

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)
*VENUE: High MR unit
*DATE:
*ID: Patient28
*INTERVIEWER: DJW

INT: FIRST OF ALL THANK YOU FOR AGREEING TO BE INTERVIEWED. I'D LIKE TO START WITH QUESTION ONE. CAN YOU TELL ME A BIT ABOUT WHAT YOU KNEW OR UNDERSTOOD ABOUT BREAST CANCER BEFORE YOU REALISED SOMETHING WRONG WITH YOUR BREAST?

Patient: I didn't know anything was wrong with my breast 'til I went for the mammogram.

INT: AH RIGHT, SO YOU WERE PICKED UP ON SCREENING, WERE YOU?

Patient: Yeah, and couldn't, there was no, I mean even the consultant couldn't feel it.

INT: AH RIGHT, SO IT VERY SMALL.

Patient: It was that small, so until I just went for my routine mammogram thinking, 'cos I'd got this other problem brewing at the same time, which I was waiting to see the consultant about, and I just thought, 'Let's get this mammogram over and done with and ...' because I don't know if it was my third or fourth one, you know, and everything had always been fine. So I didn't know until I got recalled.

INT: RIGHT, OK THEN. ERM, AND HAVE YOU GOT ANY FAMILY HISTORY OF BREAST CANCER? DO YOU HAVE ANY FRIENDS OR RELATIONS [?]

Patient: My sister in law, my husband's sister, she had, she's dead now, but not through the breast cancer, it was a heart attack. She had a breast, a mastectomy, well, God, it must be getting on for 20 years ago. And she only died a couple of years ago, you know, I mean so, what contact I've had with people with breast cancer has always been positive.

INT: RIGHT.

Patient: You know?

INT: MM, OK.

Patient: But that's it really.

INT: MM, OK. SO YOU WENT ALONG TO TAKE A MAMMOGRAM, WHAT HAPPENED AFTER THAT?

Patient: I had a letter for a recall, recall, went, had another mammogram, saw some doctor, I can't remember his name there's that many in my head, he did a biopsy, come back next week, went back the following week, saw Mr Holliday, 'Yes you have breast cancer, I will have you in next Tuesday,' and that was it.

INT: OK. SO WHEN YOU GOT THE LETTER TO GET RECALLED, WHAT WAS, WHAT WENT THROUGH YOUR MIND AT THAT POINT?

Patient: Well, I'd had this one at the mobile, at the Infirmary ...

INT: OH RIGHT, OK, THE DRI, YEAH?

Patient: Yeah, where before I'd always had the one at the breast screening place at the City, and well thee they develop them, don't they, at the City, before you leave.

INT: RIGHT, YEAH.

Patient: But at the, in the mobile one they can't, so they say, you know, 'You might get recalled because the picture's not took,' 'cos they can't develop them, you know. So this is 'The camera must have moved,' you know, in my head, and that was it really.

INT: RIGHT, OK. SO WHAT HAPPENED ON YOUR SECOND VIIT THEN, YOUR SECOND ...?

Patient: The second one, as I say, I had another, another mammogram and they ...

INT: DID THEY DO A BIOPSY AT THE SAME TIME?

Patient: And they did the biopsy on the same day.

INT: WHAT DID YOU THINK ABOUT THAT THEN?

Patient: Well I thought it was good, let's get it sorted and, you know, [???] lop it out, you know, [chuckles] this is what I was thinking, you know. Well if there is something there, you know ... and you still thinking it's just perhaps a cyst, you know, until ... so when Mr Holliday said it was definitely cancer, so you know, well, that's it then. And within the week he had me in to, that was one Tuesday and the following Tuesday I was in having my surgery, you know.

INT: MM. SO BETWEEN THE TWO MAMMOGRAMS HOW LONG DO YOU THINK IT WAS, ABOUT A WEEK, TEN DAYS?

Patient: Oh God I can't ... it was a fortnight, because I went for the mammogram on the Thursday and I had to go and see Mr Simons about the womb problem on the Friday, so I'm thinking in my head, 'Right, we'll go and have the mammogram, like I say, get that out of the way and I can [???] tomorrow and sought the other out.' The following Wednesday I had to go in for a D and C because they couldn't get a sample, a biopsy sample, at the clinic I went to on the Friday, and then the Thursday, which was a week, I got the letter recalling me for the Tuesday. So it was 10 days between mammograms, I suppose, yeah. So, you know, that was on the Thursday I got the letter recalling me and I went on the following Tuesday, had the biopsy, went back the following Tuesday for the results ...

INT: YEAH, AND THEN WITH TWELVE DAYS OR SOMETHING YOU HAD THE SURGERY, IS THAT WHAT YOU'RE SAYING? WITHIN TWELVE ... YOU WERE DIAGNOSED, YOU HAD ABOUT, WHAT, TWELVE DAYS?

Patient: No, I had seven, from Tuesday to Tuesday. I went on the Tuesday, got the result, and he said, 'I'll have you in next Tuesday.'

INT: AH, SO IT' LIKE ROUGHLY ABOUT FOUR ...

Patient: Four or five weeks, yeah.

INT: OH IT'S NO TOO BAD.

Patient: I think it's pretty good really. I mean it was the same the womb cancer, you know, I went to my doctors the first Monday of the new year, she said, 'I'll fax the hospital, you'll get an appointment within a fortnight,' which I did, then I went that Friday, he couldn't get it, the sample he wanted, so I went in on the Wednesday and had the scrape, saw him the following Thursday after I'd the Tuesday with breast cancer, and they just aid, 'Right,' you know he said, 'I've made an appointment for you to see whoever the surgeon was that was gonna do the hysterectomy on Tuesday,' I said, 'Well you'd better send him to ward 7 to me then.' He goes, 'Pardon?' I said, 'Well, I was diagnosed with breast cancer on Tuesday.' 'Oh, my God,' he said, and after we chewed the fat a little between us he decided that he was gonna have a ring round and have a case conference on the Friday morning and see if they could ...

INT: MM, [???] TOGETHER.

