

## **Written evidence submitted by Group 4 (ECS0041)**

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

### **Group 4**

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

**Jeanette Dickson:** OK, thanks. So that's a big group of folks across the spectrums of the professions. So I sort of trailed with our workforce question. Who wants to be the first, or shall I just call you off in order? Participant A, do you want to start? The question is: what's your experience of levels of staff in cancer care? Do you think the levels of staff are equal across the country? Do you think there are certain rules or specialties which are particularly well or particularly poorly staffed?

**Participant A:** I do think it's a little bit variable throughout the country. Roles that are particularly poorly staffed... in my experience pathology seems to be a problem that we have in our cancer network, and then with regard to interventional radiology and getting lung biopsies for lung cancer, they seem to be the two problem areas with regard to workforce.

**Participant B:** Hi, yeah, thanks. So in the in the far north, which is my stomping ground, we have a particular problem with radiology. But if I speak from a nursing point of view, which is my predominant area, I suppose, I think there's a real inequity around some of those supportive roles. There's a real difference around banding of roles and attraction to certain areas, and so certain trusts will have different grades delivering similar roles, I suppose. My particular interest around workforce is underpinning the workforce with a better kind of admin and a patient facing health and wellbeing type role, and that's to underpin all areas so, you know, consultants, nursing teams, radiologists, the whole lot help those wheels keep turning, so that's a particular interest I've got.

**Jeanette Dickson:** Can I just ask you a direct question? You said differences in banding, differences in access, differences in whatever: do you mean lack of access, or just enough of the nurses, but not necessarily in attractiveness to the different banding groups?

**Participant B:** I think what I was referring to there is you look at a number of trusts, you'll have real inequity across different tumour groups with the quantity of the CNSs, there's only lung where we actually have a published recommendation around ratio, and I think that's really challenging. As well as that quantity, you also then have banding differences. A lot of our clinical nurse specialists will be band six and seven's, you get the occasional eight – this is in the North; I know in the South they can tend to have slightly higher banding – but there seems to be no real equity across there. So what you will get is if the trust has placed value in saying, 'ok, we're going to have a lot of band sevens, the CNSs, we're going to make sure they're all prescribers and can perform the clinical assessments. You then get your band sixes and in other trusts go for those jobs, so you've constantly got a higher turnover in certain trusts because you lose those skilled nurses externally. I think that's a real problem, actually. Again, that band 4 level with the quality navigation roles – cancer care coordinators, cancer support workers – they're in radiology as well, they're in all kinds of areas. You have some trusts who have a real wealth of those, really well supported, really valued in the trust, and other trusts that really struggle to get them in the running, [that are] on temporary funding constantly and you get a high turnover of staff. That's a local view; you might be interested in elsewhere.

**Jeanette Dickson:** We're interested in that huge view because you can never get one view. One view is not correct, but you know [we want] a feeling for all the different views.

**Participant C:** Yeah, from a personal perspective I think there are several things. I think there's the non-patient facing services that I think are really important, so I can't emphasize that enough. Pathology and radiology often get forgotten and people often talk about, 'well, you've got imaging, you've got MRI and CT', but you need somebody to report, so I think that's a real issue that's often forgotten. My wife is a pathologist, so I hear it from the other end, and they'll often expand numbers within oncology and other surgical services without thinking about pathology, which I think is really important. I say haematologists: I think a lot of us do haemato-oncology and also general haematology. But I think we have been forgotten in the workforce planning. I've heard a figure to say that in ten years 40% of haematologists will retire. I could obviously verify that figure, but I think that we've got a significant problem in terms of consultant workforce, and I think that haematologists as oncologists are often forgotten when there's workforce planning. From a personal experience, I don't think that necessarily we've got an acute shortage of haematologists on the ground from where I work, particularly in London, but that I'm sure it's not the case in other parts of the country. I think there's a good regional variation in workforce.

**Participant D:** I think I could probably echo a lot of that. So in Sussex we're in newly merged organization and I think we're now the fourth biggest acute trust in the country. We cover most of Sussex and four hospital acute sites with the Cancer Centre at Brighton. We have significant workforce shortages across everywhere. We certainly have a significant problem with oncologist cover. I think that's partly local issues, but also we are unfortunately a bit too close to London, so it's quite easy to have a brain drain from us to London because it's commutable. Certainly, as Participant B said, we have significant issues around our nursing workforce, [in] our chemotherapy trained nurses. Again, that brain drain to London is a significant problem. We can train people up and then they move on. We've got an aging workforce across from medicine, certain nursing, pharmacy, you know, we do not have enough of anyone. I'd also agree with Participant B: the disparity in banding can be an issue. There's also a plethora of job titles; we don't do ourselves any favours. I would say in nursing that we do have that pleasure of job titles without actually specifying what you need to have acquired up to have that job title, and there's that lack of clarity of roles. I think there hasn't been enough investment in the cancer nursing workforce development, and I know HCE are focusing on that and were heavily involved with the project that they're undertaking around that. But I think we are very much looking as a newly merged organization at a consultant lead but multi professionally delivered service, specifically within our oncology services, because we just stretch our oncologists too thin, and we're also covering a larger geographical area. So sadly across the board for us, we've got shortages.

**Jeanette Dickson:** Well, it's always nice to be happy isn't it, on a Tuesday afternoon.

**Participant E:** Yeah, so I think in terms of experience across the UK what I've noticed was that not that long ago I went to CMT, so core medical training, where they turned up to I think it was the Reebok Stadium in Bolton, and there's hundreds of them. What struck me was when we were told, 'think about this, there aren't enough people and you've got to decide whether a gap in the service is better than taking somebody who is poor, you know, who performs really badly at these interviews', and that struck me for the first time; it was a few years ago. Boy, are we in trouble if in medicine, that's what we are, if that is the best that we can do, and things have gone down since then. So I've also been a TPD in my day— and, you know, you've seen the change in gender and you've seen all the less-than full-time training, and you've also seen again with the national recruitment where the gaps are and how the gaps emerge – and this isn't London bashing but, you

know, people who come from London don't want to move outside of London unless specifically for family purposes. We had asked these questions – by the way, I'm old enough to remember MMC; that disaster – so we had asked those questions: 'are people going to go in for career or are they going to go for geography', and everybody said that they told us career. Well that wasn't true: it's geography. So places like Durham struggled to get people, and all sorts of shenanigans, and we'd had different people trying to change from one to another to stay geographically. So that was shortages. Consultant shortages: again, I lived through huge, terrible, terrible, terrible consultant shortages, and this is not the worst that I've lived through. But that is because I have been in a major teaching hospital and now a cancer centre, but as somebody who sits as an AAC for the college... I can't remember the last time that there was... certainly most of them are one person and at most two people that are turning up, and very often for specific jobs that they have been waiting quite a while for. I've seen some very good practice, some excellent people; I've also seen people try to blackmail, I'm going to say at the very last moment, the trusts about what they will do and what they won't do, and it's been quite interesting to listen to some of the cross table negotiations. So still clearly huge [shortages] in services, and I do think smaller centres do lose out. There is a difference between district hospital delivery and teaching hospital delivery in things like haematology, where I go, like most clinical oncologists, and where the pathology is, where the radiology is, and so I bow completely to my colleague at UCH, but I do see a disparity in just horrible workloads, just inundated. If you said to me, 'what's been the best thing that's ever happened in all your years', I'd say the MDT and, you know, building up an MDT; and if you said, 'what's the worst thing that ever happened to the NHS', it's the IT system. So all these people that we're talking about in admin... You know, one of the things is – good God – how many systems do we all have to work in? And also the other thing I would say is lack of good leadership. We don't value sometimes our radiographers to make them clinically engaged. We do have issues with, as you say, pathology and radiology. We have issues in admin. We have issues in middle management, quite often, and clinical engagement is very variable depending on the ethos of the department. Maybe I should stop there.

