

Written evidence submitted by Group 1 (ECS0044)

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 1

*Due to technical issues the beginning of the session was not recorded. The first question that participants were asked was 'how would you describe your cancer treatment in one word' with space given for participants to provide information on why they choose that word.

Participant A: I have a specialist cancer nurse, and I've found that I've had to go through them for everything, but they never pick up their phone. They never get back to me and overall it's been quite stressful. That combined with my GP being nowhere to be seen, impossible to get hold of, means I've found that aspect very stressful. But in terms of the medical care I've been very, very lucky and had brilliant doctors.

Participant B: The key word that I would use is varied, a bit of a curate's egg. For my disease, the average amount of times you have to go to the doctor before it's diagnosed is six times, and I was spot on. I went to the GP five times, because they kept spotting anomalies in the blood count, before I went to the specialist. I was told that it's very good for the GP to pick it up, because it's a fairly rare disease, and the average GP will only see it once every two years maybe, but he suspected it and told me what he thought it was, and that I needed a specialist to confirm it. He said that you'll get a letter, and when I got the letter it said that I had six weeks before I saw a specialist. And I got tunnel hearing; I heard cancer, I heard leukaemia and I heard incurable. It doesn't fill you with confidence. So, I did the old Dr Google, which you shouldn't do, but I did. At the start it was very poor, I would say, until I was diagnosed. I had a lot of cancellations. With it being a chronic disease there is a lot of monitoring- watch and worry as I call it- and the day before I was going in for my next three-month check-up the appointment would be cancelled because they were too busy. As I've talked to other people who've got the disease, they always say it's the stress of the build up to knowing you are getting near treatment, and you build up the courage to go and then you get a cancellation. Since I've started treatment on a trial, it's gotten a lot better, whether it's because of the extra trial resources I don't know. I know that some trusts do get a specialist nurse etc, but I didn't get any of that until I joined the trial.

Participant C: I'm not talking from personal experience, apart from my father having had a massive delay between visiting his GP and starting to receive treatment. It was the jargon used as well; my father was the only one who hadn't realised that he had cancer because the doctor had said that I think you're got a carcinoma, and it went completely over his head. We're hearing similar stories to what Participant B was saying within the charity as well. It's the lack of support at the beginning, it's non-existent. Once treatment starts going underway it improves, but there is that aspect at the beginning.

Participant D: I would go with varied as well. I've got a different perspective on it in comparison to everyone else. I found a lump and I went to the GP three days later- obviously they did the initial telephone call, but you can't feel a lump over the phone, so they got me in straight away. They transferred me to the breast clinic, which I was really surprised about because with my age they don't usually suspect breast cancer, and I got a referral within two weeks which was fantastic. I didn't realise it at the time, but I actually didn't get a lot of support from my oncologist. I had a

support nurse and she told me my diagnosis, she told me everything, gave me a step by step run through of what was going to happen, but at no point did I ever speak to an oncologist, which is really weird. And then everything was really quick, and I did surgery. At the time they told me that I didn't need chemo and I went straight to radiotherapy. But then I transferred down to a hospital in London- I was originally diagnosed in Yorkshire- and I met with an oncologist for the first time, they told me that I should always have had chemotherapy, and they don't really know what happened. At the time I had no idea, I thought I'd had a really amazing team and it was really supportive, but actually looking back not being able to have the opportunity to speak to an oncologist, and not being given any options regarding chemo, or what could happen with or without chemo, was really bad. At the London hospital, I was again given a support nurse, but they were less supportive than the one I had had. So a similar situation to others, where you make a phone call and it goes to voicemail and they eventually ring you back, which when you are absolutely terrified about something, is a bit weird.

Participant A: Sorry to interrupt, but I'm at the same hospital so we must have the same team which makes me feel better.

Participant D: When you're really worried about something, or really scared about something, and you call a voicemail...you don't want to have to wait five hours for them to get back to you, I need to know now that I'm not dying. Or waiting for ages when you've seen something dramatic when you've been on Google. But the oncologists I have are amazing, absolutely amazing, and now that I've finished it's still good, but I'm just a month out of it. So a bit of a mixed story overall.

