

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)
*VENUE: Low MR unit
*DATE:
*ID: Patient49
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: Er, nothing very much, basically. I'm not somebody who's terribly interested in this, or, you know, I don't watch sort of television programmes and that sort of thing, I steer clear of anything to do with [chuckles] [???

INT: OK.

Patient: I've got lots of friends who know lots because they watch things but, I don't know, I didn't really know very much about it until, only what, you know, very basic information really about it.

INT: RIGHT, OK. AND HAVE YOU HAD ANY FAMILY HISTORY OF BREAST CANCER AT ALL?

Patient: No, none at all.

INT: ANY FRIENDS HAVE HAD BREAST CANCER?

Patient: No.

INT: ANY RELATIONS OR ANYTHING?

Patient: No.

INT: OK. Erm, so can you tell me how you first came about to find there was something wrong?

Patient: Erm, I thought I'd got an abscess or a ... something, because I'd got a lump that came up and was large, made an appointment to see the doctor, er by the time I got to see the doctor, because in this area it takes quite a while before you can get a doctor's appointment. I wanted, I particularly wanted to see my doctor. In the end I couldn't because it was two or three weeks before I could get an appointment, and I wasn't convinced that it was terribly urgent at that point because it went down again, right? So I went to see a doctor, a young doctor, who was obviously being overseen by the other doctors in the practice as it turned out, and she couldn't find anything at all really, but finally we found this little thing 'Oh, oh' and she said, 'All right, come back in a week and we'll see if it's still there, if it's got worse or if it's gone, or what-have-you.' So I went back in a week and it's in exactly the same situation again, it's only very tiny. So at this point the other doctor who was overseeing her was in the room as well, although he never entered into any of the conversation, and she said, 'I think we will refer you just to check,' which they did and within a week I got an appointment and then I went to the Breast Care Centre in Leicester.

INT: YEAH, IN GLENFIELD.

Patient: Yeah.

INT: YEAH.

Patient: And ... do you want me to continue with the saga? [chuckles]

INT: I WAS JUST GOING TO ASK YOU, WHEN THEY SAID THEY WERE GOING TO REFER YOU TO THE BREAST CENTRE, I MEAN, AT THIS POINT WHAT WAS, WHAT WAS GOING THROUGH YOUR MIND?

Patient: I still thought that it was ...

INT: JUST AN ABSCESS.

Patient: ... an abscess or something like that, yeah.

INT: OK.

Patient: And I did right up until I was told that it wasn't. And the doctor had thought it probably was as well because it had come up and gone down again.

INT: YEAH, MM. SO WHAT HAPPENED WHEN YOU WENT TO THE FIRST VISIT TO GLENFIELD, WHAT HAPPENED THERE?

Patient: Erm, I had a mammogram; I had ultrasound; they also injected me, I don't quite know what's that called, where they take cells out.

INT: ERM, A BIOPSY.

Patient: Yeah.

INT: WHEN THEY TAKE SOME OF THE ACTUAL ...

Patient: Yeah, yeah. But it was no, there was no cutting or anything, it was just a needle.

INT: NO SORT OF A NEEDLE, YEAH.

Patient: Yeah.

INT: I THINK IT'S CALLED, IT MIGHT BE CALLED A FINE NEEDLE ASPIRATION, FNA.

Patient: Oh yes, that's right, I think I've read that now since. Erm, and then we waited around a bit and we spoke to, erm, the breast care registrar, I think it was as well, I think that's what his title is, I don't know his name, and various nurses. And then I went and they just said, and he actually gave me the information and just said that they were, what they had found were bad cells and that the lump that I had found was only very tiny but there was a much larger one which I had not known anything about, and in fact the doctor hadn't felt or anything like that.

INT: WAS IT BEHIND THAT SMALL ONE?

Patient: I think it must have been, I think it was more deep-seated, I think that's why it hadn't been felt. I mean not that anybody's told me that, but that's the only thing I can presume. Erm, and then they said that they would, they then told me the two alternatives ... that one was the lumpectomy or, erm, a mastectomy. I mean not knowing anything about I was willing to be told, you know, exactly what they would advise. I mean I just, I've no ...

INT: WAS THIS ALL ON THE SAME VISIT, WAS IT?

Patient: This was all in the same ...

INT: IT WAS A ONE-STOP CLINIC, THEN?

Patient: This was all in the same visit at this point, yes. And, erm, they then said they thought that because the second, or the other lump that they had found, and obviously something to do with the ultrasound - what they did tell me actually, they didn't know that when they'd taken this sample of cells which actual lump that they had gone into.

INT: OH RIGHT.

Patient: So, so I suppose at the back of my mind I rather thought that maybe it was one and not the other, and so on. And they said that they would obviously give me, erm, more information about this when they had, when it had been investigated. They did say that it's, that what they thought was that a mastectomy would have been the thing to have, although that it was up to me to choose, and they gave me the information about, they gave me two leaflets, one on lumpectomy and one on mastectomy. They didn't say, 'This is what you should do,' they said 'Go away and think about it,' and obviously told me it was my decision. But they did advise, although they weren't, they didn't use those words, they didn't say, 'We would advise you that you have a mastectomy,' they just said that it is a large lump and that to get enough good cells around it, erm, and what they told me was that if you had a lumpectomy it would, it would be very disfiguring ...

INT: RIGHT.

Patient: I mean a mastectomy can be ... but it would be, you'd be less able to compensate for that with some sort of prosthesis than ...

INT: RIGHT, YEAH, OK.

Patient: ... than if you had a mastectomy. So that was all the information I was given at that point.

INT: OH RIGHT, OK. AND YOU DON'T REMEMBER THE PERSON'S NAME ... WAS IT AN SpR?

Patient: The registrar?

INT: WAS IT A REGISTRAR, WAS IT? IS THAT WHAT IT WAS?

Patient: Mm. I think that's, I think that was his title, Breast Care Registrar I think.

INT: RIGHT, OK.

Patient: I mean he was very, very kind, very kind.

INT: YEAH, I MEAN JUST TRYING TO THINK WHO IT IS. I KNOW THE SURGEONS AND I KNOW THEY HAVE A COUPLE OF GENERAL PRACTITIONERS WHO COME IN AND HELP. ERM ...

Patient: Yeah. Well I'm afraid I don't know his name [???

INT: DID YOU SEE HIS NAME AND JUST CAN'T REMEMBER IT?

Patient: I don't think I even, or even noticed what his name was. I wasn't, I mean I say that I think he was the registrar, it's not that he was, he may well have been introduced as that but I can't remember that exactly. It's just something that I've gathered somehow. And he probably was introduced as his name

but I mean I think the circumstances were such that, you know, my brain wasn't quite, you know ...

INT: NO, OF COURSE, YOU KNOW, IT IS VERY, IT'S A VERY DIFFICULT SITUATION TO BE IN.

Patient: Yeah, yeah.

INT: ERM, SO, AND IS THAT WHAT HE SAID? HE SAID THEY'D FOUND SOME BAD CELLS?

Patient: Yeah.

INT: YEAH? WERE THOSE HIS WORDS, WERE THEY, OR YOURS?

Patient: Yes. No, he, no, he used, he used those words, he said bad cells or nasty cells, I can't remember which, but at that point I thought it was fine, you know, my husband was sitting outside, I'd gone in there to see and then he said, you know, 'Do you want your husband to come?' and the breast care nurse was there as well at the same time when he was telling me this. Erm, and then he, then my husband came in, yeah. Yeah, that was, bad cells I think he said, or nasty cells ... nasty cells I think.

INT: YEAH, OK. AND, ERM, SO THERE'S YOUR HUSBAND AND THERE WAS A BREAST CARE NURSE AND THERE WAS THIS GENTLEMAN, WAS ANYBODY ELSE IN THE ROOM AT THE TIME, DO YOU REMEMBER?

Patient: No.

INT: OK. SO WHAT HAPPENED AFTER THAT, THEY TOLD YOU ABOUT THESE OPTIONS?

Patient: Erm ... they, erm, oh I had at that point, I think I had ... oh dear ... I had a blood test ... I can't remember whether it was that visit or the next visit that I had an x-ray. I went ... er, do you know, I just can't remember. But it was ... and they then said that they would send me an appointment to see a Miss Stotter.

INT: OH, ANNE STOTTER, YEAH, SHE'S THE LEAD CLINICIAN AND A BREAST SURGEON THERE.

