

Written evidence submitted by Group 5 (ECS0042)

Transcript of roundtable event with cancer services clinicians and practitioners held on Tuesday 1st February 2022 for the Health and Social Care Committee Cancer Services Expert Panel.

Group 5

Due to technical problems the first couple of minutes was not recorded. Participants were asked to introduce themselves to the group.

Participant A: Thank you so much for having me today. I'm a consultant radiographer in palliative radiotherapy.

Participant B: I'm an acute oncology nurse consultant. I'm also a UKONS member.

Participant C: I'm a consultant oncologist. I'm interested in acute oncology, and I organise our admissions area. I'm also a clinical ambassador for Maggie's charity.

Participant D: I'm a delivery need for personalised care, based in the North East.

Participant E: I am a consultant clinical oncologist based in Yorkshire.

Nikki Morris: Thank you everyone. As you know we have four areas that we want to work through. John and I will do a bit of a Richard and Judy act, so we will jump into things if that's ok. So the first question, is a broad one around your experiences of staffing levels in cancer care?

Participant C: I think this is going to be a universal story; cancer care staff membership levels are low, to the point of crisis, or peri-crisis, the vast majority of the time. That is certainly true in our area, and we know that we are not unique. It is a perfect storm across the entire board, there is not one staff group that is in excess by any means, and it is having a clear detriment to our ability to function. We've had episodes of being unable to offer patient care in the way that anyone would find acceptable. As well as causing staff stress as well.

Nikki Morris: Can I ask when you say it's across the board, and in every group, are there any staff groups that are worse than others.

Participant C: So I suppose where you notice it the most is at the very end point, where you want to deliver the patient care. That is not necessarily where the pressure is the worst, but it's where you notice it the most, because that is what you can measure. So we had an episode in October that made the press, where for several weeks we were unable to treat patients with chemotherapy, according to a prioritisation basis, we were cancelling patients chemotherapy for several weeks at a time because we didn't have enough nurses to deliver the chemotherapy. We're not unique in that situation, but it was a very painful time. That was a combination of not enough nursing staff with the skills to give chemotherapy, but the background story of that was that there were also not enough specialist cancer pharmacists to prepare the chemotherapy in a timely way. And there were further pressures upstream from that, with not enough consultants or prescriber of chemotherapy to be able to make the system churn fast enough to cope with the increasing demand and the dropping levels of staff. And it wasn't just COVID that caused that, it is a background problem of lack of staff.

John Appleby: I just wanted to ask about your feelings and impressions of trends in staffing. So presumably what you're saying is what it's like now, and ignoring COVID, was what it was like three or five years ago. Which was is the line going?

Participant C: The line, I think, is difficult to draw. The important thing is demand, the requirement is going up. Each patient who comes for chemotherapy now, thankfully, is potentially going to live for longer and is going to have more lines of therapy available to them. So the pressure on chemotherapy delivery has gone up and up, and that is not kept in line with our ability to meeting that need. And you can get these figures from the various reports produced by groups who have an interest in staffing levels, our background level in staffing hasn't increased in the same way that demand has increased, but they have actually fallen. So it's a perfect combination to make things really difficult; staffing levels not improving, but the demand is certainly going up.

Participant D: Just building on what Participant C was saying, I don't think that staff levels within trusts are very sustainable. So a piece of work that we're focusing on at the moment in the alliance, is around cancer care coordinators. They are a brilliant resource within cancer pathways, offering that single point of contact with patients at different points. They're invaluable. But a lot of them are funded on fixed-term contracts over one or two years by brilliant organisations like Macmillan, but when it comes to the end of the two years, that's it, and unless the trust can pick up that funding in some way there isn't a job. And on the flipside for those people who are in those posts, once they get towards the end of their 18 months, they start looking for something that's more permanent. So you lose the knowledge and experience of those post holder that have done a brilliant job for the time they've been in post. That's just one example, but there are loads of positions where it is similar, and I think that's a real detriment to the service.

Nikki Morris: Is that the retention of the knowledge and skill set, as well as the numbers?

Participant D: Yes, definitely.

Participant F: I echo everything that's been said already. Similar to Participant C, in my previous hospital we have a similar issue of being called out in a nation paper for having to ration chemotherapy due to our nursing workforce, and that was in 2018, well before COVID. My experience of managing, I was a matron, and it's incredibly exhausting trying to keep on top of staffing levels continuously to try and deliver the level of care that you want to. In my current role now as a stem cell transplant nurse, the level of staffing needed to deliver that kind of care is a slightly higher ratio than a standard oncology ward, for example, but there's a continuous need to try and justify that. That's quite difficult. Just before I left the NHS, the nursing workforce were all safe care tools, so you grade your patients each day, twice a day, on their clinical acuteness. But that's the same tool used across every single in-patient area, whether it's surgical, medical, oncology, and that's very difficult then to get a true sense of what an inpatient is when you're grading them all exactly the same. You cannot take a colorectal nurse and put them in a stem cell ward and expect the same level of care to be given. That's absolutely impossible. So I think that thinking about specialism is really important here.

Participant E: It is very clear from what we've heard that the workforce shortage is pronounced and that during the COVID period it became very open and visible. The college that I am linked to organises staff surveys every year, and it clearly shows from the 2021 findings that we are short of skilful staff to manage cancer patients non-surgically, which includes radiotherapy and chemotherapy. The findings also confirm that this workforce shortage has a knock-on effect on satisfaction levels amongst current staff. The findings also showed that there is a concern about the care that is being delivered and provided at this time. There is also no forward planning about improving the current services and there is not enough investment for future planning and for the retaining of current staffing. There are also concerns about potential unsafe patient care in some

areas. COVID has made the problems more open and visible to us, and unfortunately, it's moving into a negative direction.