Participant E: So I've had a varied journey in my care. Like many with blood cancer, I was diagnosed in A&E. I'd gone to the GP I think it was six times over a five-month period, to the point where the GP said, 'do you think you're coming here a bit too often', I think he thought I was a hypochondriac. I had a breathing problem at Christmas, and we called 111 who said that I should go to A&E, and they ended up doing blood tests and that was where they picked up an extremely high white count. Part of that issue is that blood cancer symptoms...we tend not to get tumours, we have a collection of symptoms which can be very similar to general infections. I think when you go to the GP you go in with a clear idea that you have a short window of time with them, and whilst you might have a few things that are niggling you, you tend to go into the one that's giving you the most jip at the time. For me it was a chest infection, so I didn't think to bring out the other symptoms because you don't know what the collection of symptoms could be. You don't think you've got cancer when you're 45. Initial diagnosis was fine I guess, but you don't really take a lot of it in and there's a lot of terminology. You just hear the word cancer and your brain just partly shuts down. I didn't have the best time at the initial trust, the local one where I live, I was assigned a clinical nurse specialist who was really quite abrupt and dismissive. In those first few weeks you've got things happening to your body that you haven't experienced before, it's quite scary, and you just need to speak to someone to find out is this normal, is this right. I don't think she appreciated my calls and so I stopped calling her in the end. Having had my blood samples lost five times, I decided to move my care to a specialist centre for CML and they've been brilliant. You realise the disparity that there is between the trusts and the different experiences with different people. I've had exemplary care there, I have to say.

Participant F: I was diagnosed with cancer almost three years ago now. If I had to describe my treatment in one word it would be disjointed. Some of it has been excellent, some of it is lacking, and the lack of connections has been a real problem. The amount of energy that somebody with cancer has to put into just making sure the admin is right is extraordinary and scary. I'm young, I've got a Masters degree, I'm very motivated, educated and I don't have a lot of pressure- other than having a small child- and I have to chase appointments, I have to constantly check where I need to

be. I've got an appointment tomorrow, but my letter tells me it's a phone appointment next week, so it's just ongoing and constant. Because of the stage of my cancer I had some surgery in my local hospital, but then I had radiotherapy at another hospital, and the communication between the two hospitals- even though they meet at the MDT- is a lot of mismatch and a lot of things fall through the cracks. After my treatment was over, I fell through the monitoring gap, and no one was keeping an eye on me. But my GP, once I fought my way through reception, my GP has been my hero. My GP is the thing that holds it altogether.

Jeanette Dickson: That's really interesting and thank you all for sharing. What I'm hearing from all of you is that some of you have had great care, and some of you have had bits that are not so great, but it's all different bits of a thing. I think that's not actually surprising to me, perhaps I have spent too long in the NHS, but it's interesting to hear that quite so graphically. We've heard about GPs, Participant F mentioned surgeons, we've heard about haematologists and oncologists briefly. We've also talked a bit about nursing and nursing support. The only people we've not heard about is radiographers, who would normally do the radiography aspects of it, and would anyone want to talk about radiography? Just because I'm a clinical oncologist and we can't pass on without talking a bit about radiotherapy.

Participant F: I did have radiotherapy and I felt like that was going into another zone, another world, a sort of semi-private world. It was the big machines in basement, and it has this shiny feeling to it. It was my first interaction with treatment- which is probably quite different to breast cancer where you have it at the end of your treatment- so I still had all of my energy. I think that also might influence how you experience it.

Jeanette Dickson: Thank you, that's a really interesting point actually.

Participant A: I had breast cancer so I had it at the end, and I would say that it was probably the best part of my journey. Although my body was exhausted, it was very well run and you knew where you had to be every day, at the same time and with the same people, and you can tick off your appointment every day, so it was relatively straightforward from that perspective. This experience is very personal to me, so I'll keep it brief, but I had one criticism. I was told by three different doctors from the medical oncology side that they thought that I'd need five days radiotherapy. And so I planned the next few months, and then I turned up for my first appointment and the clinical oncologist said, I have no idea why they're telling your type of cancer that you only need five days. You actually need four weeks of having it every day. And that's obviously fine, but the mismanagement of expectations was quite crushing and not ideal. Obviously, the MDT is there to stop miscommunication happening, but that's one example of various points where it has happened to me between the teams, where I've been told something about my care, and it actually turns out to be much worse. Whereas I think if you're told the worst possible case scenario, you can get your head around it. It is just the other way round where it is harder to take.

Jeanette Dickson: Miscommunication is always hideous from every angle, especially for the patient, but it's not good for anybody.

