

Written evidence submitted by Group 3 (ECS0046)

Transcript of roundtable with cancer patients and service users for the Health and Social Care Committee Cancer Services Expert Panel on Thursday 27th January 2022.

Group 3

Minesh Patel: Thank you everyone for coming today. One of the big areas of this inquiry is about the number of staff in the NHS who are providing cancer care, and what that mix of staff looks like. Our first question is asking, if you could pick one word to describe what your care was like, or what it's been like if you're currently going through treatment. Does anybody want to share their initial reflections on that and overall, how their care has been?

Participant A: I don't mind going first. My one word would be variable, because I had different experiences at different stages of my treatment. I went to the doctors and my nurse found something, and I was fast tracked within two weeks, which was great. I'd literally just started a job as a head teacher, but because I'd had lumps before I told myself it's a morning out of work so I can just look at my emails. I had to go on my own to the hospital for the ultrasounds and tests and I was told to come back in a week with my husband, which obviously was quite hard to hear. I came back and I was told that the tumour was a different size and that I had to go for an MRI. If you've got breast cancer the MRI is so unladylike, you have to lie on your front in the MRI machine. It broke twice whilst I was in the hospital, and it felt like every many in the hospital was coming in to fix the machine- I'm sure that was a one off, but it was horrific. I was put on a course of chemotherapy. I had an oncologist who I could just talk to the phone, she told me that you have a very big cancer and you're going to need this drug. On my first day of chemo I had a really bad reaction, and I was with a lovely junior doctor who looked terrified and some amazing nurses. I was supposed to do six rounds of chemo, but I couldn't take it, so I did four. I had a mastectomy, and I wasn't offered reconstruction because of radiotherapy, and I wasn't offered an expander as well. The care I received in hospital was amazing. It was absolutely brilliant. Then I did radiotherapy and the care I received from the radiotherapist at that hospital was brilliant. I'm now on various drugs and bone infusions and all sorts. One thing for me, as a woman, is the reconstruction and I've been told that it's a 3-4 year wait. I know that it might not seem like an important thing, but I've had to pay to go privately for an appointment and I'm not on a waiting list on the NHS. That's my treatment journey.

Minesh Patel: Thank you, that's really helpful. Just a quick follow up on that. With those experiences where you said that you received good care, we've got some questions further down the line about personalised care, can you say a bit more about what your staff team was like? What was good about them that helped you to receive good, quality care.

Participant A: When I went in for surgery, I was just so scared and the nurses on the ward were amazing. They took time, because you weren't allowed visitors, to sit me with and talk to me. They were just amazing. At radiotherapy, it was a really young buzzy team of people that were just lovely. It was just a joy to go. Chemotherapy, I can't even go there, it was just horrendous and it's nothing to do with the team- one of the parents at my school was a nurse there. It was just a bad time really. But where it was good was that you got that extra bit of TLC, because you were going in on your own. And it's good when things were explained properly. The first time I looked at my scar, I had a nurse with me, and they didn't just leave me on my own.

Minesh Patel: Thank you, and yes that personalised care and those interactions are incredibly helpful from what we hear at Macmillan.

Robert Francis: I just had a quick question. You said that right at the beginning you were told to come back in two weeks and to bring your husband, and I'm sure you thought that that wouldn't be good news. And it's a long time. I understand why they said that, but would you have preferred that it was done in a different way?

Participant A: I think I would have preferred for them to be honest and say it's very likely that it could be something. She just kept saying that she wasn't sure. I would rather people were a little bit more upfront because you know, and they know and it's just the elephant in the room. I know they need the scan to confirm it, but the waiting... they told me to wait for two weeks. I phoned up my consultant, and I know the secretary has to be assertive with the consultants, but she was very dismissive and said I'll get my appointment when it's ready. And I was just like you have no idea, because not only was I going through cancer, which in itself is horrible, but it was in a pandemic which is double stress.

Robert Francis: Thank you very much for that.

Minesh Patel: Thank you and thank you Robert for that question. Does anyone want to share their reflections on their care and specifics on what the workforce team has been like in that process.

