

## **Written evidence submitted by Group 2 (ECS0045)**

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

#### **Group 2**

**Nikki Morris:** I want to start off by saying thank you so much for giving up your time and coming to this. It's so valuable. We know that people have shared experiences, but people also have different experiences, and we want to hear your experiences and, collectively, some of the themes that come out. These themes may be for all of you, or maybe just for some, or one, of you. As they say there are no wrong answers, and there is no answer that we're particularly looking for. We just want to hear your views. As I said in the introduction, I'm Nikki, I'm Chair of the Royal College of Nursing Cancer Forum, CEO of a charity and I've got a background as a specialist cancer nurse. So shall we just go around and do a brief introduction.

**Participant A:** I'm a retired Health Visitor and I am a Patient Advocate for Myeloma UK. I live with multiple myeloma and have done for 12 and a half years.

**Participant B:** I'm a member of the NHS England Cancer Programme Patient and Public Voices Forum. I'm also patient advocates on the board of my region's Cancer Alliance and I'm a member of a newly formed black men's prostate cancer group.

**Participant C:** I'm a retired social worker and I'm a thymoma patient and have been for the past seven years. I'm now receiving palliative care, although I'm not terminally ill.

**Participant D:** I'm a registered nurse and member of the RCN. I've been living with Neuroendocrine cancer- or rather it's been living with me- for several years, pre and post diagnosis, and I have metastatic disease.

**Participant E:** I sit on the Patients Policy and Communications Panel at CRUK, and I sit on the board of trustees at a National HIV charity. I'm here on behalf of Live Through This an LGBT charity that supports the needs of LGBT people with cancer. I'm living with HIV and myeloma, and I've been living with myeloma since my diagnosis in 2017.

**Participant F:** I am the Chair of the Patients and Public Forum for the NHS England cancer programme. I'm also a founder of Shine Cancer Support, we support people in their 20s, 30s and 40s with any type of cancer and at any stage. I had cancer myself, I had stage four Non-Hodgkin's Lymphoma- almost 12 years ago actually- but still living with the impact of that, on my immune system in particular.

**Participant G:** I was diagnosed with prostate cancer a little while ago, and I was treated with cryotherapy in a London hospital in August. So, I'm recovering from that at the moment.

**Nikki Morris:** Great to have you all and a real breadth of experience, so thank you very much. We've got a number of questions that we want to ask you and the first one, which is always an interesting one, but in one word, how would you describe the care that you received during your treatment?

**Participant D:** Fractured.

**Nikki Morris:** We've got lots of others nodding their heads, which is interesting, so tell us a bit about why you say fractured.

**Participant D:** Because the doctor who diagnosed me, who was the gastroenterologist, said 'I have no idea what this is, I have no idea what neuroendocrine cancer is. I don't know what it means, but it'll be three weeks before you can speak to anybody at the local hospital. We don't know if it's metastasized or not, but the lesions are 6.5 centimetres. See you.' And then, because they didn't know, the referrals went to the wrong places. And in the end, it's only because I'm a nurse that I knew what to do. My referral went to neurology, to endocrinology, to oncology, podiatry, physio, but it never went to neuroendocrine cancer because nobody knew what it was. And when I had complications from it, I went to the hospital, and I needed emergency surgery. I told them that I have neuroendocrine cancer, and they said no, you must be wrong as you can't have that, it's either neuro cancer or it's endocrine cancer. And they put my life at risk because they would not believe that I was at risk from carcinoid crisis. And these are doctors, and I've had to say to them 'let me show you Google, it's an amazing thing, now look up neuroendocrine cancer.' I shouldn't have that much responsibility. And what if I was, you know, 71 year old Doris that worked in the Potteries and I didn't know how to say to a doctor 'I'm not impressed by you, you don't know what you're talking about. Could I have your GMC number please?' It shouldn't be that hard, and that's what I mean by fractured. The other thing is, I haven't had any blood work, and diagnostics, nothing for two and a half years. I can't get any help because I'm not considered palliative, but they won't do other things for me because I'm incurable.

**Nikki Morris:** Hold on to that thought for the moment, and we'll come back to that. Participant E, what is one word that you would use?

