

Health and Social Care Committee

Oral evidence: Future cancer, HC 1250

Wednesday 21 June 2023

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Members present: Steve Brine (Chair); Paul Blomfield; Paul Bristow; Mrs Paulette Hamilton; Rachael Maskell; James Morris.

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Witnesses

I: Anna Jewell, Chair, Less Survivable Cancers Taskforce; Jane Lyons, Chief Executive Officer, Cancer52; Michelle Mitchell OBE, Chief Executive Officer, Cancer Research UK; and Gemma Peters, Chief Executive Officer, Macmillan Cancer Support.

Examination of witnesses

Witnesses: Anna Jewell, Jane Lyons, Michelle Mitchell and Gemma Peters.

Chair: This is our second meeting in as many days, and it is even hotter than it was yesterday. This is the first public evidence session, which we are very excited about—everything is relative—into our “Future cancer” inquiry.

The aim of this inquiry is to raise our gaze to the future of cancer, both its detection and its treatment. This oral evidence session has some fantastic leaders of the cancer sector and, hopefully, you are going to set the scene for the inquiry. The purpose is to explore the direction of travel in improving the outcomes and the experience of cancer, understanding what patients might want and expect from cancer services in the future—obviously, all of you interact with service users regularly—and to identify the principles that will underpin innovation in cancer care.

We have heard from a lot of organisations and individuals already, kicking off this inquiry, and I am grateful to all your organisations for responding to that. I will introduce our panel. We have Jane Lyons, chief executive officer at Cancer52; Michelle Mitchell OBE, chief executive officer at Cancer Research UK; Gemma Peters, chief executive officer at Macmillan Cancer Support; and Anna Jewell, chair of the Less Survivable Cancers Taskforce.

We should declare our interests first. As is well known, I used to be the cancer Minister and I worked with three of the four of you during that period of time. During that time, I launched the Less Survivable Cancers Taskforce, and obviously I have met with you all subsequently and since. So my interest is declared, and my love for this sector, and the desire for it to do better and better and better. Are there any other colleagues who wish to declare interests?

Paul Bristow: My entry in the Register of Members’ Interests is clear but I want to add to that that, prior to becoming a Member of Parliament, I had a PR and public affairs healthcare agency and, during that time, we did some pro bono work with Jane Lyons of Cancer52.

Q1 **Chair:** If no one else has any interests to declare, we will get started. For those watching, we are probably going to have some votes in the House of Commons shortly, at which point we will suspend the Committee and carry on again afterwards. I do not know whether they play hold music during the suspensions, but I would like to see that—perhaps footage of the gates opening at Glastonbury, which is what is going to happen today. There’s an idea.

Michelle Mitchell: Or maybe the first wicket at the Ashes.

Chair: Or the Ashes, yes. Let’s start with you, Michelle.

Michelle Mitchell: I should not have made the joke.

Chair: No, you shouldn’t—you drew attention to yourself.



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Q2 Chair: What I want to understand is your vision for what future cancer looks like in this country. We all know about the ongoing challenges, and so far, in my short tenure as Chair, this Committee has had Cally Palmer and Peter Johnson in twice to go through the absolute detail on where we are on 28 days and 62 days; and we will touch on all of that today, I promise. But I would like to get a sense from you in your opening remarks of what the vision is for where we will be in 20 and 30 years.

Michelle Mitchell: What we want as a country is to be world-leading, not world-lagging, in cancer survival. To be enabled to do that, we have to retain our position as a global leader in science and cancer research. We have significantly to speed up our ability to translate science, innovation, and diagnostics to patient benefit as quickly as possible, and we need an engaged citizenry who come forward with signs and symptoms. Of course, underpinning that is an NHS free at the point of need, which is delivering for everybody who has cancer. What we want to do is to organise ourselves as a country, as a charity sector and as the NHS to deliver on that goal and on that vision.

Q3 Chair: That is fantastic. Gemma, from Macmillan, Michelle talked about partnership between Government, the third sector, NHS and the public. What would be the vision that Macmillan has for where we are going?

Gemma Peters: We really welcome this focus, the future focus on cancer, and our thanks to all of you for thinking about it. We share the view that focusing on cancer is really important because of how many people will be affected, but it is also important because cancer has always been a comet of innovation, whether innovation in medical science or in care; other diseases get carried forward if we get innovation in cancer right. All of us share a real appreciation for the area that you are looking at.

Of course I am really supportive of everything that Michelle is doing, and we work closely together. From a Macmillan perspective, we will always want to have the person with cancer, human-centred thinking, right at the heart of any innovation. Some of you might be familiar with the idea that, with innovation in medicine and surgery, one of the things that the team does, if you are about to go into surgery, is to get around the table and try to anticipate what might kill the patient in the surgical procedure, and essentially do a pre-mortem. It is really important to touch on what you said earlier: let's understand what is happening in the system right now, in order that we are able to predict what might fail in the innovations that we are going to come on to talk about.

Macmillan is very engaged at the moment in the impact of waits and you will see in our "What are we waiting for?" campaign quite how important that is. From a Macmillan perspective, there are three tests that we think about, as we think about innovation going forward.

The first is whether it is deliverable. Can we deliver it? When we think about that, we think about the staff, the skills, the capability and capacity in the system to deliver the innovation. We can all think of amazing



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examples where an innovation that already exists has not been adopted, so we think about delivery.

Secondly, we think about reach. Have we designed for the most vulnerable first? Have we really thought about how it will reach everyone, because inequity is an area that all of us are very concerned about? When we think about innovation, we have an equity test.

The third test is about support for patients. Who is it, in whatever the innovation is, and how will we wrap support around patients so that they are able to understand what this means for them, so that shared decision making can work effectively? I know that we will come on to talk about specifics, but actually understanding what it will mean, and then allowing everyone to take advantage of whatever that innovation is, are the things that we think about.

Q4 Chair: That is great. Anna, you also work with Pancreatic Cancer UK and, as I introduced you, with the Less Survivable Cancers Taskforce. Nowhere is it more important than in the cancers that you represent for us to somehow get ahead of the game and get upstream of symptomatic detection. As somebody who has lost a parent to pancreatic cancer, I know how it is not symptomatic until it is lethal. Is the GRAIL trial and what the Galleri trial promises the future?

Anna Jewell: Thank you for this opportunity to talk to the Committee, and I echo the points that Michelle and Gemma have made. I represent, as you said, the less survivable common cancers, which are brain, oesophageal, pancreatic, liver, lung and stomach cancers. Just to remind you, those are 25% of the cancer cases diagnosed each year and round about 40% of those who die from cancer each year. We have an average five-year survival rate of just 16%, so these are devastating cancers to be diagnosed with, at the moment, with far too short a prognosis. For pancreatic cancer, for example, half of those diagnosed die within just three months. We know, as you rightly said, that early detection is a huge issue for patients diagnosed with less survivable cancers. Vague symptoms are a huge challenge, and we need to see innovation in that area if we are going to help to get people diagnosed early enough to have treatment and survive longer, as we look ahead to the next 20 to 30 years.

We definitely think that GRAIL is a big opportunity, as it can help in terms of diagnosis. We also think that new opportunities like the roll-out of lung cancer screening could be hugely important, and there are other exciting innovations on the horizon such as breath tests being developed for pancreatic, oesophageal and stomach cancers, and blood tests being developed, like GRAIL, for brain tumours and other cancer types. It is hugely important that we look at those innovations, to see how we can track them and get them into the system as quickly as possible. I think, as you rightly said, that the vague symptoms make it very challenging for primary care to pick up and detect these problems and these cancers. So we need to look at the potential for case control studies to try to pick up these cancers earlier, look at the opportunities that AI offers, and look at



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the opportunities, as I said, of the new tests, if we are really to help these cancer types to catch up and take the leap forward in survival rates that we really want to see.