Participant A: A lot of what I'm saying is echoing what has been saying, but I think there has been an exasperation of things in the last couple of years. But also, on the dropping staff numbers we are seeing it downstream, but particularly within radiotherapy and in the diagnostics workforce. There's not the equipment there, but there is also not the staff to use it. So you can invest all day long in new machines, but if there is no one there to actually use them then that is a huge problem. I think one of the biggest things that I would want to get forward is I'm in a consultant radiographer role, which is a fairly new concept, but from our consultant nursing colleagues this idea of forward planning is always being talked about, but it is always the last thing that's done. It always seems to be last minute, kind of thrown together, and a lot of stress to get people signed off at the right time, rather than we knew this was happening, what can we do in order to secure different roles and help people advance in their roles and keep that knowledge in the workforce? So the forward planning element needs to be backed up. We're showing that data, let's show it once, and we don't have to this every year to show you that we actually need those posts.

Participant B: I agree with everything that's been said, and we definitely don't have the workforce numbers there at all. I think what we don't have, and it's going to be difficult, is that experience and knowledge and skill that takes years and years to obtain. 50% of CNSs are retiring in the next five years in the South West. It's ok recruiting people into those posts, but you can't just have that skillset overnight and I think that's something that needs to be really considered as well.

Participant C: The difficulty of obtaining staff is right across the board, including absolutely in diagnostic work. We certainly have a shortage of people who are able to make the diagnosis of cancer under the microscope, histopathology, so right at the very early stage of the cancer pathway. That, in some ways, is beneficial to those of us at the treating end, because patients come through more slowly, but you can't underestimate the absolute across the board crisis in staffing and skill. And there is not one area that I could tell you is doing well, and that's what you need to take forward, that this is a systemic crisis and fixing one but is only going to uncover their problems elsewhere.

Nikki Morris: Thank you very much, that was extremely helpful. The second question on this section, is in your experience do cancer patients have access to the right professionals? I'm not necessarily saying the right number, but do they have access to the right professionals during the course of their care?

Participant F: No, would be the overarching answer. I think in-patients tend to take the resources more often than not. So our therapy colleagues, dieticians, physios, OTs are drawn into discharge planning, and the end of care, as opposed to being integrated in all care and outpatient care to try and prevent patients needing to be in-patients in the first place.

Nikki Morris: So, are you saying that you don't think that they have access at the right time? The colleagues might be there, but they're not always accessible?

Participant F: Yes, they're not. They're not resourced enough, so they are then drawn to the crisis point as opposed to being able to put in the interventions early. And that's across the board, be it dietetics, physio or psychological care. There are pockets of very good practice, but I think across the board it's really poor.

Nikki Morris: Thank you. It will be good to know because some of this came up during our meeting last week with people that were patients, when we asked them if there were people that they would like to see, that they can't see. We talked about fertility experts, and people like that, so it would be interesting to know if any of those people missing as well.

Participant F: Particularly with prehab being such a big topic now, I just don't know how it's going to be delivered when we can't rehab appropriately. How are we going to move that resource down the line, without much more investment in it?

Participant A: Before I answer this, I would be quite keen to know if there were any key things that came up from the patients point of view in that meeting, because I think one of the big things that we see in oncology to a big degree, is the fact that you actually don't know what you don't know, you don't know what you need. We probably knew what you needed there months ago, but nobody says in that patient-friendly language, what we thought would be a really good idea for you. So I think it would be really interesting if in that patient meetings, people had said that they were aware of some of the community services, or areas of really excellent clinical care, that are out there and that should be echoes around the country. I certainly see in some areas, just as Participant F said, people get pulled into the in-patient care, and what we would have liked to have had happened is for the dietician to be able to see the patient before they reached crisis point. It may not have avoided the admission, but it might have halved the number of days they had to spend in the hospital. There is some great work being done, as many of you will know, with the enhanced supportive care teams, and they shown the reduction in hours for in-patients, but it's that investment and the specialty of staff.

Nikki Morris: I won't go into too much detail, but what I will say is that there were some specific issues, and some subgroups, so younger patients wanted to see fertility experts at an early stage. Some had comorbidities, so they wanted to have links between the different services that support their needs.

John Appleby: Just quickly Participant A, I'm not quite clear on what you're saying there. Is it that there are some good services, but patients may not know about them, or that perhaps they don't have the right knowledge to know what they should be getting or could get? Is it supply or demand?

Participant A: I think there is an element of both, if I'm being honest. In radiotherapy in particular, the first thing that I ask my patients is 'do you know anything about radiotherapy?' And the common answer is that they actually know very little about it, because they've never had to deal with it. They'll know about drug treatments, but radiotherapies are quite alien. It's the same for speech and language, or occupational therapy. Unless they've had someone that has needed to engage with them before, they don't know that this is actually the care that they could be getting. I think a big advertising campaign could empower the patients, but obviously that worsens the crisis that we're already in with regards to staffing. The only way to get the staffing and funding seems to be about showing the huge demand that's there.

John Appleby: Thank you, and I think we'll pick this up in the next bit on lived experience.

Participant B: I was just going to pick up that point about seeing the right professionals during the course of their cancer care. For acute cancer patients, that are admitted as in-patients, I think that in places across the country, services for them are a really under-invested service. I know lots of small DGHs have very few staff looking after these patients, and offering specialist advice and services, when these patients are admitted acutely unwell into hospital. So I'd say from that aspect, no, they're not seeing the right professionals.

Participant C: For a reasonable amount of time, most patients have been able to access something called a holistic needs assessment, which tries to capture most of the things that Participant C mentioned. And certainly when we have done that, it's a really good way of measuring the need that you can't meet. And that is done nationally, there is a lot of requirement for CNSs to try and do, but you will uncover that many CNS teams don't have the time to do that holistic needs assessment- and that in itself is a story. So we have the services in place to try and capture patients needs, but then you've got these big lacunar infarct that mean you're unable to meet their requirements. It's not because patients don't know what's available, it's because it is not available.

Nikki Morris: Are there any specific things that you think are commonly not available that are needed.

Participant C: For us here it's dietetic support and psychological support. Those are the things that are asked for the most that we are most unable to meet. There are some other things we all, they don't know we can't meet because we conceal that by extreme efforts, and that is based around, as Participant B said, acute oncology and how we manage them when they come in in a crisis. We're on a split site and I struggle to get around the ring roads to go and see the patients who arrive at the wrong campus.