Patient: ... do it all together, you know. And Mr Sibbering said he ... and then on the Monday I went in for my pre-op and we had another little case conference in the breast unit, Mr Sibbering and Mr Simons were both there and the nurse, you know, the breast care nurse, and John obviously, and that was it, and I was in the next day. And he said, 'Don't you think it's, you know, you're not thinking it's a little bit fast, are you?' I said, 'No, I'd have come in on Friday if the truth was known,' [chuckles] you know.

INT: YOU WANT IT DONE AS QUICK A POSSIBLE, [???]

Patient: Yeah, yeah. It's, once you ... it's bad enough not knowing and hanging about, but once you know, I think, the sooner the better.

INT: YEAH, MM. YOU KNOW THE SECOND TIME YOU WENT TO GET YOUR SECOND MAMMOGRAM, YOU GOT YOUR BIOPSY, DID ANYONE IN THE CLINIC THAT YOU SPOKE TO GIVE YOU AN INDICATION THAT THERE MIGHT BE SOMETHING AMISS?

Patient: Yeah, ooh yeah, I mean the radiographer who did it, well I asked as well, you see, because I'm that sort of a person. I said, you know, 'What's this all about then?' so she says, 'Well we found something on the plate, like, you know, on the x-ray and mammogram. We just want to check,' she says, 'it could just be a blip or it could be something, you know,' she says, 'if it ...' So I had to wait while they did it and then she came in, she says, 'Well, we think it is something, you know, and go and see ...' I can't remember what his name was, this chappy anyway, 'and he'll do a biopsy,' you know. And I says, 'My God, there's more of me in the path lab than there is walking around,' [chuckles] But, erm, and that, you know, he did say, you know, but he did say like it could be just a cyst or, but I suppose he sees that many he must have known. But they don't, they don't say it until they've got it for sure, do they? You know.

INT: YEAH, THEY TEND TO LEAVE THAT SORT OF, THE FINAL TELLING TO THE CONSULTANT, YEAH, JUST IN CASE THEY'RE WRONG. BECAUSE THE OTHER THING IS YOU'RE GONNA GO AWAY FOR A WEEK AND OBVIOUSLY BE WORRIED ABOUT IT.

Patient: Yeah, yeah.

INT: SO, ERM, WHEN YOU WENT TO THE CLINIC TO HEAR ABOUT YOUR DIAGNOSIS FOR YOUR BREAST CANCER, CAN YOU TELL ME ABOUT WHAT HAPPENED THEN FROM WHEN YOU WENT, HOW THE CONSULTATION WENT ETC, WHAT YOU TALKED ABOUT?

Patient: Well it was ... with a plate up on the screen, and he says, 'There it is.' I says, 'Yes, I can see it.' He says ...

INT: WHO WAS IT, MR HOLLIDAY.

Patient: Yeah, well you know everybody knows what he's like, don't they? I mean he's, he's the consultant, isn't he? [chuckles] I don't think he means to be that way, it's just, erm, some people find him very brusque.

INT: YEAH HE IS.

Patient: You know? Er, and he had a feel like, you know, and he says, 'Can you feel it?' I said, 'No.' He says, 'No, neither can I, but it's definitely there,' he says, 'And I'll have you in next Tuesday for surgery.' I says, 'Yeah, what, you know,' He says, well, it was him that it actually, 'Well, the choice is yours, you can either have ...' he didn't call it a lumpectomy, he called a ...

INT: WIDE LOCAL EXCISION.

Patient: Yeah, '... or a mastectomy.' I said, 'And ...' 'And what?' he said. I said, 'Well, you know, can I have a bit of inf-?' 'Well just think yourself lucky you've got the choice,' he says. I said, 'Well, I'm sorry, you know ...' He says, 'Well some ladies don't have the choice, it's a mastectomy and that's the end of the matter,' he says, 'but we've caught yours early and you've got a choice. But I haven't got to know your decision yet, you can give it us the day of the surgery, if you like,' he said. And that was more or less it. And then I came out of there and ...

INT: WAS JOHN WITH YOU? [???

Patient: No, because he'd had to go and park the car.

INT: OH RIGHT.

Patient: And he, he was in the waiting room, waiting for me. And when we came out, they took me through to, erm, which he did come then to see the ...

INT: THE BREAST CARE NURSE?

Patient: ... nurse, you know, the breast care nurse.

INT: SO WHEN YOU WERE IN WITH MR HOLLIDAY WHO ELSE WAS WITH YOU? WAS THERE A ...?

Patient: There was another nurse, there was a nurse.

INT: A CLINIC NURSE, IN A UNIFORM?

Patient: A clinic nurse, yeah, wasn't one of the breast care nurses. And she took me through and then one of the breast care nurses came up and we went in one of the little rooms, like, you know, and ... and that was that.

INT: SO DID YOU, BEFORE YOU HEARD ABOUT YOUR DIAGNOSIS, I MEAN YOU'D BEEN FOR YOUR BIOPSY, DID YOU TALK TO ANYBODY ABOUT YOUR INITIAL THOUGHT ABOUT WHAT IT MIGHT BE?

Patient: Well, yeah, I mean, all the family knew, you know, John and the kids and ...

INT: HOW DID THEY TAKE IT THEN, HOW WERE THEY?

Patient: Phew, John didn't take it very well, no. And then the Thursday get upset because of him, which ...

INT: YEAH, I CAN IMAGINE, YEAH. OFTEN SPOUSES, IT IS VERY HARD FOR THEM, THEY FEEL A BIT POWERLESS, DON'T THEY?

Patient: Yeah, I mean, yeah I think that's it.

INT: YOU TAKE YOUR TIME, IT'S OK.

Patient: I mean he kept ringing and ringing 'cos I wasn't back.

INT: OH RIGHT, OF COURSE.

Patient: So it was ... that didn't do it a lot of good either.

INT: NO, I BET IT DIDN'T. NO.

Patient: They do tell me, my daughter came to see me at half past 11 ... I can't remember ...

INT: OH YOU MEAN AFTER YOUR ...

