

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)
*VENUE: Low MR unit
*DATE:
*ID: Patient51
INTERVIEWER: DJW

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

Patient: Nothing really.

INT: HAVE YOU HAD ANY FAMILY MEMBERS WITH BREAST CANCER BEFORE?

Patient: No, not at all.

INT: DO YOU KNOW ANY FRIENDS OR COLLEAGUES THAT HAVE GOT IT?

Patient: No, no, I don't know anybody. [chuckles]

INT: OOH, SO YOU REALLY DIDN'T HAVE ANY KIND OF EXPERIENCE AT ALL ABOUT IT?

Patient: No, no.

INT: ERM, SO CAN YOU TELL ME HOW EXACTLY YOU CAME ABOUT TO FIND YOU HAD BREAST CANCER?

Patient: Well I just found when I was in the shower.

INT: RIGHT, OK. SO DO YOU REGULARLY INSPECT YOURSELF?

Patient: IO don't particular to be honest, no I don't, but it's at the top part as well where it's bony so I noticed it.

INT: OH, OK.

Patient: And went to the doctor?

INT: THE GP?

Patient: Yeah.

INT: MM. AND WHAT HAPPENED WHEN YOU WENT TO SEE, IS IT HIM OR HER?

Patient: Sorry?

INT: IS IT HIM OR HER?

Patient: It's a him, yeah.

INT: YEAH, WHAT DID HE SAY?

Patient: He was very good, he tried to see if it was a cyst and tried to ...

INT: DRAIN IT.

Patient: ... drain it.

INT: YEAH.

Patient: And it didn't, but I found the lump two days before I was going on my holiday to America for three weeks.

INT: OH, RIGHT.

Patient: So he insisted that the government guidelines were a fortnight everybody should be seen, so he insisted I went on holiday and when I got home there'd be an appointment there for me. As it actually happened, I had an appointment five days later, after I'd left, which was quite good, and my daughter had to ring it up to say can you change it, so I did have one waiting for me when I went.

INT: OH, RIGHT, OK.

Patient: And, er, then I had all the, you know, all the treatment.

INT: MM. SO WHAT ACTUALLY HAPPENED AT, ON THAT TIME WHEN YOU WENT TO THE FIRST APPOINTMENT AT GLENFIELD?

Patient: Yeah, erm, I had a mammogram first; then an ultrasound; then I went to see the consultant, who then wanted me to do a cone [?] biopsy by ultrasound which means taking cells out; and then I had to wait round for the results and at the end of the day they told me I'd got cancer.

INT: ON THE SAME, THE SAME DAY?

Patient: In about four hours.

INT: ALL IN ABOUT FOUR HOURS, RIGHT, SO IT'S LIKE A PROPER ONE-STOP CLINIC IN THAT RESPECT?

Patient: Yeah, it was really, I was really impressed.

INT: YEAH, RIGHT. WHICH CONSULTANT DID YOU SEE THAT DAY?

Patient: Miss Stotter.

INT: ANNE STOTTER, YEAH. ERM, SO WHEN YOU FIRST FOUND THE LUMP AND YOU WENT TO THE, YOU KNOW, YOU OBVIOUSLY WENT TO GO AND SEE YOUR GP, I MEAN WHAT WENT THROUGH YOUR MIND AT THAT PARTICULAR POINT?

Patient: That it wasn't really a lump, [chuckles] I was imagining it.

INT: RIGHT, OK.

Patient: Yeah, erm, I don't know really, all sorts, all sorts.

INT: DID YOU THINK IT WAS, IT COULD BE CANCER?

Patient: Yeah.

INT: YEAH, YOU DID, RIGHT.

Patient: Well I'm sort of a bit of an unlucky person, [chuckles] and I thought if it's gonna happen it's gonna happen to me, I'm dead unlucky.

INT: RIGHT, OK. ERM, SO YOU WENT ALONG TO THE ACTUAL CLINIC AND, YOU KNOW, AND YOU GOT TOLD BY MISS STOTTER THAT YOU HAD CANCER, CAN YOU JUST EXPLAIN FROM WHEN YOU WENT BACK FROM YOUR TESTS TO WHEN YOU ACTUALLY SAW MISS STOTTER ...?

Patient: Actually, I didn't have Miss Stotter that day, it was another con-, you know, a stand-in, if you like, I just can't remember his name.

INT: OH, OK, A REGISTRAR?

Patient: Yeah ...

INT: CHAND, POSSIBLY OR SOMETHING LIKE THAT, CAN'T REMEMBER.

Patient: He was an Asian fellow.

INT: YEAH. SO HE, YOU SAW HIM FIRST, IS THAT RIGHT?

Patient: Yeah, yeah.

INT: AND DID YOU SEE HIM AFTER YOU'D HAD THE TESTS ...

Patient: Yeah.

INT: ... OR DID YOU SEE MISS STOTTER?

Patient: No, I don't see Miss ... did I, let me think, no I didn't see her at all that first time, no, Miss Stotter, I didn't see her at all the first time.

INT: SO AFTER YOU'D HAD THE TESTS WHEN YOU WENT BACK TO SEE THIS REGISTRAR, CAN YOU JUST TELL ME EXACTLY WHAT HAPPENED THEN, WHAT WAS SAID AND HOW THINGS WENT?