**Participant E:** I was going to say kind. I was going to say that because I had treatment for myeloma in 2017/2018, so that was chemo, then in the beginning of 2018 I had high dose chemotherapy and then a bone marrow transplant. And then right at the end of the first year of the pandemic, so the end of 2020, I was told that my cancer had come back. For that whole year in 2020 I had been here in my flat all on my own, I hadn't had any contact with anyone because I was shielding, and it became very obvious when I started treatment in February 2021- I didn't need a transplant but I was having twice weekly chemo, some of which I was administering here at home- that I had no idea how frail I had become, emotionally, psychologically and spiritually. I had used up all my resources. And on the few occasions that I was going into hospital (around once a week) during the pandemic I was going in with no friends and no family, and as I live on my own, I was on my own post-treatment, and they treated me with such incredible kindness. They very gently helped me, and identified where I needed more support, and they did so with such incredible kindness. There is some stuff I want to say later on, about where it didn't join up, which was problematic, but overall, I just wanted to say that my care has been incredibly kind which is not easy because of the pandemic.

**Participant A:** I've got two descriptions actually, because I've had two stem cell transplants. For the one I had in 2012 the care was absolutely superb, so when I came to have my second one during the pandemic in 2020, I was actually quite disappointed. And for the same reasons that Participant E raised, you've got nobody with you, you're lonely, you're by yourself. And even the fact of getting my stem cells back, I had to go to the Transport Centre at my local hospital with nobody with me. And when you have stem cells back, that is like a new birthday, and it's something to celebrate, but I've got nobody with me. So, the whole day just went flat. And then bitty care since then.

**Participant C:** To choose one word, I would have to say something like patchy. There have been bits of it that haven't been particularly good, but there have been bits of it that have been excellent. I think to start with it was difficult because nobody knew what it was. I'd been really healthy up to being 54, I'd been very blessed with that, and then suddenly I had breathing problems, was admitted through A&E, thinking I had a chest infection but, no, it was a thymoma that had invaded my lung and

my heart. I think I felt very lonely to start with, although I went to a local hospital whilst there were tests carried out, and I felt like it was a kind of period of asylum for which I was very grateful. It was a bit like being taken out of my normal life because I'd been a middle manager social worker, and suddenly, you know, I might die so that was protective. Nobody really knew what it was, though there were lots of suggestions, people saying it could be sarcoma or it could be this. The whole process took about a month altogether, where it became quite clear that I was going to have to have some really big heart surgery. And I was fortunate to have that with an absolutely epic doctor, who for me is God himself, he's retired now but he was head of transplant at the hospital. People were frightened because they didn't know what it was, they kept saying things like 'don't ask me for prognoses.

**Nikki Morris:** I might just stop you there, only because we're going to get onto this. Don't be sorry at all, because it's all so valuable, and I really hear the patchiness, so it's a good example of how that was. Participant G, if you had to use one word to sum up your experience of cancer care what would it be?

**Participant G:** I think overall, very good. The patchiness I'd agree with though, in the sense that communication between different bits of the NHS was poor. I wanted a particular therapy that was not available in the hospitals in my county, but I went to London in the end. There was even some name calling by an oncologist, who said that we see the failures from the therapy that they offer in London. When I got to London, and I said that to the urologist there, he said the same back. There is no need for that, it's just poor treatment, and it caused anxiety for me and my wife. But overall, the care I received was very good and very quick as well. However, the quickness- this is something that I want to come onto- was only because I absolutely insisted that various consultations with oncologists and urologists should be referred because I wanted alternative therapy from the therapy that's offered in my local hospitals.

**Nikki Morris:** Thank you, and we'll come back to that point in a later question.

**Participant F:** Obviously, I had my treatment quite a long time ago, and if I look back on that and everything that's happened, because I have an immune deficiency as a result of my treatment, I think the word patchy comes up again just in terms of how parts of the NHS communicate with one another. I think there is a lot of room for improvement. In my own case, I have this ridiculous situation where one of my hospitals sends me a vial of blood, and I have to find somebody and get them to fill it up with my own blood. And then I have to put it in the post and mail it back to them because the hospitals can't talk to one another. I just think we can put someone on the moon, this is crazy. I speak to a lot of cancer patients through Shine, and also through the forum, and I think there is a real sense that a lot of patients, like Participant G said, have to advocate for themselves. And actually that's not easy for a lot of people. Everyone on this call speaks really good English- I don't know if English is your first language- but if English isn't your first language, if you're not as well educated, all of these things, I think, make it really difficult to advocate for yourself. People had to fight beforehand, but over the last couple of years I get the sense that they have had to fight even more and really be their own advocate. And if you're not at the top of your game then things just slide, and if you're not on it, that's where mistakes get made. I think that's my concern really.