Participant B: I'm a bit of a veteran at this, having started in 2003. I actually moved location, so the first 15 years I was living in London and just under control of an oncologist. Just before I moved to the North of England, I had scans that identified progression of the disease into the liver, and I was referred to a specialist centre in the North West. When I got there, I got my first introduction to a full multi-disciplinary team. So there is a dietician, obviously the neuroendocrine consultants, diabetes consultant and specialist nurses available at the end of the phone practically 24/7 when you needed them. It was a change of mindset and certainly a change of how I was being looked after. Up until that time, although I'd had my pancreas removed, it was still not really treated as cancer, it was neuroendocrine tumours which were described as slow growing tumours, so it was never really explained that the disease would progress into the liver. So it was a new start. The new team have been really good, the specialist nurses are just brilliant, and it's easier to talk to them than a junior doctor. I've found that for getting information, if you can get through to the specialist nurse then that is the best place to be. For the first time now I'm on a treatment, taking something called lanreotide, which is designed to slow the progression of the cancer and the tumours. So, that's good. I'm having six monthly scans, which I've had for 15 years, occasionally they drop to 12 monthly, but then the cancer throws a curveball and you get back to three monthly scans. But I'm finding that the help and the guidance that I'm getting now is certainly a lot better. Whether that's because of the specialist centre, or whether it's because I've found Neuroendocrine Cancer UK, I've got so much more information available now. When we get to one of your questions later on about what you would like to see in your care plan, I don't think that the NHS can necessarily provide everything and I think the care plan should look to bring in the specialist cancer charities and the specialist support groups. I think there is a lot to be said for meeting and talking to other people. When I was first diagnosed, I had never heard of neuroendocrine cancer, I didn't meet anyone with neuroendocrine cancer for 15 years. When I had my pancreas taken out, I didn't know anybody with diabetes so that was a shock, but at least I was referred to a specialist Diabetic Centre. And actually when I had my pancreas taken out and I was sent back to the ward, I ended up back in ICU, as nobody had told the ward that I was diabetic and needed insulin. I think experience helps and talking to people that have been there before you or are on the same journey helps and is important.

Minesh Patel: Thank you, that's really helpful and it's good to hear about some of the positives there. It sounds like there is a common theme emerging about the important role of specialist nurses and having that tailored support. You've also mentioned that suddenly you enter this world and you're trying to understand treatment and having that specialist support, whether that's charities or just speaking to people with a similar experience, is useful.

Participant B: Yes, it's difficult. You turn up for your consultation and you never know who you're going to see, you don't know whether it will be the primary consultant, a junior doctor or a nurse specialist. I certainly think that seeing a nurse specialist is a hell of a lot better than seeing a junior doctor. I know that everyone has got to be trained up and get the experience but, I'd still prefer the nurse specialist whilst on a watch and wait cycle or when you're trying to understand possible symptoms. However, if the scan shows disease progression, then you would need this explained by the consultant.

Participant C: I was just trying to write down so that I can remember the order that things happened. I'm going back four years now and where my head was then is totally different to where my head is now, so you forget and blank things out. I had my first bout of cancer, it was cervical cancer when I was 26, I'm now 57 so it was a few years ago. I ended up having a full hysterectomy- as I call it a full gear box removal- many years ago and been fine ever since. Four years ago, I had an attack of diverticulitis, which I'd never had before and was a bit of a shock to the system. It was arranged for me to have a flexible sigmoidoscopy and during that they decided to bring me back for a colonoscopy so that they could do a biopsy. I should say that over the course of a year I ended up doing six colonoscopies, with four different consultants and two different students. So my one word would be disjointed. The colorectal team went through a huge turnover of staff within just one year, it was absolutely crazy. On my first colonoscopy, they took a biopsy and the person who did it at the time told me 'don't worry, I've had a look and I'm pretty confident that it's nothing to worry about.' And then two weeks to the date from a consultant secretary, saying that I need to come in within 24 hours. And I said I had a good idea of what it is, because it's two weeks to the day and I've been waiting for this, and then I heard her turn round to the consultant and say that 'she's got a good idea of what she's going to be told tomorrow.' So I'll never forget that conversation. Going back in for the next colonoscopy, a student started it, and it was horrific. I was told that I had 23 polyps, it was a mess and it got to the point where the student was struggling so the consultant had to take over. So in the next colonoscopy, they asked if a student could do it and I said no, I wasn't prepared to go through that again. After that it was six months. I'm fine now and everything was sorted. But if you're asking about the people side of things, I think the colonoscopy department in my local trust is still not brilliant. They're having trouble recruiting people. Not everyone wants a career looking up people's bowels, I get that, but they're struggling with numbers. You've got this ongoing disjointed communications. I had to wait months for letters. It seems that if you were actively having to hit their deadlines of two weeks, or the 63 days, then you were seen, but if it was negative or there was nothing else found then it could be months before you got a copy of that confirmation letter. You know you didn't have anything, because you know there are targets to hit if you did, but it would have been nice to have those confirmation letters in a timelier fashion.