Participant D: Because of the issue regarding what treatment I should have had, and what I shouldn't have had, I actually had radiotherapy first, so I completely agree that it's one of the better aspects of the whole treatment process. They tell you where you're going to be and they don't change it, whereas with chemo I could be in at 9 o'clock in the morning and they will say 'oh sorry, it's been move until 2', and I might have had plans, so it was really annoying. I tried to work throughout my chemo, so it was really frustrating for me. But they were super easy for me with the

radiotherapy, and if I needed to change the time for whatever reason, they would. I was driving an hour there and an hour back, so when they gave me an 8:30 appointment, I asked if I could move it so that I wasn't sitting for ages in rush hour traffic, and they were so easy going and told me to come whenever worked for me. Whereas moving a chemo appointment is like trying to find a golden egg in Australia when you're in the UK- it is impossible. They put you through to the MDU, and then they say you have to go to the breast care team who in turn tell you to go back to the MDU. It's frustrating. You're on the phone for about four hours and when you actually get to the point where you can change your appointment you don't even care anymore, you've moved everything around so it doesn't matter. So radiotherapy for me was so great, I loved knowing when I was in, they didn't change the times and they didn't change the ballpark. I had a similar thing where they said, you might be able to do five days or four weeks, which is quite frustrating when you're not sure if you're going to need to shift 20 working days around, but once it was confirmed as 20 days it was fine. But yes, I completely agree that radiotherapy was great.

Jeanette Dickson: So we've heard some good things, we've heard some bad things, and this is the workforce bit. Participant A, at the beginning you hinted that you didn't get enough support from the support nurse, but as we go round again, I just want you all to think about what specialisms or support that you didn't feel you received or that you would have liked in your pathway.

Jane Dacre: Can I interrupt? Because of the way the conversations are coming out, I wonder whether we can look at the living well aspects as well because they're overlapping a bit and it give you more time to go round. Is that ok?

Jeanette Dickson: Yes, that sounds good. So, Participant A, a slight reframe. So yes, what did you need but also, for example, did you have a specific care plan that was written down? Did you access that and did you feel that it was personalised, or did you feel like you were a Jaffa cake? Apologies to anybody who likes Jaffa cakes, but you know the small hole on the conveyor belt.

Participant A: I like it , and I felt a bit like I was a Jaffa cake. I also learnt- and I'm stating the obvious to everyone in the room- that cancer isn't straightforward. So what I was told on day one obviously changed every week, every month, and I wish that somebody had told me that at the beginning. In that first session when I was diagnosed, and they're like 'you're going to have XYZ' and then for me it all changed. I think if they could have said that this might change, but this is what we're imagining at the moment, that would have been more helpful. So that's care plan. On the support, I think Participant D, summed up my issue with breast support nurses. You can never get hold of the breast support nurses. They have the longest answer phone message in the world, and when you're feeling ill and tired and frustrated, you just don't want to have to go through that every time. The hospital have this incredible helpline, the Macmillan helpline, but what happened was I ended up phoning them for things that weren't life threatening because I couldn't get support elsewhere, which obviously isn't ideal. Obviously, they were serious problems but... My main bugbear throughout my care- which I think would take the pressure off the hospital- is my GP. I know that resources are tight, but a check in every few weeks or months would have helped. I didn't hear once from my GP and to get an appointment I had to go through horrible receptionists (I'm sure they're lovely behind closed doors) who had no sympathy whatsoever. When you're not feeling well and you're scared or emotional, having to go through someone who just make it impossible to get an appointment is tough- cancer just doesn't mean anything to them, but I was 32 and I was young. When I did finally get through to the doctor- because I thought I can't keep phoning the helpline- I found that they didn't have a clue about the things I was asking them. Google was far more useful. I know they can't be specialists in everything, but I just think some more knowledge about how to deal with, and support, cancer patients would be helpful.

Jeanette Dickson: We're here to get this information and you're giving us that information and that's good. Participant B, is there anything you would like to add, because you talked about a trial which nobody else has mentioned, and you said the resources changed when you went into that. Would you like to expand on that?