**Participant B:** The word for me would be scary. I was diagnosed after surgery to reduce an enlarged prostate and in a bit that was taken out, they found cancer cells. I was called into hospital, and I thought it was a follow up appointment. I wasn't told that I could bring anyone with me, though I wouldn't have been able to bring my partner anyway because she was in another part of the hospital having her fourth chemotherapy session for breast cancer. So, I attended urology on my

own, to be told that they had found a very aggressive high-grade cancer and didn't know what the prognosis was, and 'here is a list of appointments for you to attend and we'll see you again in three weeks.' That three weeks turned into two and a half months, for a range of reasons- such as AGMs or meetings- during which time I was certain I was going to die. I couldn't sleep at night and would wake up again and again to go to the toilet, because that's one of the things that prostate cancer does to you. I planned my funeral- I still have it on my computer now. And while all of that was going on I was one of the victims of the Windrush scandal which meant that I wasn't allowed to work, I wasn't allowed to claim benefits, and somebody that I know who was in the same situation in a hospital down the road with prostate cancer had been told that they would have to pay for their treatment up front, and that they wanted £42,000. Fortunately, my hospital, my trust, never asked that question about eligibility and about right to be in the UK. But it was something that I was always scared of, every time I went for another appointment, even on the day of the surgery which was about a year afterwards because the waiting list was so long. So yeah, scary.

**Nikki Morris:** That's been incredibly helpful. It's taken us quite a while, and hopefully I can pull some of those trends into the other questions, but it's been incredibly helpful. One of the things we quickly want to do, is to create a list of the roles that were in your care teams. So, who were the people that you had as part of your care team?

**Participant B:** Well, I had a urologist, a surgeon, and a CNS- a cancer nurse specialist- who I was never able to get hold of. So, two people really.

**Participant F:** So I had a haematologist- I still have a haematologist- a clinical nurse specialist as well. Because of some of the impact of the treatment, I also have an immunologist and an immunology team that helps as well. Just one other thing, I think one of the other issues that's tangential to being diagnosed with cancer, but because I was younger I had just had a baby (my baby was six weeks old) and people in my position often have a fertility specialist as well, and I think that's really important. That doesn't get looked at a lot, and it's something I think we need to improve, so that was quite a difficult thing for me, but that was part of the care as well.

**Participant E:** The paraproteins that showed up in my blood which would indicate that I may go on to develop myeloma showed up first of all in my HIV blood, so the team that care for me in terms of my HIV, were the people that picked those proteins up. I get my cancer care and my HIV care at the same London hospital, and actually it's really a combined ward now and a day care unit for HIV and cancer. Everything kind of works together now, but I do totally understand about the communication. For my cancer, for my myeloma, there's a consultant, the CNS and I have her mobile number, so I can call her or text her anytime to speak to her. Then there's the nursing team. And where I've got most of my non-clinical, emotional support has been through the Maggie's Centre and Live Through This.

**Participant A:** In the very beginning. I was under a gastroenterologist. And also, as part of the treatment following the first stem cell transplant, I've now got a Respiratory consultant that I can refer to, if I need to, because I've developed asthma. Apart from that, it's as everybody else.

**Participant D:** I've had a lot of support from a specialist dietician and the specialist diabetes centre, because I have a monster that I didn't know existed; Type 3C diabetes. The GP has been really integral in trying to pull the services together and the specialist nurse from Neuroendocrine Cancer UK has been the same one.

**Participant C:** I've got different specialists. I've got cardiology, hepatobiliary and the oncology on and off. The GP I would definitely agree is important, but I think the person who you really have to get to be your new best friend is your consultant secretary.

**Participant G:** The only thing that I would like to add is that I was referred to a prehab person, which was really helpful. I was a bit confused as to who he was when he first contacted me, in that I don't know how I was referred to him, but really helpful. And fact I'm getting him to speak to our urology support group at some point this year. Could I just add one thing, the urology department is based at one hospital but the oncology people are based in another hospital, so I was referred from one hospital to another and that actually was quite, I'd use the word distressing. I just thought I don't want to have to travel from different hospitals, which is a bit of a trek. So, I was a bit confused and distressed about that.

**Nikki Morris:** For the next question, I am not going to ask all of you to respond, but just those who want to respond. When you received your care, did you feel like you could access these staff members for the amount of time that you wanted to?

**Participant B:** I didn't. The urology department of the trust where I was treated had one of the longest waiting lists in the country. The CNSs were understaffed and rushed off their feet. You'd leave a voicemail message, and if they called you back and you didn't answer the onus is on you to try and call again. I ended up getting my support, that I should have got through that service, from Prostate Cancer UK. I think I'm on record as having one of the longest calls which is about an hour and 15 minutes, sobbing about my situation where I couldn't get answers elsewhere.

