[Helena:

Hello. I'd first like to thank the patients who've shared their experiences with me, for me to share them with you. You won't be able to identify them, I've made quite sure of that. I wish I'd spoken to more than one, for whom English wasn't a first language, but it didn't work out like that.

In the rush of a maternity situation, in which an urgent caesarean section was needed, Jenny did sign the consent form and the conversation was well documented in the patient notes but afterwards she had no recollection of that having happened. She did have the copy which, showed really importantly why it was good to have that, and I think you'll all be familiar with patients in shock or terror, whatever. It's just physiologically impossible to lay down memories, so that written information was vital for Jenny, as it was for the clinician. Quite a few of the people I spoke to said “well, we got handed the form, but the person hadn't pressed hard enough, so it didn't come through onto my copy”, and you'll know a lot will say “I could not read it.” It was illegible.” So that clarity and that information is really key for patients to have.

And some of those difficulties that arise in those shock situations we've touched on, about people not really being able to fully understand English, they might have some working knowledge of it, and of interpreters not being available or information not being available in different languages, and of clinicians not really having quite checked that the patient really did understand what was said to them.

Isla was born with a lot of musculoskeletal issues and had many operations during her childhood and teenage years, and although as she grew older, she was in on the discussions, her parents had always signed the consent form and she felt they dealt with all the legal thing. And then suddenly there she was, now transferred to adult services, and having to go through the consent process herself. And she found that really daunting. She did say she understood quite a lot of what they said, but she didn't really understand 'was there some legality about this?' She felt she was perhaps signing her body and her life away. So she wasn't really very aware of the process, and she certainly felt that she would have welcomed some non-parental support as she transitioned from paediatrics to adult services, and she found it just too big a leap to manage.

Hannah went for an outpatient appointment to receive the results of her breast lump biopsy. She was told straightway that yes, she had breast cancer, triple negative breast cancer, and then she felt completely bombarded. She was given a leaflet about living with cancer, a leaflet about chemotherapy, a leaflet about so many things, a great wodge of things. And then she was also told "now you need to sign the consent form for chemotherapy. Now you need to sign the consent form for genetic testing." At that point, she said, "whoa, hang on, what what's this genetic testing for?" So they said it was to look for the BRCA gene.

What they didn't know was that Hannah had a PhD in genetics. So she refused to sign the consent form and said she wanted to go away and think about it. She has two daughters and a son, she knew the implications for them, but actually no counselling was offered, and she went away and she did her own thinking and then sort of came back and decided to sign the

form because she was willing to have the test. And I think, she and I in our conversation, we agreed that whilst we understand the pressures that so many of you are under, it isn't right for the patient to feel pressured into signing for reasons of expediency of the service.

And the other thing that Hannah found odd was that she was told 'we will do this, you will have this, you will have that. And nobody said, 'but if we don't do this', there wasn't perhaps an alternative, but she said, 'but the alternative I knew was not to be treated, and that the cancer would progress and I would die, and she said 'actually I wanted someone to say that, I wanted someone to put those two options out there to me so that I could feel I'd made that choice. It was me deciding to have this treatment and it was me deciding to take on the risks of whatever that treatment might bring for me.' because she said, 'otherwise, I just felt like I was this commodity on this conveyor belt.'

And that was sort of enhanced for her by being given a treatment plan. Which then was given to everyone, but even right at the start, when they knew that because of a pre-existing condition she would never be able to have immunotherapy, was never modified. And she struggled getting her head around 'well they're telling me this, but then they're changing that', and she felt really she wasn't quite sure what she had been fully consented for because it all kept changing. And things were added and she had to have some injection treatment that she had to do herself, but nobody talked to her, and someone else we know, about how to give those injections. And she said, 'you know, I felt that was quite an invasive thing, but I wasn't consented for that.' So she had quite a few concerns about how the process had worked for her.

