

SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

*VENUE: High MR unit

*DATE:

*ID: Patient24

*INTERVIEWER: DJW

*Q1. I'D LIKE TO START, MY FIRST QUESTION HERE IS CAN YOU TELL ME A LITTLE BIT ABOUT WHAT YOU KNEW OR UNDERSTOOD ABOUT BREAST CANCER BEFORE YOU REALISED THERE WAS SOMETHING WRONG WITH YOUR BREAST?

Patient: As a general ...?

INT: YEAH, JUST WHATEVER YOU SORT OF KNEW ABOUT ...

Patient: Erm, well I was, I used to be an OGA so I worked in [???] before, so my experiences with breast cancer were really frozen sections, running the sample over to Histology and doing a full mastectomy, so that was really sort of my experience with breast cancer. I know there used to be a lot of talk that breast cancers were secondaries and not primary sites, so that had been a worry. I mean Mum had had a [???] tumour, hadn't she, so we'd had a bit of contact there I suppose. I mean Mum's always been really worried about having a mastectomy and as far as I was aware if you had breast cancer you had a mastectomy. So, but, yeah, not, I don't suppose, I'd never really thought about in any great detail.

INT: RIGHT, OK, YEAH. DID YOU SAY YOUR MAM HAS HAD A BREAST CANCER, IS THAT RIGHT?

Patient: Well it was [???] tumour, which is a, well a non-invasive sort of in site kind of carcinoma: she just had a lump, the lump taken away and ...

INT: RIGHT, OK.

Patient: ... and that was it.

INT: IS THAT SORT OF SIMILAR TO DUCTAL CARCINOMA IN SITU, DCIA?

Patient: I'm not sure, it might be.

INT: I'M NOT PARTICULARLY AU FAIT WITH THE SURGICAL SIDE OF THINGS REALLY, MY BACKGROUND'S SORT OF PSYCHOLOGY AND STUFF. HAS ANYBODY ELSE IN YOUR FAMILY HAD ... YOUR GRANDMOTHER OR ANYONE ELSE HAD BREAST CANCER?

Patient: No, no.

INT: OK. AND YOUR PREVIOUS KNOWLEDGE, SO YOU BASICALLY, YOUR IDEA WAS THAT IF YOU GOT BREAST CANCER IT WAS GOING TO BE MASTECTOMY, IS THAT RIGHT?

Patient: Mm, yeah.

INT: OK. WHEN YOU SORT OF, CAN YOU TELL ME FROM THE TIME WHEN YOU FIRST REALISED SOMETHING WAS WRONG WITH YOUR BREAST TO THE TIME YOU WENT TO HEAR ABOUT YOUR RESULTS, CAN YOU SORT OF TELL ME ABOUT THAT TIME? WERE YOU PICKED UP THROUGH SCREENING OR DID YOU PRESENT WITH ...

Patient: No, I found the lump myself.

INT: YOU FOUND THE LUMP YOURSELF. SO CAN YOU TELL ME FROM THAT POINT ONWARDS TO WHEN YOU WENT TO THE CLINIC AND GOT YOUR RESULTS?

Patient: Mm, sure. I was, we were watching the television, I was sat, sort of lying back on my husband and I saw a lump through my top, and I said, 'Heyup, look at this,' and felt it, and there was a lump, quite hard, on my breast. Realised that I was due on the next week so 'Fine, due on,' you know, I was happy, so ignored it then. And my period came and went and then my next period came, I mean the lump was still there. It hadn't really bothered me, it had moved down slightly, it was very smooth and it wasn't in any way what I thought was a nasty lump. And it was coming towards Christmas as well and Chris, my husband, had actually said to me, he said, 'You ought to get it checked out.' And I said 'Well I'll go after Christmas, I don't want to bother the doctor before Christmas, 'cos it'll be busy.' So went on the Monday after Christmas and it was quite low down in the breast by then and he looked at it and felt it and it was smooth and it was moveable, and he felt it was a cyst because it was presenting. There was a very red, heated area on the surface of the skin, so it was like there was an infection there. I mean I felt quite confident that it was just an infection, which was why I'd sort of left it about five weeks before I'd seen the doctor. So he prescribed me some antibiotics and told me that he thought it would be gone within a week, and wasn't going to bother sending for a mammogram at that point, and then he said, 'Ooh,' he said, 'with how long we have to wait we'd better send you, send for an appointment,' he said, 'when your appointment comes through, if the lump's gone and you're quite happy that everything's OK then just cancel it,' he said, 'and if it hasn't gone or you're worried about anything go along and have the mammogram and they'll sort it from there.' Which is what we did. So I took these antibiotics for a week, with my fingers crossed I think by that point, and it didn't go, hadn't gone. I was starting to have a lot of pain by then as well, it was, you know, just sort of sitting, you didn't have to move it, I'd get a lot of pain. And it was six weeks before I got my mammogram, which was a long time, and went along for that, had a ...

INT: SIX WEEKS FROM ...?

Patient: Seeing the doctor.

INT: WHEN YOU FIRST, OR WHEN YOU FIRST SAW THE DOCTOR, SO THAT'S WHAT, LIKE ...?

Patient: So I'd had it about 11 weeks.

INT: 11 WEEKS, YEAH.

Patient: That I knew that I'd had it for 11 weeks, I mean how long it was there before I'm not sure. But I'd known about it for 11 weeks. So we went along, had the mammogram, went through for the ultrasound part and the chap that was doing the ultrasound said, he said, 'I can tell you now this isn't a cyst, it's a solid mass and we will want to do a biopsy today.' So of course then panic sets in, doesn't it?

INT: MM, I IMAGINE IT WOULD DO, YEAH.

Patient: Went through to see the consultant and she said, 'Ooh, yes,' I mean you could see it, the lump was quite obvious through the breast, and she said 'I'll do a biopsy now.' So this was on the Friday and then I had to go back for my results the following Thursday, in Clinic. So, I knew, I knew when they did the biopsy.

INT: YEAH, THAT'S MY NEXT QUESTION WAS WHAT WAS GOING THROUGH YOUR MIND?

Patient: I just knew.

INT: MM, JUST KNEW YOURSELF.

Patient: Mm, yeah, instinctively knew.

INT: AND WHEN THE, DID YOU SAY THE RADIOLOGIST SAID SOMETHING TO YOU?

Patient: He'd said it's a solid mass from the ultrasound and that they'd be doing a biopsy because it wasn't a cyst. It was obviously not a cyst on the ultrasound.

INT: MM, SO WHEN HE SAID THAT SORT OF DID THAT, THAT ALMOST LIKE CONFIRMED [???

Patient: It kind of sparked things off then, yeah. I mean I had been convinced up until then that it wasn't anything sinister because, you know, you read about it and like the doctor had said, you know, it's, they're very, usually you can feel that it's irregular on the surface and they don't move much and, and this had moved and it had moved around the breast and it was very smooth to the touch, so I really didn't think it was anything nasty until they did the biopsy.

INT: RIGHT, OK.

Patient: Then I was quite sure it was.

INT: AND DID YOU TALK ABOUT YOUR INITIAL THOUGHTS TO ANYBODY WHAT IT MIGHT BE OR, YOU KNOW, WHEN YOU ...?

Patient: What, from after the biopsy?

INT: WELL FROM KIND OF WHEN YOU'D BEEN TOLD BY THE GP THAT HE WAS GOING TO REFER YOU TO THE CLINIC?

Patient: Erm, my sister knew. I don't think I'd ever said, thought it was cancer.

Patient's sister: I never thought it was, I just, 'cos we'd both been previously before a mammogram ...

Patient: She'd had a mammogram, hadn't you?

Patient's sister: ... for lumps that we'd found, and they were nothing, so I just said, 'Oh, it'll be fine, it'll be nothing.'

Patient: Yeah, yeah, no I really didn't think it was anything before then.

INT: AND SO, YEAH, YOU THOUGHT IT MIGHT HAVE BEEN A BREAST CANCER. DID YOU AT ANY POINT WHEN YOU THOUGHT THAT, DID ANYTHING ABOUT WHAT YOU MIGHT DO ABOUT IT IN THE LONG RUN?

Patient: Erm ... before the biopsy?