Patient: At the night-time.

INT: OH I SEE, YEAH.

Patient: Yeah, when they took me in to [???] down. And they told, Ward 7 eventually knew where I was, like, you know, 'cos they didn't know where I was, just kept saying, 'She's not back yet.' And, erm ... he came, [???] down to see me.

INT: THAT WAS AT NIGHT, 11 O'CLOCK.

Patient: Got back 11 at night. I mean I couldn't remember it, [???]

INT: NO, YOU'D HAVE BEEN STILL IN THE ANAESTHETIC, WOULDN'T YOU?

Patient: Well I can't even remember ... I vaguely recall, I must have been in the recovery room, looking at the clock and it was half past 10, and that's the only recollection I've got. And I was thinking, 'That clock must have stopped,' because it was so late, you know, not knowing what had gone off. So ... that was that.

INT: MM, OK. ERM, SO YOU, WE GOT AS FAR DIDN'T WE AS YOU DESCRIBED YOU, YOU SAID YOU'D HAD YOUR DIAGNOSIS AND YOU SAID THAT YOU HAD A CHOICE, YEAH? AND THE IDEA THAT THIS CHOICE, I MEAN HOW DID YOU ABOUT THAT WHEN HE SAID YOU HAD A CHOICE?

Patient: Well ... like I say, you know, this wanting to make this choice and I don't feel qualified to make it, you know, and I was still thinking that I'd got the results to come of the womb problems ...

INT: THAT WAS ON THE THURSDAY?

Patient: ... the gynae ones I was having on the Thursday, and I'm thinking, 'Phew, you know, if it's both, what do I do? Or the gynae's OK, do I have a mastectomy or ...' and I was, I didn't really make up my mind until the day of the op, when I went to see Mr Sibbering, erm, before I went down, well in the morning before he started his surgery, like, you know, doing his list. And I told him then.

INT: OH RIGHT, OK.

Patient: Yeah, I said to him, I said, like, you know, I think with having the hysterectomy as well, I wanted the least invasive ...

INT: YEAH, SURGERY, YEAH ...

Patient: ... surgery.

INT: SO YOU WENT FOR THE WIDE LOCAL?

Patient: Yeah, and ..

INT: HOW DID YOU FIND MR SIBBERING?

Patient: Lovely man.

INT: HE'S NICE, ISN'T HE?

Patient: He should be, he should be a Welsh hill farmer [chuckles].

INT: HE IS A FUNNY GUY. I'VE INTERVIEWED ALL THE STAFF AT THE DERBY ...

Patient: He should, he should be a big Welsh hill farmer, well that's how I think of him anyway. Lovely, you know, really ... I found Mr Holliday very, like I say, brusque, but other people think really well of him.

INT: YEAH, IT'S, I THINK, THE PROBLEM I HAVE REALLY I SUPPOSE IS THAT WHEN YOU GET THE PATIENT IN YOU'VE GOT TO, YOU KNOW, I MEAN YOU'RE TOTALLY DIFFERENT FROM THE WOMAN I INTERVIEWED THIS MORNING, AND YOU KNOW WHEN YOU START TO READ A PATIENT THE SORT OF THINGS YOU CAN SAY AND WHAT YOU CAN'T SAY, AND I THINK WITH CERTAINLY THE OTHER TWO CONSULTANTS, THEY'RE VERY GOOD AT READING PEOPLE WHERE I THINK MR HOLLIDAY HAS A STYLE HE KIND OF JUST STICK TO AND HE CAN'T SAY ...

Patient: I mean the Saturday before he operated on my granddaughter - she'd got a cyst on her eye - she's only 18 month old, and there was, they'd been waiting, you know, it's gradually grown and grown, and so they said she was ready to have it done, like, and she went in on the Saturday morning, only in the morning like to have it done. And my son said, 'I didn't like him when he came in in his suit, he was all business-like,' but afterwards when he came through in his greens, in his scrubs, he said he was a different, different man altogether, you know, I mean ... So I suppose it's just his persona that he puts on, but as I say Mr Sibbering, lovely man. And, like, my gynae man, he was as well.

INT: I MEAN MR SIBBERING DID THE OPERATION, DID HE?

Patient: Yes, for the breast cancer, yeah, and Mr Simons, because I had both of them like. He did the, Mr Sibbering did the breast cancer and Mr Simons did the hysterectomy. Mr Simons, he was, no, he was a different sort of fellow again, [???] very quiet, erm, very proper. I don't think he could believe some of the things I said to him, you know, and I'm a bit of an unknown quantity I think to him. Just used to shake his head [chuckles] you know, well I am cheeky, I know I am. And some of the things I said to him he ... 'Er ... right, which way do I take her?' like, you know. And where Mr Sibbering took it and laughed, but Mr Simons was a bit ... but there you go. That was that.

INT: SO ONCE YOU'D HAD YOUR DIAGNOSIS AND I MEAN WHAT WERE YOUR FEELINGS THEN KNOWING THAT YOU DID HAVE A BREAST CANCER?

Patient: Well I'm not one of these people that say, 'Why me?' you know. I didn't like not being in control, I mean ask the kids, they'll tell you, I'm, you know, a bit of a control freak. I didn't like not being in control. Something was happening that I couldn't ...

INT: DO ANYTHING ABOUT [???]

Patient: ... do something about it, you know. Er, and that was it really, as I say, and the next thing I wanted 'Well, let's get the surgery over and done with, let's get it sorted and we can be on the road to recovery, hopefully, you know.' That's how I was thinking about it.

INT: AND WHILE MR HOLLIDAY WAS DESCRIBING THE DIAGNOSIS AND THE TREATMENT OPTIONS, DID YOU FEEL YOU UNDERSTOOD EVERYTHING, WAS THERE ANYTHING YOU DIDN'T UNDERSTAND?

Patient: No, no, I think I understood everything, you know, I could see that it was, you know, on the mammogram, it was only ...

INT: YEAH, VERY SMALL.