Patient: Yeah, that's right. And then I had, and within a week I think I had the inf-, and I went within a week, or about a week, and I went to see her, erm, armed at that point now, at this point, with some questions that wanted to be, that we wanted the answers to, that we sort of looked things up on the internet - my daughter looked up a whole load of stuff as well. And I think it was the following week, it might have been a fortnight afterwards, I just, I just can't remember, it's a bit of a haze. We went straight down to, we were going to see my son in Bristol so the night that I was given the information we actually drove down to Bristol, so it's all a bit of a haze of how long ago it was and that sort of thing. But anyway and then I was given an appointment to see Miss Stotter who was going to give me more information, obviously, having had ... erm ... I don't know, yeah, was just going to give me more information. Oh I had to go away and decide whether I thought it was lumpectomy or mastectomy, [???].

INT: AND DID YOU SEE, AFTER YOU SAW THIS FIRST DOCTOR, THE REGISTRAR, DID YOU SEE THE BREAST CARE NURSE AFTERWARDS?

Patient: Yes.

INT: YES? AND WHAT DID SHE SAY, DO YOU REMEMBER?

Patient: Erm ... mm ... I'm not very good, am I? I can't remember.

INT: DO YOU KNOW WHO WAS, WAS IT ... JANE, SUE ...?

Patient: It was Jane.

INT: JANE [???] YES, SHE'S [???] NOW.

Patient: She's very, very ... very, very kind.

INT: YEAH, VERY TALLISH ONE ...

Patient: Ooh no ... I think it was Jane, was it Jane? I know she's got [chuckles] not long had a little baby, he's about six months old.

INT: OH, JANE REYNOLDS.

Patient: Yeah, brown hair.

INT: YES. THERE'S TWO JANES, SORRY, JANE REYNOLDS.

Patient: Slightly plump. Yeah, very sweet. Very sweet and very helpful. She was very kind to my husband. He was absolutely devastated actually, he was [???] And I managed to, you know, hold it together really because ... I suppose it all happened so quickly that I was in a state of shock and it didn't really register that it was anything to do with me at all.

INT: YEAH, WELL THAT'S, THAT'S ...

Patient: You know, I mean it still isn't, quite frankly, only every now and again you.

INT: MM, YEAH, THAT'S NOT UNCOMMON I THINK EVERY PERSON I SPEAK TO, DESPITE HAVING, EVERY PERSON'S [???] UNIQUE OR PERSONAL EXPERIENCE, INDIVIDUAL EXPERIENCE, BUT ONE THING THAT'S COMMON ACROSS ALL OF THEM IS THAT WHEN THEY GET TOLD THAT THEY'VE HAD CANCER, THE PROBLEM WHATEVER, IT STOPS THEM DEAD IN THEIR TRACKS AND THEY OFTEN SAY, 'I JUST CAN'T REMEMBER WHAT WAS SAID IN THE CONSULTATION.'

Patient: Yeah, yeah.

INT: YOU KNOW, IMMEDIATELY THEY COME AND THEN THEY GO HOME, THAT'S WHEN THE QUESTIONS START TO COME IN/

Patient: That's right, that's right, that's right. So, I mean she obviously gave us some information about those people to speak to and about, and gave us lots of leaflets and sat and talked to us - we went into a room with her and sat and talked to us for about half an hour or so and said, you know, 'Is there any questions you need to ask?' and all that sort of thing. But at that point, this is before we saw Miss Stotter, I think all I wanted to do was actually get out of the place really. I don't know why, but I just, but I wanted to get away from it, you know. [chuckles]

INT: WELL, YEAH. NO THAT'S ABSOLUTELY, SOME PEOPLE DON'T SEE THE BREAST CARE NURSE/ I MEAN, SOME PEOPLE LITERALLY AS SOON AS THEY HEAR THEY DIAGNOSIS THEY DON'T EVEN WAIT FOR THE TREATMENT OPTIONS, THEY GET UP AND JUST WALK OUT, THEY JUST DON'T WANT TO BE THERE.

Patient: Yeah, yeah.

INT: YEAH, SO THAT'S NOT UNCOMMON.

Patient: Yeah, it wasn't quite as conscious as that that I wanted to get out of it but I was aware of the fact that I wanted to be on my way and going home. I suppose home becomes the sort of safe little haven, doesn't it? [chuckles] And you want to get back to that situation. But she was very kind, she was very to my husband. Erm, but that was all I had, I think, as far as I can remember. But I can't, I certainly can't remember this man's name.

INT: IT DOESN'T MATTER. IF IT WAS A REGISTRAR THEN I'LL PROBABLY KNOW WHO HE IS. THE THING WITH REGISTRARS IS WE DON'T INTERVIEW THE REGISTRARS BECAUSE THEY TEND TO MOVE IN A ROTATION EVERY SIX MONTHS ...

Patient: Oh, do they?

INT: SO IT COULD BE THAT MOST PEOPLE WON'T GET, WE INTERVIEW, PROBABLY WON'T GET THE SAME, WHEREAS THE SURGEONS ARE PERMANENT, SO.

Patient: Yeah. I mean he certainly, I've certainly seen him since, not to speak to but I've seen him around so, he's certainly working within that area at the moment as far as I know.

INT: YEAH, THEY USUALLY CHANGE EVERY SIX MONTHS OR SOMETHING, SO. SO WHEN YOU HEARD YOUR ACTUAL DIAGNOSIS FIRST OF ALL FROM THIS GUY, THIS REGISTRAR, I MEAN WHAT WENT THROUGH YOUR MIND AT THAT POINT THEN?

Patient: Erm ... well I ... I don't know really. Erm I suppose it, there were certain things that I thought, that I had to go away and decide what I thought would be best, erm I also I suppose thought maybe it was only, because they'd only tested one of the lumps, I thought maybe the other one was OK and that it would be ... so that was a slightly worry in the back of my mind that, even at that point, that maybe they should have tested both and mastectomy may not be necessary, because if it was the smaller lump then, you know ...

INT: YEAH [???

Patient: Yeah, and that, and I suppose that that remained in my mind until I saw Miss Stotter actually.

INT: RIGHT, OK.

Patient: But, erm, apart from that, I mean, it was a rather devastating week, erm, and I ... not knowing much about it and not knowing much about cancer never mind breast cancer, I didn't really know what the future might hold, you know, I was so ignorant really of what might be going to happen. And my main thing, my main feeling was that I had to tell my children really because I thought that, whatever was going to happen, they needed to know right at the beginning, so they could all sort of come to terms with whatever might happen. And as I said we went down to Bristol and I saw my son, and ... but I didn't, I waited until I saw all of them before I told them, you know, sort of face to face, so the next week really was spent ... that's what happened, yeah, my mother son came up the following week and my daughter, I saw my daughter as well, so the whole week was really taken up with that. And looking, as I said, on the internet and looking at questions that we should ask. And my main worry was the disfigurement I think at that point: it was nothing to do with was I going to live or die from cancer, it was really the disfigurement that really got me. Erm ... and so what I looked at was all the sort of surgery that you could have, erm, like reconstruction or implants or whatever, so I was looking at, from that point of view, almost immediately.

INT: RIGHT, OK.

Patient: Erm, and that was my thing, my first concern was really.

INT: YEAH, ONE OF THE QUESTIONS I WAS GOING TO ASK YOU WAS SORT OF AT THIS POINT DID YOU HAVE ANY THOUGHTS ABOUT WHAT OPERATION YOU WERE ACTUALLY GONNA HAVE?

Patient: Well I didn't know anything about it, you see, so, erm, during that week, having found out things, I was hoping that you could have had, I could have a ... what I would have liked would have been to have had a reconstruction almost immediately. I mean obviously because then that cuts out the disfigurement and the ... and I did feel, I felt very, very strongly that it was some sort of mutilation, you know, really got me. But when I found that you could have reconstruction or you could have some sort of implants, I began to feel a little bit better about it because I felt that it wasn't going to be quite as bad as I thought. So a lot of my investigation was into that. I did, as I said, I looked at things on the internet, which is the wrong thing to do I think actually.

INT: DEPENDS WHICH WEBSITES [???

Patient: Oh my goodness. I'd turn onto one website that, because I didn't want to see any pictures, I didn't want to know what it was going to look like, and I turned onto one website which was decisions about something, I can't remember what it was now, and there was, the first thing that came on the screen was a picture of a woman who had just had the operation and it was just absolutely, you know, it just horrified me, I was just sick quite honestly, and my husband wondered what on earth was wrong with me, you know [chuckles] but that was ...