INT: YEAH, YEAH, WHEN YOU, WHEN THE GP SAID GO TO THE CLINIC ...

Patient: Yeah, went with the cyst, yeah, I mean, with it not going away with the antibiotics, my immediate reaction was, 'Oh, blimey, I'm going to have this one cut out.' That was, that did go through my mind, yeah, because I knew it was still there and I knew that it hadn't gone, so obviously something was gonna happen, and I thought they'd either drain it

in clinic, you know, through a needle or that, at the worst, I might have to have the lump itself removed.

INT: RIGHT YEAH.

Patient: But I really didn't think it was anything more sinister at that point, I really did it.

*Q2. RIGHT, OK. AND SO WHAT HAPPENED THEN WHEN YOU WENT TO THE CLINIC TO GET YOUR RESULTS AND YOU WERE TOLD THEN IT WAS BREAST CANCER, CAN YOU TELL ME A BIT ABOUT THAT?

Patient: To get my results?

INT: YEAH.

Patient: Erm, my husband came with me ... erm, we were taken straight down to the consultant and the breast care nurse was in the room as well so that kind of confirmed it straight away. And she was very good, we sat down and she said, 'Right, we're here to discuss your biopsy results from last week. I can confirm that it is breast cancer.'

INT: SO WAS IT A FEMALE CONSULTANT?

Patient: Yes, it was, yeah. I don't think it would have mattered, it wouldn't have bothered me.

INT: NO, JUST 'COS I KNOW THERE'S ONE THERE AND THERE'S TWO ARE GUYS, I'M TRYING TO WORK OUT WHICH ONE IT IS. MISS WAHEDNA.

Patient: Miss Wahedna.

INT: THAT'S RIGHT, YEAH.

Patient: So, yes, she, and then she gave me time to sort of absorb that fact, erm, and then said to me that I'd got an option. Well she said, you know, 'We want you in next week for surgery.' Well we were going away a fortnight on the Saturday on I was like, 'We're going away a fortnight on Saturday.' She says, 'No, you're not, sorry,' you know, 'You're coming in. So straight away I assumed I would be having a mastectomy, I never gave it any thought. And she said, 'I can tell you, you've got a choice in your surgical procedure: you can either have a mastectomy or you can the wide local excision, an axillary node excision.' So I just said straight away, 'Mastectomy.' And she said, 'No, you know, this is too quick, you need to think about your options and what you want to have done,' but my reaction was, obviously from working in theatre when I did, mastectomy, get rid, want it gone, you know. And she said, she said, 'No, you really have got the choice,' she says, 'If I didn't think you'd got the choice I wouldn't give it you,' she says, 'but you have got the choice. You can have either the mastectomy or you could just have the local excision.' So we talked about that for a little bit because I was obviously a bit concerned about whether all the cancer would go, and she just explained that they take a good safety area and that would obviously be checked to make sure that it was a good enough safety area and the nodes would be taken to see if it had spread to the lymph glands, and they told me you'd need radiotherapy with this option. So obviously there was something else to think about there. But then I think, straight away, I decided that that was the way to go. I think it's less invasive ...

INT: WHICH, THE ...

Patient: The local excision ...

INT: THE LOCAL EXCISION, YEAH.

Patient: Yeah, it's less traumatic.

INT: WERE YOU AWARE OF THAT TYPE OF SURGERY BEFORE YOU WENT THERE?

Patient: No, no really, not for breast cancer. No.

INT: RIGHT.

Patient: No, which was why I sort of immediately thought, 'Oh, I don't want anything leaving behind or ...' but after she'd explained about the radiotherapy and the fact that the lymph nodes'd still be picked up because they do an axillary bit as well, yeah, it seemed the most obvious choice. Less trauma for me, for my husband, for my son and the rest of the family [chuckles].

INT: SO, I MEAN, YOUR HUSBAND WENT WITH YOU ...

Patient: He did yeah.

INT: HOW WAS HE THEN WHEN HE HEARD?

Patient: He was in a dreadful state.

INT: MM, I CAN IMAGINE.

Patient: Absolutely dreadful. He just grabbed my hand and he just, well he was white. And he thought I was gonna die basically, so did my son, I mean we had to come home, tell Lewis: Lewis is 12 ... tell Lewis that his Mum's got breast cancer and he's not going to Florida in a fortnight's time [chuckles] for his holidays. So that was lovely.

INT: HOW DID HE TAKE IT THEN?

Patient: Not well, not well at all. I mean he just cried, he just burst out crying and I just said to him, I said, 'What do you understand by cancer?' because it's not something we'd ever really discussed in any ... well in any sort of, I don't we'd ever touched on cancer really, ever. And he just said, he said, 'It kills you,' you know, and his question since really, he just keeps saying to me, 'When are you gonna die?' When I went to see the oncologist, it's, 'He's the man that's going to tell you when you're going to die, isn't he?' and, you know, it's very hard.

INT: [??] I'M SURE.

Patient: But he'll get there, he'll get there.

INT: AND HAD YOU DISCUSSED THIS, IF IT WAS GOING TO BE BREAST CANCER, WITH YOUR HUSBAND BEFORE YOU WENT TO THE CLINIC?

Patient: No, no. No. I don't think he could have discussed it that week. I mean that week before I found out for sure after the biopsy, I was pretty sure what it was and I thought I was looking at a mastectomy. I did a lot

of research on the internet that week as to different types of cancer and ... I wanted to be a little clued up as to what questions to ask or what I thought I wanted to ask. Never really looked into the surgical side of it at all, didn't cross my mind to do that, I just really thought it would be a mastectomy. But I didn't discuss it with Chris really: I think everybody tried to spend that week thinking it was nothing, you know. I suppose you don't think about the worst until it really happens, do you?

INT: I THINK YOU'VE GOT TO HOPE ON, YOU JUST KIND OF FINGERS CROSSED ...

Patient: But ... always, yeah, but I knew, I did know for some reason, but I needed to, I mean Chris tends to, 'Well we'll work from the worst scenario and we'll build up from there,' whereas I tend to, you know, try and be positive all the time. So I don't think I could have possibly discussed it with him that week, I don't think he could have handled it to be quite honest. I think that would have shattered any hope he had: if he thought for one minute that I thought it was cancer, I don't think he'd have got through that week.

INT: OK.

Patient: I really don't.

INT: IT'S ACTUALLY A VERY UNDER-RESEARCHED AREA ABOUT SPOUSES, YOU KNOW, PARTNERS WHO'VE HAD CANCER. SO YOU HAD, DID YOU HAVE EXPECTATIONS ABOUT WHAT YOU MIGHT BE TOLD AND WHAT WAS GONNA HAPPEN AFTERWARDS?

Patient: Erm, I suppose as far as expectations were going I was expecting to be told it was cancer and I was expecting to be told I needed a mastectomy. My fear was that whether it was a primary site or not: that was my fear that week.

INT: MM. AND CAN YOU TELL ME WHAT THAT OUTCOME WAS?

Patient: It is a primary.

INT: YEAH, IT IS A PRIMARY.

Patient: Thank God, yeah.

INT: SO IT HASN'T COME FROM SOMEWHERE ELSE?

Patient: No. So that, that was biggest fear, mm, definitely.

INT: SO YOU'VE TOLD ME A LITTLE BIT ABOUT WHAT HAPPENED IN THE CLINIC, YOU SAID THAT YOU WENT IN, THERE WAS THE BREAST CARE NURSE THERE AND THERE WAS YOUR HUSBAND THERE AND MISS WAHEDNA WHO BROKE THE NEWS TO YOU, IS THAT RIGHT, YEAH?

Patient: Yeah.

INT: WHEN SHE BROKE THE NEWS, DID SHE USE ANYTHING LIKE MAMMOGRAMS OR DIAGRAMS OR PICTURES ...

Patient: No.

INT: ... ANYTHING LIKE THAT?

Patient: No.

INT: SHE DIDN'T DRAW ANYTHING FOR YOU OR ANYTHING LIKE THAT?

Patient: No.

INT: OK.

Patient: No, she just told me that that was the result of the biopsy.

