

Written evidence submitted by Group 4 (ECS0047)

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

Group 4

Facilitator: Professor Janet E. Brown

Nicholas Caley: I think we should begin with introductions if that's ok? I think a few people are running late, so Siobhan will put them into our group and hopefully they can introduce themselves as they arrive. It shouldn't be too long.

Janet Brown: Ok, so I think we've introduced ourselves from the panel. Should we maybe start with you, Participant A? Do you want to just give us a brief introduction?

Participant A: Yeah, hi. I'm a myeloma patient and I've been having treatment for 10 years. I won't go into all the detail. It's a lot to sum up and I'm sure some of it will come out in the discussion.

Janet Brown: Great. Yeah, so lots of experience, so that's good. Participant B?

Participant B: My name is Participant B. I'm based in the North West, and I went through a brain tumour operation in October, and we just going through the second phase of chemotherapy about to start next week.

Janet Brown: Ok, and Participant C?

Participant C: Hello, I'm Participant C. I was diagnosed with breast cancer in October 2020. There's been a lot of drama with my treatment with it being lockdown as it started, and I am now secondary breast cancer.

Janet Brown: Ok, and then have we got Participant D?

Participant D: Hello everyone, I'm Participant D. I'm currently based in London, but I was born in Australia. I was diagnosed with bowel cancer in September. I'm gone through six rounds of chemo and about to start radio in two weeks. That's my story. Lovely to meet you all.

Janet Brown: Nice to meet you too. And then we've got Participant E I think now.

Participant E: Yeah, I'm based in London. I was diagnosed with mycosis fungoides back in 2007 and it moved to my lymph nodes in November 2020. I've had various treatments which I'm sure as you say we'll discuss as the afternoon goes on.

Janet Brown: OK, brilliant. So the first thing for me is if anyone needs a break, or to move around or anything, please do so. Just to let you know, there's quite a lot on this agenda. I think we're going to spend more time on the first two parts because the last two sections are more direct questions, and so we'll see how we get on with that. But don't worry if we don't absolutely cover absolutely every point; it's more to get your overall opinion. The other thing is that if anyone has any special requests like if I'm not talking loud enough or anything like that, or if I suddenly disappear off the screen, do let us know. Ok, so I think one of the areas we were particularly interested in was around workforce. I know you've got the questions and things, so maybe just to start off by going round, asking a couple of things together. So in a single word can you describe the care you received during your

treatment, and maybe each of you say who's made up your care team – like specialist nurse, radiographer, oncologist, and others that you're aware of? So should we start with Participant B?

Participant B: Yeah, mine's been excellent to be fair, absolutely excellent. The specialist I've been dealing with at the local infirmary has been absolutely brilliant. They've been very direct with the information that they've given us. I'm well aware that [the cancer] might come back, and it is going to be life shortening and that sort of stuff so, you know, they haven't pulled any punches. But I prefer that, and I'd rather know exactly what's happening, and they have been brilliant.

Janet Brown: Ok, and who's been in your care team in terms of the staff? Is it the oncologist, and who else maybe that you're aware of?

Participant B: Yeah, the oncologist. I've been talking with them. The surgery itself was actually done in Newcastle at the RVI (Royal Victoria Infirmary). But recently, I think as recently as late last year, just before I was diagnosed, there was a cancer centre opened in Carlisle, which rather than being 2 hours away, which Newcastle is, it's an hour away. That's where I've been dealing with the specialist nurse for rare cancers, and she's been great – brilliant.

Janet Brown: Ok, and Participant C?

Participant C: So my treatment, I would say it has been absolutely awesome, but it has been terrifying and very lonely because of all the isolation and stuff to do with the COVID nonsense, really. My care team has been my oncologist, chemotherapist radiologists, physiotherapists, specialist care nurses, breast cancer nurses, [and] a masseuse. The thing that I would say is missing is a psychologist, because I'd really love to speak to somebody about the shit that's been going on.

Janet Brown: Ok, that's really useful feedback. And Participant E?

Participant E: Mine really falls into two sections, because as I said I was diagnosed in 2007 and cutaneous T cell lymphoma is normally not life threatening. So it's also rare in that there's about 200 cases a year only in the UK, so it took a long time to be diagnosed, so I probably had it since about 2000. And then I've had various treatments throughout for that. But the two key people that have looked after me have been a professor of dermatology and an oncologist at a London hospital. When it moved to the lymph nodes in November... the treatment has been absolutely fantastic throughout, and leading up to help through Anthony Nolan I actually had a stem cell transplant in October. As I say, I've been very lucky because I'm now 100% donor, both blood and T-cell.

Janet Brown: And Participant A?

Participant A: I would say that my experience has been mixed, but please bear in mind that's over the course of 10 years which is a long time. I've had a whole range of people involved in my care over that time. It's a long list but there are haematologists with a specialism in myeloma; I've got a myeloma specialist nurse; I have haematology nurse specialists; a variety of locums and registrars; I have staff in the day care team; I've been treated by the in-patient team; I have physio, and like somebody else I've had support from the ophthalmology team. I had double vision for a long time. I've had radiotherapy, so I've been supported by the radiologists and somebody – was it Participant C? – you were saying psychologist. I've just actually after 10 years I've had my first appointment with a psychologist, which was really helpful. So that's the range of professionals that have involved in my team.

Janet Brown: And we've got Participant D, no?

Nicholas Caley: I'm not sure if Participant D has lost connection... A colleague of mine is going to give her a call and find out, but we do have Participant F with us now.

Janet Brown: Yeah, Participant F, I'm sorry and did you just want to introduce yourself, and then did you catch the question?

Participant F: No, no, I've been having tech issues, I've just got into the room. So are we just doing introductions and treatment?