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

Patient: ... but that was really bad.

INT: REALLY [???] IT'S AFTER THE FACT I SUPPOSE NOW, BUT THE BEST ONES REALLY ARE FROM THE DEPARTMENT OF HEALTH, CANCER BACUP, PLACES LIKE THAT. THEY'RE MUCH MORE SENSITIVE AND, YOU KNOW, THE INFORMATION YOU GET IS RELEVANT TO THE TREATMENT YOU'RE LIKELY TO RECEIVE IN ENGLAND ANYHOW. SOME OF THESE AMERICAN SITES OF COURSE THEY GIVE ALL KINDS OF TREATMENT BUT THEY'RE NOT, PERHAPS NOT AVAILABLE IN THIS COUNTRY MORE OR LESS, SO THEY'RE VERY DIFFERENT. AND SOME YOU GET, YOU KNOW, THEY'RE VERY, SOME OF THEM ARE VERY GRAPHIC AND PERSONAL EXPERIENCES AND YOU REALLY, YOU KNOW, YOU CAN GET ALL KINDS OF INFORMATION THERE.

Patient: Yeah. Well I didn't want anything like that, you see, I didn't want anything too detailed, I just wanted to know what my options were. One site I looked at was, I think it probably was an American one, but it gave you a whole list of questions that you could ask, which we downloaded, and another one was a BUPA site which was quite good, but not being in BUPA it didn't help very much. But, so that's really what my concern was in that first week before I saw Miss Stotter certainly, that, how I could get over this what I felt was [???] ...

INT: DID YOU EVER DISCUSS ANY OF THESE ISSUES WITH, YOU KNOW, WHEN YOU MENTIONED ABOUT RECONSTRUCTION AND IMPLANTS, DID YOU DISCUSS ANYTHING WITH JANE REYNOLDS?

Patient: No, because I didn't know, when I first saw her, which was when I was first told, erm, I didn't know anything about that, so I didn't know at that point, so it wasn't until ... and then I went again to see Miss Stotter, erm, so at this point, when I'd seen all these things and I was, I'd noticed that you could have reconstruction and that sort of thing, there was no, I wasn't

speaking to any, you know, I wasn't, erm, those people weren't available. I don't think at any point did I really discuss it in depth with Jane at all.

INT: BECAUSE, I DON'T KNOW IF YOU REALISE, THAT JANE'S PREVIOUS HISTORY WAS I THINK IT WAS HEAD AND NECK PATIENTS AND REHABILITATION AND STUFF LIKE THAT, AND SHE'S WORKED ROUND BODY IMAGE AND STUFF LIKE THAT.

Patient: Yeah, she did say ...

INT: YEAH, 'COS I'VE INTERVIEWED AND SHE SAID, IT WAS A REALLY INTERESTING INTERVIEW TALKING TO HER. BUT I MEAN SHE BRINGS A VERY UNIQUE FOCUS IN THAT UNIT, BECAUSE I'VE NEVER, I KNOW ALL OF THEM ARE AWARE OF IT, BUT I THINK SHE'S HAD A LOT OF EXPERIENCE, OBVIOUSLY WITH HEAD AND NECK PATIENTS AND THERE'S SOME AWFUL SORT OF INJURIES, SURGERIES YOU CAN HAVE THERE, SO YOU KNOW, IT'S QUITE PERTINENT. SO, YEAH, I MEAN ...

Patient: I think at one point, probably at the later, after I'd seen Miss Stotter, I did speak to her about it, because, and I'm sure it was her and she said that she'd worked in plastic surgery.

INT: MM.

Patient: And I was talking about reconstruction and the only thing she did say about that, she said, 'Well, that can be quite an involved operation,' erm, and obviously they take, erm, from your sort of stomach area or what-have-you can leave sort of unpleasant scars and is quite a major operation, is what she said, at that point.

INT: WAS THIS MISS STOTTER OR ...?

Patient: No, this was Jane.

INT: JANE, MM.

Patient: Miss Stotter didn't want to discuss it at all.

INT: MM. CAN YOU TELL ME WHAT HAPPENED WHEN YOU WENT TO SEE MISS STOTTER? SORRY, WE'VE GOT BACKED, WE'VE GONE OFF THE TRACK A LITTLE BIT ...

Patient: Yeah.

INT: BUT, YEAH ...

Patient: Yeah, so about a week later I think or it may have been a fortnight, but I know it wasn't long, it could have been a fortnight that I, before I saw Miss Stotter, and I went, we went in to see Miss Stotter. Erm, she told me that ... that ... oh, she asked me what I thought, whether I thought it should be a lumpectomy or a mastectomy. At that point I said that I thought, erm, it seemed that it ... but no, no wait a minute - ooh, can't remember the order - but I know at one point I did ask her about both lumps and she said that the larger lump showed all the signs of being a cancerous cell anyway, and she told me that it was, erm, that the cells were cancerous and she told me that, and she asked me what I thought about a lumpectomy or a mastectomy, to which I said, 'Well it seems as though it has to be a mastectomy to remove the lump to cut good cells all the way round. She told me about removing the nodes from under my arm, which obviously I'd read about at this stage, because I'd been given a leaflet about that. My husband had a list of questions to ask her which - possibly I'm - and some of them were in the leaflets, right, that we'd been given. Erm, I mean I would imagine Miss Stotter's quite a character actually [chuckles] but I left it to my husband to ask the questions because I felt that he would have them, you

know, I might be affected by whatever was going to be said to me, so I thought well if he asked the questions I'd be OK, but I think she, she found this a little bit tedious, to be truthful.

INT: RIGHT, OK.

Patient: And asked him at one point if he could read ... [laughs] which he took in very good ...

INT: YES, I MEAN ...

Patient: I mean she wasn't being too unpleasant, but it was a bit rude.

INT: WELL SHE'S VERY ECONOMICAL IN HER EMAILS AND EVERYTHING, ERM, I MEAN I WENT TO HER, I MEAN I'VE ONLY JUST DONE AN INTERVIEW WITH ONE OF HER STAFF AND I SAW HER IN THE CORRIDOR AND SAID, 'OH HI, HI, IT'S VERY NICE TO ... OH, IS SO-AND-SO AROUND?' AND SHE SAID, 'WELL IF YOU'RE GOING TO INTERVIEW HER I SUPPOSE SHE WILL BE,' WHICH IS PERFECTLY LOGICAL, ISN'T IT? BUT IT WAS JUST HOW, THE WAY SHE SAID IT, AND I THOUGHT, 'AH ...' AND IT WAS SUCH A CHANGE FROM WHAT WE'D JUST BEEN TALKING ABOUT, JUST CHANGED LIKE THAT. [???] AND THEN OF COURSE I'VE HAD A FEW ENCOUNTERS AND I REALISED THAT SHE'S NOT BEING RUDE OR ANYTHING LIKE THAT, SHE'S JUST QUITE, YOU KNOW, SHE SAYS WHAT SHE'S GOT TO SAY AND [???]

Patient: That's right, yeah. I mean I did ask her about, at that point then I asked her about reconstruction or implants and she said that, because I had read that it could be done at the same time, and obviously that's what I would have hoped to have. She told me at that point that that wouldn't be the case, that they would wait and see what the results were after the operation, and that they, either they don't do, or they certainly weren't going to do, or entertain the idea of any reconstruction at that point, because it would affect whatever treatment I might have, no, might make it difficult for whatever treatment I might have after that. Although I have read differently, I must admit, I've read that if you had reconstruction it wouldn't make much difference to whatever, but she was saying that 'You will have to have ... probably chemotherapy and then radiotherapy,' and I think it was the radiotherapy that obviously damages the skin, or can make the skin quite vulnerable, let's put it that way. Erm, and therefore she didn't advise this reconstruction and what-have-you. In fact really she wasn't really prepared to discuss that at all I didn't feel. Erm, and I had been asking about that and at that point she rather cut me short and said, 'Well don't you want to know what you're gonna have, what's going to happen in the operation?' so I said 'Well, yes, I do I suppose.' [chuckles] [???]

INT: I HAD YOU MADE YOUR DECISION BY THIS POINT WHAT YOU WERE GOING TO HAVE?

Patient: Well, I, yes, because I'm, well I'd taken their advice really. As I said, I knew nothing about it and I could see that it was, that really they were advising me, as you were saying before, earlier on, that really they were advising me to have a mastectomy. They were saying 'It's your choice, look at this and look at that,' but the odd things that were said it was obviously the only choice.