**Participant D:** I've had a lot of problems contacting them. Sometimes the hospital, if I've called them and said I need the neuroendocrine cancer team, they'll say 'the what.' The hospital doesn't even know what it is. I've had difficulty getting information shared, it's definitely a medical hierarchy team and as a patient I'm beneath then. And if you push, they get angry. I'm autistic so I will present a certain way, and they're like 'well if you're going to be that way, we're not even going to talk to you.' It's just like, please don't judge me. And I've now been waiting four weeks for a call back from dieticians, because you leave a message, and they just don't pass it along. They're not joined up.

**Nikki Morris:** Participant E, did you want to add anything?

**Participant E:** I think it was Participant F that mentioned about being able to advocate for oneself. I am able to most of the time, however when you're very unwell and in the middle of treatment as I was and trying to pull in the various teams and people...I live with three conditions for which I'm medicated; cancer, HIV and I also take ADHD medication. When I was having treatment last year, I asked the oncologist that he had checked that they could start treatment with the HIV meds that I was on, and I asked if they were sure, because the last time I had to change my HIV meds. They said "no, no, no we've checked." I started chemo on the Friday and that evening, and into the Saturday, I was getting frantic calls from various teams telling me not to take the HIV meds. I had been correct, but it was so difficult to try and get them to communicate with each other. They eventually admitted that they hadn't spoken to each other. I was taking the lead on that, and they weren't listening. And then, I believed there was a problem with taking dexamethasone and lisdexamfetamine for my ADHD. I felt that I was too high and too wired, and I kept saying is it because of the medication, and they kept saying no. Then right at the very end, where they could see that I was teetering on the edge of losing my mind, one very young, new consultant came in and said that that was exactly what was going on. They just weren't listening. I'd hate to think what would have happened if I was lying unconscious and they were trying to work out what was going on, because I was telling them what

was going on with me. Not being able to get them to communicate with each other is hugely frustrating. I think a lot of the time, for me watching them, it's about arrogance. It's about ego. They think that they know what they're talking about. I've locked horns with a young registrar; he said that I was being aggressive, and I said that I'm frustrated and angry, but I'm not being aggressive. I went on the NHS Expert Patients Program when I was diagnosed in 2004, where you are taught how to prepare for these appointments, including making a list of everything that you want to talk about and handing that list over. I told the young registrar, that this is about building a partnership with you, but you're not willing to do this with me. He said 'well, you're being' and I told him that I was not being anything, I said I'm being a patient that can advocate for himself and that it should be teamwork. Eventually a nurse who was standing behind the registrar was going like this (*makes jokey punching/boxing gesture*) because she could see that he wasn't prepared to listen to me, the patient. I'm the expert in living with cancer. But it's just hugely frustrating getting them so speak to each other so that I can feel better. That's all that I was looking for.

**Participant F:** Just to follow up on what Participant E was saying, everyone on this call was nodding and I think everyone can see that that is a common experience. Just from what I've been hearing from patients, particularly since 2020 and through the pandemic, where you've had high rates of staff illness, and people aren't allowed to go into appointments with you in the same place, not being able to see everyone's face because of facemask, it has meant that you have had a different relationships with teams and it's made it even more difficult. A lot of patients constantly have to chase appointments, chase scans and chase their nurses. Everyone is meant to have a clinical nurse specialist and they don't. There's good evidence that shows that if you do have a CNS you get better care, but a lot of people don't have that- I think it's quite cancer specific as well. I know one of the questions that you're looking at is workforce, and I think that is a part of what this boils down to. I think the sort of medical industrial complex where you have a hugely hierarchical system is also a massive problem, but we also need more people.

**Participant B:** Can I just add one more thing as well? I think discrimination. Participant E mentioned the adjective aggression. It's something that has been used to describe me going way back, all the way back to being at school. As a black man if I ask a question that linked to me being aggressive. It's not being assertive, it's not being positive, it's aggression. It's just something I've lived with for as long as I can remember. It doesn't help when you're sick, you're worried about whether you're going to survive or not, but you're having to deal with that kind of view as you walk into the room.

**Participant E:** There's just one thing that I wanted to add. There are only four people in my family- my mum, my dad, my brother and me- and three out of the four of us are living with cancer right now and having treatment right now. When I try to explain to clinicians that this has an impact on me and the support that I get, they just say stuff like 'that sounds a lot, or that must be difficult,' and you're like no, actually it is. It just feels really hopeless sometimes. The other thing about discrimination, at one point during my treatment last year I went into urinary retention, and I was in and out of hospital three times in one day through A&E to try and get things sorted out, and I came home and collapsed at home that night. Anyway, there was an investigation into what happened, but I believe that he just would not look at me, other than normal urological problems, because I was a gay man. It was very clear to me that that was why. It's years since I've come across homophobia myself, and I was really shocked. He just wouldn't touch me or look at me. I was asking him questions about my prostate, about anal sex, and he was having none of it and he couldn't get out quickly enough. And so I didn't get the care that I needed.