Patient: ... very small, about as big as your nail really, you know. And having large boobs it looked quite lost in there [chuckles] actually, you know, er, but, I mean this was something else that, oh, why I plumped just to have the lumpectomy, like, was because I was thinking of it would be quite lop-sided, with being big-breasted, and having a prosthesis, you know, and I thought, 'I don't really fancy that,' [chuckles] so this was one of the reasons that I, you know, in the end, thinking of the, of, you know, that as well - not that I'm a vain person, 'cos I'm not, but I was thinking of more my comfort.

INT: YEAH, OF COURSE. I MEAN, BODY IMAGE IS IMPORTANT AS WELL, OF COURSE, YEAH.

Patient: Yeah, definite I'd be lop-sided, you know, a bit ... [chuckles]

INT: SO, WHEN YOU FIRST HEARD ABOUT YOUR DIAGNOSIS AND YOUR TREATMENT, DID YOU HAVE ANY IMMEDIATE THOUGHTS ABOUT WHAT TREATMENT YOU WERE GONNA GO FOR?

Patient: No, no. Like I say, I was just mulling it over in my head, thinking 'We'll see what Thursday brings.' You know, that was it really, 'We'll see what Thursday brings and then I'll make my decision.' And then I still couldn't make after Thursday. And as I say I think it was the Tuesday morning when I said to Mr Sibbering, you know, 'We'll plump for the lumpectomy,' and that's it.

INT: AND WHEN YOU CAME OUT AFTER SPEAKING TO MR HOLLIDAY, YOU'LL HAVE THEN, WELL JOHN'LL HAVE BEEN THERE, BECAUSE HE'LL HAVE PARKED THE CAR BY THEN, YEAH?

Patient: Yeah.

INT: AND THEN DID YOU GO AND SEE THE BREAST CARE NURS, YEAH?

Patient: Yeah, that was when we went down.

INT: CAN YOU TELL ME A LITTLE BIT ABOUT WHAT HAPPENED AT THAT POINT?

Patient: Well, I can't remember how I saw her, because I only saw her the once and then I had, the one who I've had ever since, who actually, I know the family, so I don't if that's because she came to me or what, but, erm, and she was very ... I can't remember what her name was, the first one, but she was very good, you know, talked things over with me, what it entailed. And it was her that actually, that showed us the prosthesis and what-have-you, you know, but we'd seen them before because of John's sister, like, you know. But no, they were, she was very good, you know, and she said, like, you know, like he said, you make the decision, and she said, when I said, I said to her, like, you know, this not being in control thing, and so she says, 'Well, once you've made your decision you are in control and you'll feel better.' Well I can't say I really did but, erm, you know ... that was ... but like I say, people that I've come across that have had breast cancer, it's always been positive. So, that, it wasn't really a downer, you know, in that respect. So, just positive thoughts about it, you know, 'Let's get it over and done with and get it out and ... doings,' you know, if I'd have known the faffing this radiotherapy was, I might have had a mastectomy ... [chuckles]. Well I've got spondylitis you see in my neck and I couldn't get my head down ...

INT: OH, OK.

Patient: ... far enough on that ... so I had two sessions of setting me up because the first one I couldn't get my head down so they couldn't, so they had, the technician had to make me a special pillow, so, you know. Then I went for my first treatment on Tuesday night, and they couldn't find my pillow.

INT: OH NO.

Patient: So I had to, so I was there two hours, mm, on Tuesday night, the first night, like, they were running late anyway and they'd had quite a few new patients which takes longer to set up, you know, and then they lost my pillow. Then she come through and she says, 'We've found it,' she says, 'We prayed to St Anthony.' I says, 'Well I always knew I was a bloody lost cause, anyway so ... She says, 'We found it after ...

INT: IS YOUR RADIOTHERAPY EVERY TIME THE SAME DAY, IS IT?

Patient: Sorry?

INT: IS IT EVERY TIME, IS IT THE SAME TIME EVERY DAY, SORRY?

Patient: Yes, yes. Half past six at night which is great because the traffic's died down and the parking's easier.

INT: AH RIGHT, YEAH, THAT' A BIT OF A BONUS REALLY, ISN'T IT?

Patient: I have changed one appointment, Bank Holiday weekend because we've got a caravan and, well, I can't go, can I? Every, you know, so, erm, I've changed one of my appointments to, on the Friday, to early in the morning so then we can get away Friday afternoon, then it's Bank Holiday weekend and I won't have to come back 'til Tuesday morning [chuckles]. So I thought, and by the next Bank Holiday I will have finished my treatment, so ...

INT: THAT'S GOOD.

Patient: That's that, you know. But it is a bit of a faff, but hey-ho, got to be done.

INT: AND AFTER YOU, DID SHE GIVE YOU AN INFORMATION PACK?

Patient: Yes.

INT: YEAH? AND DID SHE TALK IT THROUGH WITH YOU ABOUT WHAT IT WAS ABOUT AND EVERYTHING?

Patient: Yes, yes. As I say, they were very good, the breast care nurses, they were brilliant.

INT: DID YOU READ THE INFORMATION?

Patient: Yes, yes.

INT: YEAH? AND DID YOU FIND ANY OF IT USEFUL?

Patient: Erm, well, well it's more or less common-sense, a lot of it, isn't it? You know? And as I say the breast care nurses were brilliant, they talked it over with you anyway, so most of the stuff you did know. But I mean, they were very, they were very good really.

INT: MM. AND SO AFTER YOU SAW THE BREAST CARE NURSES OBVIOUSLY YOU COME AND STUFF, WHEN YOU WERE, REGARDING YOUR TREATMENT OPTIONS, DID YOU DISCUSS THOSE WITH YOUR FAMILY AT ALL?

Patient: Yeah.

[Interruption]

INT: YEAH, SO DID YOU DISCUSS WHAT YOUR TREATMENT OPTIONS WERE GONNA BE?

[Interruption]

Patient: Yeah, we did, we did, erm, you know, with my daughter and my son, and their partners, you know, we was all pretty much involved in it, and, er, she's not a niece but she is by marriage, my sister's niece, she'd had the same thing three years ago. And, you know, my niece had told her and so she rang me and, you know, 'Oh just have the lumpectomy, you know, you'll be fine, you know,' and just, everybody, you know, even the extended family were very, very supportive and ...