Participant E: I think there are things that have slightly improved in the active phase of cancer patients in the hospital, but when we have finished the active phase of treatment, and they're into the follow-ups I think we are declining. As a cancer radiation oncologist, I see most of my metastatic patients when they are coming in as acute oncology patients. And that is because of lack of services, that would have been picked up when they were in the early stage of their treatment are not- because they're not seeing people at the right time- so they are coming in as emergency patients. And a lot of the time this can be avoided if they are seen by the dedicated staff at an early stage.

Participant F: I just wanted to highlight that where psychological care isn't provided, or where waiting time are too long to get in there is the stepped care model of giving specialists in the MDT psychological skills. Whilst there are really good schemes to try and do that across networks, I don't think the training for staff is coming through quickly enough, or at the rate required for the turnover of staff, to be able to really make an impact.

Nikki Morris: Thank you everyone, that's been really helpful. As John said, some of this tips into the next section so I'm going to hand over to the next section.

John Appleby: Just to say that staffing was a key issues in mental health and maternity, so it's a general issue. The next area is living well with and beyond cancer, and we're picking up on the commitment- which should have been met by 2021- which is that where appropriate, every person diagnosed with cancer will have access to personalised care, include a needs assessment, a care plan and health and wellbeing information and support. So that's the commitment we're trying to assess, and we have a couple of questions. The first one is, is it your experience that most cancer patients receive a personalised care plan following their diagnosis? And the second question is supplementary, around the quality of that care plan.

Participant C: To some extent, yes, but incompletely. And the reason for that is, I'm lucky I have access to clinical nurse specialists, but many colleagues don't, and many patients done- thousands probably don't. And it is that system, the clinical nurse specialist, that predominately allows you to make and communicate a personalised care plan, so that is the vacuum that would need to be filled for that to be universally appropriate. As a clinician, I try to make a personalised care plan, and share that with the patient and their doctor, but it's all very difficult when you haven't got the support

staff around you to be able to do that and communicate that in a systematic way. Just as a moment of tedium, my clinic letters are three weeks behind, because my secretary is a secretary for five people, and again the universality of the lack of staff and extreme pressure means that an idea of communicating with anyone in a written form is going to be delayed and difficult.

John Appleby: By the way, I've taken it as a given that you all think that a care plan is a good thing.

Participant C: I understand the principle behind it, and it's very reasonable, and it's something to aspire to, but they shouldn't be set in stone. Patients need change, and actually what those patients really need is care. They don't need a care plan; they need care and to be able to access care. It doesn't really matter what is written down on a piece of paper that might tick some boxes, but they really need to be able to access people when things change. That is much more important than a care plan.

John Appleby: That's very interesting. Part of our assessment is considering that whilst the government may have a target, it may be the wrong one, so it's no good doing brilliantly on a target that nobody cares about.

Participant C: It's a task of measuring a task, not a task of itself.

Participant B: I agree with what Participant C says, it's a variable thing whether they are completed or not. An issue that we find is that when we complete the holistic needs assessment on patients, we have issues that we don't have the resources to assign patients to. That's the biggest problem. We had a huge investment here in assistant practitioners to complete the holistic needs assessments because our CNSs didn't have time to do it, and that was fantastic for every site of disease. But then when they completed the care plans, they didn't know where to go, and we didn't have anyone for these patients to do to, so it was almost a waste of time having them completed. So it's sort of a tick box exercise to say they've completed their needs assessment, that's great, but actually it didn't help the patient at all. So it's frustrating for us and the patients.

Participant A: I'm not going to take too much time, because I think Participant C and B covered it, but I think the tagline for the whole of this session should be the three words 'patients need care'. That is the take home message. Those holistic needs assessments, those care plans, need to be fluid and they shouldn't just be a tick-box exercise. At the moment if it's done once then you've met the criteria, but actually it needs to be continually revisited, and I don't know anywhere that is able to do that.

John Appleby: Just sticking with the care plan for a second, when you look at the national patient surveys, one of the biggest complaints is lack of information in terms of care. And I just wanted to get your thoughts on whether the care plan is an attempt to address that, or is it, as you were saying earlier, measuring a thing for the sake of measuring a thing and that that information does get communicated in other ways.

Participant C: I suspect that that complaint is really a manifestation of complaints about delays, and complaints about confusion and stress. I suspect it's not a complaint about the information being inadequate or untimely, it's more that 'I had to wait for a scan, don't know where the report is' or 'I've had to wait and see a doctor in a clinic, and I don't know why I have to wait'. I think some of that is legitimate, but some of it is also just the distress and the system is extremely high and we cannot meet that.

Participant E: I think the care plan is definitely a good thing to have, and I don't think anyone can argue about that. It's just a matter of how it is delivered. I specialise in neck cancer, and have worked

in it for nearly 30 years, but in the last few years I have noticed changes in the team structure of allied health care professionals. In the past, we used to be in the same room and doing joint things, but now, for lots of reasons, we are fragmented and doing the same things in different rooms. I have meetings with my personal patients, and I try to leave 15 minutes to talk about treatment and needs, and the feedback I hear is why do we have to do this extra time. Because if they see six members of staff, and they all give 15 minutes then that becomes 90 minutes for the patient. For me, as a practitioner, I don't think we define the minimum required things to do timely, and what are the essentials. Also, on the last point about patients reflections, some of them say that they want to start treatment in 7 days, not 31 days. They are dissatisfied because they have everything, but they had treatment in two months.

Participant D: In addition to staff to be able to do care plans, I think the system needs to work digitally, so that patients aren't having the same conversation about what's concerning them with someone in the Macmillan Information Centres, that they're having with CNSs, cancer care coordinators and navigators, which I think is a massive issue across the whole of the NHS.