Patient: Erm, well he just tried to, he explained as much as he could, that he'd found a very tiny amount of cancerous cells. The breast care nurse was in there as well, so he told me best he could what would happen, you know, well he did say about having it removed etc, and then he went. And then the breast care nurse was talking to me and ...

INT: RIGHT, [???

Patient: ... explaining things, what would happen next.

INT: YEAH, MM.

Patient: So then I had to go back the following Thursday ...

INT: AND THAT'S WHEN YOU SAW MISS STOTTER?

Patient: ... and I saw Miss Stotter, but apparently, because these consultants have a consultation with each other, don't they, after [???], and she couldn't decide whether it was or it wasn't cancer.

INT: OH, RIGHT, OK.

Patient: So I had to have another cone biopsy.

INT: OH, RIGHT.

Patient: And so I went back the following week, I didn't get an answer that day.

INT: RIGHT, OK.

Patient: And she said it was cancer.

INT: RIGHT. SO WHEN YOU FIRST SAW THIS SpR, AND YOU WAS GIVING YOU YOUR DIAGNOSIS, DID THEY TALK ABOUT, DID THEY MENTION TREATMENT OPTIONS AT ALL?

Patient: Not in such great details that first time, no. I think they were wanting me to take it all in first, because I was going then the following week anyway so, but I can't really remember to be honest, I don't think he said an awful lot, I think they let you take it all in first.

INT: RIGHT, YEAH.

Patient: And the breast cancer nurse was there to answer any questions that I asked.

INT: SO WHEN YOU WERE, WHEN HE ACTUALLY SORT OF SAID TO YOU, YOU KNOW, THEY SAID, YOU'D GOT THESE CANCEROUS CELLS, THEY FOUND CANCER, WHAT WENT THROUGH YOUR MIND AT THAT POINT, THEN?

Patient: Erm, I was dumbstruck. [chuckles]

INT: MM. IT HITS YOU QUITE HARD, DOESN'T IT?

Patient; Yeah, yeah, I couldn't think at all. And I'd taken my friend with me, because they say that because you can't remember to ask questions and that, and she was in bits. [chuckles] So she wasn't use.

INT: AH, SO SHE WAS THERE AS WELL, WAS SHE THEN?

Patient: Yeah.

INT: THAT PARTICULAR CONSULTATION, YEAH.

Patient: Yeah, so I was actually better than she was. I was just completely numb, to be honest, yeah, completely numb.

INT: MM. AND THE BREAST CARE NURSE, DO YOU KNOW WHO IT WAS WHO YOU SAW?

Patient: Sue I think her name was.

INT: SUE [???] SHORTISH, DARK HAIR?

Patient: Yeah.

INT: YEAH? SHE'S NICE SUE.

Patient: Yeah, she is, yeah. They're all so lovely there, yeah, she tried to explain a lot of things because what happened, when I was in America and went to visit my friend and she'd got lots of nurse friends and one of them is a breast cancer nurse. So I told her I'd got this lump and she didn't really say a lot about it but both the nurses that I was talking emphatically said that if they had a breast lump and it was malignant they would have both their breasts off.

INT: MM, [???] BILATERAL MASTECTOMY, SOME PEOPLE [???]

Patient: Yeah. So I asked Sue that and she was horrified.

INT: YEAH, IT'S ...

Patient: Yeah, and as Miss Stotter said, 'Well, that's America for you,' so you know, but that confused me a lot.

INT: RIGHT, OK.

Patient: I'm thinking, 'Do they know something they're not telling me?' sort of thing.

INT: YEAH I THINK IT'S A VERY INDIVIDUAL THING ...

Patient: Yeah.

INT: SOME PEOPLE, YOU KNOW, THEY'RE SO FRIGHTENED BY IT I THINK THAT THEY THINK THAT IF THEY GET BOTH BREASTS REMOVED IT'S NOT GOING TO COME BACK ANYWAY.

Patient: Yeah, that's it, yeah, it's gone, yeah.

INT: ERM, AND OF COURSE, WELL I DON'T KNOW WHAT YOU'VE BEEN TOLD BUT IT'S STRICTLY TRUE, YOU KNOW, YOU CAN ALWAYS GET A RECURRENCE IN SOME WOMEN[?]

Patient: That's right, yeah.

INT: ERM, YOU KNOW, SO, BUT IT IS, IT'S JUST A FEAR OF THE WORD AND A FEAR OF WHAT'S GONNA HAPPEN AND STUFF, AND, ER, SO ... YEAH, SO YOU HAD A CHAT WITH SUE AND THEN OF COURSE YOU'LL COME BACK, AND IN BETWEEN THAT AND GOING BACK TO SEE MISS STOTTER THE FIRST TIME, I MEAN, HOW WERE YOU THEN?

Patient: What during the week?

INT: YEAH, I MEAN, LONG WEEK PROBABLY ...

Patient: Yeah, I think I was in total denial. [chuckles]

INT: YEAH, REALLY?

Patient: Yeah. I was more bothered of the reaction of my friends. I was more upset for them than for me.

INT: RIGHT. DID YOU SPEAK WITH YOUR FAMILY AND FRIENDS DURING THIS ...

Patient: I did, yeah, yeah.

INT: OK.

Patient: And I was more upset for them than me. But that's me. [chuckles]

INT: YEAH, OK.

Patient: Yeah, how I dealt with it, yeah.