INT: AND HOW DID YOU GET ON WITH THE CONSULTANT, MISS WAHEDNA? HOW DID YOU GET ON WITH HER?

Patient: I liked her. I say that now, I had a scare, shall we call it, two years ago, as she reminded me in clinic, almost to the day actually, and I'd had a lump on and off for a while and the pressure, you know, has been for a few years now - you get a lump, you see your doctor, you follow it up, you don't leave it. So I had had this lump and I had been for a mammogram before, and she told me - I'd actually seen her then - and she'd told me that I was a very silly woman because it was just normal breast tissue. So that had been niggling a little bit with this time, which was why I probably put off going to the GP a bit longer than I should have done. And I wasn't looking forward to seeing her, and when I first saw that it was her I wasn't very happy about it. But, having said that ... we're all allowed an off-day I think aren't we?

INT: WELL YEAH ...

Patient: And, you know, my GP was quite upset because I said, 'Oh, you know, I don't really want to go and have a mammogram if it's not necessary,' and he said, 'Why?' and I told him. And he said that she shouldn't have said that to me and ...

INT: WELL QUITE RIGHT, SHE SHOULDN'T HAVE.

Patient: Yeah, and I mean it did stay with me funnily enough. But she's been absolutely fantastic this time. And it's like he says, you know, with hindsight we can all say, 'Well, yes, OK, so you've got a lump and it's normal breast tissue.' He said, 'I can't sit here and tell you that a lump is normal breast tissue until, you know, I've got ...

INT: OF COURSE, YEAH.

Patient: ... the things to look at that she's got in clinic, you know, mammograms and ultrasounds and you can see, can't you?' So, but, yeah, I've really got on with her this time.

INT: AH, THAT'S GOOD. AND SHE IS THE ONE THAT ACTUALLY CARRIED OUT YOUR OPERATION AS WELL?

Patient: No.

INT: NO, SHE DIDN'T DO THE OPERATION. OH, OK.

Patient: [chuckles] Mr Sibbering.

INT: OK WELL ...

Patient: They pass me round, don't they.

INT: OK, WE'LL COME TO THAT IN A SECOND. RIGHT THEN, ERM, YEAH, SO HOW MUCH DID YOU ACTUALLY UNDERSTAND ABOUT, YOU KNOW, WHEN YOU WERE ACTUALLY TOLD

YOU HAD CANCER? HOW MUCH DID YOU UNDERSTAND FROM WHAT THEY TOLD YOU, I SHOULD SAY?

Patient: I'm not sure what you mean.

INT: ALL RIGHT, OK. SO WHEN THEY WERE TELLING YOU ABOUT YOUR DIAGNOSIS AND YOUR TREATMENT OPTIONS, HOW MUCH DID YOU ACTUALLY UNDERSTAND FROM ALL THAT?

Patient: From what they ... I thought understood all of it, yeah, yeah. I means he told me it was a very aggressive cancer, that it was a primary site, and that it needed operating on, because I mean I did sort of say, 'Can we leave it till have the holiday?' because I was worried about my son, and she said, 'No, because you'll be climbing the walls,' which, in retrospect, I would have been you know. She says, 'We really need to get you in and get it sorted.' So, yeah, I think I understood everything she said.

INT: THERE WAS NOTHING YOU FOUND DIFFICULT OR HARD TO TAKE IN, NOTHING THAT YOU FOUND TO UNDERSTAND OR ANYTHING?

Patient: No.

INT: OK. YOU SAID THAT, EARLIER ON YOU SAID THAT INITIALLY YOU WERE THINKING MASTECTOMY BUT THEN YOU WERE PRESENTED WITH THIS WIDE LOCAL EXCISION OPERAITON, CHOICE, ERM, WHEN YOU WERE OFFERED THAT CHOICE, SORT OF, WHAT WERE YOUR INITIAL THOUGHTS, YOU KNOW, WHEN YOU WERE OFFERED A CHOICE?

Patient: My initial thoughts were that it wouldn't be a good enough operation, that was what went through my head first. Erm, then when she said that I had got the choice, that there really was a choice and that either way just as good, then my next thought was Chris, my husband, that it would be so much easier for him, you know, physically, to look at, and my son. I mean he was the first one to, you know, whip my top up afterwards, 'Let's see what they've done to you' [chuckles] you know, so there's always other people to consider, isn't there, you know?

INT: THAT'S TRUE. IT'S YOUR BODY BUT YOU'RE RIGHT, YEAH, YOU'RE RIGHT, THERE IS.

Patient: Yeah, no, she convinced me that it really was just as good an option.

INT: YEAH, IT IS.

Patient: So obviously, if it's just as, really it's a better option because it is less traumatic. I think, I mean I've never, obviously women talk about these things, and I've always said, you know, a mastectomy wouldn't bother me, it's if it was a secondary that would bother me.

INT: YEAH, OF COURSE.

Patient: And that's always sort of been my concern. So, and I'd spent a week preparing myself for a mastectomy as such, so it wasn't really an issue for me, it was more, it was more for other people, it was more for Chris and Lewis, I think, that the decision became easier to make. I mean I knew there was the radiotherapy to sort of add on but that didn't seem too bad a deal really.

INT: RIGHT, AND HOW LONG WAS THE RADIOTHERAPY FOR, THEN?

Patient: Six weeks.

INT: IS THAT COMPLETED NOW, IS IT?

Patient: No [chuckles] because I'm having chemo.

INT: OH, RIGHT, OK. OK, LET'S ...

Patient: Things got complication.

INT: RIGHT, OK, SO LET'S TAKE THE STORY BIT BY BIT SO WE DON'T MISS ANY OUT. SO AFTER YOU'D BEEN IN YOUR CONSULTATION, YOU'VE SEEN MISS WAHEDNA AND SHE'S TOLD YOU YOUR DIAGNOSIS AND DISCUSSED TREATMENT OPTIONS, HOW SOON THEN DO YOU THINK YOU MADE YOUR MIND UP ABOUT WHAT TREATMENT YOU WERE GOING TO HAVE BECAUSE OBVIOUSLY YOU'D JUST ...

Patient: I told her there.

INT: YOU TOLD HER THERE AND THEN, YEAH.

Patient: Yeah, and she said, 'Well, you know, go away and talk to the breast nurse about it a bit,' and I mean she said, I was scheduled for surgery on the Tuesday, this was the Thursday, I was scheduled on the Tuesday, she said, 'We don't need to know until Tuesday,' but I told her, and I said, you know, 'I doubt if I'll change my mind,' and I did actually tell her there and then.

INT: OH RIGHT, OK. AND AFTER THAT, WHAT HAPPENED THEN? YOU WERE WITH THE BREAST CARE NURSE, DID YOU GO SOMEWHERE ELSE?

Patient: Yeah, she took us to a room.

INT: CAN YOU TELL ME A BIT ABOUT WHAT HAPPENED THEN?

Patient: Erm, well they just give you lots of information really, little booklets, erm, breast awareness groups, contact numbers, a bit of time really I think to let it sink in as to what has actually happened. She was very nice and I cried a lot and, needless to say, erm, I don't remember an awful lot I got this little, I've still got it, this little pack with bits of information in, and obviously a bit, a booklet about radiotherapy because that was part and parcel of the WLE.

INT: RIGHT, YEAH.

Patient: So ... and she talked a bit about that. Chris, I think, we touched on chemotherapy, erm, but she said obviously at this point she didn't want to sort of give you too much ...

INT: RIGHT, OF COURSE, YEAH, TAKE IT STAGE BY STAGE, SORT OF THING.

Patient: Yeah, absolutely, because we weren't really looking at anything like that then anyway. Erm, yeah, just really, it was time for us to reflect a little and see if there was any questions that wanted, that needed to come out there and then, I suppose, about the surgery, I suppose more than anything. How we were immediately feeling. So we were there a little while with her. Yeah.

INT: AND DID YOU HAVE ANY FURTHER CONTACT WITH THE BREAST CARE NURSE AFTER THAT THEN, BETWEEN THAT AND YOUR SURGERY?

Patient: Between then and the surgery? Erm ...

INT: DID YOU CALL. DID THEY COME TO THE HOUSE, DID YOU RING THEM OR ANYTHING LIKE THAT?