Mike, he was given choices. He was told all the treatment options for his particular form of prostate cancer and he opted for surgery. And he said to me, ‘I always trust them to do what's best. I can't remember anything about the conversation and I don't care. I was just happy to sign the form.’ Whether he was informed or not, I don't know. (Laughs)

Jane, this was a really interesting one. So, she needed open-heart valve replacement surgery. She also has Atrial fibrillation. And while the consultant was completing the consent form in the outpatient's appointment for the valve replacement surgery, Jane said to him, ‘oh, you know, what about ablation for my AF?’. So he said ‘oh yes, that's a good idea. We'll do that’, but Jane's prior reading about doing that was only about the minimally invasive sort of ablation.

After the surgery, the consultant explained that he'd performed a maze procedure. Jane told me she still had no idea what that was. She questioned in an interested but unconcerned way, whether she had been consented for it as to her it meant she'd undergone three procedures: valve replacement, ablation, and maze. Please correct me if I've understood this incorrectly, but maze is a form of ablation, suited to open heart surgery. And actually when I read what maze was, Jane explained it perfectly. They’d made cuts at different angles but she still didn't understand that she'd actually had a form of ablation, so she wasn't really sure whether they'd done that, and she wondered what on earth else had been done to her.

And I think the difficulty there had been that she's an intelligent woman. The surgeon had taken that she understood what ablation was, but they hadn't checked out ‘Did she know there were different ways in which

this could be done?'. Dr. Google only takes us patients so far and it leads us down some blind alleys. And Jane said she was definitely one of the people for whom, when death was mentioned as a complication, that was the end of what she really heard about the other risks of the surgery. And that was a really common theme with many of the people I spoke to.

Jane part two. She was asked to sign a consent for an investigative procedure, whilst lying on the table for the procedure. And she didn't really feel that was very satisfactory. She hadn't been given time to think about. She didn't fully understand the risks, but she said, "You know, what do you do?" She said "I knew, even if they told me all those, I would still say yes". So she just carried on, but she wasn't too happy that that had been the way.

Harry locked his front door, turned round, fell over and fractured his Neck of Femur. He was admitted, and the surgery only took place in 24 hours, which I think is quite fast for some people, but nonetheless, it was a whole day. So he'd had a lot of painkillers and he wasn't really sure that he was in a fit state to give consent. I don't think he thought that at the time, I think he thought it afterwards because he said to me, "you know really, all those painkillers, they made me really woozy" and he said "in fact, I think they made me a bit weird."

So he did question, did he have consent if he was under the influence of those drugs? But when he reflected on it, he could remember that he had been given options that, I think they could have pinned and plate it or do the hip replacement, and he said "I do remember thinking I'll have the hip because it'll see me out."

So I went for an outpatient appointment recently and got a bit of a shock that I hadn't expected, to be consented between asking to give this talk and actually doing it, but I was. I didn't own up to coming here and the surgeon from NUH is not here so don't think, 'oh, was it me? Have I forgotten it?' It wasn't. So I thought, right, I'm going to observe this process, as well as trying to pay attention to it. So the complications of the surgery, they were explained clearly. I was told I would have a general anaesthetic and none of the risks of that were explained to me, although I did say I'd had some problems before and that was noted on the consent form. For one complication, the surgeon told me the risk was one in a thousand and I thought, 'well, what does that mean? How do I work out is that significant for me or not?' But what I found much more reassuring was when the surgeon said that in 25 years of doing this procedure, fairly regularly, this complication had never occurred while she was operating. So I was pleased to learn that, but then she said, "but I might not do the operation." So I think was that really helpful or wasn't it?

I told her some other things and that was written on the forms, so I was pleased about that because, if you've got two things of something in your body and you lose one, that's a bit different than in my situation. I've only got one of this something, so if I lost that, it would be dramatic. And I came out not knowing, well, who will the surgeon be? I did say, "please don't let someone who've doing this for the first time do it because, you know, if this complication occurs, I'm stuffed." She said, "no, I won't do that." But I'll turn upon the day. I think I'll I go for a pre-assessment, but there'll be no surgeon there. I'll turn up on the day and this might be completely different surgeon. And how do I know

what the risks are for that particular surgeon? And should I know that? Should something different be done at that point?