INT: MM, RIGHT. AND, ERM, THEN YOU WENT BACK TO SEE MISS STOTTER AND SHE SAID THAT SHE WASN'T QUITE CONVINCED IT WAS, THE RESULT WAS RIGHT, AND WHAT WENT THROUGH YOUR MIND AT THAT POINT, YOU THOUGHT?

Patient: I don't know, they don't know what they're doing [chuckles]... a bit.

INT: OH RIGHT, YEAH, OK.

Patient: Well, she, what I didn't like was but I suppose they have to do is that, whether it was cancerous or not, the lump was going to be taken out. So to

me you wasted a week and their time having another cone biopsy, to be honest. That's how I felt. That if it was a lump anyway and it's coming out, you can find out later, at a later date whether it is or it isn't, that was irrelevant to me, I just wanted it out.

INT: YEAH, MM.

Patient: So, that was just my feeling on it really.

INT: DID MISS STOTTER TALK ABOUT TREATMENT OPTIONS OR ...?

Patient: Yes, I could have either a mastectomy or ...

INT: SHE MENTIONED IT AT THAT PARTICULAR INTERVIEW, DO YOU REMEMBER?

Patient: Yeah, yeah.

INT: OK.

Patient: Yeah, she did.

INT: WERE YOU AT ALL SURPRISED THAT YOU HAD A CHOICE OF SURGERIES?

Patient: Yes.

INT: YES?

Patient: And I found it a very hard decision.

INT: YEAH, A LOT OF PEOPLE DO, YEAH.

Patient: And, you know, I asked her, she says, 'Well if there wasn't a choice I wouldn't be asking you.'

INT: RIGHT, OK.

Patient: In other words I wanted her to make the decision I suppose.

INT: OK. SO HOW DID SHE ACTUALLY DESCRIBE THE OPERATIONS, DO YOU REMEMBER?

Patient: ... Not really [chuckles] no, not really.

INT: SO WHAT DID YOU UNDERSTAND ...

Patient: The breast care nurses did, they explained that they have drains in and ...

INT: RIGHT, OK.

Patient: ... and stuff like that, yeah.

INT: OK. AND I MEAN WHEN YOU, WHEN YOU FIRST HEARD ABOUT THE TYPE OF OPERATION, DID YOU HAVE ANY IMMEDIATE THOUGHTS ABOUT WHICH ONE YOU'D GO FOR?

Patient: No, just couldn't decide, couldn't decide at all.

INT: YEAH, OK. AND SO, AND THEN, YOU HAD TO WAIT ANOTHER WEEK FOR THE FINAL RESULTS SORT OF THING?

Patient: Yeah.

INT: YEAH. AND THEN YOU WENT BACK TO SEE MISS STOTTER THEN?

Patient: Yeah.

INT: SO CAN YOU TELL ME A BIT ABOUT WHAT HAPPENED AT THAT ...?

Patient: Well it was a similar sort of thing really, about, erm, which, I'd got to decide there and then whether I had a mastectomy or a lumpectomy.

INT: IS THAT WHAT, IS THAT WHAT SHE SAID, YOU HAD TO DECIDE THERE AND THEN?

Patient: Yeah.

INT: YEAH.

Patient: More or less, yeah. And, 'Are you doing anything next week because you've probably got to come in on Tuesday?' you know, on the Tuesday, so I decided on the lumpectomy and within minutes all the paperwork was there and I'm going on four days' time. [chuckles]

INT: RIGHT, OK.

Patient: Yeah. She explained that I was having, erm, a metal whatever put into the lump ...

INT: YEAH, THEY A NEEDLED MARKER SO THEY CAN ACTUALLY FIND IT.

Patient: Yeah.

INT: BECAUSE IT WASN'T A BIT CANCER, WAS IT?

Patient: I don't think so, no, about that big, I think, not really big.

INT: RIGHT, OK. ERM, AND THEN DID YOU SEE THE BREAST CARE NURSE AFTER THAT AS WELL?

Patient: Yes, yes, yes, she was always there.

INT: AND WAS IT THE SAME ONE, WAS IT?

Patient: No, it was a different one.

INT: OH, OK.

Patient: One, erm, when you go down they all talk to you, if you know what I mean, they were all so friendly, so ...

INT: I HAVE INTERVIEWED ALL THE STAFF THERE.

Patient: Have you?

INT: YEAH-YEAH, DONE ALL THE NURSES ON THERE.

Patient: They're absolutely wonderful, aren't they?

INT: THEY'RE A NICE BUNCH OF PEOPLE.

Patient: I think they are.

INT: THEY REALLY ARE, YEAH.

Patient: And like the one I did have remembered me from the week before, so, yeah, yeah, they were really nice.

INT: AND DID ANYONE GO WITH YOU TO THAT CONSULTATION, ANY FRIENDS OR FAMILY OR ...?

Patient: My daughter I think, yeah, my daughter went.

INT: MM, RIGHT. ERM, AND THEN THAT WAS ON THE THURSDAY?

Patient: Mm.

INT: AND THEN DID YOU GO FOR YOUR OPERATION THE FOLLOWING TUESDAY, DID YOU?

Patient: Yeah.

INT: SO IN BETWEEN THAT AND THE ACTUAL OPERATION, I MEAN, ...

Patient: Well the next day, on the Friday, I had to go for pre-assessment ...