**Jeanette Dickson:** You're on a roll. It's fine. Participant F, do you want to add anything to that?

**Participant F:** Oh, yes please. I've only had since this morning to think about it, but I've also got things to say. So yeah, bringing it back to Participant E's point that actually before the pandemic, if we can remember back to then, we were already struggling. So [we are] a victim of our own success with all our brilliant treatments all needing input into them. So my melanoma clinics began to expand as [indecipherable] patients come in, and as well as people live for years and years on treatments. Less research began to happen, more service, the whole culture shifting. Then – and I am going to mention this – pensions became a huge issue. I distinctly remember sitting in a meeting and looking around and realizing I was the oldest person in there, and I'm not 50 yet, and everybody had gone because of the punitive pension taxation. They'd all gone years before they needed to, taking all of their expertise with them, and nothing was done to try and change that. And now, of course, in the pandemic I've diversified a bit. I did a bit of looking at the mental health burden in our NHS staff and it's huge, and it's going to go on forever because the PTSD that is going to be endemic throughout our population is also going to be there in our NHS workforce. We can already see that every day we come in and we get an email that these people are off sick. These people off sick because of COVID, these people are off sick often because of stress, and we're all then covering for those gaps and again, you know, having the burdens of that. I do think there's huge variability around the country. I can see that where you've got high levels of COVID, and perhaps high levels of COVID research, you have low service capacity on your machines and low research as well. It's horrible to hear other parts of the country where they're talking about stopping treating certain cancers. Of course we can't stop treating those patients completely, so they're going to have to go to

other units that don't have any capacity. In terms of where the gaps are, well, certainly oncologists. So I believe there's about 1000 clinical oncology posts and 200 vacancies of those. We can't fill our slots. Every month another person retires for the reasons mentioned already. Of those remaining that are older than me, they all have a date in the diary when they're going, and what's really concerned me over the last few months is that new consultants have started to go because they do not want to be in this environment for the next 40 years. So they're going to pharma, or for some it's so bad they're leaving without even having another plan as to where to go. In other areas: support services, absolutely. So, you know, our pathologists and radiologists are outsourcing things, but then they just get the things being put back on the MDT because you can't discuss that patient with the person that's reported it, so you're still adding to the workload. Pharmacies are overloaded and we're now – a new thing – cardiology. I can't get anything done following someone up on standard of care treatments or for research because, of course, cardiology, and having all of the delayed diagnoses, delayed cardiac diagnosis coming through as well. And then I'll look at the secretarial staff who are having to cover more than anywhere else that I can see as well. So yeah, that's the situation as I'm afraid I see it at the moment, which is why I was so keen to be here.

**Jeanette Dickson:** Ok. So I'm hearing definitely geographical differences, definitely differences between big teaching hospitals and smaller DGHs as we would expect, definite differences. I think you probably failed to mention a lack in surgery, Participant A, which I feel if I went back to you that you'd say yes. But it's huge things and diagnostics. Pathology is a recurrent theme, radiology is a recurrent theme, but also oncology. We're hearing about all of the allied professions – nurses, pharmacists, radiographers – and we're also hearing about the underlying admin support to allow people to do clinical care. We're also talking about not helping ourselves, not necessarily making the best of the people who want to work in cancer by having different adverts, different job titles, different training needs, different bandings. So I'm hearing that. We had Participant E talking about MDTs being good. Are we kind of agreeing on that one about a fully staffed MDT being better for patient outcomes as one of the questions?

**Participant E:** I think it's the best thing that had happened, but I'm not saying that they've changed into and continue to be. But yes.

**Participant C:** I think they are. One of the issues we have is the requirement appropriately to have a specialist haemato pathologist in our MDT, and because of all the structure services we don't have, certainly in the district general I work in, a haemato pathologist is able to dial into the MDT. So I think that again talks of regional variation, but even within a specific location between the centre and the district general for lack of pathology. Can I just quickly make the point that haematology I always think is the forgotten oncology discipline? I appreciate haematologists do lots of things: so they do sickle, they do the coagulation, they do lovely things – transplantation – but actually we have about 1000 haematologists, almost an equivalent I think to the number of oncologists, of which I would say at least half of our workload, if not more, is actually oncology, and thinking about haematology as an oncology discipline and also, workforce planning. It's not just who you have now, it's the concept of an aging population of consultants that are going to retire or not recruiting them. The final comment, if I may, is [from] when I was a training program director, there isn't really a shortage of people applying for the discipline. I don't know about oncology for haematology, there isn't a shortage of people coming through core medical training who want to be haematologists, it's just the number of posts that we have defined as we're able to train, and that is something certainly we or the government could potentially invest in.

**Participant A:** Yeah, I sort of agree with that. The MDTs are probably one of the best things that have happened, and I know in lung cancers since we've had MDTs in this country the resection rates

for lung cancer have quadrupled in some areas, which I think is very good. But we did get to the stage where every single clinical decision was going through an MDT, and the MDT was using a hell of a lot of resources up. The number of consultants sitting around that table for hours on end discussing, 'should this patient go for a PET scan?' Of course they do; that's what the guidelines say. It's been streamlined a little bit, but I'm sure the MDTs can be streamlined more than they have been at present to make the most of consultant time. Also I think it's important that as MDTs, which isn't always the case, that you have more than one specialty. So in lung cancer you should have two thoracic surgeons there, two oncologists there, because one person's opinion may differ from the other. So you have a balanced opinion, and not just one surgeon who may be a bit risk averse going, 'no, I don't like the look of that', and, you know, he may have had a recent death that clouds his opinion for the next couple of months. So I think it's important you get the right patients discussed at the MDTs at the right time, and have enough of the appropriate experts there, but again not too many so you're inundating people with unnecessary MDTs.

**Jeanette Dickson:** So a view of MDTs as being a good thing, but maybe in need of an overhaul.

**Participant D:** I do think that they're a good thing, but we can also have some very highly complex and tortuous pathways for MDTs between local ones and specialists ones, especially when you're in a large geographical area. We have one site that sits under a different cancer centre because it historically didn't sit within the same trust as where our cancer centre sits at Brighton. So if we have patients treated via a different cancer centre, and that leads to inequity of access to specialist MDTs. So cancer of unknown primary, for example, can be referred easily into a cup MDT for Worthing patients, but for our Chichester patients that doesn't exist in the same format to the West. So there is that issue, and I think as well it's also time put aside for the MDT leads to engage with the MDTs. I think we have struggled, we've tried for our cancer board to really engage with that with our CD leading on that, and really being able to give them that time and for their engagement into that process too so that we can streamline and improve how MDTs function.