Patient: No, no. She's phoned ... mm ... no, I think the next time I saw her was in clinic again after surgery. I didn't feel I needed to call her. I'm sure I could have done, I did feel as though I could have done. It wasn't, you know, because she was unapproachable it was just, it was such a short time I think, you know ...

INT: YEAH, OF COURSE.

Patient: ... as well. And this was Thursday, 4 o'clock I think my appointment was and I was in 7.30 Tuesday morning, so it was only a few days, four days, I had to go and buy some pyjamas [chuckles].

INT: SO, DID THE BREAST CARE NURSE USE ANYTHING LIKE MAMMOGRAMS OR DIAGRAMS, ANYTHING LIKE THAT?

Patient: To talk through my diagnosis? No, no. I'd seen the mammograms when I was having the ultrasound but that's only because he'd got them on the board and I had a little look while I was lying there. Apart from that ...

INT: SO THROUGHOUT THIS PROCESS OF CONSULTAING WITH MISS WAHEDNA AND THE BREAST CARE NURSE, DURING THAT TIME, WHO DO YOU THINK DID MOST OF THE TALKING AND WHO ASKED MOST OF THE QUESTIONS?

Patient: Ooh. What, of the professionals?

INT: YEAH, SORRY, WHEN YOU WERE TALKING TO THE CONSULTANT ...

Patient: When I was talking?

INT: ... WHEN YOU WERE TALKING TO THE BREAST CARE NURSE, WHO DO YOU THINK WAS ASKING MOST OF THE QUESTIONS, WHO WAS DOING MOST OF THE TALKING?

Patient: I don't know really. Asking, who was asking me the most questions or ... who was I asking the most questions of?

INT: WHO WAS, JUST WHO IN GENERAL WAS ASKING THE MOST ..

Patient: Who was doing the talking? Me probably, as usual. [chuckles] Erm, yeah, ... yeah, probably me.

INT: RIGHT, ASKING THE MOST QUESTIONS?

Patient: Mm.

INT: YEAH, OK. NOW, SO, DID YOU HAVE ANY MORE, NO, CAN YOU TELL ME WHAT HAPPENED AFTER THAT, BECAUSE THEN YOU WENT FOR YOUR SURGERY AND THEN YOU SAID THERE'S BEEN COMPLICATIONS ...

Patient: On the Tuesday.

INT: SO COULD YOU SORT OF DESCRIBE THAT?

Patient: Well, basically, node positive, aren't I?

INT: AH, RIGHT, YEAH.

Patient: So, had the surgery on the Tuesday, came home on the Thursday, erm, was due in the clinic the Thursday after, so that like just over a week after. We knew then, we'd already been informed that, at that one, if the nodes were positive then there was a possibility there's a cancer somewhere else, it'd be chemotherapy. Then if that was clear then it would just be the radiotherapy. So went back to clinic on the Thursday and were told ...

INT: THAT'S A WEEK LATER, YEAH?

Patient: ... just over a week later, yeah, a week after I'd been discharged, and was told that it was node positive and that I'd need chemotherapy. [chuckles]

INT: AH, RIGHT.

Patient: Can't ever do anything by halves, you know, have to, you know ...

INT: HOW DID YOU FEEL ABOUT THAT?

Patient: Guttled. Absolutely gutted.

INT: AND HOW LONG WILL THE CHEMOTHERAPY GO ON FOR?

Patient: Erm, well I've agreed to a trial [chuckles].

INT: OH, YOU'RE IN A CLINICAL TRIAL?

Patient: Yeah [chuckles] so I had my first one last Tuesday.

INT: MY FIRST PROJECT HERE WAS ASKING WOMEN COLORECTAL PATIENTS AND BREAST CANCER PATIENTS WHY THEY DO AND DON'T JOIN CLINICAL TRIALS.

Patient: Oh, really?

INT: SO THEY MUST HAVE OFFERED YOU ONE THEN?

Patient: They offered me a trial.

INT: WHEN YOU GOT YOUR RESULTS THE SECOND TIME FROM THE ...

Patient: The chemo, yeah. Well, they didn't, they didn't, it was Mr Sibbering did my surgery, and I saw him in clinic and he told me that they'd taken five nodes and two were positive, so it would be chemo. And then I'm passed on to the oncologist. So at the oncologist there's a research nurse who comes and asks you if you want to do this trial, you see. So, erm ...

INT: AND YOU SAID YES?

Patient: Mm.

INT: YOU MUST LIKE RESEARCH: YOU'VE SAID YES TO THIS, YOU'VE SAID YES TO A CLINICAL TRIAL ...

Patient: I've said yes to another one as well, but I didn't get that one.

INT: [???] SHE'S KEEN THIS ONE.

Patient: If I can be useful, yes. No, I didn't get the, I went for a third one as well and I didn't get that one. [chuckles] Can't give it away, I know. Erm, so I'm having eight sessions instead of six, basically. That was the answer to your question, wasn't it, how long will it last? It takes me through till about the end of August, I think, the chemo and then I've got about a four-week break and then I've got six weeks in radiotherapy, and five years of Tamoxafen unless I manage to get on to this other one that's floating around in the papers.

INT: IS THIS THE BIG ONE, IS THE STUDY A FIVE-YEAR ONE? IS THIS THE BIG FIVE-YEAR TRIAL THAT'S GOING TO BE STARTING?

Patient: Ooh, I don't know.

INT: I DON'T KNOW, I'M NOT SURE, [???] I'VE GOT THAT WRONG. NO, I HAVNE'T GOT IT WRONG, [???]

Patient: There's all sorts, so I'm on the internet all the time at the moment because there's always new things coming up.

INT: YEAH, THERE'S A THING [???] FOR FIVE YEARS BECAUSE I KNOW THAT ONE OF OUR DATA MANAGERS WENT FOR THE PROJECT MANAGER'S JOB FOR THAT, IN THE SHEFFIELD VERSION OF IT.

Patient: Right, right.

INT: BUT IT'S A BIG ONE, IT'S NATION-, IT'S WORLD-WIDE I THINK, IT'S A ABIG ONE. ERM, I JUST WONDERED IF IT WAS THAT ONE. BUT THERE IS, THERE'S DIFFERENT, IT DEPENDS ON THE KIND OF TUMOUR YOU'VE HAD, THE GRADE AND ALL THIS KIND OF STUFF, THEY'RE VERY STRICT CRITERIA. YEAH. SO, YEAH, SO MR SIBBERING DID YOUR OPERATION. HOW DID YOU FIND MR SIBBERING, GETTING ON WITH HIM?

Patient: He was lovely.

INT: IS HE?

Patient: Yes, he was really lovely. I didn't see him till, oh the Tuesday morning when I was in, obviously, and he came onto the ward to see his patients and saw him. So, yeah, he was really nice.

INT: AH, HE'S LOVELY. YEAH, I INTERVIEWED HIM, HE'S A REALLY NICE GUY, GOT ON VERY, VERY WELL WITH HIM, VERY, VERY HELPFUL. SO, HAVE YOU ACTUALLY STARTED YOUR CGHEMO NOW?

Patient: Last Tuesday, yeah.

INT: AND HOW DID THE FIRST SESSION GO?

Patient: All right. The session's fine, that's not a problem [chuckles] ...

INT: IT'S ABOUT A DAY OR TWO AFTER, YEAH.

Patient: Wednesday I was just a bit tired; Thursday I was just wiped out, absolutely, I just lay on here all day and couldn't move, felt really weepy, sick on and off, you know. But, OK, I'm gradually getting better ...

INT: DID THEY PREPARE YOU FOR ALL THIS, I MEAN, WHEN THEY DID IT?

Patient: With the chemo?

INT: YEAH, TELLING YOU ABOUT WHAT WAS GOING TO HAPPEN?

Patient: I think in some respects you can be over-prepared, to be quite honest. There's that much to take on board that can happen to you, and again I did a lot of research and looked into all sorts of studies and everything else, as you do, and decided this was what I was going to eat while I was having my chemo, and all the rest of it, and [??] today, except, well, and yesterday, I've had the most awful, awful heartburn. That's been the worst, just chronic, really bad heartburn. And of course everything I'd, they sort of said that you should have soy and onions and garlic and tomatoes and all these sorts of things, are all things you shouldn't have with heartburn. So yesterday I went onto old-lady food: I had rice pudding and boiled egg and porridge.