Janet Brown: So we're doing introductions and just sort of saying how you would describe the care received during your treatment and who's made up your care team like oncologist nurses.

Participant F: Oh, so the first two points from the email? Gotcha. So my name is Participant F. I use they/them pronouns, I have chronic myeloid leukaemia, and I've been on treatment for that for about four years at this point. I was diagnosed in Germany and came back to England for ongoing treatment and care. The care I've had has been relatively good, to be fair, but a lot of my care is dealt with in an outpatient manner because of the way it's sort-of handled, and obviously I was diagnosed in different country. One of the things that was a bit tricky was shifting to the British system. There was a lot of re-testing and doing things over from scratch, which was pretty intense. Also, the rarity of my cancer made my care a bit disjointed, so I was living in Brighton but my specialist was in London. Having to travel for that was quite difficult in the beginning, to the point that I actually moved to London because my health was getting worse, and I was expected to turn up to appointment at 10:00 AM in London when I lived in Brighton, and it was expensive and far. So I moved to London to sort-of move that along, and that sort of works better, especially because my health got worse over time. So I stayed with the same specialists, which I'm lucky for, but I've been through four different types of chemo, or TKIs. Finally, on the last line, my care team is quite small if I'm honest. It's pretty much my specialist and my CNS, but during the pandemic my CNS was redeployed so I had no contact with her, which means throughout the whole pandemic I really had no additional support other than just seeing or hearing from my specialist via phone for five minutes. I'm not very responsive to chemo so I have to be sort-of seen every couple of months and always have to be. When I entered the [virtual] room I heard about psychological therapies. I'm quite lucky that I'm treated at King's [College London] because they have a specialist hemo/onc psychotherapist which was amazing. I started to receive that about two-and-a-half or three years into my care, so it kind of came a bit late. The services offered to me before that point were pretty lacklustre if I'm honest, I wasn't really offered anything. I mean, it took almost two years before I was told that I can get free prescriptions. So there was a lot of stuff that I was sort-of missing out on. Generally I think the other thing that's missing, at least in my experience, is the, you know, they're doing HNA and all that stuff, but there wasn't really any consideration for social or additional support outside of the sort-of treatment parts. So things like my life and the support groups I can access. And me being a queer person, there wasn't really any kind of consideration or knowledge around that, so I feel like that bit was kind of lacking. But generally my CNS is lovely when I can get in touch with her.

Janet Brown: Brilliant. And Participant B?

Participant B: Yeah, I spoke originally there and I mentioned there's just really a team of maybe two or three that's been looking after me directly. But yeah, it's been great.

Janet Brown: And Participant D, are you with us now again?

Participant D: Ah, I hope so. Yeah, you may not see my face, but hopefully you can hear my voice.

Janet Brown: Yeah, we can hear you. So we were really just looking at how you'd describe in one word the care you received in the treatment and who made up your care team.

Participant D: So in one word I would say that I surprisingly felt empowered, like I think that I've gone into this maybe as a 32-year-old who just really, really wanted to advocate for myself just because my diagnosis took a very long time to get there. I think I walked in and just said, 'I know that I need to show up and I know that I need to know, I need to ask the right questions but also be given all of the right information'. So I think yes, I feel empowered in the fact that my care team told me everything straight out which has been sometimes quite overwhelming. But it's given me the time to be able to process [it], and they've also been very kind to whenever I've told them to hold up when that was enough information for me. So yeah, I'd say empathetic. And so at the moment I'm dealing with an oncologist [indistinguishable – bad signal] ...chemo. I've just been passed over now to a radiologist, and then I've got us a surgeon as well. So in terms of oncology I've got three, then I've got one care nurse as well who is lovely. She's quite to the point, so when I cry, it's kind of, I get tissues and that's kind of it. But maybe that's OK. I have found my care incredible... [indistinguishable – bad signal]

Janet Brown: Yeah, good. Has anybody not had a chance to speak? My other fault is I am dyslexic, so I sometimes find it, you know, everyone coming and going... So if I miss anyone out it's not intentional, and Nick, it would be good if there's anything in the chat box I miss if you could let me know if it's important? So I think we've covered some of the next point, but just to sort-of broaden that a little bit. Did you feel – because I know some of you talked about the psychologist – but was there a specialism that perhaps wasn't available in the team? And even the staff you accessed, did you feel you had the amount of time you wanted with them? Could you see a consultant when you wanted, those kind of things? Would anyone like to start us off perhaps on that?

Participant F: Yeah, I'm happy to go first. Some additional kind of referrals and therapies that I sort-of asked for and haven't got have been an issue. The medication I'm on affects my ability to walk when it's in higher doses, and it was never passed over to physio until I had to do my own referral through a GP a couple of years later where my muscles sort-of wasted away and I couldn't get up the stairs. That was a pretty annoying one, even though they could kind-of see me coming in with, you know, a walking aid and things like that. And then another one was that I've been having problems with my eyes on starting chemo. It causes an irritation and again, the specialist didn't really pursue it. The CNS heard about it and said that she would make a secondary referral, and that never happened. I find that happens quite a lot with my care, like when it comes to the blood cancer they're kind-of on it, but when it comes to actually connecting me with other parts, it just very rarely happens.

Janet Brown: Ok, and I think Participant C, you've got your hand up as well, is that right?