INT: YEAH. SO DURING THOSE CONVERSATIONS DID YOU FEEL THAT YOU WERE COMING TO A DECISION SOMEWHERE ALONG THE LINE?

Patient: I suppose I did really, yeah. And as I say, once I'd been diagnosed with the womb cancer as well, and that was major surgery, you know, a hysterectomy, [???] everything, you know, a complete one, [???] I think were going. And I was thinking, well, it's bad enough having one big, if they, you know, and having two, and if a small one will suffice ...

INT: YEAH, OF COURSE.

Patient: ... you know, we'll go for that.

INT: DID THE BREAST CARE NURSE USE ANY PICTURES OR DIAGRAMS OR ANYTHING WHEN THEY WERE TALKING TO YOU ABOUT YOUR TREATMENT OPTIONS, DID THEY [???]

Patient: No, I don't think so, no, no. They just ...

INT: I KNOW THEY SHOWED YOU THE PROSTHESIS.

Patient: Yeah, and that's about, yeah, and that was it really, yeah.

INT: AND BETWEEN YOUR, THE FIRST TIME YOU SAW THE BREAST CARE NURSE TO WHEN YOU HAD YOUR OPERATION, DID YOU HAVE ANY FURTHER CONTACT WITH THE BREAST CARE NURSES?

Patient: Yeah, because I was diagnosed, I was diagnosed on the Tuesday and I saw the breast care nurse then, erm, and then on the Monday when I went for my pre-op, which was only less than a week,

wasn't it, well it was just seven days, and I had a meeting with Mr Sibbering and Mr Simons up in the breast care unit and the breast care nurse came in then. Then she couldn't find after I'd my op, 'cos she [chuckles] because she didn't know where I ... because after they'd moved me out of set-down they didn't me back in ward 7, they took me up to gynae ward ...

INT: RIGHT, MM.

Patient: you know, 'cos, like they said, with my breast off I would have been probably discharged on the Thursday or the Friday, where I had to stay in longer because of the gynae, so they moved me onto a gynae ward, so Veronica couldn't find me, could she?

INT: MUSICAL PATIENTS, EH?

Patient: Mm?

INT: MUSICAL PATIENTS.

Patient: Yeah it was. But then I did, on the day I was coming out, erm, on the Monday when I was discharged, I had to have another ECG before they let me go, and one of the fellows doing the ECG said, 'I've had a message, I've got a message from one of the breast care nurses, she'll come and see you,' you know, and this was it. And then when I went after, the week after my op, I came out of hospital on the Monday and I went to the clinic on the Thursday to see the results of test and things, and the breast care nurse was there then, and she's been here twice since.

INT: OH SHE'S DOING HOME VISITS? OH RIGHT, THAT'S NICE.

Patient: Mm, yeah. And she's coming again, I think it's Monday.

INT: YEAH, IS THAT VERONICA, IS IT?

Patient: Mm.

INT: YEAH, VERONICA'S NICE.

Patient: Yeah.

INT: WELL THEY ALL ARE ACTUALLY.

Patient: Well her uncle is my daughter's godfather. So, you know, I know the family, I know them [???] I don't know Veronica that well but I do know, you know, because of my ... I mean I know her, but I know the family as well, you know. So, er, yeah.

INT: AND THINKING BACK TO WHEN YOU HAD YOUR CONSULTATION WITH MR HOLLIDAY AND TALKING TO THE BREAST CARE NURSE AS WELL, WHO DO YOU THINK ASKED MOST OF THE QUESTIONS AND WHO DO YOU THINK DID MOST OF THE TALKING?

Patient: [chuckles] Me.

INT: MOST OF THE TALKING ... YOU?

Patient: Mm.

INT: ALL RIGHT, OK.

Patient: Well I think you can gather, can't you [chuckles].

INT: YEAH BUT [???

Patient: Oh, no, what's her name of this first breast care nurse I saw that day, er ...

INT: KAREN, JILL ...

Patient: Tall, auburn-haired one.

INT: ER, JILL.

Patient: Jill.

INT: YEAH.

Patient: It was a funny name like a ...

INT: M-, OR SOMETHING.

Patient: That's it, yah, that's who I saw, yeah, she was very nice, yeah. And I saw her, did I see her ... I saw her when I went for my appointment with Mr Sibbering after, you know, the clinic after the surgery. And then I saw Veronica when I went to see Dr [???] at the Infirmary for the radiotherapy. And they were, they were good. I mean I wouldn't, I've got to say I can't fault the nurses, you know, the clinical breast care nurses, they were brilliant. They were much better than the gynae ones. I never saw a gynae nurse - there is two - but I didn't see one. I had a phone call saying that she's made an appointment for me to see this oncologist at the Infirmary after, that was after I'd seen Mr Simons on the Thursday, it was the Friday she rang said that she'd made an appointment for me at the Infirmary and that, and 'I'll give you a ring when you've been to see her ...' never had another phone call. So, you know, not very ...

INT: THE HOME VIITS THAT VERONICA DID, WERE THEY AFTER THE OPERATION, WERE THEY ALL ...?

Patient: Yeah, yeah.

INT: OK. WHEN YOU WERE TALKING WITH MR HOLLIDAY, DID YOU FEEL THAT MR HOLLIDAY WAS LISTENING TO YOU? DID YOU FEEL HE UNDERSTOOD YOUR NEEDS AND CONCERNS AT ALL?

Patient: No.

INT: NO?

Patient: No.

INT: OK. AND DID THE DOCTOR, DID MR HOLLIDAY, DID YOU GET THE IMPRESSION HE HAD A PARTICULAR TREATMENT IN MIND OR NOT?

Patient: Er ... no, no, I didn't, no, it was just, er, 'You got it and you've got this or this, we'll see you next Tuesday.'

INT: RIGHT, OK.

Patient: That, you know.