Participant B: As I said before, from the time I was eventually diagnosed I wasn't getting any support or answers to my questions, and it suddenly clicked for me that it's not a National Health Service, it's a National Sick Service, because of the limited resources. I've got nothing but plaudits for the work that they're doing, especially at the moment with the pandemic, but really they've got to focus on diagnosis and actual treatment. Answering questions, emotional support, understanding, anything like that they just don't have time for. Through Google I stumbled across a bit of a unique charity called the CLL Forum, which are researchers, scientists and specialists in the UK who work together and formed a patient arm of it. They feed in information, and they do webinars and conferences, and it was like stumbling across Nirvana, going there to find other people in a similar situation at different stages of treatment, with experts and guidance in there. I also suddenly realised that there is such a high variance in trusts. So, on CLL I would talk to a doctor in Oxford, about how they do it there, with clinical nurses and planning, and I would think it's a million miles away from the 90% of the people who are treated in local hospitals. I used to be Chief Knowledge Officer in a global company, and I'm now striving to see how we can tap in the good quality charity resources and information that are out there, so a doctor or specialist can say 'speak to these people, phone this helpline, got that conference, you can trust them' and they can get on with doing the diagnostic work.

Jeanette Dickson: I think that's a really good point, because there's a huge amount of support out there, if you know where to get it, but it's also that thing about Doctor Google and Twitter (which is my personal bugbear at the moment) where a lot of the stuff on it is pants, and you shouldn't go near it because it will scare you and it's wrong. So, how do we signpost appropriate information. Participant D, what about yourself?

Participant D: At the start I definitely felt a bit like a Jaffa cake. To be honest it felt like they were trying to get me out, and because I was 24 at the time, I was a bit young and naïve and I put all my trust into the doctors, and I never questioned a single thing, and I think that is where I went 100% wrong. I should have questioned them. Because I was so young, and I obviously wasn't expecting cancer, I was a bit like 'Oh my God I will do whatever you say. If you tell me to jump off a cliff, I'll jump off a cliff' and that was the problem. They're now saying that I wasn't offered chemo because of the pandemic, and also their fertility clinics were shut down because obviously I would normally have stored my eggs. They were basically weighing up the pros and cons. But when I went to the London hospital, they said you should always have had chemo and they gave me the percentage that if they were to leave me as I was without chemo there's an 85% chance that the cancer won't come back, whereas with chemo there was a 95% chance it won't come back. The problem is that when it comes back it's in stage 4, it's incurable and spread everywhere. That was the big issue for me, and I wasn't given that information previously. I'd also been on tamoxifen for five months, which is the oestrogen lowering thing and quite toxic if you want to get pregnant, and we then started this process of chemo. I was in this six-month banding, where they said it was close to them not knowing if chemo was going to be relevant anymore, because you're on the cusp and we don't know any facts after that. So they had to rush me off tamoxifen for a least a month, because it's super toxic. I had a terrible experience with IVF because the eggs just disintegrated, so I don't have a great IVF situation. The decisions that the doctors made really early on to try and just get me out, because of the pandemic, have actually really impacted my life going forward, and I think in that sense it's really

difficult. I definitely did feel like I was on a conveyer belt. I've got to take my hat off to them, because I know they were stretched really thin because of the pandemic, but I've also got to look after myself, and I really do feel like I was pushed out of the door. It was like she's 25, she's going to survive for the next 10 years, and then we'll deal with it in 10 years time. That's not really what I wanted to feel like. So, my experience in that respect is quite negative, but at the London hospital they've been great, and my oncologist has been great and really listened to me. I've questioned everything she's done, and she always comes back with answers which is amazing.

Jeanette Dickson: So, it's that personalised approach that is important to you at this point in time?

Participant D: Exactly. Because she didn't want to do the IVF, but I pushed her on it, saying 'please, please, please', and I should have listened because it was awful, but it was good that she listened to me. She's actually taking on my opinions and giving me answers back.

Jeanette Dickson: Thank you. Participant C, as you said, it's not a personal experience but you talked about being the CEO of a charity and do you have a theme about the particular support needs or care plans that people have.

Participant C: My concern is around personalised care, and the lack of it basically. So treatment is one thing. I'm having to explain to elderly veterans and their wives about the emotional part of this which does seem to be lacking. It's the jargon and it's telling patients to actually say how they feel and open-ended talking that isn't encouraged enough.

Jeanette Dickson: It's a tricky one isn't it? When the workforce is spread as thin as it is, how do you give people enough time and space. And there used to be a waiting room full of people to talk to but now it's a telephone queue with other people.