John Appleby: Is there anything more that we want to add on care plans? No. This is a longer question, which came out of the roundtable event we had with patients who'd had their lived experience of cancer services, and it was clear that they as patients had met healthcare professionals outside of their oncology specific team, such as dieticians and fertility experts, as part of their long-term care. How would you describe or what's your experience of the communication between the different types of teams which care for someone with cancer?

Participant F: I think that Participant C summarised it really well there, when she said that her current letters are three weeks behind. No GP can do much with that patient in front of them if they haven't got that up to date information from the hospital. A lot of patients are now on electronic record now, and not in paper notes, but something happened when a patient arrives in A&E that night and you're looking for the notes. It can sometimes be hard within the same hospitals to share information about that patient, let alone across primary and secondary care. Even more so with specialist cancer services, we're now moving to tertiary referral centres, patients aren't staying in district hospitals. There is layer upon layer of different healthcare systems that these patients have to traverse. So I think it's almost impossible for a patient to be looked after without up to date information about them available quickly.

Participant C: Just to add to that, I think you should be aware that because of the staffing pressures, and because of the number of patients who need tasks doing, many areas are trying to use more and more skill mix, which is an entirely appropriate response in many circumstances. But when it's being done because of volume and pressure, rather than because they want to use people's skills to the best of their abilities, it becomes really onerous. I don't think I'm a particular megalomaniac, but maybe I am, but I think my service runs quite well, and that is largely because I have a small team who I know well, and we talk very regularly, and we know what is going on with the patients as a group. Under pressure to try and provide more and more services, and see more and more patients, that group is going to get bigger and I'm going to have patients who are under my name, having care with my signature on it, who I haven't seen for a prolonged period of time. That becomes really fragmented, and really difficult, and it is not the way that I want to practise medicine. But that is where we're going because of the volume and pressure. And that is one of the reasons why people end up leaving, because they're being shoehorned into practicing a type of medicine that they don't want to be doing, entirely because of the pressure of staffing. So fragment care, and fragment communication cause us stress, and I think also cause potential risk to patients.

John Appleby: Before we bring others in, we haven't mentioned COVID, and I'm just talking about pressures in the short and medium term, what are the issues around COVID?

Participant C: It hasn't helped, but we were already in crisis. Very little of this is due to COVID. In fact, COVID helped us a little bit, sadly, because patients weren't coming forward, so they haven't been diagnosed. The corollary of that is that patients who are arriving now with cancers are in a mess, with very advanced disease, and it's a disaster. But in terms of period of pressure during COVID, none of it has been about COVID, and we must not get distracted, and this isn't going to get better when COVID passes. The systemic flaws have been in play for a decade.

John Appleby: Thank you. I just wanted to check, and I think it has been used as an outright excuse by some people.

Participant F: I just wanted to give an example from my previous role, where I had a KPI where blood results had to be endorsed within seven days of being taken. They had to go under a consultant name, and that consultant would then be put on a grading list around whether or not they had managed to clear results. I absolutely recognise that blood results need to be looked at and endorsed, but if they're just going to be cleared because we have a target then patient care is going to be compromised. And that's an example of doing things for the sake of it and not using the patients records appropriately.

Participant E: On your question around what happened with COVID, and different parts of the country did different things, but in Yorkshire as clinical oncologists we did provide direct patient care. There were staff shortages, and it did have a further impact on cancer services, which is inevitable. Another indirect effect of COVID is that in the last six months, we are seeing patients come in at much later stages. The current stage of the cancer patients being referred in my field, I now call them T40 because they are beyond any classification. This is for many reasons including, not having face to face clinics in different levels from GP services to hospitals. Everybody talks about using virtual clinics, and it is applicable in some areas, but cancer medicine without examining the patients in-person, I can't understand, and it is the wrong way to do things. And in ten years' time this will be a problem, and we will realise that we missed it because we haven't seen the patient.

John Appleby: I just want to end this section of a question, that again, may have come up at the patients roundtable, but it's on your views about charities and how important they are in providing support and information for those living with cancer.

Participant F: I'm going to say invaluable, but that's because I work for one.

Participant C: I would say invaluable as well. And I say that's a shame and an embarrassment, and we should not be happy about that. We've got charities providing a core service which is absurd and the taxpayers should be appalled that that's the situation that we find ourselves in. I couldn't operate without access to the charitable goods that we have here, who predominately fill a major gap in terms of giving me time and brain-space, by helping us with the psychological support of our patients. Despite endless rounds of clinician time, spent burning the midnight oil to write convincing business cases to get psychologists in the department, we cannot do that so we have to turn to a charity to provide something that is actually essential. We have Maggie's on site here so we're really lucky, and we also rely on our Macmillan colleagues a lot. So I mentioned the pump priming aspects earlier, and that is important because we have no other way of trying to churn the chunky wheels of business cases to be able to do a proof of concept for, again, quite basic services like clinical nurse specialists without money from Macmillan, and again that is quite an embarrassment. We also need them to provide written information like booklets, that haven't been printed out from a printer

that's dead. I can't explain to you John, the shame that we should be feeling about the quality of what we're able to do on our own, and I spend quite a lot of time feeling embarrassed.

John Appleby: And I can imagine the effort and feeling of having to stitch together pieces from different organisations could be quite exhausting.

Participant E: Charities are an essential part of society, as has already been said. One thing that is very clear is that they fill the gap, but the core services need to be covered by the taxpayers. From the charities point of view I have mixed feelings, and I think it comes back to governance. There are hundreds of different charities, and they all have different aims, but they all rely on funding, and we need to be transparent about where that funding comes from. Sometimes there is a lack of transparency.

John Appleby: The final thing on charities, and they're not a bad thing necessarily it's nice that people want to do these things, but it doesn't lead to the resource allocation that you would get in the NHS.

Participant C: And thank goodness John, because we're massively ineffective. We've had quotes for £500 to put a single plug point in. Don't think that charities running themselves in a certain way, means that they're doing it less well.

John Appleby: I just meant in a geographical sense, where different areas of the country have different access, but I take your point.

