# What we did

Helen Davies, Specialist Adviser

# How your experience is making a difference: taking insights from you and your communities to Macmillan leaders and decision-makers

MACMILLAN CANCER SUPPORT

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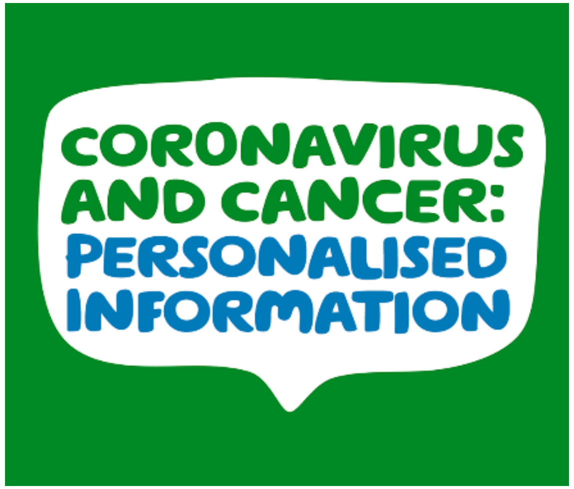
# Building a Collective voice

# Current priorities – supporting people with cancer, influencing others, securing our future…



MACMILLAN
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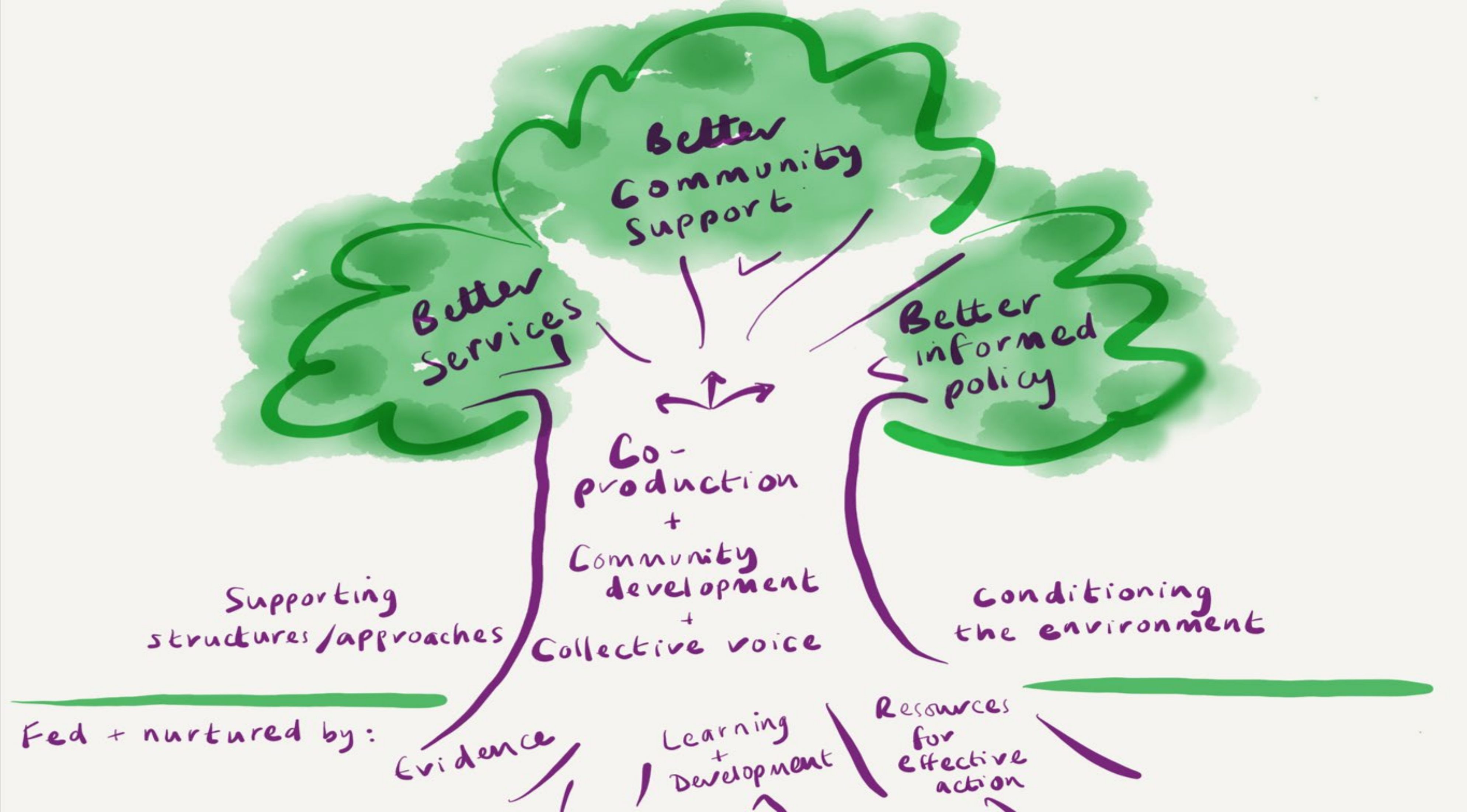
# Macmillan’s commitments to improving equality, diversity and inclusion