**Participant B:** Yeah, I think just to echo what both Participants A and D have said where I think the minimum quoracy is a good thing when you're a DGH, because I think particularly when you've got oncologist shortages you've got that lever where you have got that quoracy so that's really powerful. But [I'm] hearing very strongly what Participant A said there, just having one voice. So for example, in County Durham and Darlington we have two split MDTs because we refer to two tertiary centres, both going north to Newcastle, and South to South Tees. You see huge differences. You'll have one oncologist sitting on each from each area with really variable outcomes. So I think it just needs a refresh back to what you said. I think the [indecipherable] is great. I think they're a brilliant thing and yeah, having protocolized decision-making as well where you can I think is really important when you know it's open and shut cases.

**Jeanette Dickson:** Ok, thanks everyone. So if I hand over to you, Rob, is that alright?

**Robert Francis:** Yeah, sure Jeanette, thank you. [It's been] interesting so far. What I'm going to ask you about is personal care plans, and also as it were non-satellite services and how they coordinate. But firstly, what are your views about personal care plans, whether you perceive them actually being used after diagnosis, and the extent to which you think they're useful and important both to the patient and yourselves? So those are the questions really. [Could we] have a nursing view of it?

**Participant D:** I'm happy to start. So I mean, yes, absolutely personalised care [is] very important. We're doing a lot of work around health needs assessment and ensuring that we have that pathway. Stratified follow-up: ensuring that that's implemented is very challenging, because we're coming up

speciality's from both sides. I mean we've got huge problems in our diagnostic pathways, which is a massive focus which obviously we are focusing on, but then we're asking teams to also focus on stratified follow up which helps, you know, give a capacity in the system, but it only helps give capacity if you've got the headspace and the time to focus on implementing that, and you actually have the staff to support that. I do think it's the capacity in the system, because I think across the board we all, you know, we're all desperately looking at ways to support our services. So when there's a shortage of medical teams, there's been that drive towards extended practice, advanced practice roles in other team members, which is excellent. I was a nurse consultant [and] I completely buy into that. But we don't have enough nurses and we don't have enough pharmacists, so there's that constant pressure to almost pass, not the buck, but pass the work to ensure that the work is met. One of the things with personalized care is it does tend to fall on nurse specialist folders a lot of the time to try and support that moving forward, because there isn't – not because medical colleagues aren't engaged with it necessarily – just because it's the capacity in the system, and we don't have the capacity in the CNS workforce. Similarly, I will put adverts out for CNSs. I'm not getting people applying with the skill set needed for those roles, and I've got an aging workforce like everyone else. So, you know, it's very important – personalised care – but it is also a challenge for us then to implement that and manage it across the whole pathway.

**Robert Francis:** I'm hearing it's [easy] in theory but pretty difficult in practice, yeah?

**Participant B:** This is an area that I am the clinical lead for in the region, so it's something I guess I kind-of live and breathe and I suppose I have quite a close eye on this one. I totally hear what Participant D just said there, but I think this goes back to my initial comment on workforce where I think if we really want to focus on what matters to patients and, you know, we know that if we can address what matters to them it removes some of those barriers to treatment care, [it] can even sometimes speed up them starting the treatment if a patient is deferring for various personal reasons. [The] ICR band for workforce [is] absolutely invaluable, and our voluntary workforce, and I don't think we place enough emphasis on both of those areas. So if we can actually get those non-clinical aspects of a holistic needs assessment and care plan undertaken at the right point by the right person, that paves the way. So when a patient comes in, if all they're thinking about – we know it's a barrier to, you know, a clinical discussion – if a patient is just thinking, 'oh my goodness, I can't afford my travel', or, 'who's going to look after the dog?' All these things that really matter to patients. We can remove those barriers when they then see the specialist, be that the radiologist, nurse, or consultant. We know that that interaction will run smoother. I'm quite passionate that it is about getting them done, but it shouldn't keep falling to the nursing workforce. I think there's an element of the nursing workforce where it has to be that clinical part of your care plan, but actually a lot of this can be done by other parts of our workforce. But yes, I do place a great importance, it's like a domino effect as well. Just to add, I think if you don't have your right care plan in place, then you move on to treatment summaries, cancer care reviews in a GP, stratified follow up. Your care plan really is the very first thing. And then what you need to do is just keep revisiting to make sure things haven't changed. But if you get that right straight off, it paves the way for the rest of your personalized care interventions to be effective.

**Robert Francis:** And what you're saying is patients feel happier about all this if they've got one in place?

**Participant B:** Absolutely. If they've had what matters to them addressed, absolutely they do. You can see that through, you know... hopefully the National Cancer Patient Experience Survey this year has changed quite a lot, and some of its questioning to hope to reflect some of that. But you need to

get your local patient experience data to support whether you're getting it right, because it's about asking the right questions at the right time for our patients to share what matters.

**Robert Francis:** Ok, anyone else want to comment?

**Participant D:** Could I just interject? Sorry Participant B, just to say... we have a really good patient support worker process, and they pick up the HNAs for the patients and then we utilize the nurse specialist skills to deal with the complex aspects of those pathways. So absolutely, I agree. It's ensuring that you've got the right people doing the right things, and that we streamline how our clinicians are working so that they're not doing unnecessary roles, which is quite challenging sometimes. But I think the challenge, especially for stratified follow up with us locally, is that getting that engagement – and also engagement to be in primary and secondary care, but some chemo sites, you know, certainly prostate, for example – is more challenging, and ensuring that it all works across the board. And as Participant E said, that IT 'joy' that we all have to deal with and the lack of systems talking to each other, it just feels like we're always fighting against things that we don't have control over, which seems to make it much harder for clinicians to operate efficiently.

**Participant A:** I think it is quite variable from trust to trust. I think it probably goes back to the specialist care nurses – their band and their numbers – certainly after surgery. If there's a shortage of specialist nurses, these patients after lung cancer surgery [are] deemed cured and then they're sort of left out in the wilderness, yet they often have problems with breathlessness and pain from their operation and they have really no one to turn to. I think one of the eight hospitals that we cover, their specialist nurses will run a sort-of survivorship clinic for these cancer patients and follow them up because they have the staffing, and the benefits that these patients get from that sort of service is incredible, especially as we know the re-admission rates in these patients are very high. You spend the money on the specialist nurses to provide this service, you keep these patients out of hospital, which is so good for them and so good for the service.

**Robert Francis:** Probably the doctors, who I might... you won't like it, but certainly the patient group I was in the other week, patients unanimously supported... their nurses were fantastic; their views about doctors were more varied. But I think a lot of that was probably due to the planning.