Participant F: I just want to add another point regarding patient information. For example, trying to collect patient information leaflets written in an NHS trust is probably the most painful thing that you've ever tried to experience in your life. The problem is that whatever you're trying to write about in the information leaflet, has changed inordinately by the time the leaflet is published. It becomes useless. We therefore rely on charities because they can churn the information out quicker. And as a ward sister, giving a bereaved family a rubbish photocopied bereavement leaflet, that's been copied 10 times over, is not a good place to be. So there needs to be better provision, and if the charities fill that then I think that's fine for the time being. Not having a colour printer in a hospital to save money is rubbish.

John Appleby: Thank you everyone, that was very useful indeed, and I'm going to pass over to Nikki now.

Nikki Morris: So we're taking a bit of a jump now to diagnostics. There are two commitments that we are looking at here; the first is on the 28 day target from screening to diagnosis and the second is on diagnosing a higher percentage of patients at stage one or two. Do we think we're meeting both of those targets, one of them, or none of them?

Participant C: I think we know the answer is none, and that is well established. This is an interest of mine, and I'm going to try not to whittle on too much, but these are two different questions. So diagnosing cancer in a symptomatic patient within 28 days should be achievable, however it's not, largely because of the extreme pressures on the diagnostic services. I think none of us on the team are diagnosticians, and we have to remember that our diagnostic colleagues are seeing 95% of the patients in each pathway who do not have cancer. Picking up cancer from a two week pathway is a largely fruitless task; the rates of picking up a cancer in two week referral is about 3-5%. That is a matter of fact that that is because the science behind what is a red flag symptom is extremely woolly, and the risk of you having cancer with a red flag symptom is very low. It's much more worrisome that a quarter of patients who end up with a cancer diagnosis, have come through an

emergency admission or they have been through a routine treatment pathway and a routine referral. And that second group is really relevant, because what's happening now is that patients whom Participant E described have not been through a two-week pathway, but they may very well have had a routine hospital referral a year earlier that would have picked up their cancer at an earlier stage. That work has not been happening, so we're not reaping the rewards of that delay in routine care. Every time we prioritise two week wait care, we push back on routine care, and you're just as likely to get a diagnosis out of a routine referral as a two-week wait referral. We forget that, and there is really good evidence for that, but it seems to not be of interest to people who are in a position to allocate where the money goes. So that's one thing. The other thing is that trying to pick up cancers at an early stage is really difficult, and the reason for that is because you're asking us to pick up a cancer before a patient has necessarily had a symptom. The only way of successfully doing that is with screening, and by that I mean investigating people without symptoms. By the time somebody has a symptom, particularly a nebulous symptom like weight loss, that is their stage 4 cancer telling them it's there. So attempting to try and achieve this is a really big thing, and it's not going to be achieved by turning up the pressure on symptoms that already exist. We can't just push the same pathways a little bit more quickly, because those are not going to make the grades to transform someone's cancer from being diagnosed this month, to being diagnosed six months ago.

Nikki Morris: Can I jump in there, because looking at the question, it's focusing on screening to diagnosis, and do you think that is an issue for the 28 day target?

Participant C: Screening was withheld for a large number of tumour types during most of COVID, so the answer to that is no. Screening is also a terrible way of picking up cancer, as if you look at the totality of all of our patients who have cancer, the number of those who come through screening is about 10%. So I don't know why we focus on screening, apart from we know that it's to pick up these early stages of cancers. Is it possible to roll out screening programmes more? They're already pretty comprehensive. I think it's a really big request of a system that doesn't have the science behind it. You wouldn't expect the numbers to come out of that game, however hard you flog it.

Nikki Morris: Do you think that the issue with meeting that 28 day target from screening to diagnosis was a problem before COVID?

Participant C: Partly. It's worse now. My colleague is on the call in another group, is a gastroenterologist, and she had her endoscopy list cancelled this morning because there were no nurses to run the endoscopy unit. And that is a consequence of a lot of things, including that people have left the profession because of the pressure, and one of those pressures has been COVID, but I don't think that pre-COVID was a time where everything was wonderful and we were meeting all of our targets. That is not the case, we were already dying on our feet then.

Participant E: We use the word cancer all the time, but cancer doesn't represent each cancer. When it comes to screening, only one screening tool is available for breast cancer or early cervical cancer, and unfortunately there is no scientifically proven screening tools for other types of cancers at this stage. If you ask me, specifically, if screening for breast cancer is effective, my answer is yes because they can go in one day and get a triple assessment and a mammogram. But that is just one site. When it comes to the diagnosis of cancer within 28 days, that should be applicable to all cancers for everybody who has symptoms and should be achieved. However, the barriers to us achieving this includes workforce. The radiology pathway workforce is insufficient, as was confirmed by findings from the Royal College of Radiology.

Nikki Morris: If we look specifically at screening and diagnosis, do you think that that is equal across the country, or do you think that some areas are able to provide that throughput faster than others?

Participant E: I think there might be some inequalities, but for example with breast screening, compared to others that inequality is probably minimum, because it's comparatively easy, and the potential patients are more sensible females, and their age group are active and they do not have comorbidities, or other health problems. But when you take this against screening to diagnosis for lung cancer, add another 15 years for a heavy smoker, and the tools that you use is not specific enough, so it brings an additional lot of health problems that you need to sort out, when you identify small nodules to be investigated. There's no immediate answer, as in the breast example that we can have a biopsy and clear a clear-cut answer, because there might be lots of other problems that need to be sorted out.

Nikki Morris: Thank you, and when providing responses, it would also be interesting to hear your thoughts around access to diagnostic equipment and whether it's equally distributed across the country.

Participant C: That is a measurable item, and I'm sure the answer is no. It would surprise me if the answer was yes. I guess there are questions about how you ensure that distribution and how you're counting it. So counting per head of the population is one way, but you should really be counting it according to the comorbidity and the illness rate of the population. I'm from the East Midlands, the East Midlands is a poor area, and we have more cancers than we should, and yet we have less cancer doctors than the rest of England. So we're in a double bind of more patients with cancer because they're poorer, and yet there are fewer doctors to treat them. That's partly because it's a poor area and people don't want to live here. So there is social inequality, and we know that the best way to become unwell is to become poor. And there's no way that you're going to live in a poor area, and have access to an all singing, all dancing, open all hours, Marsden type rapid diagnostic centre, where you can just amble in and have your breast screening.