1. Make tackling inequality – including racial inequality – a core goal for every service we provide for people living with cancer
2. Challenge UK Governments to address the inequalities in cancer care
3. Actively engage people from BAME backgrounds to become Macmillan professionals, and provide support for those who already are
4. Review our fundraising and volunteering activities, communications and information to ensure they are relevant to all communities
5. Break down our internal systems and barriers to ensure we are a truly inclusive organisation.

# People and Community Engagement approach



# Hearing from you about what matters…

Maura McLean, Macmillan Engagement Lead

- ✓ Pre-Covid
- ✓ Insights from the Covid pandemic
- ✓ What matters most to you

# How we have heard from you

- Consultation with people affected by cancer 1
- Cancer Voices survey 2
- Collective Voice engagement event 3
- Seldom Heard Groups report 4
- Cancer Voices conferences 5
- Reflective summaries 6

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# What we heard from you

**Emotional consequences of cancer and its treatment**

*“More acknowledgement is needed that cancer patients are adjusting to a new normal, both physically and mentally”*

*“I felt when I was told the diagnosis that he (the consultant) had already had exactly the same conversation with other patients and it was just very matter of fact for him”.*

**Person-centred, holistic Treatment and care**

**Information and advice**

*“.. I felt physically sick thinking they might reduce my money. I had no idea what to do or who to contact. It was such a helpless feeling….. I had no idea where to turn”*

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# What we heard from you

## Communication

*“ I felt the communication about my diagnosis was poor and I had no-one else to talk to about my other health needs….”*

*“it is life saving…here I can be me, I don’t have to pretend….”*
*.. “ it is important I am in a room with people who are like me…”*

## Peer Support

*“..we don’t use the ‘C’ word because we are afraid if we say it we will catch it..”*

## Addressing barriers

*“My treatment was delayed for 3 months because the hospital did not book a female BSL interpreter..”*

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# COVID-19: impact on you

**Cancer related anxieties and uncertainty**

*"Missing a chunk of treatment is really unsettling…what if my cancer gets worse?"*

*"Stopping chemo feels like signing a death warrant"*

*"I feel so upset..I have spent so much money in that store over the years, but I feel like they couldn't care less about me now. They are just not there for me when I need them most"*

**Practical challenges and concerns**

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# COVID-19: impact on you

**Covid communications and guidance**

*“ I appreciate that we are a devolved nation, but as someone who is told they must shield, I would appreciate updates that are relevant to me..there is so much information and it seems like much of it relates to England only”*

*“I don’t know whether I am dying through loneliness or my cancer, but I cant cope on my own”*

**Emotional & mental health consequences**

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# What matters to you?

- Support for me where I am
- The right information at the right time
- Understanding and empathy

# Responses to questions and comments from the Cancer Voices webinar, 30th July 2020

Some of you asked questions using the ‘chat’ function during the webinar and we promised to respond to your questions and comments in our feedback to you after the event. We have drafted brief responses below, numbered just to make it easier to refer back to them, not to indicate any order of importance.

In some cases, we have **grouped similar questions and comments together** and provided a themed reply, and in other cases where questions were very specific, we have tried to add some general information to the specific reply to make it relevant to others too.

We are making sure the concerns you raised are **shared with relevant colleagues** as part of our ongoing work to make sure we hear and use your feedback to improve how we work across the organisation. We will also **continue to explore the issues your questions and comments raise** in our ongoing contact with you over coming months.