Minesh Patel: Thank you. It's massively helpful in that bit around communications. I can imagine that adding to the general anxiety and how that affects you during what is a really difficult time. Participant D, is there anything you want to share about your experience?

Participant D: I got the first indication that something might be wrong in March 2020, which was when COVID was really coming into the UK. I had my first doctors appointment in London, it was very fast that I got some more news. I had to come home because all of the students were sent

home, and because my doctor was in London, I ended up getting diagnosed over the phone. That was a bit of a shock. But the consultant himself was brilliant, and I don't have any issues with that given it was very extraordinary circumstances. I understand why it happened. I then got transferred to a specialist centre in the North West and the one word that I can use for my treatment from that point on was just incredible. Obviously COVID was there, and parents couldn't come in, so it was just me. It was 12 lots of chemo, every two weeks, over six months. I had my consultant, and I was in the Teenage and Young Adult Unit, so I also got a specialist nurse and the two of them were just incredible. From the second I started speaking to them I felt a lot calmer about the situation. Throughout the whole thing that made everything a lot easier, and they incorporated my parents as much as they could. I would go in and my mum or dad would be sat in the car, and they would video call them into the consultations, so they did everything they could to involve them. I go back every six months now, for the next five years. The workforce itself at the Christies I don't have anything but amazing things to say about them. They really helped me through it.

Minesh Patel: It's really nice to hear those good stories, when you've got those supporting teams around you. We hear so much about gaps in workforce, and teams overstretched, but I think ultimately people want to do their best and provide quality care so it's nice to hear your experiences with your team. Participant E, would you like to share your experiences of cancer care and the staff that helped you?

Participant E: I was diagnosed with non-invasive bladder cancer at the end of December 2020. I went in with haematuria to my GP and within a fortnight I was seen at my local hospital, and I was diagnosed. My diagnosis was on the 13 December and the visit for the procedure to remove my tumour was the middle of January, the 14th, if I remember correctly. So that felt fine, and it felt like I was on the fast track so to speak. With it being high-grade but non-invasive, I was assigned the BCG treatment- the BCG vaccine. Almost all the time, I've felt as if I'm within some sort of standard set of routine procedures, I've just felt that I'm on a journey somehow. Which is good, of course. I am particularly lucky with the diagnosis, and I have learnt through this, and some other experiences, that I appear to be the sort of person that just accepts it for what it is and gets on with it. I'm happy to report. Since then there hasn't been much change in turnover in personnel, except that the flexible cystoscopy, which is the three or four monthly examination to see that things are still clear, has been done by a different person every time. They appear to be part of the same team, but it's an introduction time every time. The specialist nurse that gives me the treatment is great and we have a good relationship. I have absolutely no question marks about any of the staff team at all. The only other thing I would say is, and I think this is significant, there has been a shortage in supplies in the BCG vaccine. I've been told twice that I'm coming off the treatment, and then back on, and then off it again. I had the six induction treatments, then I had the first three maintenance treatments, and then the second maintenance sequence was stopped after the first treatment. So I had 10 altogether, and then we missed two or three months, and then because the supplies hadn't been restored sufficient for to be included- even though I was told at one point they had been restored. I've now been on mitomycin C for two applications, two installations, the last one of which was yesterday. I think the jargon is suboptimal in terms of my grade of cancer, my condition, and what the treatment is. I've tried to find out why there is this lack of supplies, and it seems to be local to the North East. I've written to my MP, who is Secretary of State, but we've got nothing back yet. And I was told yesterday that my local hospital is still low on the BCG that I was on, but they're just about to validate another strain of the BCG vaccine, so all being well I will be back on the optimal treatment in a month to six weeks' time.