INT: RIGHT, OK.

Patient: ... for the operation. So I did all that bit.

INT: AHA. AND DID YOU SEE ANY OF THE BREAST CARE NURSES THERE OR THE CONSULTANT?

Patient: Er, no, I don't think so, no.

INT: OK. AND THEN YOU WENT IN FOR THE OPERATION ON THE TUESDAY, SO JUST TELL ME ABOUT WHAT HAPPENED WHEN YOU WENT IN THEN.

Patient: Well I had to, have to ring first to make sure they've got a bed and I had to be there for eight o'clock in the morning, but I wasn't having my operation until half past one in the afternoon, but they'd got no room on the ward so I was taken to a different ward at the time. But they assured me after the operation that I could go back, go to the normal ward, which is what happened. So Miss Stotter came up to see me and the anaesthetist came up to see me, so ...

INT: AND WHAT DID YOU TALK ABOUT WITH MISS STOTTER?

Patient: Er, she just said, you know, well the thing is, as I say, I was in denial where I didn't want to know anything, she came up and said, 'Is there any questions?' and I said no. [chuckles.] So, but I thought it was nice that she'd actually come up to see me.

INT: YEAH, MM. AND THE BREAST CARE NURSES, WERE THEY THERE AT ALL?

Patient: Mm ... I don't think so, I don't think so, no.

INT: RIGHT. AND THEN YOU WENT DOWN FOR YOUR OPERATION AT ONE, ONE-THIRTY, DID YOU SAY?

Patient: Mm.

INT: HOW WERE YOU WHEN YOU CAME ROUND?

Patient: Fine.

INT: YEAH?

Patient: Yeah.

INT: NO SICKNESS OR ANYTHING?

Patient: No, no, I never am, I'm OK. I was high as a kite. [chuckles]

INT: OH, WELL THEN, ERM, AND THEN WHAT HAPPENED AFTER THAT? I MEAN YOU WERE IN HOSPITAL FOR A BIT, HOW ...?

Patient: In for a week, yeah.

INT: YOU WERE IN FOR A WEEK, WERE YOU?

Patient: Yeah, in ward [???] whatever, 94A is it? Something like that anyway. Erm, yeah, the nurses were wonderful. I had two drains in that are checked every day, you get your obs taken every so often, you know, they were all very attentive and good. They were lovely.

INT: OH RIGHT.

Patient: Yeah. And as I say I met a nice crowd of girls as well, so we had a laugh.

INT: OH, RIGHT, OK.

Patient: Yeah, you wouldn't think we were ill at all. [chuckles]

INT: YEAH. THEN OBVIOUSLY THEY'VE GIVEN YOU SOME INFORMATION AND THIS STUDY AS WELL, DID THEY, AT THAT TIME?

Patient: Well, no, the breast care nurse, I think it was Sue that came up with that the day after the operation and I don't even remember saying that I was gonna do it, but I took it anyway, so, you know ...

INT: RIGHT.

Patient: So it was just left at that. Yeah, she just asked if I'd got any questions or anything, but as I say I didn't want to know anything at the time, I don't know why. I don't ...

INT: NO, SOME PEOPLE DON'T, SOME PEOPLE DON'T WANT ANY INFORMATION AT ALL, IT'S JUST LIKE 'YOU'RE THE DOCTORS, DO IT.'

Patient: Yeah, yeah.

INT: AND EVERY, OTHER PEOPLE'LL ASK EVERY SINGLE DETAIL ...

Patient: That's right.

INT: EVEN SORT OF TO THE POINT WHERE YOU SAY, 'WELL, YOU KNOW, HOW QUALIFIED ARE YOU AS A SURGEON?'

Patient: Yeah, that's right, yeah. No, I just wanted them to do it and that was it. I think I learnt more from talking to the other patients.

INT: RIGHT, OK.

Patient: About different procedures, because I didn't ask those questions I actually met the people that were having different ...

INT: YEAH, ON THE WARD?

Patient: Yeah.

INT: YEAH. AND, ERM, AND THEN, AFTER YOU GOT, YOU CAME HOME, YEAH? AND THEN HAVE YOU BEEN BACK TO SEE MISS STOTTER?

Patient: Yeah, yeah.

INT: TO GET THE HISTOLOGY RESULTS, I THINK IT IS.

Patient: Yeah, yeah.

INT: AND JUST TELL ME ABOUT THAT CONSULTATION, WHAT HAPPENED THERE?

Patient: She was great because I actually, she'd been to see me on the ward prior to that, and I was told her it was called Glenfield Hotel, and she remembered that. She said, 'Did you enjoy your holiday?' and, erm, she just said it was, 'Well, ask me then,' she said, 'It's good news.' And she was really nice because there was no cancer cells in the lymph nodes.

INT: EXCELLENT, GOOD. AHA. AND WIDE LOCALE EXCISION YOU HAD, SO THEY'LL CHECK THE MARGIN AND THAT WAS ALL CLEAR.

Patient: Yeah, that's OK, yeah.

INT: THAT'S BRILLIANT, THAT'S BRILLIANT NEWS.

Patient: So the prognosis is good.

INT: SO WHAT HAPPENS NOW THEN?

Patient: Radiotherapy, which I actually went for my first appointment yesterday and that was just to get measured all up for it.