## Your comments and feedback on the webinar

Some of you used the chat function to provide comments on the webinar, and everyone joining us for the event was also invited to complete an evaluation questionnaire, where you could let us know your thoughts and feedback. We will take what you have told us on the day or via the survey to inform and improve future events and other ways of working with you.

Your **comments on the day** about the webinar were mainly about the webinar being a **welcome opportunity to stay connected at a time when we can’t meet face-to-face, as well as being a good alternative to live events for other reasons**.

In response to feedback from you, part of our commitment to you before Covid was to look for additional ways to connect, to include more online opportunities, as well as face-to-face events such as our conferences. We know that travel is not always feasible; that attending live events can be tiring; and that many of you have busy lives and prefer more “bite-sized” opportunities to connect. We were glad to hear from your comments that the webinar felt for some of you a more accessible option to stay connected. Our ongoing commitment to you is to find, with you, more and different ways to do this and we are looking forward to working with you more on this later in the year. This will include our commitment after your feedback last year to find more ways for you to connect directly with our CEO Lynda and other senior colleagues within Macmillan.

For now, as we all know, our work together will need to take place online but, ideally, our future programme of work with you will include a mixture of online and face-to-face activities.

One of the additional benefits of the webinar was that we weren’t limited by venue capacity in the same way we might be when coming together in person. In the past, we haven’t always been able to give places to everyone who would like to join us, which is disappointing for us all. It might interest you to know that, when this happens, we aim to offer places according to a balance of people who have been able to join us before and people who are joining us for the first time, people whose experience might not always have been included at past events, and a spread of representation from across the whole of the UK.

## Questions and comments on people’s experience and how it makes a difference

1. ***Q: “Interesting to hear the <u>feelings and experiences of those affected by cancer</u>. How are Macmillan using this feedback to help bring about changes that will improve care in the future?***”

Helen’s presentation during the event summarised some of the ways we are using your feedback and experience to bring about change. Your experience – and that of others living with cancer across the UK – is being used by teams across Macmillan in their work to influence governments and health services, plan services for people with cancer during Covid and in the future, provide relevant information and advice for people living with cancer etc. Please have a look at the notes in Helen’s slides (slides two and four) for brief information on this.

We know you want more feedback about the difference your experience is making and are working on ways to improve this so please look out for future updates which we will share on the Cancer Voices website or through newsletters over coming months.

2. **Many of you used the chat function to share brief comments about <u>your cancer experience and how you are feeling</u> now.**

Thanks to all of you who shared aspects of your cancer experience and what’s important to you now. What you said reinforced what we all know to be true: it’s important to have a **space to share your experience** of cancer, not just because it is so valuable in influencing services and treatment, but also in supporting ourselves and one another to make sense of our experiences, and share tips on what helps. Again, our ongoing commitment to you is to continue to work with you to find different opportunities and ways for us to stay connected.

Some of your comments mentioned the psychological impact of cancer or referred to the need for **emotional support**. Mental health and wellbeing will continue to be a focus of our work with you, looking at ways Macmillan can develop our support in this area and influence other service providers. Some of you have previously been involved in projects on this, and we be pleased to hear from anyone who wants to be involved in future work so please contact us at cancervoices@macmillan.org.uk if you want to know more when next stages are planned. For now, we encourage you to take a look at current emotional support options from Macmillan.

3. **Some of you also shared comments and feedback around <u>your experience of shielding</u> and of <u>appointments and consultation during the pandemic</u>.**

We’re aware from our engagement work across the UK during the pandemic that many of you have made your own **shielding decisions**, whether that is not to shield due to practical, financial or other considerations; or to shield even though you have not been specifically advised to do so, because of your ongoing concerns relating to your cancer or treatment.

We have been feeding back, and will continue to do so, your **experiences of shielding** across the organisation, to inform not only the Covid Hub on our website, but also our partnering and influencing work. There is still an opportunity to take part in some conversations about coming out of shielding to inform our policy work; if you would like to do this, please email us cancervoices@macmillan.org.uk.
Another key aspect of our current work is to influence the **restoration of cancer services**, including how appointments, consultations and other aspects of care and support are offered. Some of you shared in the webinar comments how Covid is also having an impact on things like Move More or similar sessions moving online, or how access to support has become even more difficult if you live in a rural area.