Minesh Patel: That's really useful, and we'll come to some of those points about treatment in more detail. I'm really stuck again by the value of specialist nurses, which is definitely a common experience. I'm going to move onto the next topic, which is about living well with cancer. Obviously, survival and recovery from cancer is really important, and the bit we're interested in here is about the quality of your experience, the quality of care and quality of life when you're faced with diagnosis and going through treatment. Some of you have already spoken about the value of obtaining personalised care and how important that is. We've got a few questions here, and what I thought would be useful if people share experiences any relating to tailored care, things like care plans, health assessments- what has worked well and what hasn't worked well. Participant B, would you like to start with this one, as you started to speak about to talk about personalised care in the previous question.

Participant B: Prior to coming to the specialist centre three years ago I had never had a personalised care plan. I pretty much had fifteen years of living my life normally. The care was basically turning up at the hospital to have the scans every 3-6 months, getting to every 18 months eventually, and then when something catastrophic happened I had an operation. Since I've got to the specialist centre, I've got the multidisciplinary team around, and I have a regular monthly injection which was organised by the centre. I get a text message every month saying that the delivery is due, and every month my wife will inject the lanreotide for me. I have good contact with the nurse specialist. When I'm facing the day to day challenges that come from the neuroendocrine, the lanreotide and the management of blood glucose, there is always somebody there that I can turn to. I think the only thing that it's failing on at the moment is that it's not 100% integrated. So I think I know where I am with the cancer centre but my insulin management, my diabetic management, is pretty much kept separate from that. Rather than having regular appointments with the diabetic team at the cancer centre, I have to go to the hospital and unfortunately, they've been hit by COVID. I actually had my first consultation there in two years on Friday, so hopefully things will start moving again and I'll have a care plan to see the diabetic nurse specialist every eight weeks, and then a consultant every three months. Hopefully, that's back on track again. It also falls down with the GPs. I've had no interaction with the GP for the best part of two and half years. You ring them up and you can't get past reception. If you can get past, you're offered a telephone call. I don't mind telephone or video calls when I'm talking to my consultant or the nurse specialist at the cancer centre because I have a relationship with them, I know who they are and they are aware of my problems. But with a GP, certainly with our surgery, it's never the same person and more often than not it's a locum, and talking to somebody that you don't know over the phone is uncomfortable. I've also got my daughter here, and it's difficult to find somewhere to sit down and have that private talk. I'm happy with the support I'm getting from the cancer centre, and as I said earlier, I'm getting a lot of external support from Neuroendocrine Cancer UK, so that's helping the concern. Certainly, three years ago I had never heard of quality of life, I would never have considered that. But now, I'm very aware when I got to the centre that it's important to know what is happening with the tumours and the bloods, but it's the quality of life that is probably more important in my stage of life now. I think I can thank the charity Neuroendocrine Cancer UK for bringing that to the front of my mind. I'd certainly like the cancer centre or centre of excellence to be more proactive in that way. The last time I saw the consultant four weeks ago, it was very much 'I've looked at your scans, I've looked at your bloods' and I tried to discuss various issues with him and I don't think they were giving sufficient importance to quality of life. I think there is a need for something more structured, rather than just leaving it to the doctor, if there could be something in your file. So, you could go in and say that for the last three or four weeks I've been having pain, or my movements have been like this. Perhaps, now that I've

been at the centre for three years my priority is reducing. So, a bit more attention to quality of life would help.

Minesh Patel: Thanks, it's so useful for you to share that and some practical things for the panel to think about. Are there thoughts from others in the group around tailored care? What's worked well, where are there gaps and what could be improved upon?