We do not want another 50 years without seeing an improvement in survival rates for these cancer types, and, at the moment, we cannot really see where the transformational effort is going to come from. We can see small improvements on the horizon. Things like optimal care pathways being introduced could really help to ensure that people get better treatment, but without research investment, prioritisation and a focus, which is something that the Committee previously recommended for the less survivable, rare and less common cancers, we will not see the progress that we need when we look ahead.

Q5 Chair: That is a good opener. Finally, Jane, you represent Cancer52, with about 100, largely small, patient support charities, so your patient interaction is huge. When you lift your gaze to the future of cancer, presumably for you it is about support for the patient and those who live with cancer, as much as it is about detection. Is that a fair characterisation?

Jane Lyons: I think it is fair, but perhaps I could do a bit more context-setting. We do indeed have more than 100 cancer charity members, all working on rare and less common cancers, so we are delighted to be here as well, at the beginning of a debate about the future, innovation and anything else that shapes that. It is essential that those smaller numbers and the rare and less common cancer charities are in the room from the off, and, very often, they are the second ones asked, so I am delighted to be here from that point of view.

To back what has already been said, we are aware of some innovations that are starting to work in early diagnosis of rare and less common cancers: we need more investment there. We support the general view that we need to ensure that there are the people and the scope to deliver that. Having said all that, that is all critical because, as you have already pointed out, Chair, if this works, it makes for a very different patient experience, hopefully. That is the target, isn't it: to see that, if you are somebody who has a rare and less common cancer, in five, 10, 15 years' time—however fast we can shift it—the experience is a very different one from the one that is currently being faced? That is true for people from different backgrounds as well; we need to encompass both the inequalities in health deprivation and what is able to be delivered in rare and less common cancers thus far.

What are some of the key points in that? Obviously, for a person who is a patient in five years' time, everybody will have heard of their cancer, so they don't have to explain it to one and all. Their diagnosis path was quicker and easier, even though perhaps they had very vague symptoms, but the ad campaigns had continued so they knew to go to the GP and do something about it. They found that their GP was very receptive and supported the general drive through to referring quickly, into maybe a CVC. There were lots of tests which came back quickly, so the cancer was



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found really quickly, and then they knew where to get the best care. CNSs were in place. There was somebody at the hospital who could explain things to them. The charities in the sector were well supported so they had somewhere else to go where they could talk to people. Also, new treatments were getting through. We always get to this point. Are the new treatments that have been approved getting everywhere? Can I get them anywhere across the NHS, they are all free, and there is not a patchwork of delivery?

We need to look at a point where there is hope and scope and a better potential outcome, almost regardless of what comes out of that cancer diagnosis, but at least to have had the opportunity to go through those pathways with understanding and support as good as it can be.

Chair: Great. I am going to bring in some colleagues now, but at some point later on I want to ask you: what is the most exciting innovation that you are aware of—the apple of your eye in that respect?

Q6 James Morris: You have all spoken about the importance of innovation. This is a very fast-moving area from the scientific and research point of view. The UK has many advantages; we have good scientists, and so on. In order for your visions to be realised, we need to overcome some of the barriers to getting some of the new treatments operationalised in the system, as Jane Lyons was talking about, getting new clinical pathways opened up. I am interested to understand what you think are the key barriers to innovation and moving towards that vision. Michelle, maybe you could start.

Michelle Mitchell: I want briefly to pick up your point about innovation, science and research. When you look at some of the biggest innovations that have happened, the biggest impacts we have had on cancer survival—not least in relation to cervical cancer and the HPV vaccine, and screening of course—have come from science and research, so a number of areas are worth considering.

I suggest that because you can leapfrog a number of the barriers if we have the transformation in science and research. One is around deepening our understanding and use of precision medicine, which is absolutely critical. We are now able to look at the genetic make-up and molecular characteristics of cancers, how they spread and how they develop, meaning that targeted treatments could be available for each and every one of us, within a 10-year period, for certain types of cancer.

I am sure we will get into AI in cancer, and its role in detection, diagnosis and improved productivity. We have also developed, in more recent years, much greater prediction capabilities about how cancer evolves, how it hides and how it resists treatment. Of course, the Chair mentioned multi-cancer early detection. One example is blood, but we have also heard about breath tests and urine tests. All of those, in innovation terms, give us the opportunity to leapfrog some of the current challenges in the system.



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Q7 **James Morris:** But where do you think the blockages are?

Michelle Mitchell: There are a number of current blockages. One is the amount of funding there is for research. The King's Fund identified that less than 1% is available for the spread of innovation within the NHS. A huge blocker in both cancer waiting times and performance innovation is having a workforce in place to keep the system running and to enable it to transform. Capital is required to turn scientific discoveries into new tests, new treatments and new diagnostics, which are then taken up quickly in the NHS. We know that we face a gap of 10—and sometimes 20—years between adoption and implementation. Finally, we have huge, unwarranted variation across the country, where both the adoption of innovation and who benefits from that innovation is really not good enough.

Q8 **James Morris:** Gemma.

Gemma Peters: Maybe I can build on that. I agree with everything that Michelle said. From a Macmillan perspective, we have an innovation impact bond, which is essentially areas where we invest in innovation in the system, and have done for many years. Some of that comes from NHS colleagues who have ideas, and we assess them against pre-criteria on patient needs. Some of them come from the commercial sector; it comes from all over the place. There is no shortage of innovation.

There is a real problem with adoption. The barriers are, exactly as Michelle said, around workforce—the kinds of skills, capabilities and capacity of people to be able to implement change. We have submitted some of those in evidence; there are numbers of examples where, if we could just get the thing that works really well in the south-west working everywhere across the country, we would make a transformational impact. There are also technology barriers that make it difficult for things to be adopted.

Q9 **James Morris:** Do you think that there are cultural barriers in the UK to adoption in the NHS? Do you think we have a particularly conservative with a small “c” approach to adoption?

Gemma Peters: I think there is something, isn't there? We all think of the NHS as though there is some button you can press and things get pushed out. Part of the challenge is that the local contexts are so different, and decision making is so different, that the ability to roll out is really challenging and organisations like ours end up spending lots of time trying to work out where the right decision maker is, where the right lever points are, to persuade someone that this thing, for which there is really good evidence, should be adopted. I think that in that sort of lack of join-up on adoption of innovation you have identified a real challenge.

Q10 **James Morris:** Anna, I think you said that, in relation to things like artificial intelligence, we do not want to wait for 50 years before there are positive outcomes. That is an example where the UK could get left behind if we do not have a particular approach to adoption. We recently visited Stanford University, where we saw AI in practice, in chest X-rays and so



on. What was going on was quite extraordinary. How do you think that we do not get left behind?

Anna Jewell: It is really important that we look at the opportunities for this, in terms of how we bring in innovation. I come back to your point about whether we are a country that does not want to adopt things. At Pancreatic Cancer UK, we are working with a lot of clinicians around how we can improve and speed up the pathway for pancreatic cancer, because we know that speed is of the essence. We can see big barriers in the areas we are talking about, such as access to scans and access to people with the ability to read scans, and there are real workforce issues.

It is about looking at how we can embrace some of what AI might offer to help with some of those challenges, and how we can get creative with them so that we can bring in innovations, where we see that they can make a difference. For far too long, we have seen some challenges with people going back and back again to their GP with symptoms of cancer.