INT: I WISH I HAD THAT, ACTUALLY. I WOULDN'T MIND RICE PUDDING, I'LL HAVE RICE PUDDING ANY DAY.

Patient: I love rice pudding, I do.

INT: I'VE GOT TINS OF THE STUFF IN THE FRIDGE.

Patient: And I didn't actually have any heartburn yesterday which was really nice, but I popped to Sainsbury's first thing this morning and I think I overdid it a bit [??]

INT: THIS HAS NOTHING TO DO WITH THE PROJECT BUT IT'S [??] SO, THINKING BACK ABOUT YOUR TIME WITH THE, WITH MISS WAHEDNA TO START WITH, DID YOU FEEL THROUGH THIS, YOU KNOW, WHEN YOU WERE TALKING ABOUT WHAT OPERATION YOU WERE GONNA HAVE AND YOUR DIAGNOSIS AND THINGS, DID YOU FEEL THAT SHE LISTENED TO YOU?

Nurse: Yes.

INT: YEAH? DID YOU FEEL THAT SHE SORT OF UNDERSTOOD YOUR NEEDS, YOUR CONCERNS, THINGS LIKE THAT?

Nurse: Yes.

INT: YEAH? AND ...

Nurse: I mean she was really good actually because I did say to her, 'Is this a primary site?' and she said, 'You explain to me what you understand by primary site,' so any questions that I kind of asked her that were slightly medical, if you like, like I said, 'Is this an invasive cancer?' because they were my questions, and she asked me to clarify exactly what I meant by that. So she was making sure that I really did understand (a) what I was talking about and (b) what she was talking about, I think. So, yeah, I was very impressed with her.

INT: YEAH. I THINK WHAT'S HAPPENING IS, FROM THE INTERVIEWS I'VE DONE WITH THE SURGEONS AND CONSULTANTS, IS THEY'RE NOT AT ALL WORRIED ABOUT WHAT PEOPLE UNDERSTAND IN TERMS OF, AS LONG AS THE INFORMATION THEY'VE GOT IS CORRECT. WHAT THEY REALLY STRUGGLE WITH IS WHEN PATIENTS WITH INCORRECT INFORMATION, MISLEADING INFORMATION.

Patient: This, yes, and she was obviously really trying to straighten that one out, which I was impressed with, I was impressed with that.

INT: YEAH, BECAUSE IT THEN BECOMES, THEY'VE GOT TO DISPELL MYTHS AND THEN THEY'VE GOT TO ADD ON AND THAT CAN BE EVEN MORE CONFUSING.

Patient: And there's, you can find whatever you want on there now, on the computers, you know. All sorts of things on there.

INT: I MEAN I THINK THE KEY THING IS TO TRY AND KEEP TO THE BRITISH SITES, BRITISH MEDICAL JOURNALS, STUFF LIKE THAT, THOSE KIND OF SITES ARE, YOU KNOW, VERY RELEVANT TO, AND THEY'RE USING THE BEST INFORMATION, I THINK.

Patient: But I think people do take more interest now, don't they? They do. If you want to know - I think some people like to just switch it off, but, you know, you can sort of find all sorts of things to ask.

INT: AND HOW DID YOU GET ON WITH THE NURSES THEN?

Patient: The nurses?

INT: THE BREAST CARE NURSES?

Patient: Oh, fine, yeah, no problem. Yeah.

INT: YEAH, AND DID YOU FEEL THAT THEY LISTENED TO YOU?

Patient: Yes.

INT: THEY UNDERSTOOD YOUR NEEDS, CONCERNS THAT KIND OF STUFF?

Patient: Yeah, absolutely, yeah. I mean I've only met two of them, there was Karen, who was my initial breast care nurse, who was back in clinic again with Mr Sibbering to see me, and she took me off for a chat again. She's phoned me a couple of times, and then in oncology clinic it was Veronica, this is a different one, because it was Karen's day off. But she'd sort of said, 'Oh,' you know, 'Veronica'll be there,' and she was lovely as well.

INT: YEAH? AND YOU SAID THEY GAVE YOU AN INFORMATIN PACK? DID THEY GIVE YOU ANY INFORMATION AT ALL APART FROM THE PACK? WAS THERE ANY OTHER INFORMATION THEY GAVE YOU OR ...?

Patient: Erm ... I think everything really is in this pack, and they're there ...

INT: I THINK IT IS, YEAH, I DON'T THINK THERE IS ANYTHING ELSE, I JUST WONDERED IF THERE WAS ANYTHING ELSE THEY GIVE YOU. I'M THINKING IN TERMS OF THINGS LIKE IF THERE'D BE ANY DIAGRAMS DRAWN OR ANYTHING LIKE THAT, YOU KNOW, SORT OF THING, THEY PASSED TO YOU.

Patient: Oh right, no. Mr Sibbering drew a diagram.

INT: DID HE?

Patient: Yeah.

INT: OH, OK.

Patient: Only a little circle, they're your nodes and those two are cancer [chucklers] I think it was helping him really tell me more than anything.

INT: AND YOU OBVIOUSLY TOOK THE INFORMATION HOME TO LOOK AT, TO READ IT AND STUFF, I MEAN DID YOU LOOK THROUGH ALL OF IT, DID YOU?

Patient: Ooh, yes.

INT: YES? AND HOW USEFUL DID YOU FIND THAT INFORMATION?

Patient: Yeah, it's useful, yes, it is useful. And it's grown [chuckles] it's more information there now than there was.

INT: WELL, YEAH, BECAUSE YOU'VE GONE FOR THE CLINICAL TRIALS SO YOU'LL GET ANOTHER [???

Patient: Oh I've all sorts of information, I've pulled all sorts of the internet as well.

INT: YOU'VE PROBABLY GOT MORE PATIENT INFORMATION THAN LISA AND I HAVE.

?: You really research it, don't you, anything like that?

Patient: I've really, really gone into it, really, in a big way.

INT: BUT THAT'S GOOD, I MEAN, NOT EVERYBODY WANTS INFORMATION, BUT IF YOU WANT INFORMATION THE GOOD THING IS YOU'VE GOT LIKE PLENTY OF RESOURCES TO GO AT.

Patient: Yeah, mm. The thing is, it's all very well these professionals being there, but if you don't know what to ask them ... do you know what I mean? And I think it's, the breast nurses I think have a really hard job because, obviously, women are going to take this sort of news very differently and some are going to cope and some just are gonna fall to pieces. And to say, 'Are there any questions?' you don't always know what sort of questions to ask, you know. And I think they have a very difficult time trying to sort of offer information when they don't really know how much information you need as well, you know, on a personal level. So ... yeah, I think ...

INT: AND IT'S ALSO HOW MUCH A PERSON CAN TAKE IN AT ONE TIME.

Patient: Exactly, you see.

INT: SOME PEOPLE TAKE A LOT IN BUT OTHER PEOPLE WON'T EVEN GET BEYOND THAT WORD CANCER.

Patient: No.

INT: AND YOU FIND THAT THEY'LL COME HOME AND THEY'LL JUST SAY, 'WHAT DID THE PERSON SAY?' 'I CAN'T REMEMBER?'

Patient: Yeah, cancer. But I mean you see that when you speak to anybody else, you know, the family. And I can't believe how it's torn the family up so much, you know. But you say cancer to ... and their eyes change, they look at you, 'Oh, she's gonna be dead in a couple of years,' you know. And you can see it, can't you? You can, though, can't you? Yeah, but you, how did you react when I said it was cancer, you know?

?: Mm. I was [???

Patient: People still do, don't they, people still do. I mean my Dad was poorly, wasn't he, he was really poorly. It really made my Dad poorly.