Participant C: Yeah, I'd agree with what you're saying about if you need to see someone else. I had a mastectomy in November 2020. As a result of it the scar was so tight I couldn't move my arm properly. So it was discovered that I had cording, which was sorted out by a physiotherapist and I was given exercises to do. You're given exercises to do anyway after you've had a mastectomy, which I endeavoured to do, but there's a whole another story with that which I can't be bothered to go into. The scar was so tight that I couldn't move my arms properly, and I couldn't get any kind of help with that at all. Eventually I found a lady who does advanced massage locally to me, and I've

been going to her and after three or four sessions she loosened up this scar tissue and I'm now able to move again. But if that hadn't been addressed how long would I have been having that problem, which then would have gone on to potential other problems in my arm anyway?

Janet Brown: Yeah no, no, thank you for sharing that. We've got another hand up here – Participant A?

Participant A: I think for me the thing that I would say has been an issue, and again bear in mind this is over 10 years, but I find it really difficult: the consistency of the care. So because I've been around quite a long time there have been lots of changes of staff, and because my staff team seem at certain points to have been under incredible pressures... I've seen quite a few locums and registrars over the years and people who don't necessarily know me very well and haven't had time to read up on my notes, so I find I'm quite often retelling my story. I have a feeling that I have to be sort-of on top of my care and know what I should be having when, and making sure that I've got all my questions ready when I go in – which is fine, you should go in prepared – but for me what I would like, and what's missing, is more consistency in the consultations that I have. I would say with the haematologists, and I know they try their very best, but I think it basically boils down to the fact there's not enough of them.

Janet Brown: Ok, yeah. I know Participant C's got her hand up, but before I come back to Participant C, though, anybody else? Participant D?

Participant D: Yeah, I just wanted to add to what Participant A just said, and I could see a lot of others nodding their heads as well. I feel like along with wanting to advocate for yourself, but there is definitely that almost needing to know your own [indistinguishable – bad signal] ... important, as I needed to get a drug that suppressed menopause so I could look after my ovaries, which for me is like one of the most important treatments I have got. So it was only because I knew I had to have that drug that I actually asked for it. So like I think there was no crossover. There was nothing prescribed...

Janet Brown: So are you sort of saying that if you don't feel you're completely up to speed with everything, you find that it's not actually being addressed, and part of that is because of staff turnover and not seeing the same person? Is that kind of what you're saying?

Participant D: Correct. Or if it's not prescribed from the oncologist, there doesn't seem to be as much communication between the nursing staff and the oncologist, and then it's kind of left to you to remember everything, and in one way that's incredibly empowering. But when you've done six rounds of chemo and you can't even remember your own name it's pretty infuriating to be like 'what about that thing that suppresses my [indistinguishable – bad signal]?' So I think it's communication with ground staff who actually administrate the drugs and also the importance of that.

Janet Brown: Ok, and Participant E?

Participant E: Can I just say my experience has been the complete opposite? I've had the same dermatologist since 2007 and I've seen him every time, and the same oncologist since I needed to see him, and he's very keen on radiotherapy and does a lot of research into radiotherapy on the skin. They've supported me throughout all of the treatments, and I've seen them whenever necessary. I've had the same consultant throughout further stem cell transplants and they've been fantastic. Someone talked about psychological help as well. When I was diagnosed with the lymphoma, when it moved to the lymph nodes in November 2020, I said to them 'well, come on, we're going to do a

bike ride', and the two specialist joined me on a 50 odd mile bike ride as well which kept us sort of all going and fit up until the point where I'd finished the chemo.

Janet Brown: Ok, no, that's good to hear, Participant E. I know we've got Participant C and Participant F with hands up – is there anybody else who hasn't had a chance to speak about this? Then we can come back to there, but maybe also put the last couple of questions in the mix for this session. No? So I'll come to you in a second, but just kind of what we were talking about really is – and I think we've covered some of it – but, you know, do you think there's any specific needs that were met from a certain role and that support was useful? I think Participant E 's giving a bit of an example there. Or is there something that isn't there at all? We talked about the psychologist. The other thing is, it does seem to vary a little bit across the country, maybe, and whether you have a common cancer or a rare cancer, and whether there's staff shortages, and so really we do want you to tell your particular circumstances. We're not looking for you to all say everything is fantastic. This whole review process is to look at whether further improvements need to be made. So feel free to discuss. So I come with that in mind, adding the extra things in, to Participant C first, and then then back to Participant F.

Participant C: I'm actually shocked to hear your wonderful experiences, because considering I've got the most common cancer for women in the UK... So for the first five months of my treatment I saw – taking away my surgery and moving into the oncology department – I saw six different blood nurses, six different chemotherapy nurses, three different oncologists, and it was only because I asked if I could have some kind of continuity please – because the only person that I saw on a regular basis was the tea lady in the chemo unit – and then after that I had nine radiotherapists out of the fifteen radiotherapy sessions that I had, that I had to travel across – because my local hospital doesn't have a radiotherapy unit even though they've spent 15 million pounds on a new cancer unit – so I had to go to Oxford for my radiotherapy, which was about an hour and a half drive each way. Somebody had to take me to it, because otherwise I'd be asleep on the way back which made driving quite hazardous. So my treatment has also included – since I've finished my treatment for primary and then gone into secondary cancer – so I'm supposed to have had two scans which were both delayed and that meant an extra four week wait on both of those treatments. Medication for side effects that had been sent through to my doctor for me to pick up, I got the notification for that two months later by which time I'd already been back in and sorted out the problem myself, but it was a big problem. And then, as I say, this psychological impact of now being on a death sentence effectively... I was referred to psychological help at the local Hospice back in November, and I'm still waiting. And I'm probably going to be waiting another month before I can speak to somebody about what I'm actually going through.

Janet Brown: Thank you for sharing that, Participant C, and I'm sorry you're having some frustrations with everything going on. I know, I see it myself... Participant F, did you want to the chip in?