INT: RIGHT, AND WHEN DOES THAT START?

Patient: 15th for five weeks, every day apart from weekends.

INT: RIGHT, OK. YES, THEY DON'T DO IT WEEKENDS. AND THAT'S AT THE ROYAL PROBABLY?

Patient: Yeah.

INT: YEAH, OK. ERM, SO WE'VE KIND OF GOT A PICTURE NOW I THINK OF WHAT'S HAPPENED TO YOU, I'D LIKE TO JUST ASK A FEW MORE THINGS IN DETAIL, IF THAT'S IN RIGHT.

Patient: Yeah.

INT: NOW, MAKE SURE I GET ALL OF THIS RIGHT, IN THE RIGHT ORDER. ERM, WHEN YOU WERE, WHEN YOU WERE BEING, WHEN PEOPLE, ER, MISS STOTTER WAS DESCRIBING YOUR TREATMENT OPTIONS, YOU KNOW, THE TWO TYPES OF SURGERY YOU COULD HAVE AND YOUR DIAGNOSIS AND THINGS, HOW MUCH DID YOU FEEL YOU UNDERSTOOD ABOUT WHAT YOU WERE BEING TOLD?

Patient: Very good, I think, yeah.

INT: YEAH?

Patient: Very good, yeah.

INT: RIGHT, OK. WAS THERE ANYTHING YOU FOUND PARTICULARLY DIFFICULT TO UNDERSTAND?

Patient: No, not really, no.

INT: RIGHT, OK.

Patient: As I say, I think it could have been me as well, if you know what I mean, I wasn't really interested.

INT: NO, NO, OF COURSE, YEAH, THAT'S OK. ERM, AND DID YOU EVER GET THE IMPRESSION FROM EITHER THE REGISTRAR, MISS STOTTER OR ANY OF THE BREAST CARE NURSES THAT THEY PREFERRED ONE PARTICULAR OPERATION TO ANOTHER?

Patient: No, not at all.

INT: NOT AT ALL?

Patient: No.

INT: RIGHT, SO OK. AND AFTER YOU SAW THE BREAST CARE NURSE THE FIRST TIME, AND IT WAS SUE [???] DID YOU HAVE ANY FURTHER CONTACT WITH THEM AFTER THAT?

Patient: Yeah, when I've been back a few times to get the seroma drained, so I see them all. [chuckles]

INT: RIGHT, BUT IN BETWEEN THE ACTUAL DIAGNOSIS AND THE OPERATION, DID YOU HAVE ANY FURTHER CONTACT WITH THE BREAST CARE NURSES?

Patient: No.

INT: NO.

Patient: No.

INT: RIGHT, OK. YOU DIDN'T CALL THEM UP OR ANYTHING?

Patient: No, no, I didn't want to.

INT: [???]

Patient: They gave me a card and everything, you know, and all the information and everything but that was it.

INT: AND WHEN YOU CAME BACK WITH YOUR DIAGNOSIS, YOU KNOW, YOU'D OBVIOUSLY SPOKEN TO YOUR FAMILY AND FRIENDS ABOUT, I MEAN WHAT WERE THEIR REACTIONS AND WHAT DID YOU SAY TO THEM AND ...?

Patient: Shock. [chuckles] Yeah, my daughter was in bits. So, yeah, and as I say I concentrated more on them than me.

INT: MM, RIGHT.

Patient: And, erm, because I'm quite, I'm on anti-depressants anyway so I'm a depressive person, but something big like this doesn't bother me at all. It went completely ... over my head. [chuckles]

INT: YEAH. AND IT'S, I MEAN FROM FINDING IT, I MEAN, IGNORING YOUR SORT OF [???] FROM FINDING YOUR LUMP TO GETTING THE OPERATION WAS PROBABLY ABOUT FOUR WEEKS IN TOTAL, IF YOU TAKE THE THREE OUT FOR THE HOLIDAYS?

Patient: Yeah.

INT: SO THAT'S, WELL THAT'S FAIRLY ...

Patient: It's fantastic, yeah.

INT: IT'S FAIRLY QUICK [???]

Patient: I think it's brilliant, yeah.

INT: ERM, WHEN YOU WERE TALKING, CONSULTING WITH MISS STOTTER, WHO DO YOU THINK ACTUALLY ASKED MOST OF THE QUESTIONS AND WHO DO YOU THINK DID MOST OF THE TALKING AND EXPLAINING?

Patient: Erm, I think the breast care nurse spoke more of, but I think, this is again, I think it was me, you know, Miss Stotter was there to be asked any question you wanted, I just didn't. So you just, and obviously she's busy so she sees you for as long as you want her to and then she's off to the next ones. But then the breast care nurse is left with you to, you know, you talk more to them I suppose.

INT: RIGHT, OK. AND WHEN YOU WERE SPEAKING WITH MISS STOTTER, HOW DID YOU GET ON WITH MISS STOTTER?

Patient: All right. Why are you gonna ask me that? It's just every time I mention her name the nurses or the porters [???] and all the anaesthetist said was, 'Let's put it this way, she's lovely to the patients.'

INT: [CHUCKLES]

Patient: So from I came out she's a bit of a stickler.

INT: SHE IS, SHE'S ...

Patient: Yeah.