If you could see my iPad, the font size is 36. That's my comfortable reading. I was given a patient information leaflet. (Holds up and waves a piece of A4 paper that has been folded into thirds) It’s sort of about a related condition and a bit about how you do that surgery, but it's not specific to my thing, but I couldn't read it. I was asked to sign the consent form. I can't read it. I got out of the room and discovered inside is a wealth of information, which when I got home and looked at it with my magnifier, says all the suggest loads of questions that I might ask the surgeon. I'd already signed the form. So I wasn't given time, an opportunity, to take that in. I wasn't given anything in a format that I could read.

I have to say, I think I counted up, I've been probably consented 30 times, including quite a significant number of those in an eye clinic. I've never been given any information in a format I can read. I asked them in the eye clinic, “have you got enlarged print?” No. “Could you email it to me?” No. So even there, they haven't got large print information. One of the things I have succeeded in doing at NUH about accessibility is, they used to upload all the patient leaflets in publisher format, so page one, next to page 12, next to page sixteen. They do now do them in A4, so you can read them as they’re written, and you can use a screen reader on them.

So I've put my little clocks there because I do understand, you know, you're all under huge pressure, at the capacity, there’s waiting lists and everything. But actually the clock that's against you, becomes the

clock that's against me and you know, the rest of the patients. I think there's another thing about that consent process. Which is that that is suddenly the moment, and it was for, you know Isla at the beginning and the people that I talked to, where it all becomes very real. I'd come into this consultation wondering, and now suddenly, this is what's facing me. This makes the condition I have more concrete, this makes what I have to do in my life and the changes more concrete, and of course, I've now embarked for a lot of planned surgery on this unknown period of waiting, which sort of compounds all the anxiety. So I think we've sort of feel we've signed up to the procedure, but also to a lot more than that.

I ask the people "who is this consent process for?" and every single one said something "to the effect of for the surgeon so that I don't sue them." Nobody saw it as being really a process for them and I thought that was really sad and sort of quite concerning. But I think that was because for some of them, that link between the information and the consent almost wasn't there. It was like 'this is the consent they're doing that for the surgeon. This is the information for me' and somehow that joined up bit was missing and I think that is something about the missing link of the shared decision-making.

And it just felt for quite a lot of people, this was just a process. And I think I kind of can understand that a bit in that, you know, for you, you've probably consented people thousands of times. I've had a lot, but for some people, you know it's once or twice, so it's a big deal for them so it's how can you help it not to seem like an administrative process that just needs to be done, but something important for the patients.

We also, most of us felt that, going to one outpatient appointment with no prior information and being given a diagnosis, these were the treatments, asked to make options, sign a form in 10 or 15 minutes, was just not very satisfactory at all. And so it's been nice to hear of some of you who've split things, or who've made information available beforehand, and I think those sort of things will be really appreciated. As you can imagine, I'm quite keen on the digital consent platform and everything I've seen about it, because for me, it's a great thing for accessibility.

But I know from a lot of other people that they're not too happy about it because they're not digitally savvy or digitally confident. And I think I do have a bit of worry because we see it now that there'll be sort of ethical-legal issues because of this split in systems and that the emphasis seems to go to the new system and what's left, doesn't get sort of much attention. So that's going to be what's going to be left in the written paper presented information for patients.

So thank you very much for listening and I will try and answer any questions you might have, but I'm sure others will help me if I can't.

[Matthew:
Thank you very much, Helena. I once chatted with a consultant about how to explain the risk of 'one in a thousand 'and he said he tells patients not to worry because he's done like 999 of these and, it hasn't happened yet.(Everyone chuckles)

[Helena:
I'll be the one.

[Matthew:

(chuckles) I think he was joking, though. So we got some time for questions. If anybody has a question about the patient experience and the patient needs, It'd be really good.

[Dr. Ben Thomas:

I was gonna ask a question that I think we often face in clinical practice, which is the two priorities. To have a good conversation with the doctor about the decision-making process, about the procedure, but also the imperative of the waiting list time and the time to treatment. And we feel that a lot as a as a pressure that, you know, the patient we want to get the patients through the system. We want the procedure done, especially in sort of urgent, suspected cancer context.