Participant F: Yeah, just a couple of points off the back of recent points made. One is that I think I'm sort-of protected in my continuity of care simply because I have such a rare cancer, and I think there's very few people [treat] it. Obviously, that's evident by the fact I had to move nearer to my specialist and that's why I feel kind-of almost locked into it. Even though he's now moving, I'm staying at the trust because the CNS is so good, but she's pretty much the main conduit for all my care and support, not really anyone else. Another specialist gives me 5 minutes maximum if ever, even though we've been under the same treatment plan for years. You'd think we have more of a rapport here, though I know time is strained, but one of the things I find that's tricky, obviously we're talking about oncological secondary care environments but also primary care, and especially in chronic cancer management. When I go to speak to my primary care team, they have no concept of

my health whatsoever at all, so I feel like I'm lost between the two systems where, especially during redeployment of my CNS, I had no one to contact, I can't contact my specialist directly, and I wasn't given a secondary nurse or a fill in to contact, but then I was going to my GP and they would be like, 'it's nothing to do with us, I don't understand what we're supposed to do'. So I think that really kind of slowed things down. Another thing that was kind of interesting is, although I now live close to my hospital, it's still a bit of a journey because I live in London and it's on the other side of London, and in order to get updates on my health I have to regularly go in for blood tests and then when I can in person go in about a week and a half later or two weeks later, which obviously like doubles that time contacting hospital, mainly because the PCR test takes so long to run. That's been somewhat easier since we began to do phone appointments, but still it's that issue of having to go back and forth for the blood test and they won't find a way to do it remotely. There's no way that I can go to somewhere more local and they can send the blood, which gets kind of frustrating. The other quick things as well about traveling to the site, especially in the pandemic, and being, you know, immunocompromised, was I typically get my medication sent to me and they drop it off via someone on a bike, which I'm very, very grateful for, but there have been times I've had to fight for that. So the pharmacist, they've expected me to travel all the way across London just to pick up five pills and then travel all the way back during a pandemic. So there was stuff like that that I found pretty frustrating during that time.

Janet Brown: Ok. So what I think we can do is... we can keep on because there's quite a lot of overlap with some of [the topic of] living with cancer, which we kind of go on for now. And Participant G, have you had a chance to say anything yet? Nick, you had a hand up.

Nicholas Caley: Yeah, sorry. I was just going to welcome Participant G to the group who has joined a little late, and make sure she gets the chance to introduce herself to the group.

Janet Brown: Yeah. Participant G, do you want to just introduce yourself? We've just really been discussing the first set of questions, which under the title workforce are about how you value your treatment, who's been in your care team, and if you feel there's anything missing from that team. Are you able just to introduce yourself and maybe just let us know quickly about that?

Participant G: Uh, yeah hi, I'm Participant G. I'm sorry I'm a bit late. I had issues getting in on Microsoft Teams. I'm not sure I have any comments on this question at the moment, so that's ok.

Janet Brown: Well, welcome and I'm sure when you get involved a little bit more feel free to join in. So did we have any more specifically in this area? If not, we can kind of incorporate it in the living well questions. I think the first question would be good to get everyone's view on. So what that's asking is: do you think it's important that there is a care plan, and that it caters for your specific needs and. if so, why? And I would like to add something as an oncologist who maybe treats secondary cancer, that maybe it's not all one care plan. It depends where you are in that journey, because your needs are very different. So can we maybe hear from someone we've not heard from for a while. So maybe Participant B, do you want to chip in?

Participant B: Yeah, sure. When I'm talking about the care that I've had, it's in the extremely early stages so my sympathies go out to Participant F, Participant C, Participant A, Participant E who have been going through this for years and years. I've only been going through this for a matter of months, so to say there's a care package or whatever for myself, it's extremely early days and all this is coming back, so we've got further treatment to do after this second lot of chemo that I'm about to start for six months, and at the end of that is when they've told me it will be coming back again. So I guess there's a plan for the future, but as far as dealing with it personally, it's not really... I feel not

fraudulent, but I feel like what I'm saying is that I get the feeling that other people have got more qualified answers than I have because I'm in such an early stage of it, you see. But so far with me it's been great. But as I say, it is early doors, so I do apologize if that sounds a bit, I don't know what the word is... But anyway I can't complain. It's gone great for myself; I can't complain. I'm awfully sorry if that's not what you want to hear. My sympathies go out to the [other] people, because the longer it will go on, you're bound to have more issues as it gets more complicated. But currently with myself it's been great so far. I can only be positive, I'm sorry.

Janet Brown: Is there anybody else who hasn't spoken for a while who'd like to go next? Then we can get people to put their hands up and hear everybody's views because I think this is quite important. Anyone volunteering to go next? Should we hear Participant C and then Participant F?

Participant C: For me, my care plan has been a bit like Participant B's. Once I got on the roller coaster that was it, there was no getting off of it and I've been carried along on a wave. I do feel that.... knowing what's going to be happening helps, you know... Otherwise you're just stuck in this limbo of, 'oh, right. OK, what's next?' When you're waiting for those things to be sorted out, it can feel a bit like, 'blimey, these bastard things,' and I'm sorry to anybody that finds swearing offensive, but there's going to be a lot probably that pops out of my mouth because when we get on this subject it's very emotional for me. So, I don't know. This thing inside me is like an alien, and it's been spreading even while I was going through chemo. So for me, knowing what the next step is and not having those delays and waiting to find out what has been happening has been extremely important, and in some cases they haven't happened quick enough. I explained about the delays in scans because of staff shortages, or people forget – people forget, I get that – but it's when the staff aren't there to do it in the first place that it gets very frustrating.

Janet Brown: And Participant C, obviously you've had quite a long cancer journey as well. Do you feel the care plan has sort-of been looked at? Or what would you want to see improve?