**Participant G:** I'm involved in community work, and I try to involve people from different communities, such as black people, gay people, in the work. I think that Participant B and E are right,

there is still discrimination. But it's hidden and I don't know how you counteract it. The point I wanted to make is that the arrogance of the medical profession is endemic. It really is. I have a doctorate PhD, not in medicine but in pharmacology, and I find it difficult to advocate for myself and I'm articulate and intelligent. My previous marriage was to a medic, and she actually left medicine for that reason, because of the arrogance. She didn't want to go through the kowtowing to a consultant for years, which you have to do in order to be trained in whatever she wanted to do. She often used to indicate that she was not in the medical professions when she saw her GP, because the assumption would be that she would know all about this, but she didn't. Because you can't be a specialist in everything. There are thankfully exceptions and my urologist who treated me is a wonderful exception to that, because he spoke to me as somebody that was his equal. He doesn't assume that I know everything, but equally when he says something he's assuming that I'm going to be somebody who's going to research on the internet.

**Participant C:** I just wanted to endorse that, really. I've experienced that kind of patronising rubbish, but I'm also extremely blessed at the moment with the practitioners that I'm working with. Because I've got a very unusual kind of cancer, they have admitted that they know nothing, and we've gone on a journey together which is as good as it can get really.

**Participant D:** For me, I'm a wheelchair user with an assistance dog, and Participant B and E what you said made me feel sick as a nurse, I just wanted to say that. I've been asked if I have to bring my dog with me as they claim they will help me when I need it. The accessible toilets in the clinic area are used to store mops and brooms and plastic bags. There is a complete lack of regard for disability. The fact is that under the law, having cancer makes you legally disabled. The fact that they don't have basic disability awareness (is bad). The scale in the clinic you have to stand on. I just don't understand, why they don't understand. And I've heard 'if you don't like it go back to America'. And when I complained, I was told that it's not discrimination or racism if you say it to a white person. That's actually a quote from the member of staff.

**Nikki Morris:** Thank you all for your honesty because this is the only way we'll get things to change. So, thank you. The next section is around living well and care plans. How important do you think is has a care plan for your specific needs? Have you had any experience of care plans?

**Participant G:** It's something I feel very strongly about. I was given virtually nothing in terms of a care plan. What I was given was a whole load of leaflets that had inaccuracies and things that I misunderstood. They're produced by radiologists, it's from the official profession of radiologists. I've spent my life working in both music and publishing, both are communication based, and they (cancer services) just break the rules about basic ways of communicating. I don't know what the answer is, except not to throw money at it so that people can advise on how best to communicate when they only effect will be employing people who are inappropriate. The sort of thing I'm talking about; I had a catheter put in which is standard practise for somebody who's had a prostate procedure, and the inaccurate information was about the overnight bags and how to attach them. It was very distressing. And of course it was in the middle of the night, so there was nobody to phone.

**Nikki Morris:** Do you think that should have been included in your care plan?

**Participant G:** Yes, absolutely. Clearer information about what to do, and who to contact if you have a situation like that. We ran out of overnight bags, so we needed them replaced, I just assumed that wouldn't be a problem, that I could phone my GP and they would order them. But it was absolutely not. I had to make 5-6 phone calls, and on each of which you got stuck in a telephone tree, trying to

get from somebody either the London hospital, or from the urology nurses in a Kent hospital or from an outsourced organisation that supplies things like catheter drainage bags. It's so depressing.

**Participant D:** As you know the Health and Social Care Act says the right care, in the right time, in the right place and by the right people. And it was promised that we would have some kind of pathway for rare cancers 10 years ago, and we've yet to see anything about that. And that really impacts care planning. Because of the type of cancer I have, which is a systemic cancer- like myeloma is a systemic cancer- I often hear that we can't solve that, and we have to refer you to gastroenterology. Nobody told me that I was at risk of exocrine pancreatic insufficiency, for example, until I'd suffered with the side effects for a month and a half.

**Nikki Morris:** And do you think a care plan would have helped with that?

**Participant D:** Yes, because a care plan would have gone system by system, done risk assessments and said if you have this problem contact this person. It would have been a holistic, whole person approach. Well, that's what care plans are supposed to be. But there's a sense by the doctors that only the parts of my body that pertain to them are relevant to my care, instead of seeing me as an individual.