Participant C: What we're seeing is that the strain is going to the Macmillan nurse, because as Participant A said they're having to leave long answer phone messages and not getting answers from specialist nurses, or they're coming to us. So, there must be something else. There's got to be a more user-friendly way of dealing with that, even if on a phone line.

Jeanette Dickson: Thank you. Participant E, you again had some concerns about your care. Did you have a personalised care plan at all?

Participant E: My care plan is quite simple, in that it is take this tablet every day for the rest of your life, so it wasn't complex. But for me- and picking up from what everyone else has been saying- at the point of diagnosis you're a complete novice and beginner in this whole field. I'm speaking now with eight years of experience, and I would say that we become experts in our conditions and what works for us. Mine is very different, because I know with lots of cancers there is a finite plan with a finite time scale for treatment, and as my sort of cancer is, if you like, non-ending. I've got a different slant on it. Part of the problem is that when you do get that diagnosis, you suddenly get lots of follow-up questions that are highly impacting your life. Within 10 minutes of getting a diagnosis my wife and I were asked if we wanted anymore children, because if we did, we had to do something about it there and then, which is a massive thing to take on board. At the start you are compliant, you are, if you like, on the conveyer belt. And certainly I was brought up in that generation where you never question what a doctor says to you, but I've actually found the value of being part of that conversation and part of that solution and asking the right questions. As I say, for me it's simple as it's a tablet, but there are complications. When the drug came out of license it became a general drug, and suddenly you were having trusts source the cheapest deals, and though it's understandable to want to save money, there wasn't any real thought about clinical impacts and

what the side effects would be for patients. I've had some real battles, which I've managed to win, on changes to brand because of the binding and coating agents on them. Again, different trusts have different policies on drug dispensing. At my first trust we weren't trusted to have more than a month's supply at a time, so we had to keep going into hospital to pick up the prescription, which could turn into a three hour wait. Where I am now, I get prescribed 3-4 months at a time, and it gets delivered to the house, so I'm really lucky. I've got a care plan but, again, it is different as I treat myself at home or at work, so it's different from a lot of the more robust treatments that many of you guys have been through and you all have my complete respect. I have my own issues with this treatment, but I think I've had it a lot easier than other people.

Jeanette Dickson: I think any chronic illness and any chronic medication has its own problems so don't do yourself down.

Participant E: Yes. I mean, the thought of never-ending treatment does affect you more mentally, and I think it's true to say that you get two diagnoses when you get a cancer diagnosis; you get the cancer itself and then there's a mental health diagnosis that goes along with it. Again, the haematology team have to be focused on the haematology, and I found that emotional support through the charity work that I do with Blood Cancer UK. Again there's a forum group and you find that talking to peers, or people in that same group on Facebook, you feel that you're not alone. But you don't know that at the time of the diagnosis.

Jeanette Dickson: Participant F, what about yourself and your feelings of the holistic wrap-around care? You talked about how it was disjointed before, so I'm expecting that the answer isn't going to be that it was all wonderful.

Participant F: It's interesting that my experiences do echo everyone else in quite a lot of ways. I did have a care plan, in as much as I was told roughly what was going to happen, but at the beginning your brain can't take it all in. Your brain just doesn't have the capacity to understand because it's never been through it and you don't know what's going to happen, or what the complications are. I think one of the biggest things is actually not the treatment itself or the cancer- though it's massive- it's the complications that come from the cancer and nobody can plan for those. And the thing that I've felt that hasn't been there, has been support with dealing with the complications. So the physio referrals and the menopause clinic referrals, and you all those other things that you have to put in place. And I relate to the points Participant A made GPs, as I had to get into a war of words with the Practice Manager, with emails and letters going back and forth- and the letters that I was getting from her were absolutely foul and really upsetting. When I finally saw the GP and asked for advice, she told me that they did have regular appointments with their cancer patients, but I had been asking the practice manager for regular appointments and had been told that there was absolutely no way that they could do that. Now I talk to my GP every six weeks, and things like a problem with my tongue or an ache, I know I don't have to worry too much about it, as I will see the GP in a month and talk to her about it. It means that I'm not going for every little thing, so I'm taking the stress off the NHS as I'm not going in twice a week. It also means that I'm less anxious as I know if I have a problem I have those check-ins. But that should just be standard. If you have a long-term chronic condition you need to see the same person regularly, because they know you, they know what is normal for you, and they don't have to spend 15 minutes reading all of your notes because they have that information. So you're taking the stress off of the NHS again with that.