Nikki Morris: That's really interesting, and what I'm hearing is that it's not just about equipment and staff, but also there is an issue around demographics of the area.

Participant C: Absolutely, because that's what determines your health. Health care does not determine your health, what determines your health is your life. By the time you need to come to healthcare, it's already too late, you've got cancer. That's an important thing for us to remember. We're actually quite unimportant in the grand scheme of things, because we're the end event and we're just trying to mop up. So where you live and how poor you are is really important in determining your health. You mentioned equipment, and I would say that it's not really equipment, that it's staff. But it's also the ease of accessing that. So if you can't get a bus, or you can't park at hospitals, or you can't speak English and we haven't sent the screening letter in your own language, then accessing services is really difficult.

Nikki Morris: So we might go onto the next section, unless anyone else wants to come in on around access to diagnostics, if not I'll move onto the next question.

Participant E: With the diagnostic pathway, last year for NHS England, I took part in the head and neck cancers, 28 day fast diagnostic services. This identified a nationwide wide gap. I just feel that as a cancer physician they need to be diagnosed early, but when I raised this in our optimal pathway group in the region, I heard from all the diagnostic colleagues that we cannot do it. It is right that this is going to be implemented, but on the other hand I hear the screams of my colleagues that we cannot do it in this time. We are in the multidisciplinary setting. If I don't have the imagine, I can't

stage my patients, and therefore I cannot make a treatment plan. We have the guidelines, these are agreed by the responsible expert panels, but I don't think the implementation will be easy. It will be good to have the results of next year's audit, to see how much has been achieved and then we can realistically set up open discussion about where we are and how we are going to it, because otherwise bringing in further additional targets doesn't help, it just adds pressure.

Participant A: I think that's a really good point. The idea of a target is not necessarily a bad thing; it makes us question why things are taking so long. But every cancer diagnosis is different, and we've already talked about health inequalities and potential comorbidities, we've already talked about personalised healthcare, so why would their personalised health care not be specific in terms of their diagnosis. I think this arbitrary figure of 28 days, 64 days, or whatever it may be, it should be the thing that we can hold up to say for this group of people we are meeting this, and actually can we move it faster because for breast we can do it in this amount of time. But for lung patients and gynae patients, we need to do XYZ investigations, and in order to achieve this we might need this time. If it goes beyond this we still need to bring them up during a meeting to say why is this not being done, can we do this faster? I just think that we're holding all cancers under this idea of a single target, and it's completely unachievable. It's a great aim, but it shouldn't be one size fits all.

Nikki Morris: Thank you. And we're going to move onto the next question, which is do you think there is equal investment in, and drive to roll out, innovative technologies and therapies across the country?

Participant C: So is the question about distribution of innovative work across the country, are you asking is that is correct? Or are you asking if the amount of time that we spend on innovation versus core day-to-day work is correct?

Nikki Morris: I guess the way to tackle it correctly, because both are of use to us, is what your experience of investment in this area is and has it been predominately in innovative therapies or has it been in technology.

Participant C: Most of the investment in UK cancer services in terms of treatment is about drugs. It's about systemic therapy, that is the vast cost spend, it gets a lot of the attention and much of the spending. Indeed most clinical trial work that is supported by NHS trusts is based around a therapeutic drug therapy, not radiotherapy technology therapeutics. I can't really speak to diagnostic innovation, and other things that are also important to make the cancer diagnosis in the first place, but there is certainly a big skew, and a massive underinvestment that the RCR and Society of Radiographers can explain really well. In radiotherapy technology there is a real gap.

Nikki Morris: And that you know patients that have wanted to be transferred in order to receive innovative treatment?

Participant C: I have patients that want to go on clinical trials because I haven't got time, certainly for drug based treatments. They don't necessarily ask for radiotherapy, because as Participant A described it's not very famous so patients don't necessarily know what they should be asking for. But yes, patients do travel around the country. It's only recently that we stopped having to certain our patients to Sheffield for a certain type or brain radiotherapy. People are travelling for over an hour to get quite basic treatment. I think we're in an absolute crisis, and we're on the brink of not delivering very low standards of unambitious care, and for I me I think we should be concentrating on core services, not on innovation, unless that innovation is to protect the delivery. So if your innovation is that we can treat this cancer with five fractions of radiotherapy, rather than 15, then that's brilliant and let's pursue that innovation. But if the innovation is that I can give you 35

treatments of this chemotherapy compared to 20, and you might live a couple of months longer, I don't think that we should focus on that at the moment, and we're very dishonest about being able to say that.

Participant A: I think they're all really significant points. I'd just like to pick up what Participant C was saying about the investment in equipment and also around trials. We know that the centres that have historically been investors in research, are the big ones that then get the benefits of that research. They get more funding because they have staff in order to apply for that funding. It's that topple down effect, and it takes decades to arrive at another centre that was never going to get that investment. The same has gone for technology. There have been differences in investment across the UK, obviously Scotland are having a large investment at the moment, but there have been examples of where we have had to send patients across the country to receive treatment. I'm thinking about proton therapy with Christies being the only place to offer it, until the UCLH opened a few weeks ago. There's work that has been done which is very positive, but it's always the big hitters that are the ones that are getting the money. There is a big inequality across regions, but also across hospitals. Participant B made the excellent point earlier on acute oncology. It was 2009 that the report came out about acute oncology requirements, and the minimum basic standards that are required in order to ensure that if you were going to a tertiary cancer centre or a place with an A&E, you would be getting the same level of care. And we're still not able to show that we're meeting that as a minimum criteria. The work that acute oncology teams is doing is incredible, but they're not getting the support because it's not available in the trusts, or it's not forthcoming because the job descriptions that are coming out now are not reflecting the need for acute oncology within them. The jobs are obviously having to develop and move forward. But I do agree with Participant C, and the fact that we can't do everything, and we're not going to be able to do everything for a while yet, unfortunately.