INT: RIGHT, YEAH.

Patient: And so I had to go by what they suggested, I don't know, just don't know any better, so ...

INT: RIGHT, OK. WERE YOU SURPRISED THAT YOU HAD A CHOICE OR SHOCKED IN ANY WAY?

Patient: That I was given a choice?

INT: MM.

Patient: ... Er, I suppose I was mildly surprised, yes, because I would have thought that it would have either pointed in one or direction or the other; that either it was bad enough to have a mastectomy, and that was the case, or it wasn't bad enough in which case you'd have a lumpectomy. I couldn't see, that, you know, because the two things are quite drastically different.

INT: MM, YEAH.

Patient: Erm, and so I thought, yes, I suppose I did think it was slightly strange that I should be given the choice in that, that for two things that would have been quite different. That either the situation was you could have a lumpectomy and that would be good and that everything would be fine - well you know what I mean - or they would say, 'No, I'm afraid you must have a mastectomy so that's it's necessary to take all these cells.' So I mean what I felt was that they were saying 'Yes, you need to have a mastectomy,' but they were still aware that they were supposed to give me choice, and so they were giving me choice but really underneath it all there is no choice.

INT: RIGHT, YEAH, [???

Patient: Yeah, I mean I just, I don't think there was really, not as it turned out anyway.

INT: RIGHT, YEAH, SO THEY SAID LIKE, THEY, THEY'RE KIND OF OFFERING YOU A CHOICE BUT, ERM, HOW CAN I PHRASE THIS ...

Patient: It's sort of a false choice really.

INT: YEAH, BUT IT'S KIND OF

Patient: I mean I ...

INT: YEAH, THEY SORT OF THINK THAT REALLY THE BETTER OPERATION WOULD HAVE BEEN THE ... IS THAT WHAT YOU FELT, THAT THEY WERE SORT OF SAYING THAT THE BEST [???] WOULD BE THE OPER-, THE MASTECTOMY OR SOMETHING?

Patient: Yes, I felt that this is, this is what I felt I was being advised and so therefore I didn't ... I mean I suppose in a way I didn't really want the choice, I didn't want to feel that I might be making a mistake. Erm ... and in that sense ... in that sense I think that most people who would be in my situation would have opted for a mastectomy because it eliminates any future problems, doesn't it, really? Whereas you could think that, right, if I had decided I wanted a lumpectomy and it, by opting for that, they hadn't actually removed enough, no, yes, good cells around it, then in the future, if it recurred, then that would have been my decision, and it would have been a wrong decision because I should have had a mastectomy. Do you see what I mean.

INT: YEAH, MM.

Patient: I mean I think people would have opted for a mastectomy because then it's ...

INT: IT'S [???

Patient: Yeah.

INT: MM, YEAH.

Patient: And there's no doubt in your mind that perhaps you should have said that.

INT: THIS FEELING THAT YOU SORT OF GOT THAT, ERM, THE MASTECTOMY WAS THE OPERATION THAT THEY WOULD HAVE CHOSEN, IF YOU LIKE ...

Patient: Yeah.

INT: DID YOU GET THAT FROM THE REGISTRAR, FROM JANE REYNOLDS OR FROM ANNE STOTTER? WHO WAS IT FROM DO YOU THINK?

Patient: I think from the registrar really.

INT: RIGHT, OK. YEAH.

Patient: Yes. Yes, it was really because they definitely said, you know, to get good, enough good cells around it, I mean presumably what they knew was how large it was which I didn't at that time know, you see, because they had the ultrasound and the mammogram things in front of them, I didn't actually see those ...

INT: RIGHT OK.

Patient: ... Which perhaps they should have shown me, I don't know.

INT: MAYBE'S IF YOU ASKED, I DON'T THINK THEY SHOW THEM AS A MATTER OF COURSE.

Patient: They don't, no.

INT: NO. DID THEY USE ANY KIND OF VISUAL AIDS, THIS REGISTRAR? DID HE USE, DID HE DRAW ANY DIAGRAMS, OR DID ...

Patient: No, no.

INT: NOTHING?

Patient: No.

INT: ANY PICTURES, ANYTHING LIKE THAT?

Patient: No, no, no. No, not at all.

INT: WHAT ABOUT MISS STOTTER, DID SHE DRAW ANY DIAGRAMS OR ...?

Patient: No.

INT: ANY THING LIKE THAT?

Patient: No, no. No, she just said that, 'What's your, what do you think your decision is?' and I said, 'Well I think it's a mastectomy and I will go by what I feel is your advice.' So, no, no diagrams or anything. I did, I did feel over the whole thing that I should have been given in a sense more information, that the fact that I had to get together these questions to ask, even now, further on, since I've had the operation, I still have to be the one to ask the particular questions and so I do feel that people should be giving you those answers without the questions having to be put because I don't know enough about it. So, you know, in a sense I think people should be, should have been saying to me, 'Look, you had ...' for instance, now, since, 'You had so many nodes removed, these were the number that, this is the number of nodes that was bad.

This means that you have ...' like rather than me saying, 'How many nodes did you remove and how many were bad?' and then them telling me.

INT: RIGHT, OK.

Patient: That's, that's a personal thing but that's what I feel, because I just don't feel as though I'm qualified to know what questions to ask even.
[chuckles]

INT: YEAH, WELL, THIS IS THE THING. HOW DO YOU KNOW WHAT QUESTIONS TO ASK WHEN YOU DON'T EVEN KNOW WHAT THE QUESTIONS ARE?

Patient: Yeah, absolutely.

INT: AND [??] THAT IS A PROBLEM. AND I THINK PART OF, PART OF THE ISSUE HERE IS THAT YOU SEE SOME PEOPLE WANT A HELL OF A LOT OF INFORMATION, THEY WANT TO KNOW EVERYTHING, OTHER PEOPLE DON'T EVEN KNOW, WANT TO KNOW WHAT THE DIAGNOSIS IS.

Patient: Yeah, yeah.

INT: THEY KNOW THERE'S A PROBLEM, 'YOU JUST SORT IT OUT, DOCTOR,' AND THERE'S TWO EXTREMES THERE.

Patient: Yeah, this is true.

INT: SO I THINK THEY'VE GOT TO BE CAREFUL A LITTLE BIT ABOUT GIVING OUT INFORMATION THAT MIGHT ACTUALLY UPSET SOMEBODY. THEY DON'T WANT TO KNOW IT.

Patient: Yeah.

INT: IT'S ...

Patient: But then all they've got to do is, at the beginning, is to say, 'Do you want me to give you this information or not?' and then people will say yes or no.

INT: YEAH, OF COURSE.

Patient: I mean I must admit I feel as though I want to know exactly what the future might hold and to the best of people's knowledge ...

INT: YEAH, OF COURSE.

Patient: ... so that I can make rational decisions about things, you know.

INT: SO WHEN YOU WENT TO SEE, YOU HAD, YOU HAD YOUR CONSULTATION A WEEK LATER WITH MISS STOTTER, AND WHAT HAPPENED AFTER YOU SAW MISS STOTTER?

Patient: She then said to me did I want to wait, was there any reason why I needed to wait to have the operation or did I not mind how soon it was or what-have-you, and I said, well, no, I felt the sooner the better, if it's got to be done, it's got to be done. So we had to go away then and sit and wait and it may be at that point that I ... I may have had the x-ray after that, I'm not sure. So anyway we sat and waiting, by this time it was about half past six at night, having been there about two in the afternoon. Erm, somebody brought us a cup of tea which was very nice. Erm, but then she called me in and said that they had a cancellation for the following Monday and would I be willing to go in then? So I just said yes. And she did say at that point, 'Don't worry, a cancellation, you know, don't worry about this, you know, because ...' I mean I must admit I did

go away and think 'Cancellation?' [chuckles] how do people cancel a mastectomy operation ... no I don't want to come this week, I'll wait until it gets worse.

INT: NO, PEOPLE OFTEN ASK IF THEY CAN GO ON HOLIDAY AND THINGS.

Patient: That's, oh dear, do they?

INT: YEAH.

Patient: [???

INT: YEAH, 'CAN I GET MY HOLIDAY OUT THE WAY FIRST?' YEAH, YEAH, [???] SOMETIMES THEY CAN'T BUT ...