Participant C: Yeah, I mean it's definitely been re-looked at because I've gone through surgery, then I got sepsis, then I went chemotherapy, then I've had radiotherapy, then since radiotherapy I've been diagnosed with secondary and it's spreading into my lungs. So yes, it just seems to be constantly evolving. And once again to reiterate that point, I'm just on the roller coaster. I feel like I'm on the crest of a wave and there's just all these things going on underneath, and I'm just sitting there going, 'oh help...' And I am being helped. I'm not complaining about that at all.

Janet Brown: Ok, and Participant F I think was next, so if we kind-of throw all of the things in now about the care plan, whether it was right for you and what support was good on it and maybe what was missing, I think we've covered some of that with you, but if you just want to chip in that would be good.

Participant F: Yeah. So for me, one thing about the care plan is it has to be very flexible because I failed so many treatments and there's very few options available to me. There's not many options to really look laterally to other treatment options, it's just what I'm on or it's the very risky transplant. I feel like I've been well informed the whole time about what's happening next and, you know, the realities of what that might look like, and I feel quite grateful for that to be honest. I think a lot of that is also due to how personal my CNS is and her ability to sit down and really explain some of the stuff. There's definitely that element of having to be an expert in your own care and do a lot of your own research on what the next drug is going to do and all those things, but I felt like that bit was fine. The thing that I found a bit tricky in my care plan was, because I'm chronic cancer patient and my needs have changed a lot between when they first met me... So outside of the treatment – just

again that idea of signposting to other services or seeing someone needs additional support – as a result of me getting quite ill when I was on a higher dose I had to give up my work. I became homeless. There were all these other things going on. They were sort-of acknowledged, but not really much thought or support [was given] given around, it was just sort-of 'let's just deal with that' and not even the consideration of could I get to the hospital myself, and I was turning up by myself even pre-pandemic. So I feel like it was good in the sense of 'this is the drug you're on next,' but then me as a holistic patient, there was not really any consideration for that, if I'm honest. My CNS was lovely and very personable, but if I needed additional support I think that was kind-of missing.

Janet Brown: Thank you for that. That's an interesting insight. Participant A?

Participant A: Yeah, hi. I don't know if people know much about myeloma, but myeloma is a disease that can't be cured. But it can be treated, and you can live quite a long life with it. What that means is that there are a range of treatments that are available to you, and, to be fair, I've had a very clear care plan, although it's changed now. I've moved from treatment to treatment, probably a bit like you Participant F, I think. The thing that is a little bit frustrating about the pathway for myeloma – and I think this might be true for other cancers, although I don't know – is the treatments that are available to you at certain lines are very prescribed. Having had myeloma for 10 years, what's happening now, is there are new treatments that are coming in at a much earlier line than I'm on now, and there are treatments in the pipeline that look really potentially very exciting, you know, like CAR-T cell therapy which at some point I understand will be approved for myeloma treatment in the future. But I'm on my third line treatment now and my next line would be fourth line. I don't know if that would be available to me. What I would really like – and I don't know if this is at all possible – Would be for my care team to have more flexibility over the drugs that they choose for me and to make my care really personal, because I feel like I'm on a sort-of a conveyor belt and I've just got a go with what's next on the line. I don't know if that resonates for anyone, but it's quite frustrating because I'm not that old. I mean, I was 45 when I was diagnosed. I've got two children. I've got a lot to live for and I just want to be there for them as long as I can. And yeah, it's tough when you think, 'well, I wish I could've had that treatment'. You know, that's all I'd say. More flexibility, I don't know if it's possible, it's probably just a pipe dream.

Janet Brown: Thank you for sharing that. Anybody else got anything on that? Can we just kind of throw in as well: did you think as well as the care plan the personalized care improved at other areas of your life? Did it help you decide, make on other decisions and things like that? So can we hear from anybody else that wants to comment on that or any of those things, or the last area people have already commented if they wanted to add something in? So who have we not heard from for a while? Participant E?

Participant E: I suppose I feel a little bit of a fraud really, because I've had a whole series of treatments throughout and it was carefully explained to me as all the possible treatments... If I can reveal two other things, I actually have been a director of the Cutaneous Lymphoma Foundation since 2011, and I therefore have access to pretty much the world experts on CTCL from California to New York and throughout Europe, as well as in the UK. So if I want to speak to one of them, it's really not a problem. I'm also the patient representative on a on a clinical trial for cutaneous lymphoma, which is being run. I'm not on the trial, but I'm a patient representative. So again, in the UK I've got access to all the UK experts if I want to speak to any of them directly. But my treatments have been explained to me throughout, and particularly in the last 18 months when the lymphoma was diagnosed, and we've just followed the plan and I've had access to everybody, and someone was saying they had different nurses. I had 10 rounds of chemo and I had nine with one nurse, and one with another. So I've just been very fortunate, and similarly I've had the same consultant throughout

my transplant, except for when she had to go to Malaysia for three weeks, and I then had the head of department at Hammersmith. So I've really seen that the plan has been followed almost to the letter and explained to me what the side effects would have been of certain drugs. For instance, one of the treatments for CTCL is interferon. It was one that I didn't want to have because of the flu type symptoms that one gets every time you take it. So it's all been explained to me throughout. I say I must be slightly unusual in this group.

Janet Brown: OK, thank you for that. And Participant G we were going to come to you.