Participant F: What I want to say follows on from what Participant A just said. In my role as a matron across all services, I felt very torn sometimes between delivering research care and standard, coordinated NHS care. I'd be faced with an issue of a research patient who'd had a novel drug in a phase one trial needing an overnight stay, versus a septic patient who needed specialist care. But having to make a decision about who gets the bed was really tough, because the reality is that we couldn't look after the patients who were having core care, let alone the research trial patients- there was not enough capacity to be able to deliver the care needed. So having big, phase one trial units attached to use meant that you get investment, but at the same time you're having to rationalise care for everyone, as opposed to doing it well.

Nikki Morris: And would you also concur that you think that at the moment there's more investment in therapies than technologies.

Participant F: From what I've seen on the coalface I would say yes, much more. I guess the flip side to that is when I started out in haematology 20 years ago, I could probably name every chemotherapy schedule on two hands. Now there are so many that it's possible to deliver them with any real understanding of the drug combinations and what they're going to do, because you don't know them inherently and that brings out some risks as well, I think.

Participant E: I think implementation of innovative technologies into routine practice requires trials. Participant A just mentioned protons and I do not know of any superiority on the part of this treatment, apart from in some chosen areas. I am following the cases of those patients who are receiving treatment of protons in Holland and America, and two hours ago I spoke to the chief investigator for protons, and he said that the world is waiting for this therapy. The NHS is a big

institution, and we need more funding in the areas of radiotherapy clinical research. We started by talking about the core services, and the shortage of staff, and that goes hand in hand with innovation. Currently, I'm unable to recruit my patients into clinical trials because the workload of radiographers is not there. As a clinician, I would like to offer all my patients a chance to be on a trial, if they are willing to, but at the moment we are not able to do that. This again comes back to the lack of research support systems, that is sometimes data manager, sometimes an associate radiographer. I moved from Turkey, I was a professor in a medical school, and I came to be able to be able to do more research. I worked with the NICR. In terms of my patients we are able to support them to a satisfactory level, but we should be looking to do more. But thinking about what is written in research papers it is not available in the trust system. If you're an academic you have the privilege for a phase one patient to have a bed, but for a clinical phase, which is the third phase, compare the standard with the new gold standard. The average length of time for phase three trials in the UK is 9 years, and the standard is 18 months, and the reason is lack of radiologist support or other blocking systems. We all know it, but we're not taking any actions. COVID stopped them all. One thing I would suggest is that implementation of innovative technologies requires evidence, evidence only comes when comparing the gold standard treatment with the available treatment. The NHS is a good institution, helping to provide every available treatment free to all, but it needs to have more research support systems to enable it to use new technologies.

Nikki Morris: Do you think at the moment we have the balance right between core service provision and research?

Participant E: Within the NHS, my answer is definitely no. Last year we submitted 70 applications and we were only able to successfully start 8 trials. The other 62 were refused. Specialists are always competing with each other. We talk about cancer generally, but they are not united. For example, when it came to breast cancer, we were able to implement Herceptin in one night.

Nikki Morris: It just feels like quite a mixed picture from what you're saying. You want innovation, and therapies, and access to research, but in a way where you can still provide the core services, is that right?

Participant E: Yes. With the clinical oncologists currently working, none of them have any research time in their job plans. Therefore what is currently done is all within the amateurish goodwill of contributions. If you don't give, you will not get it. Over the next three years in my new role in the royal college, I will continue to emphasise that every new consultant should be provided, in the first three years, 4 hours of research time. After three years, the ones who deliver more could be supported further. We do not have supporting for professional development activities, such as attending courses. You need a clinical oncologists to do their research, but some of my team members say that that it is not in their job plans so they can't deliver it. But this is a nationwide issue, not personal, but the core should be the definition, and what is defined there should be provided, for a limited time and budget, then you can move into new positions. For example, in Holland, 90% of radiotherapy is delivered by academic institutions, whereas in this country maybe only 4% of radiotherapy is delivered by academic people. So this is where the balance lies. So how can we improve research activity, particularly in the field of non-surgical oncology.

Participant C: I think you are hearing a bit of conflict from what we've said, about the balance between research and innovation and core work. Actually, we don't want to have to choose. If you're providing a service that is going to survive and be fit for purpose in 10 or 20 years, then you have to be providing treatment that works, you have to be providing treatment that is respected around the world and you have to be providing treatment that cures patients of cancer. Because

that is the most sure-fire way that you're not going to have to see that patient again. So that involves applying innovative things, and doing research and that research working, I suppose. But the reality is that we have to make a decision...During the pandemic we will all have experienced research staff being pulled away from their research to the frontline, and that's still happening, and the reason for that is because our day-to-day work is really fragile. I would like to do more research, it would like to be offering more trials, but the reality is that I'm too tired and I haven't got the support. And it's exactly as my colleagues say, I haven't got the job plan time, so I'm doing it for free and that is not sustainable. There's dichotomy, I think, in terms of the honesty in which we're able to describe the current situation that we're in. We are a service that is working despite itself, not because of it. My anxiety about the application of innovative work is that they are such a distractor. People from management teams and commissioners get so excited about new things because they really think this is going to be the answer to the failing service. But they're not going to the answer in defending the service, it is a tiny band aid, and they are tiny percentage increments of change. The amount of energy and enthusiasm that goes into innovation, I find to be disproportionate and unrealistic. So I'm quite down at the moment about innovative techniques, because they are a real distractor.

Nikki Morris: Thank you, and there's a rather specific questions that I want to ask, because during our roundtable event one of the participants told us that they were not offered a place on a clinical trial due to the colour of their skin. What is your experience of diversity considerations when recruiting participants for clinical trials?