INT: AND WHEN YOU WERE TALKING TO THE BREAST CARE NURSES, DO YOU FEEL THAT THEY LISTENED TO YOU AND UNDERSTOOD YOUR NEEDS AND CONCERNS?

Patient: Yeah.

INT: AND DID ANY OF THOSE SEEM TO THINK THEY HAD A PARTICULAR TREATMENT IN MIND?

Patient: No, because, as I say, it was Jill obviously who I saw first, and she, that first time, and it was her that said once you've made your decision you'll be back in control, you know, she says, 'If Mr Holliday's said that about, you know, the decision being mine, well, you know,' she said, 'not being flippant or anything, but you're fortunate. But have, you now, ...' I said, 'Well I appreciate that ...' it was just the way that he ...

INT: MM, IT WAS THE WAY IT JUST CAME OUT, YEAH.

Patient: ... he came out with it, like, you know. So, that was it really.

INT: AND SO, DID YOU, FROM WHEN YOU FIRST HEARD ABOUT YOUR DIAGNOSIS TO WHEN YOU MADE YOUR DECISION, HOW LONG WAS THAT? DID YOU MAKE, DID YOU FINALLY YOU'RE YOUR DECISION ...

Patient: It was over a week. It was a week on the Tuesday, I'm sure it was the Tuesday morning ...

INT: YEAH, WHEN YOU ACTUALLY FINALLY SETTLED ON IT?

Patient: Said, that's it, yeah. It'd, over the weekend obviously it had been mulling over in my mind, and then, as I say, I went for the pre-op on the Monday, had all my tests, and then went up there to see them, and this consultation, because it was all a bit rushed on the gynae side, like, you know. Er, and it was, even then I still hadn't, and then I sat here on the Monday night, and I thought, 'Yeah, that's, it's the least invasive, I think that's what I'm gonna have.' You know, everybody was quite positive about it, that it was only a small one and it had been caught early and all this sort of, you know, er, and so that was it, on the Thursday morning ... Tuesday morning of the surgery I saw Mr Sibbering and I said, you know, 'That's it, this is what we'll do,' and he said, 'Well, that fair enough,' you know.

INT: AND I KNOW THE BREAST CARE NURSES GAVE YOU SOME INFORMATION, DID YOU GET ANY INFORMATION OFF ANYBODY ELSE, DID ANY FRIENDS OR NEIGHBOURS GIVE YOU MAGAZINES, BOOKS ...

Patient: No.

INT: DID YOUR GP GIVE YOU ANYTHING?

Patient: No, [chuckles] I haven't seen my GP actually. I've spoken to her on the phone but I haven't seen her since I went to see her the first Monday after the new years when I was, started having problems, like. She did ring me up last week because Mr Simons had been in touch with her over the heart, like, you know, 'Have you got your appointment for the cardiologist?' 'Yeah,' you know. So '[???' everything all right, if you want me you know where I am,' sort of thing, like, you know. Mm, very good GP.

INT: AND THINKING ABOUT YOUR DECISION THAT YOU MADE TO HAVE A WIDE LOCAL EXCISION, THE LUMPECTOMY, WHAT DO YOU THINK WAS THE MOST IMPORTANT THING THAT YOU WERE TOLD OR THAT YOU HEARD OR THAT YOU READ THAT HELPED YOU COME TO THAT DECISION?

Patient: Less invasive I think.

INT: WAS THAT SOMETHING YOU HEARD OR JUST SOMETHING YOU [???

Patient: No, what I ...

INT: WHAT YOU PERCEIVED YOURSELF, YEAH.

Patient: ... I realised, yeah, yeah, you know, I thought well, remembering how my sister in law scar - I suppose it's moved on since then, but it sticks in your mind, doesn't it, and my sister in law's was, you know, from the sternum right round under her, you know, because they took all the lymph nodes away as well, like, you know. And her scar was pretty horrendous. I mean mind, it's ...

INT: THAT WAS 20 YEARS AGO WHEN SHE HAD HERS?

Patient: About 20 years ...

INT: IT WAS VERY RADICAL IN THEM DAYS.

Patient: Yeah, I mean now, I mean, I think he went to the Royal Academy of Embroidery, you know, it's brilliant stitching [chuckles] it really is, you know. I said to him, you know, '[???' where I didn't expect him to do nice neat stitches for how he is, would you? But, yeah, he was ... and I think that, probably that had stuck in my mind as well, you know. So, I thought well, but I did have the lymph nodes out as well as the lump, so, and they were clear.

INT: OH, OK. THEY WERE CLEAR WERE THEY? RIGHT OK.

Patient: Yeah.

INT: THAT'S GOOD THEN. ERM, RIGHT, LET'S SEE WHERE WE ARE WITH THIS. I THINK WE'RE ON THE LAST COUPLE OF QUESTIONS NOW. LOKING BACK FROM WHEN YOU WERE FIRST DIAGNOSED UNTIL NOW, WHAT DO YOU FEEL ABOUT THE CARE YOU'VE RECEIVED FROM THE BREAST SIDE OF THINGS?

Patient: Brilliant.

INT: YEAH?

Patient: Brilliant, yeah.

INT: DO YOU THINK IT'S MET YOUR EXPECTATIONS?

Patient: Yeah. Yes, I can't fault them really. I don't knew, phew, and this might sound silly, but at the City at the time it was boom, boom, boom, boom, in you're in there, you know not just for the breast cancer, for the gynae as well, you know, everybody was like, 'We've got to get it done, and we'll do it now and we'll ...' you know, and then you come out of hospital and you go and see them in the clinics, and then, 'Oh, we're sending you to the Infirmary.' And I, I have got to say I felt a little bit abandoned.

INT: RIGHT.

Patient: Erm ... OK, Veronica was there at the Infirmary when I went, but even so, I don't know what it was, it was, erm ... er ... you was important 'cos all this was happening, you know, and then all of a sudden, well, ...

INT: IT'S DONE.

Patient: ... 'Go and sit in that chair and wait in the queue.' Er ...