It is 11 years ago today since my dad died of colorectal cancer. He had to go back and back to his GP to get a diagnosis, and we are still in that position 11 years later. We see it for pancreatic cancer. We see it for brain cancer. Often, people are going back and back to their GP with vague symptoms, but there must be ways that we can look at combinations of symptoms and use new technologies to help us to pick up those most likely to have cancer, and then, hopefully, to apply some of the new tests that are coming through, such as breath tests or the Galleri test to help us triage patients. But it comes back to the workforce—these points have been made before—because we need the workforce to implement the innovations.

Q11 **James Morris:** Jane, do you have something to say about this challenge?

Jane Lyons: I do indeed. I support all the comments on workforce in particular. There are a lot of good innovations, or things on pilot or on trial, that could speed up, particularly in the early diagnosis field, and a good number of those are in rare and less common cancers as well. In particular, in rare and less common cancers where we hear from patients a lot, it is broadly about people knowing more about their cancer, which is the awareness thing, right through from health professionals to the public and being able to have those conversations more openly and being able to push on. What is happening a lot also in the less survivable ones is that, if you have to keep going back and back and back, you lose people along the way. We need to keep investing in making sure that people know more about these cancers.

The charities in our membership play a critical role in that because they are often the ones advising patients about new drugs that are available and how to talk to their clinicians about those. I second Gemma's point that it is not "the NHS". You probably have to work at every single level. There is a new treatment coming out. How long is it going to take to reach somebody in a less heard or seldom heard group as an actual



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treatment? That is a real challenge. Investment support on cascading information about treatment awareness is critical, and that can be done only with investment in the workforce as well.

Chair: Right, we are going to bring in Paulette Hamilton.

- Q12 **Mrs Hamilton:** I have written down my question, so it will be quite succinct. We have talked about cancer care being more personalised, more targeted and less invasive. The Government stated that they were “committed to publishing an NHS Workforce plan for the next 15 years, covering doctors, nurses and other key professionals.” It should have been published in spring this year, but it has not been, as yet.

The question I would like to ask you is: what would you like the Government to consider re a future workforce plan, taking on board my original comment about cancer care being more personalised, more targeted and being less invasive? What would you like to see in the future workforce coming on board. I thought I would start with Jane, then Gemma and Michelle. If I only get two of you, I will be really grateful.

Jane Lyons: Thank you. I am not going to be able to do this in huge detail, but I know that there has been an awful lot of work trying to estimate how many of the different types of cancer disciplines, be it oncologists, radiotherapists or whatever, would actually transform the workforce into something that could deliver what is needed by the nation. I cannot remember all those, but I am happy to follow up on that. I think the original plan was that there were seven disciplines that really needed focus. From a patient perspective, those are about the expertise that gets through a pathway at some speed.

- Q13 **Mrs Hamilton:** I am more interested in what you feel, from your perspective, for patients.

Jane Lyons: To put it in context, from our perspective, what keeps coming up is the CNS route—the clinical nurse specialist. We should have a bigger proportion of clinical nurse specialists who know about rare and less common cancers. My understanding is that, currently, there are about 3,500 clinical nurse specialists in the UK. I am not sure whether that is England or the UK. Most of them are in the four more common cancers, which is completely understandable, but we need to build access to expertise for people to know about their cancer. From a personal point of view, and a patient point of view, we think that those are the people who help.

It is not just clinical nurse specialists; we have an increasing amount of feedback to show that the admin teams often know the patient better as well, in terms of booking. People booking in at different times is incredibly disruptive. In the patient-facing bit, obviously you need professionals, but you also need that human interaction with nurse specialists, admin and the support you can get—I will say it again—from the charity sector.

- Q14 **Mrs Hamilton:** I am going to go to Gemma. The reason I would like you



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to answer next is that I was a district nurse, and I know the value of a good workforce in this area.

Gemma Peters: Exactly.

Q15 **Mrs Hamilton:** Because you come from the Macmillan perspective, I would like to hear what you would like to see.

Gemma Peters: I feel like the answer must be district nurses.

Paul Bristow: She can come again, can't she?

Chair: You read her well.

Mrs Hamilton: No, no.

Gemma Peters: Thank you for the question. It is absolutely essential to everything that Macmillan worries, campaigns and talks about. I sense your frustration that we have not yet had a workforce plan, and I share it. Actually, Macmillan has just done a piece of work that was not ready in time for written submission, but we will submit it afterwards, which is looking at the future cancer pathway, because what you identified is so right. You put the patient in the middle, and all these exciting things that we are talking about mean that the pathway becomes much more complicated than it is now. The pathway already feels pretty tricky for lots and lots of patients going through cancer care. Exactly what that piece of work does is to identify 12 areas in which the pathways are likely to change and what that means for patients, and we shall certainly send that in.

When we talk about the workforce, to me, that means everybody who needs to wrap around a person with cancer in order to make their experience the best that it possibly can be. That includes clinical staff but not only clinical staff: non-clinical staff play a really important role in navigation. It is not just people in an acute setting—I am not just saying this for you, Paulette; the community setting is just as important.

In the work that Macmillan funds, as you know, a holistic needs assessment is a really important part of how we understand what is important to a patient. You can do a holistic needs assessment in an acute setting and you will get one set of answers. If you ask exactly the same question of the patient—the question is, essentially, “What matters to you? What do you need?”—in a community setting you get a different answer, and it often blurs into things like housing, financial support and child care. That stuff really matters not only for someone's physical and mental health outcomes but for their experience, how they and their family feel going through it. When we think about the workforce, my urge would be to think about them in the whole. Who are the professionals who need to wrap around someone with cancer to help them?

Q16 **Mrs Hamilton:** I am sorry about this, Chair, but I am absolutely into this. The quote for me is that the family are key here. I will come to you, but what do you feel that we need to do for the family, because



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sometimes—I am not going to answer it for you. What do you feel we need?

Gemma Peters: The family are so critical. We see it all the time, and I know that my colleagues alongside me will feel the same. The numbers of people who call the Macmillan support line, thousands of them a day, are often family members, rather than patients. Often, particularly at difficult times it will be the family member who is the carer, or the person who is able to articulate something or who is worried about something, or, I hate to say it, who is having to fight and advocate for the patient because they cannot do it for themselves. They are too sick or too tired of having to fight the system to follow up the appointment or get the information that they need, and all the things that people are experiencing. It is thinking, exactly as you say, about the unit, and how we support people.

There is another bit I want to bring into it. A few weeks ago I was spending some time with some of our services and met a woman who had missed two of her chemotherapy appointments. It transpired that the reason she had missed them—a Macmillan community nurse identified this—was that she was a single parent with two children under six; she didn't want to take them to chemotherapy with her because she didn't want them to see that and she couldn't find anyone to look after them. No one had asked the question and understood what she needed, but a relatively simple intervention was able to unlock both her physical and mental health. It is the family, and who is around you and who isn't around you—who can't we see. I worry all the time about people who are on their own going through cancer treatment, who do not have a network.

Q17 **Mrs Hamilton:** I know the Division bell has gone, but, lastly, we have talked about all the creative things around cancer and treatment, so I would like you to say a little bit about the workforce that goes along with that.

Gemma Peters: Key.

Mrs Hamilton: I absolutely agree with you. You sort of skipped over workforce, but they are key to any innovation going forward.

Chair: Hold that thought. Never has someone had so much notice of a question.