Our Chief Medical Officer, Rosie Loftus, and her team are working with people living with cancer and professionals delivering their care to **understand what is important to you** if you are having treatment now, or are being offered online consultations and we will pass on those comments you made on the webinar for that work. You can take part in the work too; to express your interest, email us cancervoices@mamcillan.org.uk. Our ongoing commitment to you in relation to Covid and its impact on people living with cancer is to continue to provide a range of ways to share your experience with us and to make sure that it is heard, inside Macmillan and out.

4. **Q: "Please make sure you also share the experiences of people coming out of shielding with the governments of the devolved nations**."

Earlier in the summer, we wrote to governments in all parts of the UK to make sure they were taking into account the needs of people who were advised to shield. As well as working with **representatives of the government** in England, we have met with the First Minister in Northern Ireland, the health minister in Wales and with civil servants in Scotland to communicate concerns over shielding to them. We have also been working in coalition with other charities on shielding.

We are continuing to work on shielding over the next few months, and the experience of people living with cancer is at the heart of what we're doing and saying on this. You may want to read a blog we've written which sets out the **'tests' we'll be using** to see if people who have been shielding are fully supported across the UK, based on what people living with cancer have been telling us over recent months.

We are keen to continue to hear from people about their **experiences of coming out of shielding**, or indeed, continuing to shield or self-isolate. We're planning some conversations with people who would like to share their experience of shielding with us, to help us shape what additional work we might choose to do about this, so if you would like to take part, please let us know by emailing us cancervoices@macmillan.org.uk.

5. **There were some other comments referring to the importance of Macmillan influencing all of the UK Governments**

Our influencing work is **UK-wide**. There can be variations in the way we do it in Scotland, Wales and Northern Ireland because health and social care are devolved in the nations, structures are different and the routes to influencing can also differ. This means that our work in the nations can sometimes be more targeted and go on different timelines and themes to influencing in Westminster.

We're also aware that some of you would like to be able to **lobby and influence your local MP or Local Authorities** and colleagues in Macmillan's Policy, Campaigns and Influencing Teams are currently looking at what's possible in terms of resources and toolkits to support you to do that.

Our Engagement Leads across the four nations send out **opportunities to be involved** in campaigning and influencing that are tailored to a specific area or nation and we will continue to send those details out in our UK-wide bulletins too, along with any opportunities to be involved in shaping or producing that work.

6. **Q: "Could you please provide me with a link to the Seldom Heard Groups Report?"**

The Seldom Heard from Groups report describes some of the work Macmillan engagement teams have been doing over the last year to reach out to, hear from, and work with different groups and communities. This and the other insight reports we referred to during the webinar, are working documents we use to shape what Macmillan does but they are not in a good enough state to share yet. But over the coming months we will be sharing information about what we've heard from different pieces of work (including the Seldom Heard from Groups report) over the last 1-2 years. We are in the process of summarising key messages from insight gathering to share with colleagues, and we'll share that with you at the same time via the cancer voices website.

## Questions and comments on involvement and ways of working together

7. **Q: "Will you be able to maintain your projects in user involvement given your reduced income"**

There are tough times ahead for Macmillan and other charities given the reduction in fundraised income. So, some investment - including some involvement projects - may need to be reduced or even stopped for now. However, as we consider options for making sure Macmillan can support as many people with cancer as well as possible in the future, we are committed to **ensuring the voice and experience of people continues to shape what we do**. At a time when cancer services are changing so rapidly, we recognise it is more important than ever that people with lived experience are involved in planning and decision-making.

We also recognise that many individuals and community networks want to work with Macmillan to make sure investments are made wisely, to achieve as much as possible to support others with cancer. Within existing engagement resources, over coming months we will focus on identifying the **strengths, skills, and experience you offer** and making sure involvement is as inclusive and influential as possible. There are some good examples of where 'asset-based' approaches are making a real difference to what can be achieved within communities and we look forward to exploring this further with you and your networks over coming months.

8. **Q: "Macmillan have withdrawn funding for user involvement in greater Manchester and Stockport Trust. This is very worrying - what does the future hold?"**

Macmillan's funding of the user involvement posts in Greater Manchester and Stockport was always planned to be for a fixed term. To make the best use of Macmillan's charitable funds, when Macmillan funds a role or post in a host organisation it is usually only for a **limited period** whilst the host organisation plans for funding the role/s directly themselves.