Patient: Mm, well I don't think I would choose to do that. I don't think I'd enjoy my holiday ... well I don't know, I suppose if they're fully aware of what the future might be ...

INT: I DON'T THINK THEY WOULD CANCEL BECAUSE OF A HOLIDAY, THAT WAS THE WRONG IMPRESSION, BUT THERE MIGHT BE OTHER REASONS, I MEAN THERE MIGHT BE ...

Patient: Well I'm sure there must be.

INT: ... PERSONAL OR FAMILY REASONS, I'M NOT REALLY SURE. BUT I DO KNOW THAT WHEN THEY'RE GIVEN A DATE, YOU KNOW, THEY SORT OF SAY, THEY DO TAKE THINGS LIKE A HOLIDAY INTO ACCOUNT.

Patient: Yeah, yeah.

INT: BECAUSE SOME PREFER TO GET THEIR HOLIDAYS OUT OF THE WAY , SOME DON'T.

Patient: Yeah, there may be things, I mean I don't work, you know, I've retired so that's, I've got all the time in the world, but I suppose there's some people who have to sort of think where they're working and all that sort of things. So, anyway, so I was in there the following Monday, from the Thursday that was, so it was all quite quick. And then I was in there for five days or so.

INT: WAS IT MISS STOTTER WHO ACTUALLY PERFORMED THE OPERATION?

Patient: No, it wasn't, and I cannot remember the person's name.

INT: MALE OR FEMALE?

Patient: Female.

INT: FEMALE.

Patient: Obviously one of her ...

INT: FOREIGN OR ENGLISH?

Patient: English.

INT: KENNY, FRANCES KENNY?

Patient: ... Yes, I think it is. Do you know her?

INT: YEAH, I'VE INTERVIEWED ALL THE STAFF THERE.

Patient: Glassed, dark, small, glasses ...

INT: YES, THAT'S HER, OH YES, SHE DID AN INTERVIEW.

Patient: Yeah, yeah, so she came and saw me before I had my operation to tell me that she was going to do the operation and ...

INT: VERY, VERY GOOD SURGEON.

Patient: Yeah.

INT: VERY, VERY GOOD SURGEON, YEAH.

Patient: Yeah, and ... yes, I felt quite confident, you know, certainly with her. Asked if I'd got any questions or anything like that and there, I had various people came and saw me actually before I actually went for the operation, and probably when I, afterwards, to tell me all about various aspects of the results of the operation and what they were going to do before and what to look out for, and then somebody, because I'd said, hadn't I, before about doing this, and then somebody came and spoke to me ...?

INT: DOING THE ...

Patient: Doing this.

INT: THE STUDY, YEAH.

Patient: Yeah, doing the study. And then after being there a week, and then before I left I was given an appointment and see Miss Stotter for, I think it was about a fortnight after, which was ...

INT: THAT WOULD BE FOR YOUR HISTOLOGY RESULTS, YEAH?

Patient: That's right.

INT: SO WHAT HAPPENED THEN?

Patient: Erm, now wait a minute, I went and saw Miss Stotter ... yes, erm, she examined me, said that I would have to have chemotherapy and followed by radiotherapy or whatever it's called, erm, that, because I asked her about the fact that there had been two lumps there, I think at this point, and she said that both lumps were cancerous. What else did she say? And she saw that I, said that I would see Dr Peat in future. Erm, and that was about it. And there was somebody else who was in there, a nurse, [??] can't remember. But anyhow my husband was in there hiding behind the curtain [chuckles] but he asked if he could ask her some questions and then she really was quite short with him then and said, 'No, I'm not answering any more questions, and if you want to ask any questions I'm ...' and, you know, she implied that she would only speak to me, she wouldn't speak to him, so ...

INT: MM.

Patient: ... which was, but anyway, we knew that we were going to see this Dr Peat and at this point I think maybe Jane had said, or somebody had said, that we would find Miss, Dr Peat far more amenable. [chuckles]

INT: OH RIGHT, OK. OH RIGHT.

Patient: So that's what, that's, so I waited to see her and, yes, I think I saw Miss Stotter the following week actually and then I think about a fortnight

later I saw Dr Peat, who I saw last week or the week before, I can't remember now ... 20--, it was probably last week.

INT: WAS THIS TO DISCUSS YOUR ...

Patient: Last Thursday it was.

INT: ... POST-OPERATION TREATMENT?

Patient: Yeah.

INT: AND WHAT WAS ...?

Patient: And she was a very, very nice person actually, and again we were armed with quite a few questions, erm, and she told me after asking, I mean, without, as I said, we weren't told as a matter of course we had to ask the questions about how many nodes were taken and what the situation was there, and I've got a friend who's a GP and she said to ask whether it was oestrogen receptor positive or negative, no positive it was, so we asked that question. We also asked what grade the tumour was. We had to ask all this though, we weren't given the information.

INT: REALLY?

Patient: No.

INT: OH, I WOULD HAVE THOUGHT MISS STOTTER WOULD HAVE DONE THAT.

Patient: No.

INT: OK. [???

Patient: Well you see ...

INT: NORMALLY WHEN YOU GO BACK THEY SORT OF GIVE YOU THAT SORT OF INFORMATION.

Patient: Yeah, well we should have obviously asked these questions but we ...

INT: THEY NORMALLY JUST TELL YOU I THINK.

Patient: ... but, but we weren't told. I mean the only thing she said was, 'You're not out of the woods yet.' 'Oh, great,' I know this.

INT: RIGHT, OK.

Patient: So I don't really know, unless my husband's pile of questions there wasn't time for [???] [laughs] 'Oh, it's that man again.'

INT: YEAH, I CAN'T UNDERSTAND, REALLY BECAUSE NORMALLY THEY SORT OF, THEY DON'T MIND QUESTIONS NORMALLY.

Patient: Mm.

INT: YEAH.

Patient: Well, I mean, yes, but I wasn't asking them.

INT: YEAH, THAT MIGHT HAVE BEEN PARTLY ... I DO KNOW THEY SORT OF, IT'S PROBABLY PART OF THE TRAINING, BUT THEY TEND TO FOCUS ON THE PATIENTS AND THEIR NEEDS

RATHER THAN ANYBODY ELSE, BECAUSE THERE IS, THERE CAN BE A TENDENCY FOR PERHAPS, I DON'T KNOW, RELATIVES, FRIENDS TO ALMOST LIKE HIJACK THE SITUATION.

Patient: Mm, yeah, well maybe she felt that then. Maybe that's what she felt.

INT: I KNOW I'VE GOT NO IDEA, I WASN'T THERE, BUT ... SO, MM, WHEN YOU WERE ACTUALLY TALKING ABOUT YOUR DIAGNOSIS THE FIRST TIME THAT YOU ACTUALLY WENT TO SEE THE REGISTRAR, ERM, WAS ANYTHING, HOW MUCH DID YOU ACTUALLY UNDERSTAND ABOUT WHAT YOU WERE BEING TOLD? WAS THERE ANYTHING YOU DIDN'T UNDERSTAND?

Patient: All I understood was that what I didn't expect, because I expected him to say that it was an abscess or a cyst or whatever it was, that he had told me that there were bad cells and that in fact I'd got cancerous cells. And I suppose, and that really the outcome of that was going to be a mastectomy. And that's really what the ...

INT: YOUR UNDERSTANDING OF THAT CONSULTATION?

Patient: Yes, yes, yes, that overall of everything, that's what came out of that.

INT: RIGHT OK. WAS HE THE ONE THAT SAID THE CELLS WERE CANCEROUS?

Patient: No, well he didn't use those words, he just said they were, as I say, you know bad cells or nasty cells or something.

INT: WHO ACTUALLY SAID TO YOU FIRST THAT YOU HAD CANCER THEN?

Patient; Him.

INT: HIM, OH HE ACTUALLY SAID IT?

Patient; Well, no, no, no, no, I see what you mean, using the word cancer?

INT: YEAH.

Patient: ... Oh, isn't that funny, because I can't remember whether anybody said that, actually said that. They must have done but I don't remember anybody saying as bluntly as that, 'You have breast cancer,' or 'You have cancer.' I don't think anybody actually ...

INT: YEAH, OK. I JUST WONDERED IF THE BREAST CARE NURSES SAID IT OR [??] JUST, I LIKE TO MAKE SURE I GET THE RIGHT, WHAT THEY'VE ACTUALLY SAID AND THE RIGHT WORDING.

Patient: I mean I may have said, 'Were they cancerous cells or ...?'

