

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)
*VENUE: Low MR unit
*DATE:
*ID: Patient58
INTERVIEWER: DJW

INT: WELL FIRST OF ALL THANK FOR AGREEING TO BE INTERVIEWED. AND I'D LIKE TO START WITH QUESTION ONE HERE 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: Erm, my grandmother had breast cancer before the War and actually lived till 80, so it was obviously very successful. I didn't really know much about it. We had the Christie Hospital in Manchester, which obviously was a very good hospital. Erm, also I have two friends, not close friends but people I know, who had actually died quite young from breast cancer.

INT: RIGHT, OK. AND WHAT OPERATIONS DID THOSE PEOPLE HAVE, DO YOU REMEMBER?

Patient: Er, no I don't really remember exactly what they did have. I wasn't terribly close to them, but it was more in the later stage that I heard about it when it had obviously spread to other parts.

INT: RIGHT, YEAH. AND CAN YOU TELL ME THEN NOW HOW YOU CAME TO FIND OUT THERE WAS SOMETHING WRONG WITH YOUR BREAST?

Patient: Erm, certainly not through lumps, it was through a routine mammogram about mid-May at the sort of the mobile breast screening unit which comes round to Loughborough every three years.

INT: AND SO YOU HAD YOUR MAMMOGRAM THERE ...

Patient: Yes.

INT: AND THEN DID YOU GET A LETTER AFTER THAT TO SAY?

Patient: Yes, I got a letter very quickly and it was quite a shock because, erm, as I said, I'd really, couldn't feel anything at all, and I couldn't right up until the operation, I couldn't feel anything.

INT: RIGHT, OK. SO, HOW LONG, HOW SOON AFTER YOU GOT THE LETTER DID YOU HAVE TO GO TO THE CLINIC?

Patient: It was within a week after receiving the letter, and the letter was within a few days of the actual mammogram taking place.

INT: RIGHT, OK, SO IT'S ALMOST LIKE WITHIN TWO, A FORTNIGHT ...

Patient; Less than a fortnight really, I think.

INT: ... YEAH, THAT YOU GOT TO THE CLINIC.

Patient: Yes, yes it was, the first time I went.

INT: AND THAT WAS, THAT WAS THE CLINIC AT GLENFIELD?

Patient: Yes, it was the breast care unit at Glenfield.

INT: MM, SO CAN YOU JUST TELL ME ABOUT THAT VISIT TO THE GLENFIELD CLINIC AT THAT TIME, WHAT HAPPENED THEN?

Patient: Er, I went on my own because I didn't want to make too much of it because I've heard of so many cases that had just been a blip or something on the screen, or even in one case no film in the camera, erm, and as soon as I walked into the room I could see quite clearly, the x-rays were on the screen and I could see the lump quite clearly and realised that, yes, this was it.

INT: RIGHT, THIS IS AFTER THEY'D DONE ANOTHER SCAN THERE? IS THAT WHAT HAPPENED?

Patient: Er, no, at the time, erm, no, I went for the appointment, they took me into a room where there was a doctor and a couple of nurses, and they had the x-ray up on the screen, as I said. They did a sort of scan or something like that there and then at the time, poked me around again, well, not, I mean for the first time they sort of felt all around, and said that they needed to do a biopsy, which they did there and then.

INT: RIGHT, OK. AND THEN WHAT HAPPENED AFTER THEY TOOK THE BIOPSY?

Patient: Erm, they made another appointment to come back to get the results. That was, it should have been one week but in fact it was two weeks, that was the worst part of all really, sort of the waiting to know, erm, because, the reason it was two weeks was because the May, not the May Day, the late Spring Bank Holiday ...

INT: OH RIGHT, OK.

Patient: And everything had to be on a Monday because they had meetings and it, you know, they couldn't just sort of make it another day because of the schedule of other things that take place within the unit and the hospital.

INT: OK.

Patient: so that was the worst part.

INT: AND ON THAT FIRST VISIT, DID YOU GET TO SPEAK TO A CONSULTANT AT ALL, OR ...?

Patient: Yes. Erm, there was, they were very, extremely good, they explained quite clearly who they were and there was a consultant who did the biopsy and another one who, when I got dressed, I went in to speak to. He was an Indian man, I can't remember his name ...

INT: RIGHT.

Patient: ... but he was quite clear, very precise as to what the options would be. I asked whether it was benign or cancerous, so when I left there, you know, I realised quite clearly there were two options and if it was cancerous there would be either the removal of the lump or a mastectomy. I also asked him the question how long are we talking about and the timescale, and he said definitely weeks rather than months.

INT: RIGHT, TO HAVE THE OPERATION?

Patient: Yes.