INT: SHE'S A PERSON, SHE'S VERY ECONOMICAL WITH HER WORDS, SHE DOESN'T, I DON'T THINK SHE SUFFERS FOOLS GLADLY, PUT IT THAT WAY, ERM, AND ...

Patient: Yeah, that's how I got [???] ...

INT: SHE IS VERY, VERY DIRECT, VERY, VERY STRAIGHTFORWARD. ERM, I THINK AS A MANAGER YOU WOULD CERTAINLY KNOW EXACTLY WHERE YOU STAND WITH HER.

Patient: Yeah, yeah.

INT: BUT I MEAN I'VE INTERVIEWED HER AND I MEAN WHEN IT COMES TO PATIENTS AND STUFF LIKE THAT SHE'S A VERY LOVELY LADY, VERY, VERY CARING.

Patient: Well, yeah, because as I say I found, it was just, everybody seemed, expression was the same as yours. 'Ooh ...' you know.

INT: NO, WE JUST WANT TO KNOW HOW YOU GET ON WITH, BECAUSE IT'S PERSONALITIES, YOU SEE, IT'S ALL ABOUT PERSONALITIES, A LOT OF IT, AND SOMETIMES YOU DO GET PEOPLE WHO, THEY JUST DO NOT GET ON WITH THE CONSULTANT AT ALL ...

Patient: No, that's right.

INT: [???

Patient: I mean I wouldn't say, yeah, as you say, she seems a person to me that knows her job very well and does her job very well and, but if you want to talk to her on a different level I think she will, because as I say I was interested that she' remembered I'd called it Glenfield Hotel, you see, so ...

INT: YEAH, EXACTLY.

Patient: Because I didn't get what she meant for a start, and I thought, 'I don't remember ask-, telling you,' but then I do, you see, so.

INT: AND WHEN YOU WERE, YOU KNOW, TALKING WITH MISS STOTTER, DID YOU FEEL THAT SHE LISTENED TO YOU, THAT SHE UNDERSTOOD YOUR NEEDS, YOUR CONCERNS?

Patient: Yeah.

INT: YEAH?

Patient: Yeah.

INT: AND WHEN YOU WERE TALKING WITH THE BREAST CARE NURSES, DID YOU FEEL THAT THEY WERE LISTENING TO YOU AND UNDERSTANDING ... WHAT YOU HAD, YOUR NEEDS AND THINGS.

Patient: Oh yeah, definitely, yeah. Yeah, they were lovely.

INT: THAT'S GOOD.

Patient: Yeah, definitely.

INT: DID THE BREAST TEAM GIVE YOU ANY SUPPORT INFORMATION, ANY WRITTEN INFORMATION?

Patient: Yeah, you know, they gave me all the leaflets and everything.

INT: AND DID YOU READ THOSE?

Patient: I did, yeah.

INT: YEAH, AND DID YOU FIND THAT USEFUL OR HELPFUL IN ANY WAY?

Patient: Yeah, yeah, it was a bit more insight into it, yeah.

INT: OK. CAN YOU REMEMBER AT ALL WHAT YOU THOUGHT WAS PARTICULARLY USEFUL ABOUT IT, ANY PARTICULAR INFORMATION YOU THOUGHT STOOD OUT?

Patient: No, not really, apart from it was telling you about the drains and seroma that you expect to keep going back afterwards, so that helped, so it didn't come as a shock.

INT: YEAH, YEAH.

Patient: When it happened.

INT: THAT'S GOOD. ERM, LET ME JUST SEE WHERE WE ARE. MAKE SURE THAT I'VE GOT EVERYTHING DOWN HERE ... WHEN THE, EITHER THE REGISTRAR, THE ASSISTANT, THAT YOU FIRST SAW, OR MISS STOTTER, WHEN THEY WERE DESCRIBING TREATMENT OPTIONS DID THEY USE ANY VISUAL AIDS LIKE, ER, DID THEY PUT YOUR MAMMOGRAMS UP, DID THEY DRAW ANY DIAGRAMS, DID THEY USE ANY KIND OF PICTURES OR ANYTHING LIKE THAT?

Patient: Erm ... I think Miss Stotter did at some point.

INT: RIGHT, OK. CAN YOU JUST DESCRIBE THAT, CAN YOU REMEMBER THAT?

Patient: No, not really. She just had, erm, like a graph drawing.

INT: OH RIGHT, OK.

Patient: She did have all my mammograms on the desk and I think if I would have asked more questions I think she would have done it.

INT: RIGHT, OK.

Patient: I just don't think I were interested.

INT: DO YOU REMEMBER AT ALL WHAT THE GRAPH WAS ABOUT WHEN SHE WAS DESCRIBING IT?

Patient: No. [chuckles] No, not really.

INT: THAT'S ALL RIGHT, DON'T WORRY. ERM, I THINK WE'VE DONE ALL OF THOSE. [???] ... WHEN YOU ACTUALLY FIRST HEARD ABOUT YOUR DIAGNOSIS, ONCE IT HAD BEEN CONFIRMED, HOW LONG WOULD YOU THINK DID IT TAKE YOU TO MAKE UP YOUR MIND WHAT SURGERY YOU WERE GOING TO HAVE? HOW LONG DO YOU THINK THAT TIME ...

Patient: Not till the day I was sat there with her, because I really couldn't decide.

INT: RIGHT, OK. YOU SAID YOU HAD A REAL, A REAL STRUGGLE WITH IT, THAT'S RIGHT.