INT: RIGHT, OK.

Patient: If it came from anybody it would have been Miss Stotter, erm, because when I asked the question about the other lump, erm, ... and when she said, she may have used the expression, 'they were cancerous cells as well,' but I think she may have said that were ... 'similar looking cells,' - this is before they'd had the report of course, that they were similar looking cells. So they were, and I think that's all she said. I mean I don't actually remember anybody saying to me 'You've got breast ...' using those actual words.

INT: OK. AND IS THERE ANYTHING ELSE YOU DIDN'T, WAS THERE ANYTHING ABOUT THAT FIRST CONSULTATION THAT YOU DIDN'T UNDERSTAND AT ALL?

Patient: No, not really, not ... no, not really. Yeah.

INT: AND THEN AFTERWARDS YOU HAD, YOU WERE WITH THE BREAST CARE NURSE AND THEY GAVE YOU SOME LEAFLETS AND THINGS TO TAKE AWAY?

Patient: Yeah, lots of leaflets and things.

INT: AND YOU READ THOSE, DIDN'T YOU?

Patient: Yeah, yeah.

INT: YEAH, THAT'S RIGHT.

Patient: Yeah I had to read those anyway.

INT: AND DID YOU FIND THEM USEFUL AT ALL?

Patient: Well they told me the difference between - not knowing anything - they certainly told me what a lumpectomy was and what a mastectomy and what the axillary node thing, [???] was.

INT: RIGHT, OK. LET ME SEE, WHERE ARE WE?

Patient: And then I've had lots of other things about lymphoedema and seroma and all sorts of things, leaflets since then.

INT: THINKING ABOUT, I MEAN YOU'VE HAD MOST, PROBABLY MOST CONTACT WITH MISS STOTTER, WOULD YOU SAY? IS THAT TRUE, IN TERMS OF AN ACTUAL ...

Patient: Well I've seen her twice whereas I've only seen the other people once except for Jane who I've seen probably three times ...

INT: SO THINKING ABOUT YOUR TIME WITH MISS STOTTER, I MEAN HOW DO YOU FEEL YOU GOT ON WITH MISS STOTTER?

Patient: Erm ... oh OK, fine, fine. No, I mean, I could appreciate that she's a very intelligent woman and probably has got all, a really good sense of humour, but [chuckles] and I wasn't offended at any time. I would, the last time I went when she had all the report in front of me, in front of her, I would have liked her to have told me more really, I would have liked her to have told me about the nodes, the size of tumour that they'd removed, erm, and because, when I came away I kept thinking to myself, 'That information must have been in front of her,' I don't think there was anything further to be told, I think she had all the information there, and that I felt that perhaps she should have passed that on to me.

INT: RIGHT, OK.

Patient: But why I didn't ask the questions then, I was, I was going to, I don't know. I don't think I was intimidated by her because she's not intimidating in that way but I did ... but you do feel as though you, you know, you're slightly walking on eggshells, you know, but, er ... I suppose in that situa-, the trouble is you're in a very, very vulnerable position I think, you know.

INT: OF COURSE, MM.

Patient: I, it's a bit like, I mean women go through this a lot, they go through it when they're pregnant and they have babies, you know, that when you're in hospital you feel very, very vulnerable and this is why pregnant particularly can be treated very, very badly by nursing staff etc, you know, because they

will not sort of stand up for themselves because they feel as though they're reliant upon these people for their welfare.

INT: ABSOLUTELY, YEAH.

Patient: And I think that's the difficulty in all these situations, that there are some questions you wouldn't ask because you don't want to upset people, because you feel they're in charge of your life somehow, you know.

INT: MM, YEAH. DO YOU THINK THAT MISS STOTTER UNDERSTOOD YOUR NEEDS AND CONCERNS? DO YOU THINK SHE LISTENED TO YOU?

Patient: Yes, she listened, I mean I just didn't ask the questions at the time, you know, it's my fault not hers really.

INT: AND THINKING ABOUT YOUR TIME WITH JANE, THE BREAST CARE NURSE, HOW DID YOU GET ON WITH HER?

Patient: Oh very well, I thought she was, yes, very, very kind and any questions that, again, I want to ask or did want to ask she answered, you know. I mean I can't remember what they were now but, because obviously when she was talking to me I was under some sort of, it was a bit, erm, I was under some sort of stress then because the second time, when I went back to see Miss Stotter I know I went away thinking that I was going to be told - oh yes, that she did tell me though, she must have told me at that stage that it had gone into the nodes, she didn't give me details of it but she must have told me that to have said that I was going to have chemotherapy and radiotherapy, because I had gone there hoping that it hadn't and that would have been the end of it, having seen people in hospital who, you know, knew other people and that where, and that had been an end of it once they'd had a mastectomy. And I did get a little bit upset then so she sort of [???] and she took me into another room with my husband and that, sort of talked and - I can't remember exactly what she said but, you know, so we got on with her quite well and I felt if I wanted to ask any questions for anything I could ask her certainly.

INT: LET ME SEE, WHERE ARE WE NOW?

Patient: There was another nurse actually who was very useful and that was because when I went back to see Miss Stotter I hadn't, I'd read this leaflet about seroma and it obviously if you get this sort of liquid building up you have to go back to the hospital and have it drained off, and Miss Stotter looked at it and said, 'Oh, there's a bit of whatever there,' and so I'd gone with this other nurse whose name was ... Muriel[?] I think, because I'd ...

INT: MARLENE.

Patient: Marlene? Because I'd phoned her up the night before because I'd been a little bit worried about, erm, whether I should go in and have this drained off, and she told me, she was quite, very helpful on the phone actually, and I, so I'd gone in to have some of this drained off, they couldn't take anything off at all, it wasn't necessary, although the only reason it was being done is because, actually because Miss Stotter thought maybe there was something. So I had this needle stuck in me two or three times, [chuckles] but, anyway, that particular, I think she was a cancer nurse, isn't she? She was very helpful, she was saying, 'Well ...' because I was talking to her and she said, 'Well you need ...' she was telling me some of the questions that I needed to ask when I went back to see Dr Peat, and that was really very useful because, you know, she said, 'Ask how many nodes, ask how many were affected, ask what percentage something or other, can't remember what that was now but, you know, so that was really quite

useful. And that was a sort of by-the-by thing really, so that was as useful as anything.

INT: YEAH, FROM WHEN YOU ACTUALLY HEARD YOUR DIAGNOSIS AND WERE FIRST TOLD ABOUT YOUR TREATMENT OPTIONS, HOW SOON DO YOU THINK IT TOOK FROM THAT POINT TO MAKE UP YOUR MIND WHAT SURGERY YOU WERE GONNA HAVE?

Patient: I don't think there was any doubt at any time. I mean having been told it I just presumed that that's what ... the fact that they told me it was a large lump, right, and I thought, 'Well that's got to be ... it's got to be a mastectomy.'

INT: RIGHT, OK. AT ANY POINT DID YOU CHANGE YOUR MIND?

Patient: No.

INT: OK. ERM, LET ME SEE, YOU SAID THAT WHEN YOU CAME HOME AFTER, WELL ACTUALLY YOU WENT TO BRISTOL FIRST, BUT IN THAT WEEK BETWEEN SEEING THE REGISTRAR AND MISS STOTTER, YOU SAID THAT YOU LOOKED FOR INFORMATION ON THE INTERNET AND THINGS LIKE THAT, DID YOU, ERM, TALK TO YOUR FRIENDS AND YOUR FAMILY ABOUT YOUR DIAGNOSIS?

Patient: Yeah.

INT: DID YOU SPEAK TO ANY FRIENDS, NEIGHBOURS, GP? DID YOU READ ANY BOOKS, MAGAZINES?

Patient: I didn't want to tell anybody.

INT: NO.

Patient: No. I didn't, I just literally didn't want anybody to know, I don't know why. It's not that, it was not for any, I just ... don't know why I didn't want to. [chuckles] Maybe I didn't want them to feel sorry for me, I don't know. It wasn't any sort of feeling I ... I mean I've read something just recently and they were saying sort of in the past, this sort of thing, you know, people didn't speak about because, you know, they were sort of ashamed about it - there wasn't anything like that at all, it was just that I just didn't want to talk about it really.

INT: YEAH.

Patient: I suppose it brought it to the forefront, that's what it would have been, you know, if I talked to people. In the end I did because I was doing some private teaching and of course I was going into hospital so I had to tell people I was going into hospital and then 'Why are you going?' so ... erm, so consequently I had to tell them but, erm, otherwise I wouldn't have chosen to tell them at all.