Macmillan initially agreed to fund the User Involvement Team at **Greater Manchester Cancer** for three years, and then extended funding for a further two beyond that. Greater Manchester Cancer have committed to continuing to fund user involvement themselves from now on, although it's not yet clear exactly what the structure of this or particular roles look like.

Similarly, in **Stockport**, Macmillan's funding of the User Involvement Coordinator post at Stockport NHS Foundation Trust was only meant to for a fixed period. The Macmillan Engagement lead for Stockport is currently working with the Involvement Coordinator and people living with cancer representatives to ensure the learning from their work is recognised, celebrated, and learned from by the Trust so that they will continue to fund the work.

9. **Q: "Would you look at a partnership with Healthwatch England (HWE)? As HWE have local Healthwatch organisations in every area and these are related to the local authorities. They did a survey of cancer services during the early part of the lockdown Support groups."**

We work with both local and national Healthwatch teams in a variety of ways, including sharing plans and working together to ensure the voice and experience of PLWC is influencing decision-making locally. We will continue to do so, including identifying with you who else we should be working with on specific initiatives as we get into the detail of planning next steps. In addition, across Macmillan we look out for and make use of information and evidence from a wide range of sources, including Healthwatch and other organisations linking to and reporting back on the experience of people living with cancer.

**10. Q: "No local opportunities in the South West? Will there be info on how to be involved in these Initiatives?"**

In the webinar, we provided a flavour of some of the activity that is happening throughout the UK, as time didn't allow for us to detail all of the local work that's taking place. Our regular bulletins are how we let you know about current and **local opportunities to get involved**, sent from your local Macmillan Engagement Lead. If you would like to receive these regular bulletins, please get in touch with your Engagement Lead in your area, you can find details here *(link go live awaiting update from one geography)*. You can also always email us with questions about our work with you on cancervoices@macmillan.org.uk

**11. Q: "How does this co-production group relate to the established Lincolnshire cancer co-production group run by Everyone?"**

The Every-one Co-production Network have received funding from Macmillan for the last 2 years to run a **co-production group in Lincolnshire**, to engage with local stakeholders and support delivery of the Macmillan Living with Cancer programme specifically in Lincolnshire. Macmillan's Midlands Engagement team have supported the group from the last two years, and can provide more information about the specific pieces of work that have been delivered. Please get in touch at cancervoices@macmillan.org.uk if you would like us to put you in touch with the Midlands team to find out more.

This webinar brought together people with lived experience of cancer from across the UK, and we hope that co-production will be of interest to many of you (as it is to us!) as we move forward. The work that Macmillan did with Everyone is specific to Lincolnshire, but the learning that comes out of it and other projects will inform development of our **future co-production activity across the UK**.

We want to work closely with you and others to *jointly* design future involvement approaches, including finding new and better ways to amplify the voice of people with experience at a UK-wide level. It's likely that we will have different groups across the UK working on different projects, according to where people's interest and experience lies. We anticipate our work with you on these projects will add to our understanding of what works for Macmillan and you in terms of co-production, as there isn't one fixed model for working in this way.

## Questions and comments on Macmillan priorities and investment decisions

**12. There were a couple of questions about equality and diversity, including some reference to specific communities, and about whether those at the top of Macmillan are committed to inclusion.**

Helen's presentation (slide number five) included the **five commitments** Macmillan has made on Equalities, Diversity and Inclusion. These commitments come from the top, and there will be a significant focus at all levels of Macmillan about what needs to happen to make progress on these ambitions.

During the webinar we spoke about the fact that Macmillan – like many organisations – is taking a long hard look at what we need to do to improve our performance in this area. Within our People and Community programme, we are committed to **increasing the diversity of our networks** and ensuring the voices of people from all communities are heard loudly and clearly across Macmillan and in our influencing work more widely. We recognise we can only achieve progress by reaching, hearing from, and being more relevant and accessible to diverse communities and want to work with you and your networks to agree priorities and achieve real change.