Jeanette Dickson: Thank you everyone. The next bit we are focusing on is diagnostics, and we have touched on this a little bit. As I said I'm the President of the Royal College of Radiologists (although I'm not a radiologist) and the radiologists are the expert doctors who interpret CT scans, imaging

tests, but diagnostics also include blood tests, the biopsies that are taken from you, and we are concerned that that bit of the pathway is longer than we would like it to be. Some of you, Participants B and E in particular, have touched on that difficulty of diagnosis. Participant D talked about a good rate of diagnosis, and Participant A not so good. So can we have a think about those diagnostic test, or those tests that you've had subsequently. Have you got any concerns about that, or anything you would like to share?

Participant A: So, I probably didn't explain it very well because I had a great diagnosis, it was the GP side of things that wasn't so great. Within two weeks of finding the lump I was diagnosed which is great. Again, in terms of another miscommunication when I was initially diagnosed after my initial scans where they take the biopsy, I was told that it was breast cancer. I was told it was probably stage one which would only need to have a bit of radiotherapy, but then a week later I was told it was stage 3. So that was probably the only bad bit of my diagnosis. In terms of scans, as a cancer patient I've had every scan under the sun, scans that I didn't know existed, but yes, all fine from my perspective.

Participant B: As I say the diagnostic phase took a long while. Again going back to your sentiment of Doctor Google and social media, when I went into my specialist and was finally diagnosed, he said that from looking at my blood tests he thought I had had chronic lymphocytic leukaemia for about 6 years, but I had looked up on Google and it said that the average life expectancy for a man with CLL is 10 years. So I'm thinking (expletive). I've got to tell the kids, I've got to get my will sorted out, and then I went to a webinar and was talking to someone else who had CLL, and he told me the average age of someone diagnosed with CLL is 72, and the average age for a man to live is 78, so he said that we are mostly not dying of CLL but old age or something else. But you don't get told that, it's not in any book you get. So on the diagnosis, it's as people have said, you hear cancer, you hear incurable and you're going to be on watch and wait and we'll see what happens on it. And of course you look things up. We look at other areas, including supplements that will help like crushed dandelion root and turmeric tea. They work well and it isn't always shared. The only thing that has some slight relevance, according to a Mayo report, is green tea but the amount you would have to drink would kill your liver and kidneys.

Jeanette Dickson: Yes, it's that window between being completely flattened and then the bit about needing to stuff that you need to know. But also, when doctors quote stuff, they quote from the diagnosis, not from when you first had it, and I don't think we make that clear.

Participant D: Like I said my actual diagnosis was great. I mean the biopsies were horrible, but it was great that they did it immediately. Any scans that I needed were great and they were pretty quick actually. Now that I'm going through chemotherapy, they obviously take your bloods every week, and they just casually dropped in after a month that I was anaemic but that it wasn't bad enough for a blood transfusion yet. I asked them where it had come from because my blood count had always been high, but they turned round and told me that my blood count had been rubbish since I started chemo, but it wasn't bad enough so now we're telling you. And then because I'm on the Herceptin injection and it impacts your heart, I have to have an echo, and I had an echo in August and another one in December. And then I had a horrible chest infection at the start of January and as I couldn't breathe they started doing CT scans and checked my notes, and the nurse said that she was concerned about why my heart rate so high, and that I had a murmur but it wasn't a major one. And I had not been told I had a murmur. It was in my notes, but nobody told me. And it was like, I was told I had cancer, but that it wasn't major only now it's major, and now I've got a murmur and anaemia. And I didn't understand why nobody was telling me these things. If I haven't heard anything after a test or scan, I presume that everything is fine, and that I'm not going to call you up

because there is nothing to call up about. But then suddenly, three weeks later, I'm anaemic and nobody thought to tell me. Why? I can handle it. I have breast cancer and I can handle that, and I can handle all those other things now because I need to. I don't know if it's intentional or not, but there is this case about trying to keep things to themselves and not necessarily tell you the full picture and, since I was diagnosed, I want the full picture. . I want every bit of information that you can give me, whether you think it's relevant or not. I might ask you five questions about it, and it might take 10 minutes of your time, but at least I know what is going on. And that's my issue with the blood tests and scans. Just take 10 minutes to explain in very simple terms what this means, even if you're not concerned about it, I want to know, and I want to know what it means for me going forward. So that's the thing that frustrates me, diagnosis wise.