INT: YEAH.

Patient: So, although I didn't know the results, I came away feeling I knew as much as was available at the time from them.

INT: RIGHT, OK, YEAH. SO WHEN YOU ASKED HIM, DID, YOU ASKED HIM DIRECTLY IF IT WAS CANCEROUS, IS THAT RIGHT?

Patient: Well, no, because they couldn't actually say at that time because they hadn't sent the results, well they took the biopsy and they hadn't got the result. It was following that first meeting where I had spoken to the consultant as well, that they did the biopsy and sent it off. So I had to wait then for two weeks.

INT: AND DID YOU SEE A BREAST CARE NURSE THAT [???] OR ... CAN YOU REMEMBER?

Patient: No, well, sorry, there was a breast care nurse present. I didn't see her individually. Erm, there was a breast care nurse in the room when I first went in; one sort of doctor, I'm not quite sure, somebody who did the scan and who took the biopsy; and then there was the consultant in the next room when I'd got dressed.

INT: OK. SO JUST GOING BACK NOW A LITTLE BIT TO WHEN YOU ACTUALLY GOT YOUR LETTER TO GO TO THE, FROM YOUR FIRST MAMMOGRAM TO GO TO THE UNIT FOR THE FIRST TIME ...

Patient: Yes.

INT: ERM, WHAT SORT OF THINGS WENT THROUGH YOUR MIND AT THAT POINT?

Patient: Erm, shock I think first of all, that there was anything wrong because, like I say, I could feel no lumps. Erm, yeah, sort of, you know, quite an anxiety. Erm, I didn't particularly think immediately, 'Oh, it's probably just a blip or something,' it was only when I started to think about it perhaps in a sort of logical way I thought, 'Well there's no reason that it shouldn't be.' Many people I know have been called back and everything's been all right.

INT: YEAH.

Patient: Erm .. yeah, I think that's it. I didn't at that point want, I mean I told my husband and I told him I didn't really want him to come with me at that point.

INT: OF COURSE.

Patient: Er, but I didn't tell anybody else about it because people start, I mean, in a way fortunately, you know, I've got a lot of good friends but they'd be starting asking and phoning and if everything had been all right then I felt it was wasting people's time.

INT: RIGHT YEAH. AND THEN, SO, YOU WENT TO THE CLINIC, YOU HAD YOUR TESTS AND YOU SAW THE INDIAN DOCTOR ...

Patient: Yes.

INT: ERM., CAN YOU, DID HE DESCRIBE, DID HE DESCRIBE THE TREATMENT OPTIONS AT THAT POINT? THAT'S RIGHT ...

Patient: yes, he described it quite clearly that if it, he didn't say what would happen if it was benign, but he said if it was cancerous there would be, erm, the choice between the lumpectomy or the mastectomy, depending on the results, erm, followed by radiotherapy.

INT: RIGHT, OK. ERM, AND THEN AFTER THAT, YOU OBVIOUSLY, YOU HAD TO WAIT TWO WEEKS?

Patient: That's when I had the wait for two weeks, that was the longest bit of waiting in fact during the whole procedure.

INT: RIGHT. SO HOW WERE YOU DURING THAT PERIOD?

Patient: Well, that was the worst, as I say, really not good at all. It was quite difficult. They suggested I brought my husband next time, or somebody with me, and in a way I can understand that, not just because the shock of what I might, they might be telling me might be too much, but because I know when I've been with other people to things that sometimes you don't take everything in, your head's a bit scrambled. But, yes, it was a very difficult time. And I told my children at the time: my son's married and lives in Leamington; my daughter lives in Cornwall and I actually went down to see my daughter for a few days to sort of have a bit of a break anyway ...

INT: RIGHT, OK.

Patient: ... during that time. Yeah, I mean it was quite, it was quite difficult. I think that was the hardest part because all sort of things sort of went through my mind at the time.

INT: YEAH, RIGHT. AND, ERM, AND THEN YOU SORT OF, AFTER TWO WEEKS YOU WENT BACK TO HEAR YOUR RESULTS?

Patient: Yes, that was on June 7th. Yes, I went back and my husband came with me. In some ways, I don't know whether it was easier or harder with him because actually I'm his second wife, we've only been married sort of a year or two, and his first wife, who I did know very well, actually died of cancer, but not, not breast cancer, it was a non-Hodgkin's Lymphoma. Erm, so obviously certain things for him would be similar and ...

INT: YEAH, QUITE EMOTIONAL I WOULD IMAGINE?

Patient: Yes, I did sort of feel a bit difficult for him. Erm, [???

[Interruption in recording?]