INT: HAVE YOU MENTIONED THIS TO VERONICA OR ANYONE, YEAH?

Patient: Yes, yeah, I did, yeah, we did talk it over. And erm, moreso with the gynae side of it because I've been to see that doctor twice and twice she's been, I mean how in a two-hour clinic you can get 50 minutes behind is beyond me. And then, you know, you 're the last appointment at half past 10, and she's 50 minutes behind, and then at five to 11 she sods off and the nurse come and said, 'She's been called away.' Well, I blue a fuse, I really blue. And there wasn't just me waiting, there was the appointment before me waiting as well. I said, 'Don't bloody lie to me.' So she says, 'Pardon?' I says, 'You heard me. I says she's gone to a meeting. If she'd have been on time and seen me at half past 10 like she should have done, she'd have finished for 11 to go to her meting, but she spent too much time doing this ...' - because she is a '...with you lot probably,' this was to the two nurses. I says, 'She's late,' I says, 'And so we've got to, now got to wait for the registrar to come.' And she didn't know what I, the two things I wanted to know, she had to send a nurse off looking for the results of these tests I'd had. And I did blow. I said, 'If I ask for information and somebody lies to me, well it's my fault for being bloody nosy. If I don't ask for information and it's volunteered to me and it's a lie, then I get angry,' you know, I says, 'And you made me angry.' You know.

INT: IS THIS THE GYNAE?

Patient: Yeah.

INT: THE GYNAE [???] YEAH?

Patient: Yeah. I said, and they don't see you in a consulting room, you're like, you're ushered into a treatment room 20 minutes before you see the doctor and then you're sitting on the chair, John and I, you know, sitting there, and they come in, the nurse and doctor, and perch on the bed, you know, on the examination bed, and ... I don't like that. I think if you're consulted you should be consulted properly, you know. And I've said this to them. 'Oh well we don't do it like that here.' I says, 'It's strange, everywhere else does.' I mean even Mr [???], Dr [???], it's a consulting room, treatment room, but it's got a curtain across and he's got his desk up this end, you know, he's, you get dressed and come back and sit at, you know. And at the City, I mean, it was like that all the way through, both for the breast and for the gynae, you know. I said, 'I just don't like it.' But anyway I've been transferred to the City, so ...[chuckles]

INT: THINKING ABOUT THE BREAST SERVICE AT THE CITY ...

Patient: [???]

INT: YEAH. IF YOU WERE TOLD YOU HAD THE POWER AND MONEY TO CHANGE ONE THING ABOUT THE SERVICE AT THE BREAST UNIT THERE, WHAT WOULD IT BE?

Patient: Mm, put the ward nearer the theatre [chuckles].

INT: WHY IS THAT THEN?

Patient: Well ward 7 ...

INT: I MEAN I'VE NEVER BEEN TO THE WARDS ...

Patient: Haven't you?

INT: NO, NEVER THE WARDS.

Patient: Ward 7 is right at the top of the corridor and the operating theatre's right down the bottom so, you know, it's not very nice being ceremoniously wheeled down, is it? You know, in your gown.

INT: I'VE ONLY HAD ONE OPERATION IN MY ENTIRE LIFE.

Patient: Well this is what did me ...

INT: I WAS HIGH.

Patient: ... 'cos I have never had an operation, never had stitches. The only time I've spent in hospital was ... I had a miscarriage before I had my daughter and I was in one night which, and it was the old Women's Hospital which we no longer have, and when I had our Jane I was in two nights, and that's the only time I've been in hospital. Never had stitches, nothing. So it was quite a shock, you know, it was a, you know, it's quite foreign to me. Visited plenty of times but never been in inmate, like, you know. Didn't like, didn't like it, I didn't at all.

INT: ERM, NOW YOU'VE BEEN THROUGH THIS EXPERIENCE, WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS THAT SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT FIRST OF ALL THEIR DIAGNOSIS? WHEN THEY'RE BEING TOLD THEIR DIAGNOSIS, WHAT DO YOU THINK THE MOST IMPORTANT THING THEY NEED TO KNOW?

Patient: Well, what your, to be, no, that's a contradiction really, it is to know your options, but with more guidance.

INT: RIGHT, OK.

Patient: Definitely with more guidance.

INT: AS TO WHAT OPERATIONS YOU CAN HAVE AND ... YEAH.

Patient: Mm, yeah. And, you know, things explained to you, erm, well I can't say that I was kept in the dark, 'cos I wasn't, erm, it's just this ... more guidance, I think, you know. As I say, I'm not ... qualified to say these things and I should imagine 90, perhaps 98, 99 per cent of women are not. And to just be, well OK, Mr Sibbering was good and he said, 'You can tell me on the day of the op,' you know, er, but that's at the City. I mean in other hospitals it might be different.

INT: YEAH.

Patient: And, you're not, as I say, 98, 99 per cent of women are not qualified to make these decision.

INT: RIGHT, OK, MM.

Patient: But I think that's where you come unstuck, you know, myself, personally.

INT: NO, THAT'S FINE. I THINK THAT, FROM WHAT YOU SAID, YOU SAID THAT YOU CAME TO THE DECISION YOU FELT THAT THAT OPERATION WAS THE LEAST INVASIVE ...

Patient: Invasive, for me .. I'm not saying, if that's all I was having I might have plumped for the mastectomy.

INT: RIGHT, OK. AND YOU FEEL THAT YOU WERE KIND OF, APART FROM HAVING TO MAKE A CHOICE, DO YOU FEEL THAT YOU KIND OF LEFT TO WORK OUT THAT CHOICE YOURSELF ...

Patient: Yes.

INT: [???] DO YOU FEEL A BIT MORE INFORMATION MIGHT HAVE BEEN HELPFUL?

Patient: Well I'd got all the information, it was just my head that wouldn't work it out.

INT: RIGHT, OK. MM.