**Participant A:** Yeah, I think I completely agree. If I've got a busy clinic and I've got a follow up to see: I'm sorry, I have not got that much time to spend with that follow up to go through all their needs. The specialist nurses, they're concentrating on those back patients' needs. They have more time to do it and they do it better than me. I've no qualms in you telling me we don't do it very well, and there's people out there that can do it better.

**Robert Francis:** Right, fantastic. Candour is everything in my book.

**Participant C:** Yeah, I think the only thing I wanted to say is the concept of a cancer where you're giving curative intent versus that which is relapsing remitting I think is really important. So when you have a cancer with curative intent health needs assessment, and then there's the pathway through to discharge, cure, and hopefully through to primary care. And then in haematology – and I'm sure in other oncological disciplines – you have a relapsing remitting illness where patients remain within secondary care. That's the first thing to say. The second thing is having time to do an appropriate health needs assessment at each time the patient relapses, because clearly their needs are changing, and there's a very different aspect for somebody who's newly diagnosed, who's going to have several years of [being], for example, 'pain free although well', through to somebody that's in the terminal phase of their illness. And I think that trying to do health needs assessments at each time somebody initiates treatment, which I'm sure is as per guidance, probably doesn't happen, and

that's mainly because there's probably a lack of resource to allow it to happen. And the thing that we shouldn't really forget is the importance of the palliative care symptom control, which we've not discussed in this meeting. They are a really important aspect of care for patients, and that's at all aspects of the journey. So I deal with a disease where people have a lot of problems with pain, so they're great for newly diagnosed patients, they're going to have years ahead of them, but they need to see a symptom control doctor rather than necessarily palliation. It's symptom control – that's what they term themselves – through to the end-of-life care. I think from a personal experience end-of-life care is actually dealt with really well, I've got to say. I think the part of care, community care setting, I've always been very, very impressed with. I think the NHS comes up trumps towards the end, I really do.

**Robert Francis:** Thank you. Going on from that one... but after treatment, as it were, and contact with what we're being asked about dietitians and fertility experts, all those sort of aspects, and really how those sort of services communicate with the central core service and vice versa, I suppose. Is there enough choice being given to people?

**Participant E:** I do some of the TYA stuff – which is why when you said fertility – and I also do prostate cancer. I think that the fertility issues have vastly changed over the last number of years, and I think we're all very conscious of it, perhaps much more so than we might have been because of the possibilities. I think the level of health literacy is really quite low generally in the UK for patients, and I think that follows along with socioeconomics and very much, certainly in my prostate practice and when I was in Leeds as well in a similar prostate practice, it was very, very different in terms of challenges, in terms of the patients that turned up, the questions that were asked, the importance put on aspects of personal care across socioeconomic groups. But in general, having worked in and seen other countries health care systems, we would see the British population as being far less health literate. But maybe that's because when I go to the states I'm in pretty high-level places, because we've gone to see something specific, like protons, for instance... We all work to clinic templates; nobody sticks to them. We can write, we want to see one new patient per hour. It's always a new patient per half hour. So I agree entirely with what's been said in that some of the things have to be taken over by other people, and we're really, really good at skill mix compared to other countries. We do not see the nurses in Germany or France or Spain taking on the roles, but in the end they are combined roles. Similarly I agree entirely: I think we've got the best palliative care system probably in the world. Certainly the best I've seen, having been in many of those other countries. So we would be very supportive of this concept of a personalized care plan. It's different to other countries who have far more doctors per population, but the patients themselves sometimes come with a very low, maybe you would say expectations, but certainly quite often a very low knowledge base of where you're starting. And I agree, you know, some of them are saying they haven't got the money to do X, Y and Z, which is an appalling situation for a country like ours to be in terms of deprivation.

**Participant D:** Just going back to health needs assessment: my slight underlying anxiety with those is there's quite a push, I don't know if this is national, but certainly to record, you know, there's a dashboard for how many have been completed, whereas I feel very strongly it's how many have been offered should be what we are looking at, because otherwise you're at risk of it becoming a tick box exercise, where they've done a health needs assessment, we've ticked that box and that's not what it should be about. I think you're talking about sort-of the other aspects, and Participant E was talking about patients coming into the system prepared, you know, with that knowledge, and I would agree; I think that can be relatively low. I think the whole prehab agenda, which is again about personalized care, prehab for patients who are coming in for systemic treatment, it's a bit more



established pre-surgery, I know, but still not that well established. We're doing quite a lot of work around looking at that and how to individualize pathways for patients, because if we actually optimize them pre-treatment, obviously they're in a better position to make a good recovery and have a successful treatment. I think as well what Participant said around the skill mix, there is evidence – I'm in the joy of a PhD and I'm looking at advanced clinical practice – certainly when you look at the research there is this evidence in advanced countries what policy has supported the development of advanced clinical practice roles. There is evidence of tasks shifting from medical colleagues to nurse colleagues in those countries, which isn't so evident in the more traditional countries where you haven't had that policy shift. At the other end of the pathway with personalized care, I think one of the things that is woefully inadequate is psychological support for patients throughout the pathway, really. Again we've been doing a lot of work looking at that and trying to mirror the model that was done across, I think it was North London Cancer Alliances, at really utilizing those different aspects of care around a charitable support, etc. But really making sure you've got that that access for patients to what they personally need. I do think it is a challenge to get that in place.

**Participant F:** I just wanted to agree that all the things that you picked up – the dietitian, physio, OT – they're all things that – certainly where I work they're outside of our sphere of influence – that we can't actually speed up, but they're really, really important to patients. So I have patients coming because their arm is swollen, because they need lymphoedema input, you know, but we can't provide that. They have to go elsewhere, but that is what is having the biggest effect on their quality of life. So certainly we need funding put in other areas as well, which brings me nicely on to having the best palliative care service in the world, but the fact that we're not funding it in the way that we should be funding it. For those that don't know, about a third of the funding – maybe even less for some hospices – comes from the government; the rest comes from charitable donations and fundraising. This is now going to fall apart because no family is now going to have that money to give money to charity, to take part in fundraising, if they're paying more tax, and if they're if they've got a higher cost of living. So the smaller hospices will go. We will lose that best in the world palliative care if we don't think about how we're going to plug those gaps, at least in the short term.

**Robert Francis:** Thank you. I'm conscious of time – can we move on, Jeanette? Do you want to have a go at the next bit?

**Jeanette Dickson:** Yeah, I'm happy. As I say, it's a bit elastic because it's about trying to fit in this stuff I didn't do earlier on. So it says we have a 28-day target from screening to diagnosis, and a target to diagnose a higher percentage of patients at stage one and stage two. Can we talk a bit about if we think that's being met? Do we think the target is being met equally across the country? Do we think it's been met for subsequent imaging or subsequent diagnostics? And it's about access. Who wants to talk about access to diagnostics?