INT: YEAH, MY DAD HAD, HE HAD BOWEL CANCER, AND HE'D NEVER BEEN ILL IN HIS LIFE, I MEAN, HE HAD THE ODD COUGH AND THE ODD SNEEZE, I MEAN I'M TALKING OVER 30-ODD YEARS, 30-ODD, 35 YEARS I KNEW HIM, ERM, AND SORT OF, YOU KNOW, HE'D ALWAYS BEEN REALLY STRONG AND FIT GUY, AND HE WENT, HE PRESENTED EARLY, HE'D GOT BOWEL CANCER, AND THAT REALLY, REALLY SHOCKED HIM, HE JUST DIDN'T EXPECT THAT KIND OF THING AT ALL. YOU KNOW, HE JUST THOUGHT, PILES AGAIN, SORT OF THING.

Patient: Yeah, but you don't expect cancer, do you?

INT: YEAH ...

Patient: You really don't.

INT: I MEAN I WAS IN THE CONSULTATION AND I SAW HOW MUCH IT HIT HIM. AND I DON'T REALLY THINK, I DON'T THINK HE EVER REALLY GOT OVER THAT, YOU KNOW, I THINK IT WAS KIND OF, FOR ME, I NOTICED A CHANGE IN HIM, HE BECAME A LOT QUIETER. EVEN THOUGH HE HAD A, HE PRESENTED EARLY, HE HAD NO PROBLEMS IN THE OPERATION, YOU KNOW, AND THIS, THAT AND THE OTHER, HE VIRTUALLY SAILED THROUGH IT. HE HAD THE BEST POSSIBLE OUTCOME SOMEONE CAN HAVE WITH THAT KIND OF ILLNESS, BUT IT DID CHANGE, IT DEFINITELY CHANGED HIM, I COULD SEE THAT. AND IT WAS SOMETHING HE REALLY STRUGGLED TO COPE WITH. SO ...

?: It is hard.

Patient: I still think some days, you know, that I haven't really accepted what they've said. I do feel as though it's like, 'Oh, it's somebody else, it's not really me,' do you know what I mean?

?: I think because you've not really, I mean, OK, with your chemo you've felt ill but before you didn't really feel that ill with it.

Patient: I've not been ill, have I? I've not been ill at all.

?: So it's just like a normal, you know, 'No, it can't be, because I don't feel any different really.'

Patient: I mean the op was nothing really, you know. They give you the ... was nothing she says ... I thought it was a laugh. Caused uproar on the ward as usual.

INT: AH, RIGHT.

Patient: You know? Well you have to have a laugh, don't you? It's life. You know, they're whipping my drains out first thing in the morning, the doctor couldn't even be bothered coming to see me, he went, 'Oh, she can have 'em out,' because I was watching the tele. [chuckles]

INT: WELL YOU WERE ONLY IN TWO DAYS SO MEAN ...

Patient: Yeah, oh no, they sent me, I was due to go home on the Friday, I was that well they sent me home on the Thursday. And I was well. And I was driving a fortnight after, don't tell any, don't tell anybody [chuckles] you know, I was back in the car. They give you these little exercises from physio, which we all did on the ward religiously, all my visitors and me, we were all doing our exercise.

INT: DID YOU HAVE AN EXERCISE RECORD?

Patient: Yeah.

INT: DID THEY GIVE YOU THAT LITTLE BOOK AND YOU HAD TO TICK THE BOXES?

Patient: Yeah.

INT: GREAT, ISN'T IT?

Patient: I did it.

?: I did as well.

[All talking together] [???

INT: [???] MACHINE [???] UP AGAINST A WALL, ALL THIS KIND OF THING.

Patient: Yeah, but they were so easy, you know. I went to see, because you have to go and see physio as well the week after so that they can check on how you're going and everything, and she said, 'And now we'll do these ones, and can you feel that?' I'm going, 'No,' but I'd done, I mean I go to the gym everyday normally, and I'd done loads of shoulder exercises recently because I wanted to sort, I felt like I was slouching a bit, and I've done, been doing loads of shoulder exercises so ...

INT: DID YOU FEEL THAT, I MEAN YOU MENTIONED THE GYM, I MEAN I GO TO THE GYM QUITE REGULARLY, BUT DO YOU FEEL THAT KIND OF LEVEL OF FITNESS HELPED YOU IN ANY WAY?

Patient: Definitely, most definitely, yeah, yeah, I really do.

INT: I'VE SPOKEN TO A COUPLE OF PATIENTS WHO'VE SAID THAT, LUNG PATIENTS MAINLY, WHO'VE SAID, YOU KNOW, THEY WERE VERY FIT PEOPLE, GYM, RUNNING, THAT KIND OF STUFF, AND THEY FELT THAT, YOU KNOW, THEIR FITNESS HAD PAID OFF IN THE LONG RUN.

Patient: Oh, absolutely. Don't you think so? I mean when you look at the lady that was next to me ...

?: Yeah, oh yeah, definitely.

Patient: You know, she was struggling, and I said, 'Come on, we can do this.' [chuckles]

?: Yeah, definitely, I do think that the gym does help really.

Patient: Yeah, yeah, I really do think that made a difference.

INT: SO YOU'VE GOT CONTACT CARDS FOR THE BREAST CARE NURSES NOW, SO YOU'VE GOT CONTACT DETAILS FOR THOSE ...

Patient: Mm.

INT: HAVE YOU CALLED THEM? HAVE YOU ...

Patient: No, I haven't actually, no.

INT: AND, ER, BUT NOW YOU'RE ON THIS TRIAL, AREN'T YOU, SO YOU'LL SORT OF, YOU'LL HAVE CONTACT CARDS FOR THOSE NURSES AS WELL, I BET, HAVE YOU?

Patient: For Diana, yeah.

INT: RIGHT, OK. AND HOW'S THAT GOING?

Patient: My friends are growing all the time [chuckles]. How's it going? It'll be interesting I think, yeah. MM, that's about as much as you can say about chemo.

INT: RIGHT, OK.

Patient: I mean what's, it's what they call the gold standard in the States, that's why I decided to do it, erm, because they've got such good results with it and it's what they use. So I thought, yeah,

?: As a norm ...

Patient: As standard, yeah, if it's good enough for them it's good enough for me.

INT: WHAT'S IT COMPARING AGAINST BY THE WAY? IS IT COMPARING [??] WITH [??] NO IT CAN'T BE, NO. WHAT'S IT COMPARING WITH?

Patient: Well it's [??] I'm having, the one [??]

INT: RIGHT, OK.

Patient: Erm, it's, the standard would have been the FVC, 5FU, do you know the drug [??]

INT: I'VE HEARD OF THEM, I'VE SEEN THEM AROUND AND STUFF, BUT I DON'T KNOW EXACTLY WHAT THEY DO, BUT JUST ...

Patient: Right. So it just takes off one of those and for my first four cycles I have an almost double dose of Epi[??] actually, the [??] and then for the second four I have [??] and [??]

INT: SO YOU KNOW THE TREATMENTS YOU'RE ACTUALLY GETTING, YEAH?

Patient: Oh yeah.

INT: IT'S NOT LIKE A DOUBLE-BLIND TRIAL OR ANYTHING, OK?

Patient: No, no, that was one of my questions. I didn't want any blind trials.

INT: RIGHT, YEAH, OK. AND YOU SAY THAT YOU'VE, YOU KNOW, YOU WERE GIVEN THE INFORMATION, BUT YOU ALSO LOOKED FOR YOURSELF, YOU'VE MENTIONED THE INTERNET, WHAT ABOUT INFORMATION FROM BOOKS, MAGAZINES, VIDEOS, TELEVISION, ANYTHING, ANY OF THOSE, DID YOU GET INFORMATION FROM?

Patient: I have, well, I've been collecting information from the newspapers since about any new drugs that the Government are refusing to allow us to have because they're expensive.

?: Money is [??]

Patient: Anything really. I mean people, my family and friends are sort of saying, 'Oh, did you see this in the paper today?' and they'll bring me an article round. I mean I tend to use the internet more than anything.

?: Hayley as well.

Patient: Hayley, yeah, one of my sister's friends, had, she had the same operation, what nearly two years ago?

?: Yeah.

Patient: So she's been, I mean, all sorts of people have had breast cancer now that have been around my life somewhere, and it's amazing how many people have come forward and sort of offered information and support.

INT: AND YOUR GP? DID YOU GET ANYTHING FROM YOUR GP OR ...?

Patient: My GP ... I've not really ...