Participant G: Hi there. I was diagnosed with secondary cancer back in 2007, so I haven't really had so much of a care plan because I think when it's secondary – I don't know about anybody else – but my treatments change every time I have a scan, and they find something else and it's moved somewhere and so the plan is always changing. So to have a plan for me wouldn't really make sense. My cancer spread so I then had to have a different chemotherapy, and then I had to have radiotherapy. I was initially diagnosed with breast cancer and then they found cells after I had a mastectomy, so then I had to have another course of chemotherapy, and so it's forever evolving, I think, with secondary cancer. You can't just have one care plan. I'm probably a bit of a novelty maybe for this group, as in I'm switching in and out of private to NHS, which is really difficult because when I go into an NHS hospital they don't have all the details of the scans or what had I've had done privately and the other way around, and so it's really difficult to have one solid care plan. For me, every time, like I said, I have a scan or have some new symptoms, then I'm normally diagnosed with it appearing somewhere else, and actually it went to my brain, so I had brain surgery back in 2017 at Queen Square in London. So that's NHS. So yeah, the jumping in and out of NHS or private is just not good. It's great that you get scans that quickly, but the care plan just doesn't work.

Janet Brown: OK, thank you for that. We'll quickly hear from Participant C and Participant D, then we'll move on to the next area to cover. But if there's anything that people also want to add in the chat, I think we can record that as well, if there are any points that you feel are important that we've not raised as we've gone along. So can we hear from Participant C?

Participant C: Since I was diagnosed with cancer, I've also looked at other ways that I can help myself to potentially make my body stronger to help fight the cancer. One of the things that I've found is an integrated clinic in London, which is a private clinic which I've spoken to my oncologist about because I don't want to do anything behind his back that may affect what he's doing. His attitude, he's a bit, 'yeah, don't bother, it's not going to make any difference, you know the NHS and science will sort out what's happening to you and there's nothing you can do to help yourself'. Even if it's not going to help me on a physical level, surely on a psychological level feeling like I'm doing something gives me some degree of control back which my oncologist doesn't seem to understand. That's a very important step in my wellbeing.

Janet Brown: OK, thank you for that. Participant D?

Participant D: I just wanted to say [indistinguishable – bad connection] but already I've had a very different care plan to what I have gone through, and it's because of testing. But I think the best thing that my oncologist did, which is the most important point I want to get across, is that he's always managed the worst-case scenario. So he's told me what he thinks might happen, but also at the end of it what could be the worst thing that's happened and unfortunately the worst things have happened, so at least I know that's coming. So when he does say they need to do X more chemo, or now we need to go into radiation, I knew that was coming rather than just getting those results. So I

think that's the best thing that's happened in terms of my care plan that yes, I know that it's flexible, but I'm being told everything up front.

Janet Brown: Ok, so I think we've got some very good views on that part, and you've been saying a little bit about, you know, how your personalized care might have improved other areas of your life, with knowing what's happening and with planning, but if anyone has any comments on that then please add them to the chat. Just to cover the last two areas, I said we'd concentrate on the first two because it was pretty very important to get your views on those. With the diagnostics I appreciate for some of you it's quite a long time ago since that initial diagnosis, but what is your experience really around the speed of diagnosis? It can either be your initial diagnosis or subsequent when the cancer spread, and you know the support at the beginning when you're originally seeking medical help and your experience of if the treatment has happened quickly and you've not had to wait very long. Have you been given a choice of options? And then I think we'll look at second question within that about the early diagnosis and things. So can we just maybe cover those first two areas? Participant B, do you want to come in, maybe because you were saying you've been diagnosed fairly recently?

Participant B: Yeah, it was in September. I'd started to notice my arm twitching. When I went to the doctor, the hospital did say, you know, it could be stroke related or whatever, but we had that diagnosed in September as being a brain tumour and it was removed less than a month later in October. There was a period of then getting used to the surgery itself, you know, it was fairly intrusive, and it was a lot of tiredness and such so that waited then until December when I could start the phase 1 chemo and radiotherapy, which I just finished a fortnight ago, and then right away I was at Carlisle yesterday for another assessment and I start phase two chemotherapy this Saturday coming and that's going to last for six months. The support has been great. A bit like Participant E, you do feel kind of fraudulent in that you come to these things with a lot of positivity – and I don't mean to belittle anybody else's experiences at all, I really don't – but it has been great and the rare cancer nurse she's actually offered services to my family as well, should they need, you know, any sort of support to find out what's going on in the background. I lost my dad a couple of years ago... she's offered support to my mum and my sister, you know, and said if there's any issues you've got, if there's something you don't really want to discuss with Participant B because it could be too emotional or whatever, they can detach from that sort of speaking and speak to the cancer care nurse. She's been brilliant.

Janet Brown: And are there any other opinions? Because I think it's good to have different opinions within the group, and is there anybody who has anything that's, you know, a different experience to that where maybe they've had issues? Participant C, do you want to go?

Participant C: I feel like this is just a Participant C 'get it out there' session, so I apologize to all of you. My experience has been completely shite from the very beginning. First of all I found a lump in June 2020, and it took me two months to even just get the doctors to pick up the phone. Then another month later I was actually in front of the doctor, first of all on a telephone call, and then she said, 'come down and see me', by which time the lump was now the size of a golf ball. And then I was referred over to the... breast care had a mammogram and biopsies and everything. By that stage it was so big that when I laid down you could actually see the lump, and I'm I've got big boobs so it's not like it was a, you know, like I'm not an 'aspirin on an ironing board' type girl. So that really made me quite angry about the fact that it took me so long to get this thing seen. Before that, I should have been screened. At some stage in the three years up to my 50th birthday, I hadn't had any screening done, so if that had been done as well, would I potentially have secondary cancer now? I'm not quite sure that I would. Once I'd got onto the roller coaster everything happened really

quickly. I was in hospital having my first operation about two weeks later, and then they found more cancer and I was back three weeks after that, having the mastectomy, and then everything else just happened really quickly. But that initial doctors not opening their doors to actually see cancer patients.