**Participant E:** I've just been reflecting on the question 'do you have a care plan', and since I was diagnosed in 2017, I don't think I've had a care plan. I think I understand a care pathway for patients with myeloma, but I certainly have never had a care plan. My big beef is that I'm not seen as a whole person, and a person with two serious health conditions and one other that affects my ability to concentrate, absorb information and relate to other people. I think if I were seen as a whole person, and that those people were communicating with each other, a plan could be put together.

**Participant B:** I never had a plan either. And what really frustrates the hell out of me is the fact that I did some work with the NHS cancer programme, developing the guidance around care planning and holistic needs assessment, and I'm so frustrated that I'm still coming across cancer patients that are being offered none of that. I didn't know what the red flags were, what signs to look out for around recurrence. I found all that out myself because I'm able to go and speak to other people, I'm able to read and all the rest of it. I had time on my hands, because I wasn't allowed to work, so I was able to delve in and research it.

**Participant F:** I didn't have a care plan, but I was treated years ago, and you would hope that things would have changed. What I hear again and again, from a lot of people, is that they don't get them. For me it goes back to capacity, because I think a lot of staff don't have the capacity to do these plans, or even if you get the plan what you're meant to do with it. There was a new program that the NHS were looking into- I think it was called discharge summaries, I'm not sure- some kind of report that was meant to go to your GP once you'd finished cancer treatment that would highlight whether you had psychological needs, or other types of assessments. But that's basically pushing that work onto the GPs, and we all know that GPs don't have time to follow it up. I'm not sure that my GP has ever read any of the letters that get sent to them until something acute comes up, and then I go in. So, there is a problem. I think sometimes we get caught up in this idea that, ok, we've created a framework for holistic needs assessments, but it's not good enough to just have the framework there. It's a question of how do we make sure everyone has it, and what do they do with it. Because you're flagging up issues, but you don't have anywhere to send people to solve these problems and that's a big issues for a lot of people.

**Participant B:** If I could just add one, very brief, point to that as well One of the things that again frustrates me is the fact they when the consultant writes to your GP, you're meant to get a copy of



that communication. What consultants are saying is that patients are not going to understand the technical terms, so they just don't bother (including them). So, things that are on a file about me, I won't necessarily know about or get told about.

**Participant E:** There is one thing that works really well for me at the London based hospital is that all of my communications from consultants, from A&E or from wherever I've been in the hospital are uploaded to the Patients Know Best system. And I can see all my blood test results come up on the screen- normally before the nurses on the ward see them- as well as letters that have gone to the GP. So they're filed there automatically, and I can see them. And I think that part of my care plan works really well. The other thing is that I have a really good relationship with my GP now, have had for about 12 years, and she does read my letters from consultants because when I go to see her, she says 'oh you've had this, this and this.' So yes, she does read them.

**Participant A:** I was going to say that you have a right to see letters from your consultants. It's your body and you have a right to ask for them. I've actually got a file which is about this thick (makes hand gestures indicating around 20 cms) of all my treatment over the years. I actually asked for my blood tests results as well; each time they're taken, I've asked for a copy. Somebody queried why, and I said because then I can follow how my myeloma is doing. So yes, I think people need to advocate for everybody to have a copy of their results and their letters. Because otherwise you're just the forgotten person, aren't you?

**Nikki Morris:** Thank you. So we've got two more sections and we wanted to concentrate most on the care and the living well side of things, and so we've got about five minutes for each of these. One is about diagnostics and what your experience of diagnostics was- the speed of it and how long it took to get treatment. Do you think enough is being done for people who don't get an early diagnosis? So, this section is on your experience of diagnosis.

**Participant D:** They estimate that I had my disease for seven years before I was actually diagnosed. I had been going to the gastroenterologist but because their education included minimal information about neuroendocrine disease, and neuroendocrine systems, they couldn't identify what, in hindsight, was abundantly clear. I think the diagnostics run into problems because there is not fundamental education in the systems and diseases related to neuroendocrine. That needs to be in fundamental education if diagnostics are going to be improved, because if they don't know what it is, they can't look for it and they can't see it.