Participant A: I feel like it didn't really have much of a care plan. I remember my oncologist saying to me 'you've actually got two tumours, but don't worry about that because that's for the surgeon to know.' But actually I wanted to know, and I was thinking 'what kind of tumours are these?' and then you start Googling things. I would definitely agree with Participant B as well, I had two teenage boys at home and trying to speak on the phone was tough, especially when talking about things that were going to affect them. And every time I went, and it could be because we were wearing the face coverings, but I just felt like they never knew me. It's hard to talk about when they're asking you to tell your whole situation again. I just felt, other than from individual nurses, there wasn't really any pastoral care. When it came to my mastectomy, they just said 'you're going to have a mastectomy, because we're keeping it simple due to COVID.' So I wouldn't say that the wellbeing was great, but I did go on a brilliant course online called the Hope Course which I would recommend.

Minesh Patel: Would you like to say more about the Hope Course, because it's not something that I've come across before.

Participant A: I've been very positive throughout, which has helped me I believe. I went to one forum, I can't remember which charity it was, and everyone was just so miserable about the whole situation, that I felt it wasn't doing me any good. So I went on the Hope Course, which was actually recommended by my hospital, and it was great. It was about trying to move forward. During treatment you have a plan, but when that treatment stops or when it starts to end, you're left with this feeling of moving on with your life and it's the mental side that is so hard, and I got like that. But the Hope Course is great, it had some brilliant TED talks and forums, and it was good to speak to people in a similar position. It's hard and I feel like it's a little bit underestimated sometimes by professionals, definitely in my oncology department. So yes, I would recommend the Hope Course. It's online and you can sign up and do little activities and simple tasks that you can achieve.

Minesh Patel: Thank you. It's been pretty good to hear more about that, and how it has helped you in particular as well.

Participant C: I work for a charity, and we have counsellors and therapists, and we work with around 6000 cancer patients a year. One of the biggest things that we get is that patients get told they have cancer and hang on while they have the physical treatment, and it's after their physical treatment has ended that they report what we call hanging off the cliff; emotionally, mentally and socially. We're working closely with the GRAIL project now and working for it to be recognised that getting a cancer diagnosis is a trauma, and like all traumas if you have early interventions, it will reduce that emotional and mental stress and build up that comes from diagnosis all lasts all the way through treatment and beyond. Time and time again we see people being told 'you're in remission now, your treatment's finished' and they go back to work, and they try to restore some normality of life before they had their diagnosis, and they just can't cope. Because cancer does affect us all massively, both emotionally and mentally. And that brings me to the second point about health needs assessments. From my personal experience of a colorectal nurse trying to do a health needs assessment, where they're asking about emotional issues and other issues, and they're not trained to do that. For years, the NHS have trained specialist nurses to think about the breast or the prostate, or whichever part of

the body or tumour type they are looking at, but it hasn't trained staff to look holistically at people. So now, when you're asking a CNS to do a health needs assessment, they are just ticking boxes and filling in forms. There is no human interaction, or even from the health needs assessment real engagement of where you can refer that patient onto. I feel passionately about the fact that the charity sector has been delating with people on a holistic basis. So they don't just treat the cancer, they look at the diabetes and look at all the other comorbidities- whatever is going on in that person's life- and appreciate that the person has many other issues, not just the cancer.

Minesh Patel: Thank you, that's really useful and I agree with that need for a holistic view of somebody's needs and to not be dismissive of the non-physical impacts of a cancer diagnosis and thinking about somebody's life after recovery.

Participant D: So in terms of care plan, mine was quite straightforward because it had a set treatment for it, and I just had to follow that so there wasn't too much to set out. One thing relating what everyone else has said, which I think benefited me more than most was the specialist young person nurse I had. Honestly, she was my guardian angel. When you first get diagnosed, you start getting weird aches and pains over your body and you've got no idea what they are, and you're quite scared, but seven days a week I could pick up my phone and text her and she would reply within half an hour. I know that's a massive ask of people, and I don't know how she does it, to always be there waiting. I'm sure she probably got a bit sick of my silly questions, but she was always so nice about it and completely understood. It's a massive ask to ask the nurses to do that, they need to have their off time. I think that what's happened with COVID means there is a massive risk that they're going to start haemorrhaging staff, because staff are being run into the ground. I think the key is to fundamentally train up more workers, so that you're able to offer that facility to more patients. Because I think out of everything, especially at the start, that was something that helped me a lot, and if that could be given to everyone it would maybe help them through it as well.