Janet Brown: Yeah, I think that's very useful, and it really chimes with what we were talking about, you know. Do we think there's enough being done or enough resource looking at early diagnosis? And I think that definitely chimes with that so...

Participant C: Yeah, sorry I'm coming back again. Also, while I was in treatment, a lot of the nurses were being deployed to other wards, so my actual breast care nurse ended up on the COVID ward and [they] ended up getting COVID, so by the time I went into chemotherapy I was only told about the wig and given the contact for the wig the day before I started chemotherapy, and then eight days after I'd started chemotherapy I was completely bald. So I haven't had chance to even get my wig sorted out, and then I'm walking around with a bald head in the middle of winter when it was really cold and really snowy, and I didn't expect any of those things. Also, because of the isolation to do with COVID, I know I sound like I'm really whinging – and I'm actually a really positive person – but this has been pants, and there's been a few people have been like, 'woah, I can't believe that all this pile of grot has just landed on my door'. So the other thing was my prosthesis – which has actually been a very important part of my psychological wellbeing, with dealing with having my boob chopped off – I didn't get that until March. Bearing in mind that I'd had my operation in November, I think that's quite a really big thing that shouldn't have been delayed quite as long, but it came back again to the fact that because the nurses were being taken off and having to look after people with COVID, which I know they can't help, it's not their fault... blah blah blah blah

Janet Brown: Thank you for some very important points, Participant C. Just to give everybody a bit of a say I'll move on, and I think is it Participant A next, just to get some input?

Participant A: Yeah, when we're talking about early diagnosis for myeloma, that's a real problem for patients. Although my experience is quite historical it's still really relevant, because I know from the work that I do for myeloma UK that most myeloma patients actually see their GP numerous times before they actually get diagnosed. So in my case I had headaches right here at the back of my head which, when I went to see the GP, I was told that it was muscular and to go and see a cranial osteopath. And that was, gosh, October. I don't know, 2012 maybe? Or even 2011, actually. And then a few months later, I just woke up with double vision and had double vision for two years and that's when I got diagnosed. I had a plasmacytoma actually, which is a collection of plasma cells at the base of my brainstem pressing on my optic nerves. I do wonder if I'd been diagnosed sooner whether I might have avoided that long time, two years, where my vision was so badly affected – it's been corrected now with an operation – but I had to wait quite a long time in order to have that operation. I won't go into the detail. I mean, it was... I had to wait to see if it corrected itself. But yeah, it's very typical of a myeloma patients journey, and I think probably a lot of blood cancer patients actually have a similar thing. Participant F, you're nodding. So that's all I wanted to say. Early diagnosis is a real issue for certain cancers.

Janet Brown: So we're going to hear from Participant D and Participant G, but I also wanted to throw in the effects of the pandemic for people receiving a cancer diagnosis, or indeed if you've already got cancer, as to what aspect that would have. So I don't know if, Participant D and Participant G, you can also put that into whatever you were going to say. That might be helpful, thank you. Participant D?

Participant D: I mean, we could say that I probably have a really good segue from Participant A. Unfortunately not the pandemic, but more just the length that it takes [for diagnosis], particularly for young people with bowel cancer [indistinguishable – bad connection] ... I'd had symptoms for about 18 months, and it was revealed that I'd had a tumour growing in me for 18 months. I had gone to numerous doctors, and I think purely because of my age my symptoms weren't taken seriously enough. So I was prescribed piles medication. I was never treated in terms of a colonoscopy; it was more just like, you know, 'that's a gluten intolerance'. I went through dieticians and then I finally met a doctor who after 18 months of me not being able to work – the exhaustion meant that I was working from my bed – I thought I had depression. It became too much, and it was a doctor, thank God, who listened to all of my symptoms in a row that actually then prescribed me to a colonoscopy, and then similarly, like Participant C, when you hear cancer, you get on the bloody rollercoaster and you don't stop. But for me it took 18 months of living through a pandemic and, again, maybe that also affected not being able to go to work or a doctor, but also me just thinking that it was exhaustion from, you know, 'Zoom fatigue' and isolation and losing a job and just life. So I think there's a lot of work in terms of bowel cancer, with young people recognizing symptoms are actually being serious, not just bloating or not just diarrhoea; and then also there was a lot of work for doctors as well who just looked at me as a 32 year old where there are, you know, thousands of people in the UK and the world, and I've heard many other stories of people that do have bowel cancer and it is because of this waiting time that we're facing down the barrel then of stage 3 and stage 4 where it isn't as easy as a few chemo sessions, it is looking at years and years of treatment there. So I think yeah, for me it's like yes, fantastic. I'm lucky enough that I've got private care through my work. So yes, I've had cancer and it was like boom, boom, boom boom... But until that point, there was zero urgency for me, and that's without [a] cancer [diagnosis], so I think that's why I wanted to be here today, just to say that there is a fair bit of work to be done globally, particularly around young people, because bowel cancer isn't a sexy cancer, and it does, you know, typically affect older people.

Janet Brown: Thank you for that. That's a very good insight as well. Participant G?