**Participant E:** If you want things to happen quickly, or your diagnostics to work really well, or be completely swamped, get a celebrity to have the cancer. That seems to be the one thing... now there used to be quite a lot of advertising and public health adverts about cancer: bleeding, haematuria, etc. They all seem to have disappeared with COVID. I mean, I think hopefully Participant A will mention this, but open access chest imaging, CT scanning for lung cancer, earlier lung cancer access: that did, when it was supported, show benefits, and yet we still seem to be arguing about whether we should do it, how we should do it, when we should do it, what access we will have. Certainly radiology is a big missing piece, and again in other countries you get your little chip, off you go, you have your scan in your local street and they do fantastic and very detailed reports; really, really good reports. But they are meaningless without an MDT and review by a specialist person, and that's the

problem with the model of being able to just access scans left, right, and centre. I don't want to open the whole argument about community ultrasound here, but I am saying it because I know that this is being recorded and therefore it can't be ignored, as it seems to be being ignored. Certainly in our MDT, the prostate MDT, personally I don't do any private practice – very few of us do – but we have noticed that patients only seemed to be accessing health care through private practice now with COVID. We would have had one new patient amongst eighty in our urology MDT who is private, and now every week we will have six or seven or eight coming through, and in our sarcoma service similarly, lumps and bumps, people coming through trying to access. GP access as well: we've shown in our audit which we put through at the RCR the horrible consequences of not being able to access your GP during COVID. Everybody is in metastatic, we have very few curative patients in the last 18 months that we looked at.

**Participant A:** COVID has caused us to take a huge step back with regards to early diagnosis of lung cancer. The recently published National Lung Cancer Audit has shown that the number of people receiving surgery for lung cancer after going up for the last five to ten years has nosedived over the last two years, which is a real shame. People aren't getting their CTs for various causes, and not going to their GPs like they were doing previously. The evidence for lung cancer screenings is just getting more and more. It's been sort-of introduced through the back door with these healthy lung checks that are being brought out in more different areas. Yes, we are looking at a national lung cancer screening program, but this needs to be brought forward, because we know if we pick lung cancer up early we can cure it with surgery. But we're only picking up 20% of lung cancers at stage one or two, and we just need to do better with that. I think one of the major problems is if we do the CT scans, who's going to look at them and the burden on radiology?

**Participant D:** I think it is a national thing. We've had quite significant pots of money allocated locally from our alliance to supporting faster diagnosis posts within our workforce, which in one respect is welcome. But my one concern with that is that is, you know, that huge focus on the diagnostic pathway for certain posts, but it doesn't resolve the issue of the pathologist and the radiologist to support that. A faster diagnostic nurse and navigator will aid streamline in that pathway, but it doesn't resolve that bottleneck that we have then with the actual process of getting those things covered. Also, it's all very well focusing on the diagnostic pathway, but then patients don't get diagnosed. We've then got to treat those patients and treatments have gotten more complex. I have felt a little bit that that drive towards the diagnosis hasn't supported... there's not the similar funding to support. Well, how do we then treat them? How do we manage them through that treatment pathway?

**Participant C:** Sorry, just a few points to mention. So when you're dealing with stage one and two, it assumes, which is clearly laudable, that you want to diagnose cancer early, but there are clearly cancers where they're metastatic by their nature, so blood cancers are often by definition multi-site, so myeloma would fit into that – leukaemia would also fit into that – so I think that clearly they're never going to meet a stage one or two metric. It's important to think that there are cancers that probably aren't going to manifest that way. I think the second point I wanted to make was the concept of the 28-day target. I think [it] is clearly laudable. I think that's great. I think the rapid diagnostic centres are very good. I think the concept that you have as a primary care physician, a place that you can send lumps or bumps, or patients that you have concerned, patients that may have lost weight. The question historically is which doctor do I send that patient to? Is it a gastroenterologist, is it a respiratory doctor, is it a general physician? So I think the rapid diagnostic centres are really important, and hopefully will improve things. And then I think a metric that should be mentioned is the number of patients who have a delay in diagnosis, the number of times that

they've seen a healthcare professional, and also the number of people but that present through A&E, because A&E should never be the appropriate route that you get your cancer diagnosis. I mean, it's awful enough as it is to go to A&E rather than being admitted through A&E, going through the tests, you're away from your family, even worse through COVID, and certainly for the cancer that I deal with, it's the cancer where patient see the highest number of healthcare professionals before they're diagnosed. So I think a metric that would deal with the number of times people are seen before the diagnosis, the time, and also trying to reduce the number of people that present as an emergency. Those are the things that I'd like to highlight.

**Jeanette Dickson:** Thanks. Yeah, I know not a one size fits all, and also that bit about if patients came the way we wanted them to come, life would be a much easier thing. It's trying to get all of the different presentations sorted. Clare?

**Participant B:** Yeah, thanks. Just a couple of things on diagnostics. I guess it's inequity maybe around equipment as well between trusts, and access to equipment. So for example, I'd give a SPECT-CT as an example of that, there's not equitable access for patients close to home with that kind of thing. And going back – so it has to go right back to the workforce – even if you have got the equipment, so we've got trusts that have got the equipment but that just cannot staff the equipment. You've got CT scanners not being used to full capacity, but yet you've got waits for, you know, for imaging. So it's back to work force. I don't think you can talk about this without thinking about our radiologists and the increased pressures on them, and again it's not through lack of having vacancies, it's through lack of having radiologists. And if you think it's bad next to London, Participant D, try coming to the cold North! It's really hard to get people to see how amazing it is up here, and so yeah, I think just those two points that I think I agree [with]. Fast diagnosis standard, crikey, you know, whether you have or haven't got cancer, 28 days is actually still a very long time to find that out, but it's a very welcome metric that we're using. Very welcome.

**Participant F:** Yeah, just a couple of things. So in terms of 'are we meeting the target of the stage one and two?' Well, Cancer Research UK has done projections about this, which the current trajectory is no, we're running [at] about 55% and continue to do so, so we're not going to hit 75% with that. And then I just wanted to put some numbers on what Participant A had said, because it really got to me last week hearing that the estimated five-year survival for lung cancer has fallen from 17.6% to 13% as a consequence of COVID. So all the good work has, you know, just been destroyed by that, so we have to clear all of that back.

**Jeanette Dickson:** Yeah. I mean, I think there's an undoubted impact of COVID on everything. It's tricky to see how we are going to get back from that, because all of this stuff that we're talking about, all of those workforce shortages in equity of access, [these] problems started before. I'm now going to be controversial, Robert, and then I'm going to leave you, because that's what I'm kind of doing, baby with the bathwater thing. You can have it. Things like rapid diagnostic centres...

**Robert Francis:** Go on Jeanette, that's fine. Yeah, just leave me the wreckage.

**Jeanette Dickson:** Yes, fine. Rapid diagnostic centres, I mean, most of the things we want to do to diagnose cancer at a curative stage is asymptomatic; rapid diagnostic centres are for symptoms. They will perhaps result in an earlier diagnosis, but not in a diagnosis of early cancer. Discuss. Participant C, I think you're talking about the fact that not one size fits all, so should we be looking at the metrics of saying, well, this cancer – I'm going to now annoy Participant E – the prostate cancer patients probably could wait longer than 28 days, whereas for oesophageal patients actually 28 days is really, really long. So I think it's about does that one size fits all? It's good to have a metric, but

should we have a more targeted metric? And I think it's this bit about: if we're talking about screening, we're talking about doing more, and that's about expanding. We think the workforce isn't enough at the moment, I am hearing, although I do not wish to put words in your mouth, but it's about what do we do to do more? So there is your car crash, Robert. I'm sorry I've got to go. It's one of them days. Take care.