Patient: Really, you know. I mean I knew that something had got to be done, but what? You know. And what is best for me? Do I want that or do I want that, or ... shall I have that, shall have it? You know, it was mind, it was my brain that, I suppose, when it comes to the crunch wouldn't make a decision, you know. And weighing up the pros and cons and talking it over with John and the kids, you know, er, I

suppose that, and you can just keep going round and round in circles, can't you? I mean I did say on the Tuesday when it was diagnosed, erm, 'Right, if I have got cancer of the womb, I'll have a mastectomy, I'll have it all off, get rid of the lot,' you know. And then I'm thinking, you know, a hysterectomy's major surgery and it'll take longer to recover,' so I just ... and this is how I, you know. And 'No, I won't, I'll leave nothing there for it to come back to,' but [chuckles] you know, in the end, well that was what I did.

INT: I THINK YOU HAD SOME QUITE SERIOUS DECISIONS TO MAKE, REALLY, QHITE A LOT TO THINK ABOUT AS WELL. [???] YOU KNOW, TO HAVE BEEN DIAGNOSED WITH TWO SEPARATE CANCERS IN THE SAME WEEK IS ... IT'S PRETTY RARE I THINK [???]

Patient: Yeah, well I always was, you know, and then, oh, OK, I am, I mean it was, what, eight weeks ago Tuesday I went for surgery and I know I had complication and what-have-you, but in myself I feel pretty good. OK, I've got some aches and pains and, oh, now and again, you know, but then I think, well, nerve-endings knitting together and all this business, you know, erm ... but everybody, really, you know, everybody who I've said it to since, 'Oh God ...' you know. I mean on the Th-, that Thursday when I went to the clinic after I'd come out of hospital on the Tuesday, and I was walking miles round that City Hospital up this corridor, down that corridor, and down the old corridor and up the new corridor and ... I thought, 'God, if I haven't had a heart attack now, I will do.' And I had to go and see the physio and she said, 'Why didn't we see you before?' I said, 'Because it was all a bit rushed,' - this was the breast, you know. So she says, 'Well, erm, you're not the lady that had the hysterectomy the same day, are you?' I said, 'Yeah.' 'You've walked all the way up here?' I said, 'Yeah, I'm gonna walk up to Mr Sibbering's clinic in a minute,' which is the other end of the hospital, like, the last room on the whole corridor. So she says, 'You're doing marvellous, you're doing marvellous,' she said. And I had, I've had no restriction at all.

INT: IN YOUR ARM MOVEMENT.

Patient: No, you know. She says, 'Can you do this?' 'Yeah, I can do that?' 'Are you doing the exercises?' 'Yeah, I'm doing my exercise.' 'You're marvellous, you're marvellous,' she said, you know. And everybody, I mean [chuckles] when I was in the hospital, 'You look better today than you did yesterday,' they're saying this to me, you know. And the first day I got up, on the Friday afternoon after the last, 'cos I'd go drains coming this way and drains coming this way, so I couldn't get out of bed, could I? You know. And the first, when they took the drains out of the breast and I got up on the Friday morning, 'cos I'd only got things this side so I could do then, and all my drips had come off, she said, erm, well I went to the bathroom and I looked at myself in the mirror, and I thought, 'My God, what must I have looked like yesterday, if I look better today?' you know. Oh dear me! And I was black and blue.

INT: OH YOU WOULD BE, YEAH.

Patient: Well they couldn't, they couldn't get a vein, could they? And my hands were that swollen they had to cut my identity bracelet off.

INT: AH RIGHT.

Patient: It was digging in, you know, because I was, they tried to get, even in my feet. And my, I had the biggest bruise round here with the blood pressure cuff.

INT: OH RIGHT, YEAH.

Patient: That automatic one that comes on every quarter of an hour taking my blood pressure. In the end I ended up with it on my leg 'cos it was just, they were just bruising me.

INT: AHA, YEAH, VERY UNCOMFORTABLE.

Patient: Well, as I say I was black and blue. And like Mr Sibbering said, 'Well you're going to have more bruises on the breast because they was giving me Ifren [?] is it, Ifren, Efren, to thin your blood.

INT: OH, HEPARIN.

Patient: Heparin, oh something like that, because of the hysterectomy, he said they don't usually give it with breast operations so consequently, because I was having that I was more bruised.

INT: RIGHT, OF COURSE, YEAH.

Patient: So ... and as I say my feet were swollen and my hands were swollen. I was bruised all up everywhere, and they eventually found a vein here, so I had one sticking out with four little attachments on it so they could feed me whatever they'd got to give me all in these ... 'cos they couldn't, oh I was in a right state, I was. But, er, that was that. Anyway, we're digressing again. [chuckles]

INT: I'M ONTO THE ALST QUESITON. IS THERE ANYTHING ELSE YOU'D LIKE TO ADD BEFORE, AS TO WHAT WE'VE BEEN TALKING ABOUT TODAY? ANYTHING THAT WE'VE MISSED, ANYTHING YOU THINK'S IMPORTANT YOU'D LIKE TO PUT IN?

Patient: No, I don't think so.

INT: OK.

Patient: I don't think so. As I say just that, you know, erm, whether we were fortunate [?] at the City, I don't know, with breast care, er, you know, that's an exception, I don't know, but I can't fault them, they were brilliant. Well they all were really, it was just I suppose Mr Holliday's initial, 'cos in my head, when I went in to see him, it was still only gonna be a cyst or something, you know, and I ...

INT: SO IT CAME AS A LITTLE BIT OF A SHOCK TO YOU?

Patient: Yeah, yeah. Well I think it is to everybody, isn't it, really? Unless you've, I suppose with not feeling the lump and, or anything, as well, you know, not having ... feeling a lump or no, erm, symptoms. Well I didn't have any symptoms of any of it actually, you know, erm, until the weekend after Christmas, after New Year. I mean with my breast I had no symptoms whatsoever, and then all the while I was in there it, and even after I came out, I didn't have any pain at all, it was only like, it's only been this last couple of weeks it's started ... twingeing and peaky and phew, you know. But like I say I suppose it's all the nerves are starting to knit together and aggravating each other, aren't they? I'll be reight! I'll get myself right, one way or the other.

[End of interview]