INT: AND HOW, YOU SAY YOU'VE GOT A DAUGHTER AND A SON?

Patient: I've got two sons and a daughter.

INT: RIGHT, AND YOUR HUSBAND. SO HOW DID YOUR FAMILY TAKE IT THEN?

Patient: Well the boys, my daughter is a little bit stronger, but, erm, no my sons, well I say the boys, my son's 40 this year [chuckles] well they were extremely upset actually ... yes. But, erm, but they've also got their partners and wives and things so, who have all known people actually. I mean that was the thing that amazed me, that when I, that when - and I mean there's still only a

handful of people that I've told, but or have, or know - but they all know two or three people who've had a similar, similar thing, which is amazing. That's the thing that's really amazed me, how widespread it is. I mean you see the things on the television which say, you know, 'Breast cancer is the commonest ...' and so on, but you don't realise how, what, quite what that means.

INT: YEAH.

Patient: And my husband went to see a friend of his whose wife had, has gone through her therapy and that sort of thing and now is back at work, and he felt much better having spoken to him because he, I mean, he just felt that I was, sort of, you know, two months down the line I wasn't going to be here.
[chuckles]

INT: YEAH, YOU SAID YOUR HUSBAND DIDN'T TAKE IT VERY WELL REALLY.

Patient: No, not at all ... no, he found it very difficult to cope with.

INT: AND HOW IS HE NOW?

Patient: Er, he ... the last time we went to see Dr Peat he felt quite ... felt better about it then. I mean, no, he's much better than he was and feels, you know, you've got to be positive. You know, people do go through these things but of course he didn't know anything about it either, and so consequently, you know, the word cancer has this sort of ...

INT: CONNOTATION.

Patient: ... doesn't it, yes, that, you know, you're here today and gone tomorrow. But, no, things are, he's not so bad now. I just [???] times every now and then, so do I, you know.

INT: MM, YEAH, YOU'RE BOUND TO.

Patient: Yeah, I mean most of the time you walk around, it's just everyday life, isn't it? And then ... foomph ... something hits you and you realise that, well it is realisation hits you I think.

INT: MM, YEAH. ERM, WHAT DO YOU THINK WAS THE MOST IMPORTANT THING THAT YOU HEARD, WERE TOLD, READ, THAT HELPED YOU MAKE YOUR DECISION?

Patient: What to have a mastectomy?

INT: TO HAVE A MASTECTOMY, YEAH.

Patient: The most important thing that I heard was the size of the ...

INT: JUST THE SIZE, YEAH, YOU MENTIONED IT EARLIER.

Patient: Yeah, because I felt that that meant that, er, I mean in actual fact I was told in the end because we asked the question of Dr Peat how large it was and she said it was 5 cms which is really quite large.

INT: MM, YEAH, 50 MMS, YEAH, [???]

Patient: Yeah, it is, isn't it?

INT: MM.

Patient: But they hadn't, obviously didn't know that at the time, but that, yes, that was the thing that I thought that really, if it was large, then ... and the fact that there was, there was a second one there that I didn't know anything about that was larger than the first. Erm, yeah, that was really the reason. I thought to get rid of that plus, you know, have good cells around everything, to have a mastectomy, I think that's the main thing.

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

Patient: Fine, fine.

INT: DO YOU THINK IT'S BEEN WHAT YOU EXPECTED?

Patient: Yes, yes, yes, no, I mean, I have no complaints about that at all, not at all. And everything's been very quick, I mean I feel I was particularly lucky because I did speak to people in the hospital who'd waited sort of three, four, five weeks to go into hospital, and I think that must have been really awful for them. I mean the fact that I went there on the Thursday and told I was going to have it done on the Monday, erm ...

INT: SO FROM YOUR FIRST EXAMINATION IT WAS, WHAT, TWO, TWO OR THREE WEEKS OR SOMETHING LIKE THAT?

Patient: Yeah, yeah. I mean ... from that point of view, having to think about going in for an operation, that was good, very good. The actual shock value has been slightly different because it all happened so quickly that, erm ... you know, I hope that it happened quickly and I've sort of passed it over, but I feel it might hit me, and it does every now and again, what's happened, you know, the reality of things.

INT: YEAH, YOU START REFLECTING, START REFLECTING ON THINGS.

Patient: That's it, yeah.

INT: YEAH, OF COURSE.

Patient; Yeah.

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

Patient: What, you mean apart from being, about having been given more information?

INT: ANYTHING. IT COULD BE ANYTHING, IF YOU'D GOT THE POWER AND MONEY TO CHANGE ONE THING ABOUT IT. [???

Patient: Erm, I think that I personally would have liked to have been given as much information as possible, erm, as far as what was actually wrong with me, without asking questions; to actually have been told ... in no uncertain terms what they thought the prognosis was or ... erm ... and I also think that I would have liked to have been told about all the alternatives for reconstruction and, erm, implants and things, in more details. In fact I think I would have liked to have been told that because it wasn't until I came home and realised all that sort of thing was possible that I began to feel a little bit better about it, and I think if I'd been told that at the same time as I'd been talked about having a mastectomy, it would have avoided that two, three week or so in which ca-, when I didn't know that that was going, that was a possibility.

INT: IS RECONSTRUCTION SOMETHING YOU'D STILL CONSIDER?

Patient: I'd have to go into it in more detail really to find out how ... I mean I have been put off slightly by the fact that I've been told that, you know, it's a really rather involved operation.

INT: RIGHT, OK.

Patient: Erm ... and I suppose it's rather early days now, but, yes, I think at the back of my mind I'd consider something like that. Yeah, some sort of implants or something like that, I think I would. I think, I mean I definitely would. You know, if I could click my fingers and say, 'That's what I want,' then I would, yeah, because obviously you want to be back the same as you were, don't you, as much as possible? I mean that's the thing that's, that's, still upsets me at the moment, you know, when reality clicks in, and it's not so much that, you know, I don't know whether I've got - I mean I don't know because they tell me they don't know either whether I've got sort of secondary cancers - they know my lungs are clear and they know blood tests seem to be OK, but having asked again in the end, you see I wasn't told that freely, I had to ask. Erm ... but the one thing is that I, the realisation is that I can never, if I have chemotherapy, right, and I get, and I cope with that and I get over that and have radiotherapy, then it appears that things can be back almost to normal again except, having had the mastectomy, it can't be. Do you know what I mean? And that still is the thing that's in my head, you know, whereas I think reconstruction or whatever, makes you, if you think that's a possibility you begin to feel that you can get back to normality, you know, really.

INT: RIGHT.

Patient: So that's just a vanity [chuckles] from a vanity point of view I think, but it is, you know, I think ... yeah.

INT: NO I THINK FOR SOME PEOPLE YOU KNOW, THEIR BODY IMAGE AND [??] THIS IS VERY IMPORTANT TO THEM AND I THINK THERE'S NOTHING WRONG WITH THAT AT ALL ACTUALLY.

Patient: Mm, it is body image, isn't it, you see, it is something that's ... it's a cultural thing isn't it, something that is sort of, within our, the cancer wasn't important.

INT: I THINK IT'S A PERSONAL THING AS WELL. I THINK, YOU KNOW, I MEAN SOME, I MEAN SOME PEOPLE JUST LITERALLY SAY, 'I DON'T NEED THEM ANY MORE.'

Patient: Yeah, I know.

INT: THEY'RE QUITE BLUNT ABOUT IT. I MEAN I'VE HEARD SOME STORIES, WITH SOME WOMEN WHO GET A BREAST CANCER, AND YOU KNOW AND IT'S QUITE SMALL AND TO ALL INTENTS AND PURPOSES A LUMPECTOMY'D BE FINE, AND THEY WANT A BILATERAL MASTECTOMY.

Patient: Really?

INT: YEAH, AND IT'S JUST LIKE, THEY'VE SAID, 'OH YES, I WANT A BILATERAL ... TAKE THEM OFF, I DON'T WANT 'EM.'

Patient: But is that because they feel that in the future it may then develop in, develop again ...

INT: YEAH.

Patient: That's it, isn't it?

INT: YEAH, THAT'S IT, THERE'S A FEAR IT COMES BACK, IT CAN COME BACK ON THE OTHER SIDE OR WHATEVER ...

Patient: That's right.

INT: ... OR THE SAME BREAST AND ...