So advising colleagues in that, from your perspective, the answer is going to be both but which is more important? Is it having that sort of two stage consent process where there's lots of time to reflect? Or is it sort of getting that procedure done that you need? Because I think for us as clinicians, that's often very difficult because we want to have those multi-stage conversations with patients, but we also want them to get the treatment that they desperately need as well. And I think with the added pressures in the NHS at the moment to sort of reduce backlogs and get through the waiting lists, I think this is going to become a more of a challenge for us as clinicians. You know, we've got to get the waiting list down, but at the same time, we recognise the need to improve that decision-making process. So it was just to say that, you know, I know the answer is both, but have you got a perspective on which is more important to you as a patient?

[Helena:

I think I'm not going to answer the question in the way you're asking it, because I don't think that's a fair choice. But I think I would say that if it's a one-stop shop, the quality of the conversation will be everything. And I think, so if you think of Hannah, I think if someone had found out a bit about Hannah before they'd flooded her with all these leaflets and information and 'sign this form', they would have had a different conversation. One conversation, done better, would have been the effective thing I think. And there are ways I would imagine in clinic, I think I was talking to one of the surgeons here, and you know you can send people out to sit in the waiting room and take some of it in and then just do that last bit or something. So there might be other ways of working just a one-stop setup.

[Dr. Ben Thomas:

I think that's what I was trying to get at. I wasn't trying to ask you an impossible question, but that's exactly the perspective I was getting at. One stop clinics, and things are very difficult to manage, those processes and expectations.

[Helena:

And some prior information because, you know, for Hannah, they knew what they were going to tell her, but there was nothing sent, and I actually looked on our hospital website and there's no information on it about consent at all. Hopefully there will be soon.

[Matthew:

And there's one more question from the gentleman who's already got the microphone, yep.

[Unnamed attendee:

The MDT process, which has sort of come up in my mind in a couple of areas, this reasonable alternative treatment. MDT started with cancer and we've got this deference about treatment for cancer as though it's somehow more special than other treatments that we might offer, and the MDT discussion delivers a treatment option to the patient without them being involved in that decision-making process. And as a deliverer of that care, that's quite challenging. As a receiver of that care, that must be even more so because I'm going against a committee of experts

when I say, 'I've heard what you've said, but I that doesn't work for me. What are the alternatives?' That happens pretty rarely, with brave and probably, maybe better educated patients. And for clinicians, that is an opportunity, I've found, to educate oneself on actually how are we evaluating risk? Because we often say, "oh, a 5% risk of recurrence means I must do, I must offer you this more dramatic, more punitive, more morbid treatment", hat patients would choose differently if they were offered part of that decision-making process I wonder, and Hannah's case seemed to come up to me as something I've seen pretty regularly.

[Matthew:

Do you want to respond to that or?

[Unnamed attendee:

And have you any experience of the MDT process with regard to decision-making?

[Helena:

Absolutely none, (chuckles) No, so. That's an interesting one, isn't it? And I think there is a question of, you know, can there ever be some patient involvement in any of those discussions? Or maybe should the MDT be coming up with two options? So that at least you could present those to the patient rather than a fait-accompli because I think that's what several people sort have found difficult, 'Well, there was no choice so', Mike was a good example because they'd offered him all the options and you felt that he had made a choice.

[Matthew:

Okay, I'm sorry, we're…Rachel quick question please.

[Rachel Power:

Just a reflection on the MDT. Actually, we did a piece of work with the independent healthcare provider network and you're completely right Helena. It is about information going into the MDT from a patient's perspective and then that clear communication back with patients afterwards around what that option is because sometimes the MDT is seen as this solution, but the patient isn't getting the communication from it. So I thought I'd just support you with that answer.

[Matthew:

Thank-you, Rachel. Well, thank-you very much, Helena. That was excellent session. Thank-you for your comments as well.

(Round of applause)

[End of transcript]