INT: [??] INTERVIEW.

Patient: ... seen him, to be quite honest. Erm, when did I see him? I know, the Friday. After I'd been told on the Thursday ...

?: [??]

Patient: No, when I went to the GP. We went to the GP on the Friday because my husband wanted, they had written in to their agreement that they could have a fortnight's sick leave for third party on a private doctor's note, so he, we went to see the GP to get this private doctor's note for that fortnight, because then it meant he had, like, he only went back to work last week, he had a month off with me, because obviously we've got the fortnight's holiday booked, so he just left as standing. So that was the only time I saw him, which was the day after, and I just said to him then, you know, 'Oh, it's breast cancer,' and he was gobsmacked, he was absolutely gobsmacked. He said, 'I really, really thought that was a cyst.' So I've not seen him apart from that at all. I'm too busy at the hospital. And of course on chemo they tell you not to, erm, see your GP, you just have a 24-hour contact number for the hospital.

INT: YEAH, THEY KIND OF TAKE THINGS OVER, DON'T THEY?

Patient: Yeah, absolutely, mm.

INT: ERM, WHAT DO YOU THINK, NOW, THINKING ABOUT THE DECISION THAT YOU MADE REGARDING YOUR TREATMENT, WHAT DO YOU THINK WAS THE MOST IMPORTANT THING YOU WERE TOLD OR HEARD THAT HELPED YOU MAKE THAT DECISION TO GET THAT TREATMENT?

Patient: The most important thing ...

INT: YEAH.

Patient: ... was that I had got the choice.

INT: THE CHOICE, YEAH.

Patient: Yeah, for surgery, yeah. That there was the choice and that it didn't matter which way I chose. I think that was really important. Because you really, I do believe that that's right, that, you know, it wouldn't have mattered which way I chose, because I do think this is better, I think it just ... when I needed that, I needed, I don't know, persuading I suppose, that it would be as good as a mastectomy, and she did, she convinced me. So I think that was really important.

INT: AND LOOKING BACK FROM WHEN YOU WERE FIRST DIAGNOSED UNTIL NOW, WHAT DO YOU FEEL ABOUT THE CARE THAT YOU'VE RECEIVED?

Patient: It's been fantastic actually, yeah.

INT: DID YOU HAVE ANY EXPECTATIONS ABOUT WHAT THAT CARE MIGHT BE?

Patient: Erm ... ooh, probably not as good as it has been. That's awful considering I used to work in [???] isn't it? Erm, I know that, from what they've said, you know, nurses are busy and they're rushed, so you tend to be kind of, I suppose I thought I'd be left to it a bit, and then nurses were absolutely fantastic on the ward, and they were there, and they knew if you were starting to feel a bit low because obviously, I mean I've not been like that, have I? I've been down there or I've been up there and ...

INT: YEAH, SURE.

Patient: And they sensed that straight away. Erm, I just think everybody, everybody seemed to be really in tune with how I've been. And the chemo suite are amazing, you know, they're really ...

INT: IS THAT ALL DONE IN DERBY?

Patient: Yeah. Yeah, they're really good, everybody, everybody's been fantastic I think. I'm very lucky.

INT: IF YOU WERE GIVEN THE MONEY AND POWER TO CHANGE ONE THING ABOUT THE SERVICE THERE AT DERBY, WHAT DO YOU THINK IT WOULD BE?

Patient: Oh ...

INT: [???]

Patient: The money and power ... anything, from the whole episode?

INT: YEAH, RIGHT THE WAY THROUGH.

Patient: I wouldn't ever let anybody wait six weeks for a mammogram.

?: I think - I don't want to but in - I think there should be, how they do this well woman, is it well woman thing, isn't it, for 50-year-olds, they should lower that age totally.

Patient: It's 40 in America.

?: It should be lower.

Patient: Mammograms are standard from 40 in America.

INT: YEAH.

?: It should be a thing that should be done on a regular basis for women.

INT: IT MAY WELL, IT MAY WELL GO DOWN. I MEAN I SUPPOSE WHAT THEY'LL DO IS THEY'RE GOING TO EVALUATE IT AND SEE HOW WELL IT WORKS AND THEN, YOU KNOW. THAT'S THE THING WITH THE WHOLE CULTURE, WE'VE GOT TO HAVE EVIDENCE FOR EVERYTHING, AND THAT'S [???] I THINK YOU'RE PROBABLY RIGHT.

Patient: Yeah, and at the moment I mean ... last year there was 41,000 women diagnosed last year and 80 per cent were over 50.

?: So at those rates you're never gonna get ...

Patient: I think 80 per cent were in their 20s and 30s and 12 per cent were in their 40s. So 12 per cent isn't going to make them ...

?: Them change that.

Patient: ... change the mammogram, but I just, I think it's disgusting that I had to wait six weeks. And it's the one thing that really hurts my husband, doesn't it, Chris? He said he really wishes he'd paid for a private mammogram and we'd have got it sorted earlier.

INT: I CAN'T REMEMBER WHAT YOU SAID RIGHT BACK AT THE BEGINNING OF THE INTERVIEW, WE'VE TALKED ABOUT SO MUCH, BUT WHAT WAS THE THING THAT MADE YOU SIX WEEKS?

Patient: It was standard, yeah, from my GP sending that letter it was 6 weeks before I had an appointment.

INT: MM, BECAUSE AREN'T YOU SUPPOSED TO BE SEEN IN TWO WEEKS, ISN'T IT TWO WEEKS?

Patient: Well I know originally when, I had a mammogram two years ago, the GP said that to me then, he said, 'It's two weeks, if you've not heard within two weeks get in touch with them.' And it was two weeks to the day that time, and this time ... obviously when it's necessary you ... you know, but he said to me, he said, 'I'm gonna send for this mammogram,' he said, 'and you can cancel it,' he said, 'because it's so hard to get an appointment,' he said, 'I'm going to send for it anyway.' Well, it's a good job he did really.

INT: WELL YES, OF COURSE, IT COULD HAVE BEEN LONGER.

Patient: But that's, I'd definitely changed that, I think that was agonising in the end.

INT: YEAH, OF COURSE, IT'S A LONG TIME TO WAIT, ISN'T IT? A LONG TIME.

Patient: Yeah, yeah.

?: And we'd been out, hadn't we and said, 'Oh, we've not heard anything again,'

Patient: Yeah, it were kind of just waiting all the time because you knew something had got to be done, you know, by this stage I knew something had got to be sorted, and it's a hell of a while to wait. But there doesn't seem to be any standards on that because, again, the lady that was in the bed next to me, she'd seen her GP the week before her mammogram.

INT: IT'S STILL VARIABLE, ISN'T IT?

Patient: Very variable. But I think that should be definitely two weeks, no more.

INT: WE'VE HAD A LOT OF STANDARDS AND THAT SINCE 1995 NOW, YOU KNOW, THE LADY I WAS TALKING TO THIS MORNING SHE HAD HER FIRST BREAST CANCER IN 1993 AND SHE SAID THERE WAS A MASSIVE DIFFERENCE BETWEEN THEN AND NOW, AND SHE HAD IT IN HER SECOND BREAST.

Patient: There does seem to be. I mean even ...

INT: NOW WE'VE HAD, HAVE YOU HEARD OF THE CALMAN-HINE REPORT?

Patient: No.

INT: AH, RIGHT, YEAH, YOU CAN LOOK ON THE INTERNET.

Patient: I was going to say, [chuckles] you see that going in then, couldn't you?

INT: CALMAN-HINE [???] TWO DOCTORS WHO DID A SURVEY OF CANCER SERVICES IN ENGLAND IN 1993/94 OR SOMETHING AND THEY PRODUCED A REPORT IN 1995 AND IT BASICALLY RIPPED INTO CANCER SERVICES SAYING IT WAS JUST TERRIBLE, YOU KNOW, WE REALLY UNDER-PERFORM IN IT IN EVERY DEPARTMENT, IT WAS SO VARIABLE, IT WAS LIKE A POSTCODE LOTTERY. AND THEY DRAFTED A WHOLE RAFT OF CHANGES AND TOTALLY REVAMPED THE WHOLE OF THE CANCER SERVICES IN ENGLAND, AND IT'S A LOT BETTER THAN WHAT IT WAS, BUT STILL YOU'RE GONNA GET ...