Patient: Well, yes.

INT: IT JUST DEPENDS, I MEAN ...

Patient: I mean I think they, I think, I think you will live with, I mean I think I will live with that fear actually [???

INT: BUT I THINK THEY DO FOLLOW-UP, YOU KNOW, I THINK, WAS IT FOLLOW UP FOR SIX MONTHS FOR A WHILE THEN, IS IT TWO YEARS OR SOMETHING [???

Patient: Is it, is it, yeah?

INT: [???

Patient: Yeah, you see I don't, you see I haven't been told that either you see, so, er, and you know this, I mean I'm going to see on Monday, I'm going to see a chemotherapy nurse who will give me more information about chemotherapy and I mean I know the ins and outs of the procedure but ...

INT: HOW LONG WILL YOU HAVE YOUR CHEMO FOR, DID THEY SAY?

Patient: Yes, I have six course, six sessions I think.

INT: WILL IT BE OVER 18 WEEKS OR SOMETHING?

Patient: Yeah, that's right, yeah, depending on your blood count presumably, yeah, yeah. So and then radiotherapy after that which I think sounds pretty drastic that, sort of continual everyday thing. No, it said not weekends [chuckles] ...

INT: YEAH, IT'S FOR FIVE DAYS A WEEK FOR HOW DON'T KNOW HOW MANY WEEKS, ABOUT, USUALLY ABOUT FIVE WEEKS OR SOMETHING ...

Patient: Is it?

INT: THREE TO FIVE WEEKS OR WHATEVER IT IS, I CAN'T REMEMBER EXACTLY ...

Patient: Well it depends, that's what they told me, yeah.

INT: [???

Patient: Yeah.

INT: AND WOULD THAT BE AT, WELL THAT'LL BE AT THE ROYAL ...

Patient: Yeah.

INT: THE ROYAL, IS THAT WHERE THE CHEMO'S AT AS WELL?

Patient: Yeah.

INT: YEAH. THOUGHT SO.

Patient: I mean that is a difficulty here of course is that it takes us an hour or more to get to the hospital. Well actually the Infirmary's not so bad but Glenfield's the other side of Leicester to us, so, it takes, well it takes about 50 minutes or so.

INT: AND THE PARKING ISN'T PARTICULARLY BRILLIANT AT GLENFIELD REALLY.

Patient: Glenfield, oh no, we just park on the grass. I think the Infirmary's worse.

INT: OH WELL I'VE NEVER BEEN TO THE INFIRMARY BUT I KNOW WHEN I'VE BEEN THERE A FEW TIMES AND YOU'VE GOT TO LIKE SIT IN THE CAR PARK AND STALK PEOPLE WHEN THEY COME BACK FROM THE HOSPITAL ...

Patient: Mm, [???

INT: SOME POOR OLD LADY'S COMING BACK AND YOU JUST TOTTER ALONG THERE AND YOU'RE DRIVING [???] CAR PARK, JUST WAITING FOR [???] [CHUCKLES] IT'S AWFUL.

Patient: Well we've been lucky then because we haven't, we've managed to park all but as I say once when we had to park on the grass, but I think the Infirmary, being, you know, more in the centre of Leicester, it's even worse.

INT: RIGHT. ERM, YEAH, WE'RE GETTING OFF THE SUBJECT, 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, FIRST OF ALL, ABOUT THEIR DIAGNOSIS, WHEN THEY'RE BEING TOLD THEIR DIAGNOSIS?

Patient: Oh, when you, when you've had the mastectomy and they have got all the reports, do you mean?

INT: NO, NO, WHEN YOU'RE ACTUALLY BEING GIVEN YOUR DIAGNOSIS, WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW?

Patient: ... Erm ... so that you can make a decision whether you have a lumpectomy or a mastectomy, do you mean?

INT: ANYTHING YOU THINK IS PARTICULARLY [???

Patient: Oh I suppose, well I suppose from my point of view it was the size of the ...

INT: THE TUMOUR ITSELF.

Patient: ... of the tumour itself really, erm, because that's what I made my decision from. I mean they can't really tell you anything else, can they, because they haven't done any other investigation into it?

INT: MM.

Patient: So I think, yes, and as I said, perhaps if they're going to tell you that you are going to have to have a mastectomy or lumpectomy, that they tell you what can be done in the ways of reconstruction or whatever to make your, again your body image, to make you feel better about what you're going to look like afterwards, I think.

INT: AND VERY SIMILAR SORT OF QUESTION, WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT THE OPERATIONS THEY CAN HAVE?

Patient: About the operation?

INT: MM.

Patient: ... Erm ... I think they need to be told exactly what to expect when they've had the operation. I mean they are told about lymphoedema which is a bit frightening and that, I mean, you're almost told too much about that. I feel, only because I haven't suffered from it, I mean I don't know how ... but I did ask somebody about it and they said, 'Well, you know, lots of people get lymphoedema, no, they're not necessarily having had any operation or anything and it is treatable and ... but having read this leaflet, you know, I was in the garden and I fell over some thorns and things and I thought, 'Oh God,' [chuckles] you know, immediately, thought I was going to end up with an arm sort of this size. But, yes, I mean I felt that was a little bit over the top. But, erm, yes, I think they need to be told more about the scar tissue and that sort of thing and how to deal with it. It's all right if you near the hospital or near wherever you can just sort of pop in and say, 'Look, is this ... what do you think about ... is this OK?' but I mean from my point of view it's 50 minutes away or I get on the telephone, and I don't do it because I think, 'Well that's just a silly thing to say,' you know. But there are little niggling things that if you, if you were nearby you would sort of go in and say, 'What about this?' So I think they need to sort of give you some more details that this could happen, but don't worry about that. This could happen but, you know, you should tell somebody if this happens, you know, and that's to do with the scar tissue and all that sort of thing.

INT: RIGHT, OK.

Patient: Erm, I think that should, yes, I think you should be given slightly more detail about that.

INT: OK.

Patient: Even if it's written down, because that's the other thing, that things have been, you know I have been told things but I don't remember the detail ...

INT: NO, QUITE.

Patient: ... erm, I don't know why, maybe it's the anaesthetics [???] [chuckles].

INT: WELL SOME OF THEM SAY CHEMO ...

Patient: Yeah, it is.

INT: IT ALL DEPENDS, FIRST OF ALL YOU'RE GIVEN A VERY NASTY DIAGNOSIS, ESPECIALLY FOR YOURSELF WEREN'T REALLY EXPECTING IT, WERE YOU?

Patient: No, no.

INT: SO YOU GIVEN A BIT OF A NASTY SHOCK AND THEM SORT OF THINGS, YOU QUITE RIGHTLY SAY THINGS MOVED QUITE QUICKLY FOR YOU, YOU DON'T REALLY SORT OF KNOW WHAT'S HAPPENING TO YOU AT CERTAIN POINT. A LOT OF PEOPLE SAY THE WEEK IN BETWEEN THE OPERA-, THEIR DIAGNOSIS AND THE OPERATION USUALLY OR SOMETHING, ERM, IS TAKING WITH PRACTICAL THINGS, ESPECIALLY IF THEY'VE GOT KIDS OR THEY'RE WORKING, THEY'VE GOT FAMILIES, WHATEVER, THEY'RE JUST GONNA DO THIS AND THAT

[???] AND THEN YOU KNOW AFTERWARDS YOU SORT OF LIKE, THEN IT STARTS TO HIT YOU, THEN YOUR QUESTIONS COME, YOU KNOW, AND THEN YOU START THINKING, 'WELL WHAT DID THEY SAY? I'M SURE THEY MENTIONED THIS,' AND ALL THIS KIND OF ... [???]

Patient: I was so vacant, when I went back to see Dr Peat last week I could not remember them testing the other breast at all, and yet I'm told that I had a mammogram and it, of that breast as well, but I can't remember.

INT: NO.

Patient: In fact I was convinced that they hadn't, and hadn't done anything about that at all. But Dr Peat said, 'Well I've got a report for one, it must be somebody's.' [chuckles] But that, that's, you know, how much I was aware of what was going on, and that was on the very first time I went.

INT: ERM, FINAL 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 INFORMATION THAT WE HAVE COVERED, ANYTHING LIKE THAT?

Patient: Not really, no.

INT: NO, OK. ERM IF THAT'S OK THEN I SHALL TURN OFF THE RECORDER.

Patient: Yeah, OK, fine.

[End of interview]