Participant C: The only thing I can really comment on is the length of time between going to primary care and then being diagnosed. It depends on the type of cancer and whether there's a lump of symptoms. That's the issue that I hear a lot, and it's that wait between the tests and the big appointment that is crippling the patient and their family.

Participant E: At the point of diagnosis in A&E, and subsequent to that, it's been pretty good in terms of the test and what have you. That was certainly my experience. In A&E they take your blood and that's when they notice the very high white blood count, and then they took more tests. And then I had a bone marrow biopsy, which was not the most pleasant experience to undergo, which checks the molecular level and thankfully I've only had one of those. It's just regular blood tests, and I think they started out every 3-4 weeks initially- it might even have been every week within the first month or two- but now it's every quarter. But, I don't know if you guys are all the same, you're only ever as good as your last result and you always have that thing in your mind. But the point prior to the diagnosis, which I touched on earlier, about going to the GP half a dozen times and being told that I was going too often...CML is a rare blood cancer, and it would be able to place the blame at the feet of the GP, but there is a case for educating the public in awareness of symptoms and conditions. I didn't know anything about blood cancer before I got thrown into this world, and there were signs there which I should have questioned. But you don't think to, you don't think at that age 'I wonder if this could be cancer.' I used to do karate, and my forearms would be covered in bruising, and it didn't occur to me to think that I didn't see those bruises on anyone else. It's hindsight experience. So I think there is work to do in that area, I don't know how it could be addressed it would help.

Jeanette Dickson: We agree with you, and it's an easy thing to say, but how do we enable and manage it is difficult.

Participant E: Yes. I like the idea of these seven rapid diagnosis centres, but you've still got to get a referral from the blockage point, the pinch point.

Participant F: On my diagnosis it depends on whether you go with the first time I went to a GP about digestive problems, or when I went with big red flag symptoms. If I go with when I went with a big red flag symptom it took four months, because I was under 50 nobody thought bowel cancer. In fact, when I went for my colonoscopy, I was told that there was nothing to worry about, but that they would do it anyway. And then they started dropping things in the colonoscopy which was a bit of a sign. I'd been going to the doctors for 10-15 years about problems that were probably early stages of bowel cancer, but as participant E said, it wasn't something that was on my radar. My biggest fear when I went in was that they wouldn't find anything and I wouldn't get an answer, I didn't think there was any chance that I had cancer. Picking up on what Participant A and D said about things cropping up after diagnosis, 3-4 months after my diagnosis I saw my oncologist and she said that

there is a nodule on your lung. And I just said 'what?' She said it was nothing to worry about, but still a big thing to hear. At one point I was looking through my notes and I saw that I had an extra nodal mass, so I actually had two tumours. Again, my thinking is that they just think that because it's not going to affect how they treat me I don't need to know about it. But, in terms of how we look after and nurture ourselves we do need to know, and it's about bodily autonomy. And, if you suddenly in a conversation with an oncologist and they say that you have a lung nodule it can derail the conversation. In terms of after diagnosis I think my staging, and the regular scans, have been really well handled and I think I'm comfortable with that. Something that happened- and I think it goes back to the beginning and not knowing what questions to ask and dealing with the onslaught of information- is I don't know what the genetics of my tumour are. It's important, as if it comes back I do need to know that, but I don't even know if that was done. Some bowel tumours emit CEA levels, and I don't know whether my tumour does. So the major monitoring about whether your cancer has come back, I don't know whether that's relevant. I think there is something here about patients just knowing the things that you should be checking are being done, something like a checklist of all the things that are normally assessed.

Participant B: I just wanted to add to the knowledge bit. The only curveball that I would throw in there, you talked about the trial, and when I took part in the trial, I was luckily in the blind selection I got the new drug. And my specialist told me that that was a relief, and when I asked why, he told me that if I was given the standard FCR then it might give you another 3-6 months but that's it. Now did I really need to know that?

Jeanette Dickson: If I had a fiver for every time I had gotten that one wrong I could retire now.

Jane Dacre: Thank you. All of these stories are meaningful and powerful, so thank you for your contribution. The next thing we want to talk about is innovative treatments, so I wonder if you could put your hand up if you've been offered some kind of advanced, cutting edge and new treatment, or whether there's something that you wanted that you know is out there, but you couldn't get hold of.