The Committee suspended for a Division in the House—

On resuming—

Chair: Last time on Health and Social Care, we were discussing workforce as the start of our "Future cancer" inquiry. We have just had some votes in the House of Commons. Paulette Hamilton was mid-flow and cruelly cut off in the middle of her questions, but she will be back later and will resume them. In the meantime, the York MP Rachael Maskell is going to pick up the baton.

Q18 **Rachael Maskell:** First, thank you all for coming in and opening the



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inquiry today. You have already given really powerful evidence. Thank you for that.

I am going to look at inequalities. Obviously, this is a major issue where, clearly, the data shows significant inequality, particularly around socioeconomic disadvantage but around certain protected characteristics. Michelle, how are we going to address the inequality around cancer in 20 years' time? Are we going to have equality for all?

Michelle Mitchell: I very much want to ensure that everybody benefits from the amazing science, new tests and treatments that are available, because we will not beat cancer unless we beat it for everybody. As you say, 20,000 cancers alone are a result of deprivation. People often do not make that connection, but I suggest that one of the ways we could innovate is by innovating policy.

We know that one of the single biggest drivers of cancer inequalities is lung cancer deaths through smoking. We want to see this Government, or any future Government, be incredibly bold about making it much harder to start smoking and much easier to stop smoking. It may not be as shiny and exciting as precision medicine and AI, but it is one intervention that could make a huge difference.

Q19 **Rachael Maskell:** I will turn to Jane next. Obviously, the causation of cancer is complex. Sometimes it is hereditary, sometimes it is down to lifestyle and sometimes it is genetic and there are other reasons. We are still learning. In the light of that, and with three national screening programmes at the moment, how far out can we push screening to ensure that there is an inclusive screening programme? What should we be doing?

Jane Lyons: To go to your broader question first, about addressing inequalities at every stage of cancer care, but obviously starting with screening and then diagnosis, what we have to learn to do, given that an early cancer diagnosis is one of the core aims of the Core20PLUS5 campaign—the health inequalities drive coming out of NHSE—is to work out how we align the information that we all hold about cancer, or our charities or our people do, to ensure that we are working with that team to try to reach the seldom heard groups.

What that means is that people are hearing information. There is no point in us just putting out information to people who are not in a receptive mode or find that it is not delivered in an appropriate, culturally competent way. It is trying to support the information going to those people by going through trusted confidantes or connectors or whatever else it is. I am a firm believer in trying to link up expertise in reaching communities with the expertise that we have within the cancer world; to which point, getting people to attend screening would fit into that broader picture as well.

There is no point in somebody you do not trust, you do not like, or you do not understand what they are on about, trying to get you to do something you do not want to do, because, for your culture, it means



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opening yourself up. Why put yourself up for a cancer test? If you get cancer, it is not going to be good news. There is a lot of translated work to be done there. I think it needs further investment in the equalities programme and linking up those areas of expertise with those who are already working in that field.

Q20 Rachael Maskell: Anna, part of prevention is around education. Where do you think education is best placed and how can that be used around addressing the inequality that we see today?

Anna Jewell: It is really important that we have national cancer awareness campaigns that can help target the public, raise awareness and get people to come forward and recognise symptoms. That is really important. That needs co-ordination, both to look at whether we are putting out signs and symptoms of different cancers, not just the most common but those less survivable and less common, and looking at a combination of vague symptoms and how we put those out in national awareness campaigns. It has been good to see some of the “knowing what’s normal to you”-style campaigns from NHS England.

We need to look at targeting those in particular areas where we can see inequities. The cancer types that I represent are in more deprived and socioeconomically deprived areas. We see higher rates of those cancers. We need to be using data more cleverly to think where to target awareness campaigns. Are we targeting them at places where there is higher incidence or higher mortality in order to make a difference? We need to combine that with education and tools for primary care, for nurses to recognise the symptoms where they come through. It is that combination of efforts that is really needed, and getting people to raise awareness.

As Jane was saying, we need to think about getting the messaging right for different groups, making sure that they are aware of the benefits of coming forward for screening and tests and of going to their GP. At the moment, with some of the workforce issues, people are worried about how long it is taking for them to get through into primary care. I know you asked about education, but one of the challenges we have at the moment is that, even when we raise awareness of symptoms, people are not sure how to get through to the GP practice sometimes. They are not sure when they should be going forward. We still see far too many people diagnosed as an emergency presentation for our cancer types when, often, it is too late for any treatment.

Q21 Rachael Maskell: Building on that, I am really conscious of what you were saying at the beginning: many people you represent will only have three months to live because they are presenting late. We know that, with people in lower socioeconomic groups, 50% have a late presentation as it is. Life expectancy can be incredibly limited for those individuals. Rather than going to your GP, should there, for instance, be a separate pathway and an “If in doubt, check it out” kind of thing? I certainly know among my constituents that people’s expectation now is that to see a GP could be a month. If you only have three months, that is a third of that



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time gone. Should there perhaps be specific pathways or routes to get rapid referral?

Anna Jewell: We have been really interested to see the work that has been happening with rapid diagnostic pathways and pathways for vague symptoms that people can go on to. At the moment there is still referral through primary care and GPs, but I know there has been interest in whether there could be more self-referral and what that might look like, and how you could help triage people into that system. At the moment, yes, we need faster ways to get people through into treatment. We cannot be waiting as long as we are at the moment. We are missing the opportunity for people to have treatment that could either lengthen their life or help them survive and get the treatment they need for long-term survival.

Q22 **Rachael Maskell:** Michelle, do you want to come in, and then I have another question for Jane.

Michelle Mitchell: Very briefly, as I am sure colleagues will want to come in, yes, let's look at what the evidence is around self-referral. In addition to the issues talked about, for example, we have what we call our cancer research UK roadshows. We identify the areas in the country of highest incidence of cancer and the highest rates of deprivation and go into those communities with trusted nurses. What we have learnt through the covid era is the importance of gaining the trust of local communities and local community leaders and taking the message into those communities through trusted sources.

Secondly, there is a role that charities play as a source of trusted information. We have 30 million unique visitors to our Cancer Research UK website. We have 17,000 people who come to our helpline. Civil society in the charity sector is an important part of building trust with citizens and reaching seldom heard groups.

Q23 **Rachael Maskell:** Jane, you wanted to come in on that.

Jane Lyons: Just very briefly to support Anna. Michelle has covered much of it. There is now a lot of targeted work going on in early diagnosis, where people are being sought out rather than waiting for them to come forward or make that leap themselves. I think it is important to support them because that makes a big difference.

There are partnerships between charities and NHSE amplifying the campaigns that they are already doing, and then taking them out into the community and reaching out to people. I think the words "targeted", "reaching out" and "seldom heard" all need to play into this. They will apply to both local communities and deprived communities—the less heard people. It is much the same point.

Q24 **Rachael Maskell:** That is a really important thing. Gemma, I know you want to come in with your own points, but what is your message to Government, to NHS England and to ICBs as to what they should be doing now?



Gemma Peters: On inequalities specifically, it is important that we think about them in the context of future excitement about innovation. What we have learnt through covid is that, actually, things that can be great for some bits of the population and move very quickly can exacerbate inequalities. It is incumbent on us as we think about the future to think about how we can design for that from the beginning. How do we make sure that from the get-go we are thinking about who are the people who need to benefit the most from this, and not to design for the masses and then see if we can retrofit away and broadcast it slightly differently? That is really important and would be one of my messages.

To build on what Michelle was saying about community work, if we are serious about tackling inequalities, often the point of diagnosis is too late. There are lots of players who need to take a much more active role in this. How can we ensure that, collectively, we build trusting relationships with communities which we know, for a whole variety of health outcomes, not just cancer, are likely to have a worse experience? They are less likely to access a clinical trial and more likely to be diagnosed late or turn up in A&E. They are more likely to have a delay in their appointment or delays in their treatment than other people in the community.