Participant G: I think mine is probably similar to Participant D, actually. So I again was turned away from my GP numerous times because she said that I was too young to have breast cancer and it was to do with hormones and [she] wasn't prepared to kind-of send me for any further treatment or to a breast cancer centre, anything like that. And to be honest I didn't think for one minute at my age I would have breast cancer, but I do feel that her not taking me seriously. In the end I was seeing a consultant privately for something else and I mentioned to him, and he said that didn't sound right and he actually referred me to a breast surgeon. That was on the Friday, and they took a sample from that day and then on the Monday I found out I had breast cancer. But they didn't tell me at the time when they first diagnosed me that it was actually secondary, they chose not to tell me, so it wasn't probably another eight months or something until I found out that it was actually secondary. So I felt very let down by my GP who sent me away kind-of with my tail between my legs really and feeling silly for keeping going back to her, and for her to keep saying to me that I was too young and, you know, it couldn't be breast cancer when actually I did have breast cancer and it had spread to my sternum. So ever since then I've been dealing with it popping up all over the place. So yeah, I think there's a lot that needs to be done for recognizing that young people can get these different cancers, whatever cancers they are, and taking this seriously, and not just sending us away because, you know, we're too young to have this kind of cancer because anyone at any age can get any cancer. So they need to listen more and that I just feel that they just pass you off very easily.

Janet Brown: Thanks for that, Participant G. Anybody on COVID because what I was... Participant E?

Participant E: Yeah, I will make two points. See my diagnosis originally was very difficult: I had various biopsies, I saw lots of different dermatologists, lots of experts in their field, but I was treated for psoriasis or eczema for a long time before one of them – and I say I had various biopsies, even from that it's difficult to tell – but it was mycosis fungoides.

Janet Brown: Ok, thank you, that's a good point. Just for the last couple of minutes, and you can also put any comments in the chat, were any of you able to access any new cutting edge advances in treatment, either immunotherapy, new types of radiotherapy, those kind of things, and if so, how do you think that's impacted your care? And were the new treatments that you wanted to receive that were not available? Participant E?

Participant E: Yeah, one of the treatments that I had early on – well not early on, but in 2013 – was that there's a total skin electron beam radiotherapy that could be used, and originally it was a five-week course, four days a week, which you can only have once, and fortunately they tried low dose and so I was able to do a low dose of that, which was two weeks. Same dose, obviously the same number of grains each time, but it was only for two weeks, which meant that when I had the transplant earlier back in the last year I was able to do further rounds of total skin electron beam radiotherapy, which I wouldn't have been able to do had we not done the low dose which was a trial at that time.

Janet Brown: OK, that's useful. Participant C?

Participant C: I'm not sure, I may be actually speaking out my arse here... So when my cancer first started spreading, we found it when I was being set up for radiotherapy and it had gone into my lymph node underneath my sternum, so radiotherapy was changed to accommodate blasting that area and the amount of grays that I had was changed and all sorts of stuff. Since then I had radiotherapy, finished that, and it was found to have spread further across on the right side into two more lymph nodes. When I asked if I could have those blasted, I was told no, that I'm now secondary and that's it.

Janet Brown: Ok, and Participant F, you had a comment here?

Participant F: Yeah, so with my treatment I got to a point where I failed three different lines of chemo and basically was given an ultimatum between – well, they didn't want to do a transplant because I don't have any direct siblings and it was a bit too risky – so I was given the option of a new drug in development or going on to [another drug] which is known for being pretty rough. I had the meeting about that study, but the conditions of the study was what put me away from it and the pressure that was put on me to take part in the study felt a little bit too much. So they kind of used my health, not against me, but they really asserted that point of, you know, almost that I should be doing it, and that felt very uncomfortable when I raised that with the team that referred me into that conversation. One of the reasons I didn't want to do it was because they would want to do it over the space of two years, eight bone marrow biopsies, and they're just not nice procedures. When I went back to the person who referred me into it and said I felt pressured – I thought the primary biopsy rate was too high. I'd rather take my risks with [the other drug] – they they kind of said to me like, 'oh, they wouldn't have pressured you, you've obviously understood that wrong, they're not allowed to do that, don't worry about it'. And I was like, 'no, I very much know what happened in that room, and I know the feeling of it, and that's why I walked out.

Janet Brown: Ok, thank you for that. Participant A?

Participant A: Yeah, I just wanted to say that it seems to me that access to cutting edge treatments is a bit of a post code lottery, and it really does depend on where you live in the country. I have had access to a large-scale trial, but some of them more cutting-edge treatments which I'm interested in, I would have to travel a long way and it wouldn't be easy. I would love for someone to look at that issue and whether there is a way of engaging people on trials around the country from a central point. I don't know how it works really, but I don't know why some of these trials cannot be taken out to some of the other sort-of teaching hospitals because it's very difficult when you're having treatment to travel a long way.

Janet Brown: No, I think that's an important really important point. Participant C?

Participant C: When I was going through primary diagnosis I was asked if I wanted to go into a POSNOC trial, which meant that my cancer could be tested to see whether I would go on to have chemotherapy. But because chemotherapy would be decided by a computer at random, and because of the amount of tumours that I had and the grades of them, I had already decided that no, I was not going to let a computer decide my future. I would do that. So then because I said no, I wouldn't go into the POSNOC trial, but could I still have this oncotype dx thing done because would it help with diagnosis and treatment of the cancer? I was told no, but I would be referred for a second opinion. So I went through the second opinion, had the chat with the lady who organizes the samples being sent away to be tested, and her words to me were, 'as you've already decided to not go into the trial, I need to apply for funding to have your cancer tested, that will take three months, but as you're having chemotherapy anyway, that's a waste of three-hundred NHS pounds. Now personally, I think that that information is important, and it shouldn't have been put to me that way, and my cancer should have still been tested. The other thing is, I'm hoping, and this is just a statement, but I'm hoping that with the way that they've managed to get the COVID trials for the vaccines done so quickly, I would really love to see those kind of advancements be used in cancer treatments, because at the moment there are possibly drugs that they've known about for five years that still aren't in trial. Well they might have saved my life. Chances are I'm going to be dead before they even get to the to the testing stage.

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