Patient: Yeah, because, I don't know really, she just, when I asked her advice as such, saying, like, 'What would you do?' she said, 'Well I wouldn't have given you choice if there wasn't one,' but I suppose what I wanted to know was ... was the outcome going to be any different and actually I think I did ask her that.

INT: RIGHT, OK.

Patient: And at the end of the day it doesn't matter apparently, but I do, I've found out since that if I had got cancer in my lymph nodes then I have, obviously having the whole breast off is better.

INT: YEAH, [???] CERTAINLY [???]

Patient: So I didn't really know that, I don't suppose.

INT: YEAH.

Patient: Really, I didn't, you have, after thought, I really didn't know. I really didn't want a choice, I don't think.

INT: NO, NO. I THINK, BECAUSE I'VE SPOKE TO A LOT OF PATIENTS IN DIFFERENT AREAS SAID EXACTLY THE SAME THING, THEY WERE ALL RIGHT WHEN THEY HEARD THE FIRST

OPTION BUT WHEN YOU'RE TOLD THE SECOND ONE, IT'S YOUR CHOICE, WHY DID YOU NOT LIKE THE CHOICE, CAN YOU TELL ME WHY YOU DIDN'T ACTUALLY LIKE THE CHOICE?

Patient: Erm, well because of the outcome, I suppose, you're thinking, if you're only taking a lump out, what are my chances of getting it again, whereas if the breast has gone you're not going to have breast cancer in that breast again, are you, so ... I think that's why I didn't want the choice. [chuckles]

INT: RIGHT, THAT'S OK. AND ONCE YOU'D MADE, YOU MADE UP YOUR MIND, AT THE SECOND CONSULTATION WITH MISS STOTTER WHEN YOU SAID YOU'D TO MAKE YOUR MIND UP TODAY, ERM, DID YOU CHANGE YOUR MIND AT ALL?

Patient: No.

INT: DID YOU HAVE ANY SECOND THOUGHTS ABOUT IT ...?

Patient: I still didn't know what I was doing, no, basically, but, no, I didn't have any after thoughts at all.

INT: RIGHT, OK.

Patient: And then talking with the girls in the hospital at the time there were a lot of them didn't have the choice, and I'm not quite sure about that either, of why they didn't have a choice.

INT: ERM, PROBABLY BECAUSE, I DON'T KNOW, I MIGHT BE WRONG, BUT I KNOW FOR CLINICAL REASONS, IF IT'S A VERY LARGE TUMOUR IN A SMALL BREAST OR A LARGE TUMOUR JUST GENERALLY, THEN THEY MIGHT NOT, THEY MIGHT NOT BE SUITABLE FOR A WIDE LOCAL EXCISION. THEY MIGHT BE, PROBABLY BECAUSE THEY'D HAVE TO REMOVE SO MUCH OF THE BREAST ...

Patient: Yeah, there's not much left, yeah.

INT: ... TISSUE THERE'D BE NOTHING LEFT, OR, YOU KNOW, JUST TO BE COMPLETELY SAFE THEY'LL TAKE IT OFF ANYWAY. THAT'LL BE THE GUIDELINES, THOUGH, THE CLINICAL GUIDELINES ANYWAY.

Patient; Yeah, that's right, yeah.

INT: ERM, WHERE ARE WE? ERM, IN BETWEEN HEARING YOUR DIAGNOSIS AND YOUR ACTUAL SURGERY, DID YOU AT ALL LOOK FOR ANY FURTHER INFORMATION? DID YOU LOOK ON THE INTERNET, DID YOU LOOK AT MAGAZINES, BOOKS OR ANYTHING?

Patient: I did, yeah, I looked on the internet.

INT: CAN YOU JUST TELL ME A LITTLE BIT ABOUT THAT, YOU KNOW, WHERE DID YOU LOOK AND ...?

Patient: Well on the internet mainly, but it, there's so much of it as well, and also I've got some paperwork that the lady in America gave me before I came over, and what it was it was from her nursing magazine ...

INT: OH, RIGHT.

Patient; ... and that actually was quite good because it shows you pictures of what they do and the different stages, you know, if your lump's only so size, and stuff like that basically. So, yeah, from the internet and, well I think my daughter did it mostly. [chuckles] I told you, I just didn't want to know.

INT: YEAH, HOW HAS SHE BEEN THROUGH ALL THIS?

Patient: She's OK now, yeah, 'Oh yeah, I'm better now,' she says. You know what kids are like.

INT: YEAH. AND YOUR FRIENDS, NEIGHBOURS, RELATIVES ...

Patient: Oh absolutely brilliant.

INT: YEAH, I MEAN HOW WERE THEY? DID THEY GIVE YOU ANY INFORMATION OR ...?

Patient: NO, not really, no.

INT: RIGHT, OK.

Patient: But they were absolutely brilliant.

INT: AND DID YOU EVER GO BACK TO YOUR GP OR ...?

Patient: I've been there this morning, actually.

INT: OH, RIGHT, OK. BUT NOT IN BETWEEN THE ...?

Patient: No.

INT: ... NOT IN BETWEEN THE DIAGNOSIS AND SURGERY. ERM, WHAT WAS THE MOST IMPORTANT THING THAT YOU WERE TOLD OR HEARD OR READ OR ANYTHING LIKE THAT THAT HELPED YOU MAKE THE DECISION TO HAVE A WIDE LOCAL EXCISION? ANYTHING IN PARTICULAR?