Minesh Patel: That's really helpful, and it's important that we have that pipeline of people coming into the profession so that people can experience the type of care that you've described. We've got around 15 minutes left, so I'm going to hand over to Robert for questions on diagnostics.

Robert Francis: Thanks Minesh. I think you've all seen the questions, and some of them we've touched on already about pace and speed of diagnosis, but what we haven't covered so much yet, is whether, at any stage, you were offered choices about the type of treatment you could get, or whether it was explained to you what the consequences of various choices might be. That would be one question. And the other, and some of you have touched on this already, is what do you think the effect of COVID has been on the speed at which things happened, or indeed the quality of what you've got. Some of you have had treatment for longer than that, some of you haven't, so some will be able to judge the difference about that. So it's about choice of treatment and the impact of COVID.

Participant E: I'll start. I don't have anything to add to the previous set of questions, by the way, because things have been reasonably straightforward for me. Regarding choices and options again I've been relatively fortunate in the diagnosis, and therefore there haven't been really any impactful decisions for me to make. Certainly all of the issues have been shared with me all of the time, and I've found my specialist nurse in particular very accessible. I can't phone her, but I can email her, and she usually comes back within the day if something changed or if I've got a particular question. What I would say in reference to the last question, was that I found the support of the charity Action for Bladder Cancer particularly helpful. Also the support of Macmillan nurses. I went to a roundtable, a sort of induction course, and what that allowed me to do was to put my position in context with all

the other people, most of whom had had some serious decisions to face up to. This is second hand but, throughout that I never heard any complaints about the level of choice and communication that there was surrounding those choices.

Robert Francis: Thank you. Once again, a thumbs up for specialist nurses, but also a thumbs up for the broader work that charities can do, and how perhaps they need to be consciously incorporated into the work of hospitals. Would anyone else like to comment on this area?

Participant A: I just wanted to say that I was definitely aware that the treatment and the options that I was given, were different in my area to other areas in the country. It was not explained to me that radiotherapy would mean that I could not have a breast implant. I still would have gone for radiotherapy because it is more important in terms of reducing the cancer coming back. I did speak to a Friend Like Me breast cancer representative on the phone, because they put me on a bisphosphonate drug that I have every six months, but the lady I spoke to told me horror stories about it deforming your face and that you can lose your teeth. So that was not helpful. And when you've lost your hair, and when you've lost parts of your body, you don't want to be losing your teeth. So yes, I think there needs to be more information around treatments and more consistency across the country.

Robert Francis: It's obviously so important isn't it. It's not necessarily that you would have made different decisions, but it can affect your feeling of independence, and if you find out that there was another choice, even if it wasn't for you, isn't helpful.

Participant B: On COVID, personally on the cancer side of things I've actually found that the treatment plan has worked better. It may seem like an odd thing to say, but it's actually been easier to get into the cancer centre building. Because they're not putting so many people in for scans at the same time the scan rooms are much more of a pleasant environment to be in. For example, I think the last three MRI scans I've not waited more than 10 minutes whereas for the previous one before COVID I was probably waiting for an hour and a half. So some things have improved, though obviously that's at the cost of people not being diagnosed in the first place. But on a personal basis, it's been better. To go back to something that Participant D said about nurse specialists, Neuroendocrine Cancer UK have advertised for a new member of their team, and I just hope that the nurse specialist at my cancer centre doesn't see that because she's doing such a good job. In my 18 years of diagnosis, there have probably been three times where the NHS has gone into overdrive with scans, endoscopies etc. but the one three years ago was just as good as the one in 2003 and 2010. I've never been given any alternative treatment options. I think this is where the internet can be quite dangerous because you can look at Facebook groups and websites, and I can think well in 2003 I had tumours, so why didn't I have chemo to slow those down and protect my pancreas for a bit longer. What I'm picking up at the moment is that, I don't know if it's now common practise, but if you have a total pancreatectomy everybody seems to have chemo after that, but again I've never had any chemo. The treatment I'm on now, lanreotide, I've been told exactly what it's going to do. Instead of giving me seven years of life, it might give me 10, it might give me 20, who knows? It's just how I'm reacting to it. I've been stable for four years now, so it's all looking good at the moment. It's also been pointed out that because of the size and the number of tumours there are no options for surgery, so that has been explained and discussed and obviously it's something that I've got my head around. I did see scope of a new project that's going through the NHS project approval process around liver transplants for patients with metastasis in the liver where primary was pancreas, and I discussed with the centre of excellence, and although in black and white I thought I'd fit the criteria there are other things within me that stopped me from meeting the proposed criteria. So yes, the