Participant E: My treatment is still relatively young, I think it was given permissions to be used in around 2001. It's Imatinib and at the time it was a game change in cancer treatment, because CML was a bit of a death sentence before, and it's turned it from a lethal disease into a manageable condition. I say it's quite young, but things have moved on dramatically in the last few years. I think that it's good it's managed, but I don't want to be a burden on the NHS, and I don't want to be taking these tablets every day for the rest of my life, and I was just wondering what the possibility of was of getting a cure rather than just managing the condition. I think something may emerge in CAR-T therapy arena, but what thought is the NHS having in making that standard treatment for everyone.

Jane Dacre: Thank you, and that must be very disconcerting, really disconcerting, for you.

Participant A: I have a positive. My drug has just been launched in an injection form, and hopefully we will be able to do it ourselves from home eventually. And that was great because it meant that I got to have my port out, so that's a positive about where science takes us.

Participant F: I haven't had any novel treatments, but one of the things- and we're obviously all worried about it coming back if you're still on the curable pathways- but knowing what it is available if it does come back, I feel that immunotherapy is very piecemeal for bowel cancer. I just don't have a feeling for how access to new treatment works and how they're fed into the NHS. It feels like a lottery, but that just may be my anxiety.

Jeanette Dickson: I can reassure you, to some extent, that there's a fairly good process for getting new drugs and it's much more rapid that it was even five years ago. Immunotherapy is very variable, and trust me people are looking at it all the time. The evidence base shifts very rapidly on all cancers.

Participant F: I think it's just the anxiety of having had the diagnostic stage, knowing that my tumour wasn't profiled, means that I wasn't future proofed for immunotherapy.

Jeanette Dickson: Parts of your bowel cancer will exist somewhere, it will have been profiled, trust me.

Participant B: Through the charity I've found this trial page, where you can find out what trials are available and that helped me get on the trial. Since I've been on the trial, as I said, it's been a revelation with the support and the resources. It's just the cynic in me as it's a six-year trial and we're halfway through, and I already know that the drug will not be approved. So I'm staying on the trail because it's doing the business. Within three days all my lymph nodes went down and within a year I'm MRD on it. But they consider the side-effects to be too bad. So, I'm sure in three years' time that things will be available, as new drugs are coming along all the time, so I can park there. But the cynic in me is wondering, and it's following Participant E's point, what is in it for the pharma companies to come with a cure as there is a lot of money to be made of a drug that keeps you alive. Call me a cynical monkey, but that's in the back of my mind.

Participant C: My comment is a question really. I'm on the genomics partnership in Wales, and I know that we're doing a lot in Wales about bringing in genetic sequencing at the instigating of pathway treatment, so that you can be clearer throughout treatment. How is this in England? Because obviously a lot of time can be wasted with trying to match a drug and having side effects and repercussions of that.

Jeanette Dickson: It's a four-nation thing. England are organising it slightly differently, but there is a big push across all four nations right now. In fact the genomics hubs were launched in the middle of COVID, in April last year

Participant E: Just before the pandemic we were on a massive roll in terms of research and therapies that were emerging from that research, which basically came to a standstill for the last year. Not just in terms of funding, and being able to raise funds for that, but also for workforce as they were focusing on the pandemic rather than cancer research. It'd be really good to see the Government address that, if they could, in any way. How do we get back onto that line of progression in research that we were on? It was exciting times.

Jeanette Dickson: I think we all agree, that we're desperately keen to get there. The fortunate thing about COVID is it's shown to the Government that trials can be run in the UK quickly and get results. And if you have the infrastructure there, you can do things rapidly. So I think it will come back quickly.

Jane Dacre: Is that something that we learnt from COVID, just out of interest.

Jeanette Dickson: I think we've always known the value of trials, but I think the Government has suddenly seen that if you put an infrastructure behind it, or you can accrue very rapidly, then you can get an outcome that is internationally accepted. I think the value of accruing business opportunities for the UK and the health sector is a positive one.

Jane Dacre: So we've come to the end of the session. It's been absolutely fascinating. I've felt humbled by you all and your honesty and the way that you've given up your time and spoken to us. We hope that you panel can give real evidence-based feedback to the Government, and that they have a response to what we say. But thank you all again for giving us your time and speaking with us today.

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