**Participant A:** Mine is in my original diagnosis, which is twelve and a half years ago. I was under a gastroenterologist for about 15 months, and they couldn't work out what was going wrong. They thought it was liver related, bowel related, and couldn't work out why I couldn't lie still while I was having a scan- an MRI technician remembered that 'you're the lady who couldn't actually lie still in a scanner'. I then got an emergency call into the hospital and what they had actually discovered at the end of an MRI was that I had a plasmacytoma, which on investigation was found to be wrapped around my spinal cord. I was told that if it hadn't had been picked up then I would have been paralysed from the waist down. So that's a bit about the diagnosis. And my GP, who I had actually worked with as a health assistant for 20 years, came to see me at home after discharge and told me that he knew all along that it was your back. He said he kept querying it with a gastroenterologist, but because he was the lead one he told the GP that he had got this and that he was looking after this. And actually the gastroenterologist apologised to me. When it came to the second one, so the end of remission from my first SCT, I knew myself that something was wrong and contacted the consultant and asked if they could bring the appointment forward as I was living on really strong painkillers. She did, and luckily that started the treatment early leading to the second SCT.

**Participant E:** I think I explained earlier that the paraproteins that showed up in my blood were found by a different clinician who knew that this could be cancer. So my diagnosis for myeloma came very early, when it went from MGUS to myeloma. But the one thing that I just wanted to say about diagnosis of another condition, my grandfather on my father's side died with, but not of, prostate cancer and my father is dying right now, he has a couple of months left of his life because of his prostate cancer which metastasized 15 years ago. As soon as I went into retention and realised that I was having problems with my prostate, I was flagging family history with the clinician and the clinician said that 'I was too young and blah, blah, blah.' And I said yes, but what about the history? Eventually I went to a different urologist at another centre, for somebody who was prepared to take me seriously. And he absolutely takes me seriously and believes that my risk of developing prostate cancer has increased to that of an Afro-Caribbean man rather than a white man. There is a risk there, and I want it to be caught as soon as possible in the way that it was with my myeloma, but to get a doctor to take me seriously around prostate cancer and family risk has been really, really difficult.

**Participant B:** My story was pretty much the same as that. I have three brothers, all of whom have prostate cancer. My oldest brother unfortunately died in June last year from prostate cancer. I also have uncles and cousins who have had prostate cancer, so a long family history of it. When I was first referred to my GP, I was told I was too young, even though black men are twice as likely as white men to develop prostate cancer- one in four black men as opposed to one in eight white men. And you're more likely to get it at a younger age, and it's likely to be more aggressive. All of that was ignored. It wasn't until they found the chippings after the surgery that prostate cancer, as far as they were concerned, was an issue.

**Participant F:** I was diagnosed by an emergency route, I was actually in the hospital for three weeks before anyone figured out what was wrong. I was acutely unwell, I had stage four non-Hodgkin lymphoma. One of the issues that I see with the cancer program in early diagnosis is that we're very focused on some specific types of cancer. Breast cancer, lung cancer for example. I think prostate to a certain extent and bowel cancer. It's not that they don't deserve a lot of attention, but a lot of the people on this call have rarer cancers and I don't think those get the attention that they deserve. There's been a real lack of progress in brain tumours. Blood cancer can be tricky to diagnose, but there are huge proportion of people with blood cancers that are diagnosed at a late stage. They're acutely unwell at stage four and I think that's a real issue.

**Participant B:** It's about achieving those big numbers though, isn't it? It's about attacking, making differences with cancers like lung and prostate and breast, the ones that most people have. And the rarer cancers well, there aren't as many as you, you don't cost us as much.

**Participant F:** Yes, and I can see the rationale for that. Definitely. Like I said, it's not that they're underserving of attention. But I think if you're outside of the big three cancer types, you definitely get less attention.

**Participant E:** I just wanted to add something about the difference in care around some cancers that women get and men get. I know that when I was seeing the urology team and I was talking to female friends about what was happening... I hear many women talking about their very kind and supportive care that they get when they're having tests and for female specific cancers and it just felt really mechanical and undignified as a man. Being treated by a woman who had no idea what was going on for me down there- though I recognise that they may have been a transwoman- and I feel that the care that I got as a man for a male specific cancer, is not the same that I hear my female friends get for their female specific cancers.

**Participant B:** I can support and attest to that. As I said, my partner had breast cancer and was being treated when I was diagnosed with prostate cancer and we both noticed the difference.

**Nikki Morris:** That's interesting, thank you. So the last question is about innovation and whether you were able to access any new or cutting edge, advanced treatments. If yes, do you think that was a good thing for your care? Was there a treatment that you wanted that wasn't available?

**Yohanna Sallberg:** I'm going to jump in and say that we do have a few minutes left and it's been great to hear from you all. We will also invite any follow up, if there is anything that wasn't covered or that you didn't get to say in this limited time. If there is any follow up, then we would be very grateful for those.