Q25 **Rachael Maskell:** They just don't have agency in the same way.

Gemma Peters: Exactly. We all know that, if you have sharp elbows at the moment, you can fight your way through the system and get what you need. If there is anything in your life that means your elbows might not be as sharp, you are less likely to get it. What I would come back to is the model of how we wrap around an individual what they need.

There are already great examples of that. Work that Macmillan funds in Glasgow, for instance, has made a massive difference in how deprived communities access cancer support. It goes to people and talks to them about what their needs are. Their needs might not be physical. They might be, but there might be other things that allow that person to get the very best of what is available to them at that moment through support around navigation.

We didn't talk about this. Michelle is going to come on to workforce issues, so she might well talk about it in her answer to Paulette. We should be thinking about navigation roles that need to be people who can get alongside people and help them to navigate a complex pathway. That is really important.

Rachael Maskell: Thank you; that is really powerful. As we go through our inquiry it will be important to think about access with regards to that demographic equality issue at the core.

Q26 **Chair:** Thank you, Rachael. Can I pick up something you said, Jane, about people being sought out? I was in Manchester last week at ConFed and I saw the big yellow bus which the Manchester Cancer Alliance is using to seek out men from BAME communities for prostate cancer screening. It was really great and having good results.



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If you have a familial link to breast cancer, of course, you would be invited to an annual screen. I wonder what the future of cancer looks like. This is probably a question for you, Michelle. What does future cancer look like in terms of lists being managed within general practice and people being sought out and plucked from the population? What does that look like? It sounds very simple, but it is very hard to do at a population level.

Michelle Mitchell: There are a couple of ways it could play when you look particularly at some of the multi-cancer diagnostic tests. You have talked about GRAIL. That is just one of them. It is a very competitive—

Q27 **Chair:** It is for many cancers, I believe.

Michelle Mitchell: Yes, 50 cancers. It is pretty early days. Part one of the study is prospective, so people who are asymptomatic. The second part of the study looks at those who have some symptoms of cancer. When we look at asymptomatic and symptomatic clinical trials, there is an opportunity to pick up cancers much earlier. We are likely to see some version of that rolled out in the future.

Q28 **Chair:** Is that controversial? Some of you will remember, in my time as cancer Minister, that there was a raging argument about breast screening. “Oh, we’re screening too much and therefore we are over-treating.” You all know my view of that thesis: screening saves lives. But is it controversial?

Michelle Mitchell: Do you mean are multi-cancer early detection trials controversial?

Chair: Yes.

Michelle Mitchell: I don’t think the trials are controversial. I think one needs to be as rigorous as we are in any clinical trials and wait to see what the results are, but it is certainly very promising. The GRAIL trial is one of a number of trials that are coming through. We will also be looking at breath tests and urine tests. It starts from the basic principle that we want to evaluate whether these tests are valuable and whether they should be rolled out in the NHS. They are certainly promising, and the science is moving in that direction. That will be essential in early detection.

We know one of the biggest ways in which we will improve cancer outcomes is by diagnosing people much earlier through a range of sources, whether it is by that type of test or a greater understanding of signs and symptoms. You have talked about primary care. We see great variation in primary care in referral from GP practices. That needs to be standardised.

Chair: Gemma, I will bring you in and then I am going to go to Paul.

Gemma Peters: This is just to build on what Michelle was saying. I would not use the word “controversial”, but something we need to think about is that, if we are able to identify many more cancers much earlier



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and do not yet have treatments, what we are doing is turning large sections of the population into patients before we have anything to do with those people.

Q29 **Chair:** That is what I mean by controversial.

Gemma Peters: For instance, in blood cancer this already exists for lots of people. We are able to identify that they have blood cancer, but we are often not able to treat them for several years because what we would treat them with is more harmful.

Q30 **Chair:** They sit on what you call "Watch and wait."

Gemma Peters: And, as you know, what lots of people call "Watch and worry." What we have done is to take a big proportion of the population and say, in the case of some of the things we have just talked about, "You have cancer but there is nothing we can do." That is incredibly anxious-making, so what support is there then for those people? Or we can say, "We think it is very likely that you will develop X or Y cancer, but there are interventions that could help." How do we wrap around people in that position? At the moment we are excited by the development, but less clear about how we are going to resource that, so we are not creating even more demand in a system that is already on its knees.

Q31 **Chair:** The system is struggling because, in many ways, it has been the victim of its own success. The more people who are coming forward, which is great and which is what we want, the more the system is struggling from that. It is really interesting. Of course, with that wrap-around for people who may be identified on the "Watch and worry," one of the things we are keen for this inquiry to look at are the ethical questions around that. There are parts of society—the insurance industry—who would have an interest in somebody who was put on that kind of trajectory. That is an issue that we, as a Parliament, surely have to think about.

Michelle Mitchell: I am not going to comment on the specific point. Funding of research is absolutely essential because we want more treatment and more treatments that are personalised and more successful, not least in the cancers of unmet need. That needs to be a really important pillar when we look at innovation more broadly. It is not just detecting and diagnosing early, but making sure there is a strong pipeline of new tests and treatments which get ever more successful.

Jane Lyons: Very briefly on your point, Chair, I thought you were talking about the ethical issue of knowing more and how we deal with that. I just want to reference at this point the work that is going on with the BRCA risk. That has been going on for quite a long time. It has been more adopted by the NHS now, but in the early days when we were seeking out people who were at higher risk of both ovarian and breast cancer there were studies around the ethics of how you tell people and deliver that information, particularly because it is genetic. You may be passing it on or have already passed it on to your children or daughters. That was a



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massive part of it, so I would recommend that there is probably a lot of learning that could be taken out of that work.

Chair: We will go to Paul Blomfield next, and then, Paulette, you can reprise your role.

Q32 **Paul Blomfield:** I want to explore some of the same themes in a little more detail. We are on the brink of emerging into really innovative initiatives around diagnosis. On the other hand, as Anna was saying earlier, we seem to be well behind in our capacity to diagnose even in fairly obvious circumstances.

Take brain tumours. There is a certain range of symptoms that pretty readily point towards a brain tumour. Some people are diagnosed by their GP pretty quickly. For others, as I think you were suggesting Anna, it is visit after visit after visit and delay. Why are we so behind the curve in being able to diagnose, even with the tools we have?

Anna Jewell: It is a real challenge, as you said. I know from my colleagues at the Brain Tumour Charity that they see far too many people, and about 40% are diagnosed through an emergency presentation. I think it is about taking another look at what guidance we have. Are the referral guidelines right that we have from NICE? Do we have the right pathways that allow people to get in to be seen quickly enough with symptoms that might point to something like a brain tumour or other cancers?

It is about how we look at the combination of symptoms that people might be coming through to a GP with and doing that in a cleverer way, so we get the right people referred for tests. We are just not looking at how we support the system enough. We are not looking at how we support GPs and primary care enough to deal both with the growing numbers of people coming through, and some of the challenges of the workforce and capacity impact that is having on GPs. I think that is really important.

It comes back to raising awareness of symptoms and the work that the charities can do to apply that. We need more investment and testing. We need more innovations to come through. The big gap that we have is the ability to triage more people. If we had the tests available—as somebody was saying, we need research to show that they are effective—that is a vital step in being able to make sure that we are identifying the right people to go on to pathways or for more invasive tests or scans, where capacity is more limited.