Patient: No.

INT: NO?

Patient: Just sort of, just plucked it out of the air basically.

INT: YEAH, RIGHT.

Patient: I really couldn't decide at all, so I just ... went for it.

INT: RIGHT, OK THEN. ERM, AND LOOKING BACK FROM WHEN YOU WERE FIRST DIAGNOSED UNTIL NOW, HOW DO YOU FEEL ABOUT THE CARE THAT YOU HAVE RECEIVED?

Patient: Absolutely wonderful.

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

Patient: Oh, more than.

INT: MORE THAN?

Patient: Yeah.

INT: IS THERE ANY PART THAT DIDN'T MEET YOUR EXPECTATIONS DO YOU THINK?

Patient: No.

INT: NO, OK.

Patient: No, not at all.

INT: ERM, IF YOU WERE TOLD YOU HAD THE POWER AND THE MONEY TO CHANGE ONE THING ABOUT THE BREAST SERVICE THAT YOU WENT THROUGH AT GLENFIELD, WHAT DO YOU THINK THAT WOULD BE?

Patient: Mm, I don't know. I didn't find anything wrong with it at all.

INT: RIGHT, OK.

Patient: No.

INT: NO?

Patient: Nothing at all, I thought it were wonderful, and to be there for four hours and go through the whole lot I thought was fantastic.

INT: YEAH.

Patient: I was really pleased, and so was everybody else, because you hear so much about the NHS, don't you, you know, but, no, this was fantastic, I thought.

INT: THAT'S GOOD. LAST COUPLE OF QUESTIONS. NOW YOU'VE BEEN THROUGH THIS EXPERIENCE, WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT THEIR DIAGNOSIS, WHEN THEY'RE BEING GIVEN THEIR DIAGNOSIS?

Patient: I think, well, what I didn't do was talk to more people.

INT: RIGHT.

Patient: Yeah.

INT: YOU MEAN PREVIOUS PATIENTS OR ...?

Patient: Yeah, yeah.

INT: YEAH, ABOUT THEIR EXPERIENCE?

Patient: Yeah.

INT: YEAH, OK.

Patient: Because, as I say, I learnt a lot from the girls and, well we learnt a lot from each other I think.

INT: RIGHT, OK.

Patient: Yeah. And actually only yesterday when I went to radiotherapy the nurse there was showing me hers because she'd had two lumps and then a reconstruction and she was just showing me and telling me how wonderful it was, [chuckles] you know.

INT: OH, OK.

Patient: Just little things like that really.

INT: AHA. AND, ERM, WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS THAT SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT THE OPERATIONS THAT THEY CAN HAVE?

Patient: I think, for me, I don't, as I say, I was a bit useless really, I didn't ask any questions, but I think for the other girls, sort of speaking for

them is the ones that had the mastectomies, I don't think a lot was told about reconstruction.

INT: RIGHT, OK.

Patient: And we know probably they're waiting till they get over it but ...

INT: THEY ARE, YEAH.

Patient: ... to some people it's important, isn't it?

INT: YEAH. YEAH, ABSOLUTELY.

Patient: So, yeah, I felt that they didn't know what they were, what was, you know, gonna become of it, sort of thing really.

INT: OK. JUST LET ME QUICKLY LOOK BACK TO MAKE SURE I HAVEN'T MISSED ANYTHING ... ERM ... I THINK WE'VE GOT EVERYTHING NOW THAT WE'RE LIKELY TO GET. YEAH. LAST QUESTION, IS THERE ANYTHING ELSE YOU'D LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY? ANYTHING YOU THINK WE'VE MISSED? ANY IMPORTANT POINTS WE HAVEN'T COVERED?

Patient: No, I don't think so. As I say, I'm totally in awe of them, they were wonderful, [chuckles] I can't say enough about actually, and the women, you know, the people there are lovely, and the nurses, they're all just ... Glenfield Hotel. [chuckles] As I say I think we, I was lucky that we had a good crowd as well, as well, and we all gelled and had a great time.

INT: DO YOU KNOW ANYBODY ELSE WHO'S DOING THIS STUDY? IS THERE ANYBODY ELSE SAID YES?

Patient: Sandra, but I saw her on Monday having a seroma drained and she said she hadn't filled hers in yet.

INT: OH RIGHT, OK.

Patient: I shall speak to her, I'll tell her to get on with it because she had a mastectomy. Her story was completely different, so it would be different.

INT: OK.

Patient; Yeah, I'll tell her to fill it in, because she had the chemo before the op.

INT: OH RIGHT.

Patient; yeah.

INT: OK.

Patient: I think she had a infection or something and they couldn't decide what was the lump and what wasn't ...

INT: AH, RIGHT.

Patient: So she had the chemo first. So I'll tell her to fill it in. She says, 'Oh I haven't got round to it yet.'

INT: ALL RIGHT THEN, OK. I'LL LET YOU PUSH, WE CAN'T DO IT [???

Patient: I had nothing to do you see so I filled the form in. [chuckles]

INT: ERM, IF THERE'S NOTHING ELSE I'LL SWITCH OFF, IS THAT OK?

Patient: Yes, fine.

INT: THANKS.

[End of interview]