Participant C: I think it's really difficult to describe a situation in which I would be conscious of that having happened. There are some things that could mean that could inadvertently occur, like off the top of head, a normal range for a creatinine clearance, for example will be different in the African-Caribbean population, than in the Caucasian population, and you could have a normal renal function for yourself, but not for entering the trial. Things like that can occur, and I suspect that does happen sometimes. But I think it also goes back to the difficulties I described about our local populations, and some ethnic groups are more likely to have different co-morbidities and have different rates of accessing primary care. So I suspect it does happen. I don't think that it is any way intentional, but unintentional harm can come about.

Participant F: This is not around a trial, but on slightly enhanced patient care. On an ambulatory care transplant, on the inclusion criteria is often that the patient is English speaking, or have an English speaking relative available, because there is a lot of onus on self-care. So yes, I've seen similar scenario play out in normal NHS care in that way.

Nikki Morris: Do you think that is linked to staffing at all, that issue?

Participant F: Yes, because I think if you had the time to sit with a patient and their relative, and to work out a personalised care plan of how they could manage ambulatory care, then yes, they could have that treatment. But that takes time, and unfortunately the system doesn't allow for that level of engagement. So it's easier to put that patient in a hospital room as an in-patient, and isolate them further.

Participant C: I don't think that it's just staffing. I think that life is unfair, and I think it's unfair across all walks of life and not just in healthcare. So I don't know that I would expect healthcare to be necessarily free of all the prejudices and the harms that come about from those other aspects of UK life.

Nikki Morris: And do you feel like there are systems in place, where participants, if they feel that has happened to them can feedback?

Participant F: There's PALS, and there are other ways of making those complaints. I guess it's making sure that patients are aware of how they can go about doing that. In my example of a non-English speaking patient or relative, they immediately on the backfoot because they're not able to access the system, which means they are not able to access the complaints procedures.

Participant B: I think that there is definitely now increases engagement with patients, in terms of giving feedback. We have the cancer alliance for site specific groups, and they have a patient representative now within that, and I feel that patients in our area are more aware of how to feedback any concern or improvements, via Care Opinion, or PALS. Here we've got our own patient experience matron, which I'm sure most places have, which has definitely helped.

Participant F: I've looked after patients who have had a stroke and need specialist drinking equipment, like a spouted cup, and when that's not where it needs to be you've got to trawl the whole hospital looking for one cup. Any patient that isn't fit and able to look after themselves poses a complication, and it's not always easy to look after them if you don't have the kit around you that you need to deliver it.

Nikki Morris: Do you think that patients are being made aware of their options for treatment? This goes back to including innovative therapies and clinical trials. Who do you think should provide that information and when?

Participant C: That's a pretty standard part of practice, isn't it? So if I'm meeting a patient with the diagnosis, who needs some treatment then that would be a normal thing that we would do. I think that's fairly routine part of care and, of all the problems that we've got, I don't think that's one.

Nikki Morris: So do you think that their options for treatment is done by you in your role?

Participant C: Predominately yes, because you have to know that the treatment that you're offering is suitable for the patient, their diagnosis, and their comorbidity. And then you have to make a decision with them, within the confines of what's available, about the best course of treatment available to them. It's not a free menu, a smorgasbord, of what they could have if only they didn't have heart disease. This is clinical treatment, so it's needs a clinical discussion.

Nikki Morris: Would you have a discussion with them about treatment that wasn't available at your place of work?

Participant C: If I felt that there was an adequate evidence base it, and it might be in their interests, I would try to do that. it's difficult, in terms of things like clinical trials that are available elsewhere and they're getting that information. But if there were established treatments that was likely to benefit, then I would offer it, and the GMC guidance is that you should discuss it with patients. That is difficult though, especially when you're talking about things that they will have to pay for.

Participant E: I think there are two things that we need to keep in mind. We are in a multidisciplinary environment, and we should ensure that for that the entry criteria for trials is inclusive as far as possible, and that every team member should be informed when a trial is open. It is the responsibly of every team member to remind and record which patients are eligible, and then the principal investigator, or the treating physician, who is leading the work should be able to discuss options about what has been recorded. Leaving it to one person can have some disadvantages, and it could be inconsistent based on their moods, and that is why it is good to have the support of a team. Every

cancer patient in the UK is treated within a multidisciplinary team, therefore we need to make sure that we are up to date in terms of education, ensuring annual updates within our new communities about new treatments and radiotherapies. They are all equal and should all be offered to eligible patients.

Participant A: As a consultant radiographer, I'm quite used to saying the phrase 'if I don't know the answer, I'll find somebody that does' and I think that's important to keep in my mind. Also, because my role is within palliative care we are also not afraid of addressing when we can say 'if you don't want treatment, this is what that means.' Telling them that stopping treatment might not lead to outcome, but it may increase quality of life. It's letting them know that that is an option. We also provide the option to get a second opinion, and being open to getting second opinions from colleagues in different trusts. It's those honest conversations, which again point you towards acute oncology, and acute oncology does incredibly well in that supportive element in the DGHs.

Nikki Morris: We've got two minutes left, and I'm going to pass you onto John. Before I do, I just want to thank you for taking part in today's session, you've been absolutely brilliant and honest and have provided rich examples. Thank you.

John Appleby: We've got to arrive at a CQC rating, and I just wondered if we could go round, and if you had had to go around and give cancer services, and in particular the government targets, a CQC rating, what would it be?

Participant F: I'd say inadequate to requires improvements. There's definitely good pocket, but I think if you're going to take the country as a whole that's where we'd end up.

Participant A: I, ever the optimist, would say requires improvement. When core services are working well they are excellent, but people are on their needs.

Participant B: I'll echo Participant and say inadequate to requires improvement.

Participant E: I would say requires improvement. There are some areas where there are real concerns. This is mainly due to inequalities between regions that have been highlighted, and because we are not able to increase NHS activity in terms of providing better care.

Participant C: Inadequate of requires improvement.

Participant D: Requires improvement from me for exactly all the reason that have been said.

John Appleby: Thanks everyone, and thank you for joining us for this really interesting discussion.

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