Patient: It's not good enough, though, is it?

INT: IT'S STILL GONNA GET VARIABLE THINGS.

Patient: It's not good enough. It's like this other study that I've been rejected for, only because you're randomised and you either get the drug or you don't basically, so unfortunately I didn't get it. And it's a drug that's for, to prevent, normally prevent osteoporosis, and they've been using it alongside chemo and they've had really good results, there's not been as much recurrence in the bones, cancer in the bones, which obviously is not curable. So I got really excited, going, 'Oh yes, I want this drug,' because they've had some fantastic results. [???] have said that all chemo patients should get this drug and the government have said it's too expensive, and I didn't get it, so I mean that's jut another one that everybody should be able to have, if they want it, and you just can have, you know, and it's ... again, you know, down the line, if I get the cancer back in my bones, I'm always gonna think, 'That could have been prevented.' You know, I met a, I had to go for a mugger [?] ECG and I met a lady in there and she was just five years on from her breast cancer and she's just got it back in her spine now. And she was only about my age. You know, all that could be prevented. You know, she'll probably be dead in two years and ... and she needn't be.

INT: LAST LOT OF QUESTIONS ...

*Q5., ERM, NOW YOU'VE BEEN THROUGH ALL OF THIS EXPEIENCE, WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT THEIR DIAGNOSIS? JUST THEIR DIAGHOSIS, WHAT DO YOU THINK IS THE MOST IMPORTANT THINGS THEY NEED TO KNOW?

Patient: Erm, again I think that's a very personal thing as well, because I don't think everybody can always, I mean for me it was knowing that it was a primary site, definitely, being told, 'Yes, it is the primary site.' But again, I mean, not everybody'd necessarily understand that or cope if they were told it wasn't. Some people might not want to know it wasn't. But, so I think that's a very individual thing again, but definitely I wanted to know from the diagnosis whether it was primary and whether it was invasive.

INT: AND NOW YOU'VE BEEN THROUGH THIS EXPEIRENCE WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT THE OPERATIONS THEY CAN HAVE?

Patient: Erm, I think more people ought to be aware that they can have just the local excision and they don't have to go through a mastectomy.

INT: RIGHT, YEAH.

Patient: That there is the choice, because this is so much easier, you've got less trauma to get over with both physically and mentally, and I think more women'd perhaps be, feel a bit better able to cope if they realised that there was more of a choice like that, definitely.

*Q6. IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY? ANYTHING YOU THINK I HAVEN'T COVERED, ANYTHING YOU NEED TO TELL ME THAT WE HAVEN'T TALKED ABOUT?

Patient: No, I don't think so.

INT: IS THERE ANYTHING YOU'D LIKE TO ADD?

Patient: She's always got something to add.

INT: AS A CARER'S PERSPECTIVE.

?: Erm, no, I've found it hard at times, that's all. There's times when I can't even phone you, isn't there, or come round, because I need to be strong myself in front of Liz, you know, and I don't want to be crying in front of her all the time. I need to be positive because I want her to be positive and then everything's gonna be all right, see.

Patient: I don't think there are enough positive cancer stories out there.

?: I think you hear all the bad stories, you pick up a magazine and somebody died, and I want to hear more of the good things, you know.

Patient: Yeah. That would be good, more positive. I mean we sat here and it could have only been, I don't know if it wasn't the first, before I had my op even, and Chris was reading the newspaper, we were sat here and I looked, and I thought, 'Oh no, if he looks at that,' and it was a good, ooh, this size ad, and there was a young girl sitting in an armchair, and it was advertising for Macmillan nurses, and it said, 'I want to be able to decide where I did. I know how I'm going to die, I've got breast cancer.' So I thought, 'Oh,...' and I'm sat and he's shaking like this and he's read and I just went, 'Ignore that, it's rubbish,' [chuckles] and started to him again and ... but it's this sort of, you know, this is why everybody thought I was gonna die.

?: Yeah, [??] on television when my friend Hayley had breast cancer was a picture of a woman with a schoolboy a front, was she doing his tie?

Patient: Oh yeah.

INT: OH, IN THE MIRROR?

Patient: Yeah.

?: And then she disappeared, didn't she? And Hayley at the time phoned them up and said, 'I hate this advert, that's not good for me.'

Patient: She's got two young boys

?: She's got two young boys, one that had just started school. And she said, 'This is ..' you know, they don't want to see this.

INT: YEAH, OF COURSE.

?: I mean you've got to get through this, I mean she had explained to the boys that she'd, you know, got breast cancer and everything, but I mean that's what they're seeing and that's how you associate cancer, that you're gonna die.

INT: ABSOLUTELY, YEAH, OF COURSE. YEAH, THEY ARE QUITE HARD-HITTING ADVERTS, AREN'T THEY, THAT'S THE THING.

Patient: Yeah, I mean I can appreciate the point that they need to be to try and get people to give money, but at the same time it's very hard on the families, you know, I mean my son's 12, older than Hayley's sons, and he still thinks you get cancer, you die, you know, and that reinforces it really. And that advert, 'Oh I've got breast cancer, I'm gonna die,' you know ... and he must think, I sometimes think he must think, you know, 'Is she telling me the truth?' And I have actually asked for an appointment with the clinical psychologist as a family and get him to talk [??]

?: I think there's a nice one now, the one that's with two women or something and it says, 'All clear' ...

Patient: All clear.

?: ... which is much nicer.

INT: YEAH, YES, THAT'S RIGHT, KIND OF MORE OF A POSITIVE SPIN, ISN'T IT, REALLY?

Patient: It is, definitely, it's much better.

INT: BECAUSE YOU CAN GET THE MESSAGE ACROSS...

Patient: Because you can still, I mean, yeah, that advertising [??]

[Talking together] [??]

Patient: Really that would make me give my money up more because I'd think they're doing something. You know, the other one, they're still dying, why would I bother giving my money? You can look at it both ways.

?: [??] We're having a disco, though, aren't we, we're jut trying to organise it ...

Patient: We're organising a ...

?: We've organised it already [??]

INT: [??] WHEN YOU'RE TALKING ABOUT IT, I MEAN THAT EVEN UPSETS ME WHEN I SEE IT, I CAN'T [??]

Patient [?]: Yeah, oh, I can't.

?: I couldn't before.

INT: I JUST CAN'T WATCH IT.

?: [??] I think she was diagnosed, was it August time? I'm just trying to think when it was, and September her son started school, she said I just couldn't watch it. She says, and her Mum and, you know, they've got together and said, she said, 'That' it, I'm going to, I'm going to complain about it.' I said, 'Well, complain,' because it was awful.

INT: YEAH, I CAN IMAGINE.

Patient: But definitely more positive. We need more positive things like out there. I'm a positive person [chuckles]. We're having a positive disco, aren't we?

?: We're having a positive disco with, you know ...

Patient: To raise some funds for breast cancer.

?: ... for breast cancer. June 19th, I'll sell you a ticket.

INT: [CHUCKLES] JUNE 19TH.

?: I've got Elvis singing ... yeah we have.

INT: THE REAL ELVIS?

Patient: Yeah, Elvis is coming, yeah.

?: My friend, Hayley, who's got, had breast cancer, erm, she sings, she's been on Michael Barrymore and so she's singing for us as well.

INT: HAS SHE?

?: So, yeah, yeah, oh it's going to be a rare old night.

Patient: Up at the Uni. We're going to have a right night.

INT: OH WELL THAT SOUNDS GREAT.

Patient: I'll let you know.

INT: OH, OK. IF THERE'S NOTHING ELSE I'LL STOP THE RECORDER AND WE'LL FINISH OFF.

CANNOT ATTRIBUTE THESE QUESTIONS TO THE INTERVIEW

*Q3. AND WHAT HAPPENED WHILE YOU WERE TALKING ABOUT WHAT TREATMENT YOU COULD HAVE?

*Q4. SO, PLEASE TELL ME WHAT OPERATION(S) YOU HAD FOR YOUR BREAST CANCER?

*Q7. THE REST OF THE TAPE HERE...
Here