We need to look at how we are preparing the NHS to get ready to adopt new innovations as they come through. It has been very slow to do that at the moment. One of our member charities was talking about the example of cytosponge, which I think Michelle might also be talking about. She has one there as a prop.

Michelle Mitchell: I will let you touch it later. If you want to touch a cytosponge, I have one.



Anna Jewell: That has been looked at for 20 years or so and still is not an innovation that we are picking up. We are too slow at developing interventions in the NHS. We need to make sure that the MHRA, NICE and NHS England look at new innovations as they are being researched and, if they show promise, think about how we get them into the system more quickly to overcome some of the challenges. It is not necessarily a quick win, but it is something that we really need to focus on. We need an action plan, and we need to think, "Right, how do we have a dedicated action plan for these cancers that are harder to pick up? How do we work together with Government, with charities, with the NHS and with researchers to make sure that we can speed up and improve diagnosis and detection for these cancer types?"

Q33 **Paul Blomfield:** You talk about the cancers that are harder to pick up. I think you are really telling us that we are not quick enough in picking up the cancers that we do know how to pick up. What you are saying—I am just checking that everybody is in the same place—is that there is a need for continual professional development, particularly with GPs, for as long as they have a triaging role across a range of cancers.

Michelle Mitchell: And application of the NICE guidance in a more uniform way. We call it a waterfall, which means that there isn't a single bullet to improve cancer survival, but we know that early diagnosis is the biggest thing we can do. The way to do that is to raise awareness of cancer symptoms. It is to ensure that primary care and GPs are referring on quickly. It is to optimise risk stratification through screening. It is to ensure that we have the right workforce and the right diagnostics in place, and that we continue to invest in research, discovery and innovation. All of those things together give us a fighting chance to move the dial on cancer survival in this country.

When we look at other countries that are doing much better than we are, we are 10 years behind Denmark and a little bit more for Australia and Norway. They have all of those ingredients in play, including—linking to Paulette's point earlier—a well-resourced workforce and long-term plans and funding for the workforce. Critically, they have the diagnostics and kit in place to have more and more tests. We need all of those things together, with ultimately, I think my colleagues would agree, a 10-year view on how we develop a cancer strategy that shifts the dial on survival in this country. A short-term one year, two years or three years really will not do it. That is the evidence of the International Cancer Benchmarking study, which shows the ingredients of success for countries that have significantly improved cancer survival over the last 10 years, looking to Norway, Denmark and Australia particularly.

Paul Blomfield: You have actually anticipated my next couple of questions.

Chair: Paul, would you mind if we give you a half-time and bring in Paul Bristow because he has to go to a commitment in about 10 minutes' time?

Paul Blomfield: Yes, of course.



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Q34 Paul Bristow: I will only be five minutes. I am chairing a conference upstairs in 13 minutes. I just want to pick up some of the points you have made. Several of you have talked about innovation and what you are hoping for the future, which is new, personalised medicine and new drugs and interventions that can look at particular types of cancers in particular individuals. That is very exciting stuff. Do you feel that NICE and its processes are fit for purpose to assess the cost-effectiveness of those interventions?

Jane Lyons: It is a complex question. NICE has a lot on its plate. It has new targets to meet in terms of the number of drugs it needs to assess. It is working hard to try to incorporate the patient voice more into what it is doing. It is setting up various forums and bodies, and that kind of thing. It is also trying to learn something about working with the smaller charities. It often has to advise on things that are massive for that cancer population but very difficult to deliver on, because it is unnerving when you get sent on a train somewhere to report on something. To answer your actual question, "Does NICE have the resources?", I suspect it could do with a lot more.

Q35 Paul Bristow: Is it fit for purpose?

Jane Lyons: I think that is a bit too strong. I think it has a lot of expertise and a lot of really good people. The people we have dealt with there have always been absolutely excellent at what they do. Do they need some more funding? That would be extraordinarily helpful.

Michelle Mitchell: One area to build on is looking, with MHRA and NICE, at creating really clear pathways for adoption and innovation. What we are going to see is a more, rather than less, treatment landscape. I would just add that point about much clearer pathways for adoption and innovation.

The second point is that, of course, there is a limit to what NICE can approve because of the affordability criteria set by NHS England which put a cap on the amount. I think that is up for review again shortly, if I recall. The affordability criteria should be under consideration.

Gemma Peters: I do not have much to add, really. I think that last point is exactly right. From a Macmillan perspective, what we see time and time again is the importance of the patient voice and the impact of approvals on individuals and their opportunities to participate. I think we are going to end up, as you think about what the future looks like, with situations where more and more personalised treatments are available at possibly higher and higher cost to smaller and smaller populations. That is a real challenge to the current system.

Q36 Paul Bristow: Anna.

Anna Jewell: Sadly, yes, we do not see enough new treatments coming through for the cancer types that I represent. We do not work as closely with NICE as we would like to. I think the big challenge is the whole system, as Gemma and others were saying. We have started to see more



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personalised medicines and treatments come through—we have had some start to come through for pancreatic cancer—but they are based on a very small subset of the population. That ties in with our values-based pricing methodology and things like that, which can make it very complex to get new treatments through and available on the NHS for small subsets of the population with certain genomic profiles. That is a challenge for us.

- Q37 **Paul Bristow:** I commend NICE. They have tried to solve their problems. When they were established in 1999, or whenever it was, it was world-beating and incredibly relevant for the patient and drug landscape then. I wonder whether they have transformed their systems enough and whether it is as relevant now. Does anyone have anything more to say about that?

Jane Lyons: They have recently got a new CEO and I think that is part of their remit.

Paul Bristow: Thank you very much.

Chair: That is a very interesting line. As there are more precision and personalised medicines, with the challenge that creates for the regulatory environment, we are going to have to explore that area more. We would welcome hearing from anybody watching this session who wants to input on that. Let's return to Paul Blomfield.

- Q38 **Paul Blomfield:** I was asking about our current diagnostic capacity with existing tools. I was interested to begin to explore how the system can cope with innovation in diagnosis. Before I come to that, Michelle, you talked about the need for a 10-year plan, and Gemma was nodding. Is the landscape now moving so quickly that a 10-year plan is still a relevant concept, or is innovation going to mean that what we are looking at now in mapping out a plan will be fundamentally different in three years' time?

Michelle Mitchell: I would say that a 10-year time period is a good one for a number of reasons in relation to cancer. When we look at the evidence through International Cancer Benchmarking, the countries that have done the best have set a long-term 10-year strategy as opposed to a plan. Obviously, you need to update your plan regularly. They have made long-term commitments to funding, not least in relation to workforce. They have set goals which they are accountable for delivering, and they have invested significantly in diagnostics, capital, kit and research and innovation.

You have to take a 10-year perspective on some of those things, not least because of where we are today. Paulette asked about the workforce. We are way behind already in the numbers of people in our workforce and the kit we have. We are lagging at the bottom of some of the OECD comparators, so a 10-year perspective is critical. With cancer, when we think about the benefits of prevention, if any Government were to be bolder about making it harder for people to start smoking and making it much easier for people to give up smoking, the benefits would be in 10,



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15 and 20 years' time. We have to take a long perspective on putting the conditions in place to see a transformation in cancer survival in this country. A two or three-year piece of work is not going to cut the mustard, I'm afraid.

Q39 **Paul Blomfield:** Everybody seemed to be agreeing with that, so I will not probe that specific one further. What I would like all your reflections on a little bit more is the point Michelle was making on how the system needs to change to adapt to innovation.