internet can be good, it can be bad, but I'm finding that I'm having good discussions with my multidisciplinary team at the moment.

Robert Francis: Thank you. What I'm getting from you, is that your questions when asked were answered, but perhaps there were times when the range of options and things being rolled out haven't necessarily been explained to you. We've got about five minutes left, and I just want to get onto new treatments. We read all the time about new treatments and the latest brilliant things, and I'm wondered if any of you have found a new treatment, that you know other people are getting, but you haven't been offered it.

All participants shake head.

Robert Francis: Thank you. I just wonder if in the last couple of minutes we wanted to leave a space if people had anything further that they want to add.

Participant E: It's been very instructive, and I'm glad that I've been able to be involved in it.

Participant C: I just applaud this initiative, that you're actually coming out and asking these questions directly to the coalface, as we say up in the Northeast, and that you are coming to us and asking, and that's fantastic. So thank you for the opportunity to be able to feed in and hopefully this will be listened to at some high level and will affect future direction in feature rollout of the personalisation plan for one.

Participant D: I just have one last thing to add. I think the key thing for me personally, and I think for cancer services in general, I've done quite a lot of work with Cancer Research in the last year, is the workforce. It's such a personal thing when you get a cancer diagnosis, and it's so important that you can build up these relationships with people because you need to be able to trust them with the treatment as it's such a big thing in your life. And if these people are under pressure, because they're understaffed and they're constantly working, it's going to affect patients. It's forecasted that there's going to be massive understaffing coming up in the next 10 years, and I would really just emphasise that the workforce is key. It allows the consultants and the nurses to build relationships which fundamentally, for me at least, was the key for getting through my cancer experience. Also, I would echo what has been said and thank you very much for giving us the chance to speak to you today.

Robert Francis: Thank you very much. Personally, it's been inspiring listening to you all with what you've been going through, but also the calmness with which you can relate your experiences.

Minesh Patel: I would echo that. Thank you for giving up your time and for sharing very personal experiences. I think we'll be asked to do a bit of a summary of the discussion, so I've tried to pull out some key points and perhaps if I relay them back to the group and see how they sound. The first point is around the importance of those relationships with nurses, specialist nurses, all you have emphasised how important and useful those relationships have been. However, on the flipside when it hasn't worked as well it can end up feeling quite disjointed and variable, and you have the same conversations with multiple people can be tricky. The second point I was going to pull out was around personalised care and thinking about quality of life more proactively. The third point that I was going to pull out, is the strong sense that there is a need to take into account people's mental health needs, psychosocial needs, as well as their physical needs and that this should be included in care plans. The fourth point is around the important role of charities and community organisations in helping you with your diagnosis, but on the flipside that can lead to information overload and could affect how you perceive treatment plans. The last point I was going to mention was around

treatment options. Some called for consistency and making sure that these are explained early, which I think link backs to those relationships that you have with healthcare professionals. I'm conscious that that doesn't cover everything, and there was more that we discussed, but those are the key points.

Robert Francis: I think the thing that I would add to that is the importance of continuing the relationship after the active treatment has stopped. I think from what I'm hearing that's when the challenges really start.

Minesh Patel: Yes. Thank you again everyone for giving us your time today.

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