**Robert Francis:** Thank you Jeanette, that's fine. Let me put in a patients point of view, if I could. A patient told us the other week that having had some screening – I can't remember now what it was – she was told, 'oh this would be fine, don't you worry about it', but well, obviously you will see the doctor a week later; she gets a phone call saying, 'could you come in two weeks' time and bring your husband with you?' Then she had to wait two weeks before obviously realizing if you bring a friend she's going to have breast cancer, that it's bad news. When we talk about 28 days, it's a very long time for people, whatever can or cannot be done about cancer, [indistinguishable – poor connection]... but to add on to Jeanette's point. So unless anyone has anything else to say on that one, shall we go on to innovation and technology? I know some of you are right into this field, but the question we have been asking is whether there is equality in terms of investments and so on all over the country. What's your experience of it, and if there has been research and innovation going on, has it been in focus in any particular areas?

**Participant B:** Yeah, just actually hot on the heels of our last question. It's around AI and radiology and imaging, and it's something we hear is happening elsewhere. I know it's not happening in [the] Northeast, North Cumbria, I'm not sure if it's happening elsewhere in the country. There may be pockets, but I think when we have such issues and we all share the same issues with radiology, we know the technologies out there are advancing quickly internationally. Why are we not investing more as a collective in the UK to possibly look at AI? But somebody else may know something I don't on that. So I just think that's an interesting area that we should probably be looking at.

**Robert Francis:** Yeah. Probably one other thing is [that] it's going to be taken away anyway, what we've got. Good point.

**Participant E:** AI is something of particular interest to us as well in radiotherapy, of course, because radiology and radiotherapy it may be... but there seems to be so much emphasis on it without any delivery at this point; it's going to be interesting to see when it comes through. The other thing to really say about with radiotherapy, is that we are clinical oncologists in the UK, which means we're also trained in systemic anti-cancer treatment and that therefore means that it's actually quite difficult for us to get or employ people from outside of the NHS who are radiation oncologists, by and large. There will be ongoing discussions about that no doubt to the end of time, but there is no doubt that there's been a huge difference in radiotherapy capacity, but also radiotherapy machines over the last ten to fifteen years. The problem is that every machine is a workhorse, but after ten years it becomes a difficult workhorse to deliver high quality radiotherapy, and there are huge differences all over the UK. When some of the technologies came in, IMRTV, etc., you know, that was very, very painful for some places and remains very painful. So I would have a lot of sympathy, for instance for Sheffield, because when I was in Leeds, and as the TPD – I was also the regional advisor – and there was quite a lot of difficulty for Sheffield, and [there] remains difficulty for Western Park in terms of access to radiotherapy. The lead for the SABR consortium was based in Sheffield, but unable to get the techniques there. I mean, protons are obviously separate, and I don't want to talk too much about protons today, because that's a different pathway within the NHS, but I see huge disparities and as I said, as an AAC going to interviews all over the UK, you know, what happens in Northern Ireland... I used to work in Brighton, and I still have friends in Brighton, I know

what happens in Brighton, I know what happens in UCH, and because we're relatively small specialty anybody that thinks there isn't a huge disparity is living in cloud cuckoo land.

**Robert Francis:** And the solution to that is..?

**Participant E:** Well, you know, we are very big in the NHS. We should be able to buy bulk and buy well, and there was a lot of support for that sometime ago when the 'radio therapy 100 years' came through, and VMAT, and all of the machines were updated and then, you know, the eye went off the ball. It was a different government, it had different priorities, different things that had happened. What we're trying to do with some of this work is to wave at people and remind [them] that we are still here. With every respect to Participant F and her work with them, which is mostly again funded by research, you know, the early stage tumours, solo tumours... solo tumours are only cured by surgery or radiotherapy; they are not, I'm afraid, cured by immunotherapy, and they're not cured by a lot of the research that is put in. So some of the questions are going to have to be along that line. Where do we put the money? Because we don't have it to spare on everything

**Participant A:** With regard to innovations and technologies in surgery, there is a wide variation in minimally invasive surgery rates in lung cancers. Some trusts have only a 30% minimally invasive resection rates; other trusts have up to an 80% minimally invasive resection rate. This seems to just be allowed to carry on. If you go to the neighbouring region you're half as likely to get a minimally invasive operation, you stay in hospital two days longer. There's evidence out there that it's better, and this variation seems to be allowed to continue. With regards to new technologies coming on, a lot of trusts are buying robots now. It's very variable which trusts will spend over £1,000,000 buying a robot, and the evidence for their benefits in certain conditions is very variable, and it seems to be fairly uncontrolled who buys them, the patients aren't getting put into trials, and I think there just needs to be more control with regards to that.

**Participant C:** I think the big issue for me is [that] I'm dealing with oncology research, chemotherapy, and obviously the new immune therapies. I think the big issue, the disparity that I really see working in a district general and also in a central hospital, is that the funding for clinical research in a teaching hospital is completely different to what's available in your local DGH. Patients living within the local DGH catchment should really have equity in terms of access to research funds, and there clearly is not equity even within a region. Without getting personal, even within London there isn't equity within hospitals, and within and outside of London I'm sure that the same would be true. I think the other thing is that research is very much dependent upon the pharmaceutical industry. I don't think anybody has discussed that, so it's the ability of the government to support translational research. Clearly, the new therapies are clearly very expensive, but I think it's really important that the government kind of supports that. The other thing is that COVID meant that a lot of the research staff left to do COVID research, which I've got to say I think some of it was of variable quality. I know that we are in a national emergency, and we wanted to support COVID-style research, but a lot of the cancer-related research certainly locally stopped, and I don't think that was necessarily of benefit to patients. The NHS is quick to stop things but slow to start, so you're in that kind of horrible transition phase. The other thing is research. Clinical research often focuses on new treatments for people with relapsed refractory disease. That's clearly really important, but I think it's really important for research to focus on early diagnosis, delay in diagnosis, patients understanding why they present, and certainly from our field in myeloma, there's very little research done towards early diagnosis, delay in diagnosis, things to encourage patients to present early. There's a huge amount of appropriate... a huge amount of resources and money that's spent on therapies that clearly have benefit, but I'm sure you'd get more bang for your buck if you were looking earlier on in the pathway.