Gemma Peters: I was nodding furiously to the 10-year strategy and shorter-term plans. On the record, we think it is really important.

On how the system needs to change, for me it is all about building in the flexibility that allows us to respond to the needs of an individual. I am telling you things you know already, but at the moment the system is very siloed. A person with cancer moving through that system has to become expert in not only their own disease but everything that might be available to them and any other opportunities there are of innovation that is happening elsewhere. The burden of that is huge.

If we reoriented around the individual as opposed to around each of our specialties, or put navigators in place that allow us to support that patient to navigate through the system, that is the single most important thing. Over a 10-year period, it is only going to get more personalised. Therefore, your journey is only going to be more complex to understand. That is the single biggest change, I think.

Q40 **Paul Blomfield:** Jane

Jane Lyons: I support what Gemma said. I think a question will come up later about the biggest innovation that we want to support.

Q41 **Paul Blomfield:** That was my next question.

Jane Lyons: Oh, sorry. It is about the people seeing you through. If you as a cancer charity, or as people working in the system, struggle with how you get people from A to B or what that means, or what that acronym does, or what that regulatory authority does, how is it for a cancer patient at, quite likely, the most critical time in their life? They need more guidance, support, navigation, clinical specialists and charity support than at any other time. As we evolve, it is going to be just as complicated, hopefully for the better. It is that support that you need to get through. I wanted to support Gemma on her point and elaborate a bit further.

Q42 **Paul Blomfield:** Gemma, you wanted to say something?

Gemma Peters: I want to come back. I answered the question, and as Jane was answering I realised I had answered it in the long term. Actually, I think there are some changes that we could make right now that would make a massive difference to the system. I would put them in four different categories. One of them is about greater integration of the



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multidisciplinary team, thinking about who is the multidisciplinary team that wraps around a patient and how we make that integrate better.

Secondly, there is something about system-wide digital interoperability. Thank goodness we are in a phase now where we do not need one single digital solution for the NHS. We have moved beyond that. The systems can be interoperable, and that is what we need. You will have heard the stories already of clinicians who have to log into 12 different systems in a day in order to do their job. That feels critical for me.

The third point is around personalised care and how we expand that offer so that it is equitable and everybody gets it. Jane talked about a CNS—a clinical nurse specialist. Access to a CNS is the single biggest indicator of what your cancer experience will be like. Not everybody has access. That is the third thing.

The fourth thing I would like to push, which we have not talked about yet, is that in the current environment what do prehabilitation and rehabilitation look like, and how do we support that in the most effective way?

All of those four things are really achievable. We know exactly what we need to do, and the system could do it. If we did it, it would make a massive difference.

Q43 **Paul Blomfield:** Thank you. Anna.

Anna Jewell: There are big steps that could be taken right now that would massively improve the outcomes of people with less survivable cancers. We talked earlier about optimal care pathways. We have seen that in other countries they have really helped. We are starting to work with the whole of the community in pancreatic and some of the other cancers to say what that pathway should look like and where there are challenges in the pathway that we need to overcome in terms of capacity.

We already know that we could see treatment and survival rates go up quite dramatically if we got people access to the best treatment care they could get now. That includes, as Gemma said, the importance of supportive care. We know, for example, that some of our patients do not get the supportive care they need early enough to help them stay well enough for treatment and care, and to live longer. We still have challenges in pancreatic cancer, with people having digestive symptoms. There is access to enzyme therapy that would help them to be able to tolerate treatment and to have a better quality of life for longer. That is key.

I echo the points made daily, on our helpline. We hear about issues with people having difficulties co-ordinating their care and navigating the system. That is exhausting for patients and families. It would make a huge difference to people if they had that navigation role to help them understand that they are getting the best treatment and care. They should have trust in the system, and know what is coming next and that they will get all the wrap-around care that they need as well. It is a



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challenge, workforce-wise, as we have said, but we know that would make a huge difference to our patient groups.

Q44 **Paul Blomfield:** That is an important point about trust in the system.

Michelle Mitchell: Given the talk of workforce and a long-term workforce plan, anybody who runs an organisation knows that you cannot transform an organisation without great people. In the NHS there has to be a stemming of attrition and support for staff. From all that we have read, morale is low, and people are leaving.

One way in which that could happen and send an important signal is for the Secretary of State for Health and Social Care and the Chancellor to announce tomorrow, as quickly as possible, substantive new funding for the long-term workforce in this country, and for cancer in particular. We estimate that there could be £35 million to £40 million-worth of investment needed to ensure that we have the right number of people who are trained in the right way, and who can build the new skills and capabilities that we need with a plethora of new technologies, new innovations and new treatments coming forward. That would send an immediate signal that there was seriousness about improving cancer survival and stemming the cancer crisis that is happening in England today.

Q45 **Paul Blomfield:** Thank you very much. I will move to the question that you anticipated, Jane, so you can answer it first. What does each of you think is probably the most transformative innovation in cancer diagnosis that we can look forward to in the next few years?

Jane Lyons: As an individual cancer test or whatever? There are a lot of targeted things going on. There are lots of individual cancer things going on, but in terms of scale, if GRAIL works, it shifts the dial quicker than anything else—the blood test on 50 cancers—just because we have all witnessed the Cancer Research UK diagrams on this and the NHSE ones on early diagnosis and which ones shift the targets, which we must do. About 75% of early diagnosis at stages 1 and 2 is only five years now, so 2028. The thing that shoves the dial out more is if something like GRAIL works.

Michelle Mitchell: In the short term, it would be the Government implementing the recommendations of the UK Screening Committee on lung cancer risk stratification. I think that is an obvious important and practical step. The Prime Minister on his first visit out went to check the lung cancer screening unit. I think it is time to follow up with a commitment to fund that work immediately. We know that lung cancer is one of the biggest single drivers of health inequalities in this country. That would be an important way of contributing to a specific problem.

Gemma Peters: I totally agree with Michelle on that. It is the inequalities area that we need to focus on when we think about diagnostics. It is not just the science of the test, but how we get to a point where we have the trust and relationship with communities that means that people themselves can come forward and know what to do.



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That would be the single biggest transformation, which would work beyond diagnosis as well.

Anna Jewell: For the less survivable cancers it is the innovation that we are waiting to see with some of the bio-marker tests: the breath and blood tests that GRAIL does. I am cheating by having more than one test, but for me the important thing is that, as soon as we have a test that could move the dial on some of those cancers and we get that landing zone, we should get it implemented into the NHS as quickly as possible. The Government, NHS and NICE should all work together to make that happen quickly rather than having a long lag. As I said earlier, we have seen that with things like the cytosponge. I echo the points about the lung cancer screening programme.

Q46 **Paul Blomfield:** Do I have time for one more question? This is picking up on one of Michelle's points. We are in a shocking position, particularly in relation to some cancers, in comparison with our neighbours in the rest of Europe in terms of survival rates. Michelle, you talked about Denmark and pointed to some of the things that are done elsewhere. What does everybody else think about anything we can learn from our neighbours and that we should aim for that is, perhaps, different from or adding to comments that you have already made?

Gemma Peters: Some of these we have made already, but to build on it, I think there is real merit in understanding international best practice. Michelle mentioned some really good examples. I would add New Zealand to that. The reason I would add that is that in New Zealand they focus on inequity first and the communities that will have the least good outcomes for cancer and how they fix that. That is a really important model for us to look at.