**Participant G:** About the time I was diagnosed- just a few months earlier- there was some reports of new treatments for men with prostate cancer. As soon as I started asking any of the experts about those innovations, they'd respond with 'oh yeah, we're vaguely aware of it.' So, it was down to me to investigate. Now I came across, as it happens, a superb little charity called Prost8 which was deliberately set up by a fundraising character who'd had exactly the same experience as me. And I became aware of an alternative therapy called focus therapy, called HIFU, which is for certain types of prostate cancer. So I was grateful to the charity, because a couple of days before getting in touch with that charity I was phoning around private clinics and they were quoting some ridiculous sums for the procedure, but I just couldn't afford it. And yet it's available on the NHS simply by being referred from one hospital to another. So, I think better communication about that would be it would be good.

**Participant E:** I have been offered advanced treatments or cutting-edge treatment. I explained my first round of treatment was chemotherapy, then high dose chemotherapy, and then a transplant which was successful. But I relapsed and this time around I was treated with similar therapies, but then also with a monoclonal antibody called daratumumab. And rather than having a transplant, I'm on maintenance daratumumab, so monoclonal antibody therapy. Transplants batter your body and I'm glad I didn't have to have that. I'm on a very tolerable every four-week dose of a monoclonal antibody, which right now is holding me exactly where I would want to be. I had COVID last two weeks ago and was treated with the monoclonal antibody as well for that.

**Participant F:** I was put on a phase two clinical trial, because my cancer was so advanced. I didn't have a great chance of survival and that clinical trial saved my life. It was a high dose chemotherapy. It was using rituximab which 12 years ago was a lot newer and is now a much more standard treatment. If we think about innovation and getting access to clinical trials, that something also where there's more work that can be done in explaining to people what clinical trials are and how they work. A lot of people think that it's a case of 'you're imminently dying so time to look for a trial,' when actually we need to be looking at them all the time. My other concern is just how much of an impact we think new innovations are going to make within the cancer program versus how much better it could be if we just made care better. Innovations are really important, but there are a lot of things that are being missed along the way which are killing people and we need to sort those out as well.

**Participant A:** I think it depends where in the country you are as to whether you can get access to some of the new treatments. We live in a rural area so it's a bit difficult for us, we're not near big places. Luckily, I've managed to have two stem cell transplants and been in remission for both, not needing any maintenance.

**Participant B:** I think there's also an issue again about discrimination. I'm a patient representative on the GRAIL trials, which is a trial that the NHS are conducting at the moment, where using a blood test they can identify 51 cancers at a very early stage before there are any symptoms. I asked a question on that implementation group about how they are going in terms to recruiting people from diverse ethnic backgrounds. And the answer was very poorly. And one of the response as to why that was, was because we've not put much effort into that because they tend to not want to take it up. So, there is an idea that I wouldn't want to be part of a clinical trial as a black man, so therefore it's not going to be offered to me.

**Participant D:** All I want to say is, it's really hard to look forward to innovations when they're not getting the basics down. Like the fact that oh, we can't say how long you have to live, so we can't refer you for palliative care. If those basics aren't in place, the innovations do nothing.

**Participant A:** Well said.

**Participant B:** Just one more thing on the question of discrimination. I made a complaint quite recently about the way a trans woman was treated in urology. The fact that this person was being mocked, you could see the nudges and the elbowing by staff. Absolutely appalling.

**Nikki Morris:** Thank you very much. So, it does just leave me to say thank you very much. It's nice to have a minute to do that because you've been very honest, very articulate about your own experience. And as you Yohanna said, if there is anything that you think that you wanted to say and we didn't have time or something that comes along, you know afterwards as a result, please do let us have it because it's so valuable. I think what we've heard today is some stories where it's gone really well, and there are great attributes, and somewhere it is really poor and where it must be better. And I think for us it is about pulling both of those out. Understanding what's working well, but also understanding you know what is happening that is unacceptable, or suboptimal. So, thank you.

**Participant F:** Can I just say, I think it's really important that we remember that all of us have been fighting for our lives. When you are worried that you're going to die, that is a terrifying place to be. And I sometimes feel that that gets missed. You know, we're talking about big numbers, but this stuff matters. It matters to our families and to us. None of us want to die. So, I just want you to keep that in the forefront of your mind that that's why we're speaking out, because we think it's important and we need to build on it. We want to live, and we want other people to live.

**Nikki Morris:** Absolutely, I think that's very well said. Thank you.

**Participant E:** Just briefly, before we go, I want to add something. I asked recently how long I will be on this monoclonal antibody treatment, and I was told that I would be on it for as long as I can tolerate it, or until it stops working, or until there's no longer any funding for it. And it's not sitting well with me, that there's something keeping me really well but there is a chance that I may not be able to have it because of funding.

**Nikki Morris:** Thank you.

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