challenges** highlighted by people in their conversations with us.

Engagement teams have identified some areas for further discussion with colleagues, partners, and people affected by cancer, based on what we've heard. Many of these issues existed before Covid; and have either continued, or worsened, as a result of the pandemic and the restrictions and disruption caused by it. We anticipate most of these issues will continue post-pandemic. Some may become even more pressing, as people return to services and areas of unmet cancer-specific needs become clearer.

- Increase awareness of where to access **advice and practical support**, including financial support, up-to-date information and advice on cancer and Covid, vaccine advice, information about attending treatment settings safely, and other issues arising for people as they come out of shielding.
- Improve signposting to **emotional and peer support**, including support groups, Macmillan's Online Community and Telephone Buddying; including further action to identify and reduce barriers to access.
- Work with people affected by cancer to identify how Macmillan and others can support them to work through residual concerns, anxiety and anger about the impact of **delayed and cancelled treatment**; and about feeling forgotten or de-prioritised as a result of Covid. Consider **additional support for people with treatable but not curable cancer**, who may have been profoundly affected by delayed treatment or being unable to be with loved ones.
- Work with partners to address the **impact of ongoing service disruption** on the quality of the patient experience, and the increased burden of care on people to get the help and support they need.
- Take the learning from Covid into partnership work to **personalise care**; notably lessons from the variable experience of virtual consultations and 'one size fits all' regulations and restrictions, eroding choice and accessibility of services for some.
- Recognise the importance of peer-led support and identifying how to **'support the supporters'** to address the increasing burden on support group leaders, coordinators and chairs, and the increased fragility of some support groups post-Covid.
- Reflect the importance of **community-based support** in future planning and investments – including learning from the value and crucial role of local, informal support from neighbours and community groups, local businesses and charities.
- Seek to identify, understand and **tackle health inequalities and address unequal access** to support - including digital exclusion; and additional barriers facing marginalised groups, such as people with learning disabilities, hearing or sight loss, mental health problems, some black and minority ethnic groups.

Engagement teams will share this summary report widely and encourage its use as a starting point for further discussion about how Macmillan can work in partnership with people affected by cancer and other organisations to act on what we've heard.

Sharing learning

There is much we can learn and share from the ways in which individuals, support groups, communities and organisations have stepped up in response to the combined challenges posed by Covid and cancer. Further work is needed to **capture and share good practice about what works to enable people to support themselves and each other** as well as more detailed case studies and stories. Engagement teams will continue to play a key role in this and will seek to support further work with people with cancer, other Macmillan teams, and external partners to identify how to build on the strengths which our insight reports highlighted:

- Building individual resilience, coping skills, well-being
- Supporting the supporters, notably peer supporters and group leaders
- Recognising and responding to the emotional toll of Covid and cancer
- Improving the accessibility of Macmillan's advice and support, including promoting digital inclusion
- Reaching out to diverse communities and seldom heard groups
- Bringing insights and learning from lived experience into planning and delivery
- Demonstrating to people how their experience is making a difference, and planning next steps together...

Where next.....

Our ambition is to ensure people's lived experiences continue to be heard and acted on by teams and partnerships throughout Macmillan. Engagement teams across Macmillan will continue to work with people affected by cancer, support groups, networks and community partners, to listen and deepen our understanding of what matters and what helps people to live life with cancer as fully as possible. We are identifying the best ways to continue to gather, understand and share what we hear through the relationships we have across the UK.

We encourage colleagues to actively consider the insights summarised in this report within your own teams, networks and partnerships, and seek to embed them in your thinking and planning.

If you would like more detail about the insights Engagement teams have gathered over the past year; or would like to discuss ways of using lived experience insight in your own work, please contact Matt Lumsden and Carol Nevison.

For information or advice about how to involve people with lived experience in your work, please contact Holly Swinckels.

For further information about the work of Macmillan's Engagement teams, updates and plans relating to this report please email PACE@Macmillan.org.uk. Macmillan colleagues can also visit the People & Communities Engagement pages on the intranet in the first instance