**Robert Francis:** That sounds very good.

**Participant D:** I was just going to say I wholeheartedly agree. I mean certainly our research portfolio in Sussex, having moved not that long ago from London and the Marsden, which obviously has a massive research portfolio, you know, there is that huge inequity, and I would agree that the problem is obviously that looking at the early part of the pathway tends to be seen as academic research, doesn't it? And the funding around research that isn't a clinical trial is much harder to come by, and has got harder, I think, increasingly. I'm not an expert on that, but certainly that's my impression. I do think as well... was this about innovation as well? It wasn't just research specific, and I do think one of the things that I find slightly unnerving is the sort of growth in apps: patient apps. On one hand I think [they are] a great thing to be embracing, but they sort pop up all over the place, and the ability to know what would be useful, and actually what would work well alongside your colleagues in the trust, possibly where your patient is going to be picked up in that DGH when they are unwell on their treatment or whatever, you know, there is that lack of communication, that lack of certain national level engagement in making sure that we're all sort of on the same page with things like that and how we utilize that innovation.

**Participant F:** Participant E won't be surprised that I'm going to just pick up on her point about me not curing people. So I used to teach that only surgery and radiotherapy cure anything, but we do now have long-term survivors who I believe are cured with our immunotherapies, so I cannot be convinced that a patient who came 12 years ago with brain metastases and received immunotherapy and is still alive and disease free is not cured. But I appreciate it is about where the money goes, and these are expensive treatments. Which brings me on to my next thing that actually the CAR-T, as has already been mentioned, are the things that are most likely to give us those long-term cures. And yes, at the moment they are not equally distributed around the country. Pharma: you're absolutely right, we need to think about that. And you know, we're dealing with the double whammy of COVID, but also Brexit, and keeping pharma involved from that point of view. So we have to be really proactive and be out there showing why the UK is the place to do research into and to bring drugs. And yeah, translational research: I do think the landscape is changing, and we need to carefully look at that. It does feel as if there's centralization of translational research. For example, if you look at the new Cancer Research UK centres that have just been announced, there are fewer of them and most of them are clustered around the 'golden triangle' with another couple of large centres and one in Scotland. But nothing in Northern Ireland; nothing in Wales, and fewer centres outside of that as well. Now is that because we do research best in that way? That's the argument to have, but I hope it's not that you have kind of that ripple effect that the further you are from one of those centres, the less likely you are to benefit from any of that work that that's happening.

**Participant B:** Yeah, thanks. Just on the inequity thing and research, I think if you sit in a DGH, it's not just about centres, it's also about individual conditions, and if they have a particular interest in undertaking research. So if you've got visiting oncologists or visiting clinicians and they don't personally show much interest in research, you have a real inequity in terms of what your patients are offered. So I think it just... ripples around oncologists as well. So just to note it's down to an individual basis and where there should be an expectation that actually patients do have access to that. But then if a patient knows they would then have to travel 100 miles or excess of 50 miles to access somebody else, they're more likely to think, 'oh no, I'll just not bother then'. So there's something about how can we make sure there is more equitable access close to home. And is that about all your data sharing and talking about innovation? We shouldn't miss out. But in this section, IT systems, data sharing and transfer of information between trusts, the ability for us to share that patient information, you know, should we be moving our patients around or is there a better way

through innovation that we can actually just share information? I don't know if that will change with Brexit; that will be one good thing to come out of it. I'm not saying GDPR is a bad thing, but I think it limits us somewhat in looking after our patients and working as a system sometimes.

**Robert Francis:** Do you have a system for offering your patients the choice of going somewhere else for an innovative treatment?

**Participant B:** It's very, very limited. So again, it's down to that clinician having that conversation with that patient. If the patient asks directly and is equipped and empowered enough to do that – we'll go back to health literacy – then yes, there may be a higher chance, but actually we do know it's very clinician dependent. It doesn't feel nice sitting here saying that, but, you know, if you see one doctor you're more likely to get offered it; if they can't offer it, they will speak to their colleagues. You see another, and they won't. So yeah, I don't want to be negative, it's not my way, but I think we have to acknowledge that it's often down to individuals.

**Participant E:** But sometimes it's inappropriate stuff as well, isn't it? So quite often there's a lot of whatever is in the Daily Mail, you know, so they'll come up with, 'I want this, actually', and that can sometimes take ten to fifteen minutes to unpick, [time] you don't have when actually you want to concentrate on some of the other stuff. Also the database is, so the LUCADA [National Lung Cancer Audit], and also there is a head and neck one [database] that was run out of Newcastle or Middlesbrough... These had a huge amount of work put into them. Did we get anything out of them? Was there any useful data that was generated that was shared when you asked about it? Was there heck. So sometimes people get a little bit teed off because they're repeatedly, you know, 'oh, let's do this, let's share this, let's put it, you know, only a clinician can fill this in', saying, 'it can't be left to anybody else you've got to do it', because then that'll be the only data that comes out, and I've yet to have anything of all the effort that we put in to actually being able to inquire and interrogate a database that comes back with anything useful.

**Robert Francis:** So going back to the patient, should they be taking your point that they shouldn't be getting their information off Google or the Daily Mail in order to decide they'd prefer to go somewhere else? The alternative seems to be what you're offering is either clinician dependent on what they know, what their preferences are, or ignorance. Is there a better way of sharing information in an informed way to give people choices that are meaningful?

**Participant E:** Well, I think that's the question, isn't it? It's about meaningful. It's about where is the data to show good comparisons? And that is not just related to something that's been driven in by – so that's clinical trials, to put people into clinical trials – that patient has to be motivated to want to go into a trial because you have to be very carefully consented because there isn't a necessarily benefit. We know there's a benefit to going into a trial, but there isn't necessarily a benefit of an individual trial being one treatment being better than the other. That's why it's a trial.

**Robert Francis:** That's right. I'm going to go to Participant D next, but one question we specifically [heard from] participants at our patient event is that they're not being offered places on the clinical trial due to their ethnicity. We don't need to comment on that in particular, but yeah, if there if you have experience of diversity considerations when we recruit participants to trials... I'm getting one nod there.

**Participant D:** I wasn't particularly going to comment on that...

**Robert Francis:** Say whatever you want. Someone else will say; we've got time.

**Participant D:** I was going to say, it can be sheer logistics as well, so, you know, a patient of ours who is based in Sussex is going to be able to potentially access a clinical trial in London a lot more easily than a patient of Participant B who is in Cumbria, I would suggest, because of the sheer logistics, and that doesn't make it easy. I mean, one of the problems as well as that we can have is they might be able to access that treatment in London from us – it's still a bit of a trek, but it's not that massive – but then when the patient becomes unwell they come back under the DGH and that communication about the side effects... I can vividly remember being in the acute oncology team at Brighton when immunotherapy sort of came in, and suddenly we were seeing all these patients coming into our A&E departments and didn't really have any information from the treating centres as to how to manage these patients, and that was a massive learning curve. So from a patient pathway perspective that's a concern, and that comes back to IT as much as it does anything else.

**Participant B:** It's also how patients are recruited – well, how trials are actually set up – they are set up and there has to be a clinician in a trust. So there's no kind of regional access to trials. So I think until that's addressed – and I know that's got its own set of logistics and safety concerns – but I think until that's addressed, we do move our clinicians around and we do move out patients around, and I think that needs to be looked at, which would be a starting point.