**13. Q: "Is there a lived experience champion on the Macmillan Board?"**

Currently there isn't. And we, as engagement leads, have flagged this as one of the governance challenges we want to further consider within Macmillan. Different charities approach accountability and governance issues in different ways and we aim to learn from best practice elsewhere and involve colleagues and people with lived experience in considering options. Much is already being achieved to ensure your experience shapes what we do and say, but we know there is more to do to increase the visibility and influence of people with lived experience throughout the organisation.

**14. There were several questions about the detail of what Macmillan is funding, how much we spend, including what we are doing to reduce inequality in services we provide across the UK and to ensure that learning from pilot services is not lost.**

Macmillan's annual report for 2019 includes an overall **summary of our services, influencing and campaigning activity, and spend** last year. It's difficult to give you accurate information on the current funding of specific services because of the need to change plans to respond to Covid, and it is also difficult to report the detail of spend on individual projects or roles at local levels. However, the 2020 annual report will provide as much detail on our services and spend as possible at a later date.

We are aware of **inequalities** in how people experience cancer services and outcomes, and our engagement work is an important ongoing part of highlighting and understanding these issues. One of the organisation-wide commitments mentioned during the webinar is to 'make tackling inequality – including racial inequality – a core goal for every service we provide for people living with cancer'. As part of the work to address Equality, Diversity and Inclusion there will be reviews of Macmillan services to understand where inequalities exist and what can be done about them.

We know that there is a lot we need to do to improve how we communicate what is happening to **pilot services**, and the learning that comes out of them. Our commitment to you is to keeping thinking together about ways of working and how we can embed your experience of accessing pilot services throughout delivery and evaluation and keep you involved and informed when pilots end and services change.

**15. There were several questions about the Macmillan Telephone buddying service, including how you can apply to be a volunteer buddy and what our plans are for promoting the service more widely.**

To ensure we offer the very best experience to both people living cancer and individuals who wish to give their time, we have taken the decision to pause recruitment of any further Volunteer Telephone Buddies. We are currently managing the demand for volunteers and client take up and will look to offer this opportunity again in the future. Until this time, please keep an eye out on the Volunteering Village for updates on this and to see if any other volunteering opportunities are of interest to you.

If you are someone who would like support, find out more about the Telephone Buddy Service.

16. **Q: “What is Macmillan doing to look at the different issues affecting those who work (whether self-employed or employed) and those who are retired... as financial pressures may be quite different.”**

We know that a cancer diagnosis can also bring a significant financial impact, as people face extra costs at a time when they may have to cut down or stop work. We have been **campaigning** for years to raise awareness of these issues and ensure people facing financial difficulty get the support that they need. Macmillan also has a range of services which work to ensure that people with cancer get support to manage their financial commitments (e.g. from their bank or insurance provider), that those who are in work know their rights and get support from their employer, and that those who aren’t able to work get access to the benefits they are entitled to.

During the pandemic our influencing teams have worked closely with Macmillan’s services to understand the issues people with cancer are facing, and to raise these with **Government ministers and decision makers** where relevant. This has included access to benefits and Government support schemes, such as the self-employment grants and the furlough scheme. One of our key priorities for influencing this year is to ensure adequate support is in place to prevent people who are facing the combined financial impact of cancer and the Covid-19 pandemic experiencing financial hardship.

**17. Q: “Are you finding that there are more stage four diagnoses since last year?”**

It takes some time to get a full picture of the number of people who have been diagnosed with cancer and, for some cancer types, what stage their cancer was diagnosed at. We work with cancer registries across the UK to make sure we have the latest data. It is **too soon to be able to say** that more people have been diagnosed at a later stage in 2020.

Our concerns during the pandemic are that people might be reluctant to visit their GP if they had a possible cancer symptom, and so wouldn’t then be referred for diagnostic tests. People also haven’t been invited for screening during the last few months, and there is reduced diagnostic capacity as it can take longer to do some procedures, like an endoscopy. These factors mean that it is possible some people haven’t been diagnosed when their cancer was at an earlier stage, and it could have progressed during that time. Our **‘Forgotten C’ campaign** to make sure the NHS has everything it needs to get cancer services back on track is trying to stop that happening – so that tests and treatment happen in a timely and safe way.

**We hope this information is helpful, and look forward to continuing to involve you in improving Macmillan’s services, support, influencing activity and campaigns,**

**Holly, Matt and Helen**