What we measure is really important. Macmillan used to talk about hitting the target and missing the point. At the moment, we are missing the target and missing the point. How do we measure change in the system? Looking at other models of that is important. For instance, we talk a lot about survival. Five-year survival is really important. The reason we talk about it is that it happens to be something we can measure rather than being the most important thing. Someone's experience of living any life they have in the best possible way is really important. We have very unsophisticated ways in the system at the moment of measuring experience. There are much better ways of doing it that I think we could implement. Those are a couple of the areas I would want to build on.

Anna Jewell: For me, it comes back to strategy and specific plans around some of the cancer types that have been harder to treat and that have been left behind. In the US they have a Recalcitrant Cancer Research Bill, which is helping to get a focus on those cancers. In Australia, we have seen a focus on action plans on cancer, like pancreatic cancer. Even last week we were delighted to see in Scotland the announcement of their 10-year cancer plan and three-year action plan for a specific focus on the less survivable cancers. We would like to see a



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dedicated target put in place to improve survival for cancer types that have been left behind.

Michelle Mitchell: And—

Q47 **Paul Blomfield:** Hang on a second. Jane.

Michelle Mitchell: Sorry I thought you were looking at me.

Q48 **Paul Blomfield:** I was going to bring you in for the last word.

Jane Lyons: There you go. You've got notice of that.

For me, the priorities are putting inequalities at the beginning. We have to put rare and less common cancers near the top of the pile. Rare and less common cancer is already an inequality because diagnosis rates are low, but death rates are higher.

In terms of what we learn from the international scene, which was your original question, we live in a world that is currently too short term. This point has been made. We need to build the confidence of the system, the people in it and everybody who is hoping to benefit from it with something that says, "This money is there for the next 10 years." I say 10 years because that seems to be the point on which everybody agrees. I just don't think you can keep running from pillar to post, shifting systems and the way you do things, and expect the best outputs.

Q49 **Paul Blomfield:** Finally, Michelle.

Michelle Mitchell: Thank you. I have put on my glasses so that I can see who you are looking at.

I would extend the point I made on what is happening both in countries that are part of the International Cancer Benchmarking study and in the US under President Biden. What we are seeing there is a real sense of a mission around cancer, where it is not the responsibility alone of health, it is not the responsibility alone of the research community and it is not the responsibility alone of cancer patients and charities. It is how you use collective agency expertise to mobilise around a mission that will save the lives of thousands, if not hundreds of thousands, of people in the future. If we can elevate the question of cancer from, "What is happening to cancer waiting times each month?" to, "How do we as a nation, together, contribute to beating cancer and improving cancer survival?", that would be an incredibly positive way forward.

Chair: Our closer. Paulette, back to you.

Q50 **Mrs Hamilton:** Can I be honest? I feel as if you guys have absolutely been answering the questions as we go along. My only question would be this, and it is slightly different. You have been talking, but I missed part of it. I don't like coming in at the end like this. How do you feel that ICSs and ICBs could really help with some of the work that you and other speakers have talked about? At the moment, they have an integral part in many of our communities out there. That is the first part of my question. I am going to do them together.



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Anna, I have been following you on Twitter. A number of members of my family at the moment are living with the cancer you specialise in. Any one of you guys can answer it, but the question for you is around pancreatic cancer. It is a very difficult cancer to spot. You have to be an expert to really get it. Once you have been diagnosed with pancreatic cancer, I think the time is about three to six months. It is as quick as that.

You may have answered this, and if you have just tell me to look back at the video. How do you feel re the workforce? What workforce would help to pick that up at an earlier stage, because it is such a difficult cancer to diagnose? I will start with you, Jane, on ICSs and then I will bring the others in because I know that people are hot and having hot flushes and what have you.

Jane Lyons: I will come in first. Anna is the absolute expert on it but thank you for referencing the temperature. She has worked for pancreatic cancer for 10 or 13 years, so she will absolutely be the expert on it.

Q51 **Mrs Hamilton:** Your question is around ICSs and cancer waiting. How is it related to local ICSs and ICBs? Where do you see that link. You do not have to answer. One of the other two ladies can.

Jane Lyons: It is not that. I am not aware of the best way to integrate them. Cancer alliances report through ICSs and ICBs. I work more closely with cancer alliance in the communities and if they have good reach into the communities, everything is about collaborating and pulling all that together. That is my only answer to that one.

Q52 **Mrs Hamilton:** Michelle.

Michelle Mitchell: I would make sure that cancer is a priority in them, but we have an infrastructure as a country through the cancer alliances. A lot of other conditions do not have the equivalent infrastructure. It is ensuring that they are fully operational, have the right capability and the capacity and are resourced well. It is important that their voice is not reduced in the ICBs. There is a big variation in capability at the moment across the country.

Q53 **Mrs Hamilton:** Is any work going on with ICSs to ensure that you improve their capability? They are the big things on the block.

Michelle Mitchell: Yes.

Gemma Peters: Can I jump in on that? We are hugely positive about the ICB structure. The reason we are is that having all those voices around the table is important. Social care being on the table is really important. Having secondary care, primary care and all the community players around the table in that system is really good.

Macmillan has had good progress driving innovation through ICBs in some areas. For instance, there is a great pilot in Cambridge at the moment involving end of life and working with the ICB there. It is all about stopping the number of blue-light incidents in the last six months of life. That involves the ambulance service, the local hospice, Macmillan,



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the hospitals and community groups. Everybody is involved and the end result has been absolutely massive. When it is working at its best, that structure is amazing.

To build on what others have said, there is huge variation in how able and ready that structure is to drive innovation and change. I think there is potential, but there is resourcing. To go back to my point about targets, some of the ICBs are very distracted about things that are not relevant to cancer. For us, as an organisation, it is complex trying to build relationships with that number of ICBs, alongside the existing relationships with all the cancer alliances, and understanding where there is capacity to innovate and where it is worth us investing the time because it might drive some patient benefit. I am really excited about the potential, but they are very far from delivering their potential at the moment.

Q54 **Mrs Hamilton:** The last word is with you, Anna.

Anna Jewell: Thank you, Paulette. It is a really good question and I have had a couple of minutes to think about it. Rather than a specific workforce in primary care or something, I would probably say that researchers are the key for us in pancreatic cancer at the moment. I say that because I think there are a number of important areas that have been looked at in terms of the breath test that I mentioned earlier. We are also doing some work with NHS England about how we can pick up people earlier with an inherited risk of pancreatic cancer. There is also research looking at the relationship to new onset diabetes and how that might help us pick up people earlier as well. I think we need a concerted research effort to help us answer the fundamental question of how we can pick up people with pancreatic cancer earlier, when they could have a more successful chance of treatment.

We have a huge issue with getting people into treatment fast enough for pancreatic cancer. For that, I think we need to look at the capacity for endoscopy, gastroenterologists and the radiologists to read scans. Those are blocks in the system that get people from referral through to treatment quickly enough, and we need the cancer nurse specialist and navigator roles that can help ensure that people can go through that pathway quickly. They are the real challenges that we need to overcome for improving diagnosis of pancreatic cancer, which really needs to happen.

Mrs Hamilton: Thank you and over to you, Chair.

Chair: Thank you, Paulette and colleagues. Thank you particularly to our guests. It is an absolutely brilliant way to start this inquiry. It is ludicrously hot in here, but thank you so much for giving us that context. I have not come back to you and asked for your most exciting innovation because we sort of did that, which is great. We work as a team.

Thank you so much. We will continue with this inquiry. We know there is a huge interest in it because cancer touches everyone. We know that. Anna Jewell from the Less Survivable Cancers Taskforce, Gemma Peters



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from Macmillan, Jane Lyons from Cancer52 and Michelle Mitchell from Cancer Research UK, thank you so much for giving us your time.