**Participant C:** Ethnicity, I think ethnicity is really important. It's sadly a big disparity in terms of trial entry. There's loads of data sadly to support it. I'm sitting on a national myeloma trial where we're looking at ethnicity, and I accept that there are regional variations in ethnicity profile, but even then there is a lower number of people from certain ethnic groups and trend trials. I think personally – and I feel very strongly about it – it relates to the fact that people can't receive or have access to trial treatment in their local district general that may not be next to their teaching hospital that has your migrating group of patients that, understandably, will want to go to what they perceive as centres of excellence, and that patients want local treatment. If you get on with the patient, the doctor, [and] the nurse, they don't want to go anywhere else, they love you for it. They don't want to move; just getting on the bus is enough. Whether you offer free parking or not is probably the most important thing. And actually the concept of having adequate research support in a district general – I speak from somebody who works in a district general and teaching hospital – and you can just struggle within your district general to provide a basic trial where patients from lower socioeconomic backgrounds would gladly enrol if they were able to. It really bugs me. I'm being polite...

**Robert Francis:** Yeah. Well, that sounds good. So I think what I'm hearing generally is that yes, there's huge variability in access to innovation and some places do very much better than the others, but it's not always clear what the rationale is behind prioritisation or whether there's any overall strategy which actually makes sense of what is chosen to be to be done. I hear from you all great concern about this area actually, and I'm one of the areas I think you're concerned about is the dependency on pharma, not necessary because it's, you know, it's obviously valuable to get the something, but there's something about how that is managed. And finally we've got the inequity of access to clinical trials. I don't know if you were talking about that earlier, but I wondered whether the people who are on the placebo side of a trial probably feel the same things anyway... So, we got a few minutes left before we go back, and we you've been commendably disciplined in the way you've talked this. Bearing in mind the questions or the issues we've been through, is there anyone who wants to add [to anything] they haven't been able to on any of those issues?

**Participant F:** I was just going to say there are simple things we could start to do to improve. Certainly the last thing that we talked about, so actually the positives that we talked about of the pandemic. So there is no reason that [for] every single trial you shouldn't be able to consent online. You should be able to do that initial consultation with your patient online then wherever they are in



the country they can then make the decision about whether that's the right thing for them, because often it's getting people through the door and having that first discussion that's the important thing. And the fact that we still don't approach certain people because we can't interpret their patient information sheet is, you know, it's not acceptable. We should always have the option of doing that and not have to put an amendment in in order to do it into a different language. So you know as well as there being champions out there in the communities and all those types of positive things that can be done, I think there are, you know, some things as I say we could say to every single centre, every single trial, that those need to be done from now.

**Participant E:** It's really from an oncologist perspective: there seems to be a big shift to acute oncology, and that is sometimes for very good reasons, but primarily because life as a medical registrar sounds as if it is probably the most miserable job in entire NHS, and being an acute physician, that's where some of the workload difficulties are, and that is putting us as in international group at a disadvantage because the GMC prioritizing acute oncology in the curriculum, for both medical and clinical oncology, is taking some of the eye off the ball of some of the important things that we should be really specializing in with that support of acute oncology elsewhere. I cannot think of anybody in the two major hospitals that I've worked in who likes their acute oncology workload, who finds it valuable or feels valued or wants to continue it. every appraisal that I do of anybody who happens to have any acute oncology in their job plan, it's the area that they want to stop, quite frankly.

**Participant D:** I was just going to say I think that's really interesting, Participant E, because I was in at the beginning of acute oncology, and from a nursing perspective it's been really embraced, and actually I switched our service locally – what was locally then – from to a medically led to a nurse led service and was involved with the changing in the guidance around it, because actually I think the reality is a lot of acute oncology services, and I'm speaking fairly anecdotally, are nurse lead. I know on the call in one of the other 'breakout rooms' is a nurse who runs a fully nurse led service in the West Country, and they're very successful because actually the reality is the acute site, you know, the nursing staff, can pick that up and then just pick the patients that the oncologist then needs to review as and when they need to be. Increasingly those episodes are pretty sporadic, and certainly I know it's one of those things I know that's not popular with oncologists, because it takes away from being able to focus on your team site. It does concern me if there's been that shift within the curriculum to sort of push that because it doesn't make much sense to me, given that there is a good model for that advanced practice role to support it.

**Participant E:** I think that it's been a huge success from a nursing perspective. I was part of the first and the second peer reviews and I think there has been a big difference and an improvement. But yeah, maybe it's an individual feeling, but clinical oncology definitely, it's taking away from, you know, the USP...

**Participant D:** And it comes back then, doesn't it? It comes back to, actually who do we need doing which jobs and how do we need them doing it? Rather than, 'actually this has traditionally been the role of an oncologist', you know, we need to move away from that, and we're all trying very hard to move away from that, but sometimes it feels like it's like wading through treacle to get those sort of structures in place and have that consultant led multidisciplinary delivered service instead.

**Robert Francis:** It takes me back actually to something I wanted to raise really about workforce. We've got this commitment looking at about increasing levels of staff, and what you're telling me I think is that there's a huge shortage of staff in all sorts of roles, But do we have the right idea? Is there a consensus within the country and the various bits that make up a cancer services to what the

priorities are, where we actually need increased staff or development and training, or is that lacking cohesion?

**Participant E:** I think we're all going to say lacks cohesion. This is the first national thing [where] we've been... we've had surgeons, medical oncologists, nurses... actually been asked the questions.

**Participant B:** I think whilst there's a lack of guidance, and in particular speak about nursing, for lung we've got information about the ballpark figure of 'there's this many new patients, this is what we'd recommend', but there are no kind of standards. There's no recommendations, so you'll also get regional variations where we might look at a regional piece of work – which we are doing – a regional nursing census. Actually, how do we then know if we have just got a regional glut of nurses? I don't think we have. Or a dearth of nurses compared to a neighbouring region or a region down South. I think until we start to get some national metrics and standards, I think it's really challenging even to do regional pieces of work and make them meaningful.

**Participant A:** We've talked about diagnostic centres to make the diagnosis: should we have cancer centres as such where cancers are diagnosed and treated? I'm quite fortunate that we work in a specialized trust without an A&E, but I've colleagues all the way around the country and in neighbouring trust through another cancer surgery, they come in in the morning and they don't know whether they're going to be operating or if it is going to be cancelled, they don't know whether they're going to have an intensive care bed for their patient. You hear stories of some people, 50% of their cases are cancelled because lack of beds, and that's just awful for a patient. For a family coming in to have major cancer surgery to have to be told, 'no, we've not got an intensive care bed today, we'll try again tomorrow', or, 'go home and come in next week'... We've got to make sure those sort of post-op facilities and beds are available and these operations aren't getting cancelled and delayed. How we do that, whether we actually need specialist cancer centres away from the acute trust is for debate.

**Robert Francis:** Right, thank you. We haven't been taken away yet, so we can carry on talking.

**Participant D:** I think on one hand it's the debate, isn't it? You have specialist centres, which are great, and you need specialist centres for rare diseases to ensure that you keep those skills, but then what about patient choice and care nearer to home? It's a really difficult one. Really difficult.

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