INT: I WAS JUST SAYING WHAT HAPPENED WHEN YOU WENT BACK TO SEE THE, GET YOUR RESULTS?

Patient: Right, so when I went back, yes. Erm, well we, the appointment, sorry when I was told to go and see Miss Stotter becau-, and I realised then straight away, even in the waiting room, that that was probably likely to be not good news because I know that a Miss or Mr or whatever is a surgeon as opposed to a doctor - well, I mean a medical doctor. And, er, yes, we went in, and she was very direct, erm, and, which I'm grateful for really, and she said, 'Yes, it is cancerous, you've got the two options, to have the lump removed followed by radiotherapy and possibly Tamoxafen, or a full mastectomy.' She said, 'If you have the full mastectomy obviously nothing will come back in that breast, it doesn't mean something will ever come back in the other, but obviously that's more radical; if you have the lumpectomy obviously the lump will be removed and the area around it, and there's the slight possibility of further surgery if, erm, if necessary.' And, oh, in both cases, removal of the lymph nodes ...

INT: RIGHT, OK.

Patient; ... under the arm. So she outlined it very clearly. Erm, I then had to sort of go away and think about that. She said, well she indicated that, I felt she was not telling me what to do in any way, but in this case she said she felt that there was nothing to be gained by a full mastectomy.

INT: RIGHT.

Patient: But obviously I had the choice, she gave me a couple of leaflets, erm, and made a, I made another appointment when I would come back with my decision and then also to, to set a date for the actual operation.

INT: RIGHT, OK.

Patient: We mentioned that actually I'm in a sort of private scheme where, if, erm, the NHS take longer than 6 weeks, then you can go privately, and we sort of mentioned that and she, quite rightly, was very derisory and said, 'Oh we definitely we do it in no longer than three weeks,' so I thought, 'Great.' So, yes, she was, again, she was very much to the point. The question that was in my mind, er, was the recovery period and when I could drive because I don't like to feel too dependent on people, I'm not used to, I've been a widow for, er, 16 years, and I've been used to doing things for myself so that was something that's quite, you know, uppermost in my mind actually ...

INT: YEAH OF COURSE.

Patient: ... about the driving and the recovery period, which again she was very reassuring in both cases, that it was just as and when one felt comfortable doing things.

INT: RIGHT, OK.

Patient: It wasn't like a hysterectomy or something where there's a set period of time.

INT: YEAH, OF COURSE. SO THERE WAS YOURSELF IN THE CONSULTATION, THERE WAS YOUR HUSBAND ...

Patient: Yes, and there were ...

INT: THERE WAS MISS STOTTER?

Patient: Miss Stotter, yes.

INT: AND WERE THE NURSES THERE OR ANYBODY ELSE?

Patient: Yes, there were I think two, because I think my husband remarked, why did it need two people sitting there. But I don't quite know why there were two, but anyway ... one came out with us when we'd got the leaflets and they took us to a little sort of sitting room which they'd obviously got - it was, I mean it was a good thing in a way because obviously in some cases people would really be in probably a terrible state. I mean I wasn't at the time at all. In one way it was a relief just to know what it was, erm, you know, in another I think it just all, my head was sort of somewhat scrambled with it all. And she just said were we all right and that sort of thing and said about the leaflets and to read them and would I be able to understand them, things like that ...

INT: RIGHT, OK.

Patient: ... which ... actually I know that perhaps sounds, I'm not saying that she was patronising in any way because I actually, as a matter of fact, I work

with adults who have got literacy difficulties, so that was quite an interesting experience, although I had no problem reading it and understanding, I did feel that that was good, and it was said again at some other point, that, you know, if anybody had difficulties they were there to help, and I did feel sort of from a literacy point of view that was quite useful.

INT: OK. ERM, NOW WHEN, ER, MISS STOTTER ACTUALLY TOLD YOU ABOUT YOUR DIAGNOSIS, THE RESULTS OF YOUR TESTS, DID SHE USE ANY, ERM, VISUAL AIDS, SUCH AS A DIAGRAM OR THE MAMMOGRAMS OR ANY PICTURES, ANYTHING LIKE THAT?

Patient: Erm, no, nothing at all at that point. No, the only time I saw anything, and it wasn't up there for my benefit, was the first time I went in ...

INT: OH YEAH, YOU SAW THE MAMMOGRAM.

Patient: ... and I could see it quite clearly on the screen. Erm, no, she did sort of indicate where it was. Well of course they had done the biopsy so there was a little sort of puncture mark anyway, and again, oh she had a poke round again, but, you know, I mean, as I say, I still couldn't feel anything, and she indicated that it probably was quite small.

INT: YEAH, MM.

Patient: She didn't exactly say in so many words and perhaps I should have asked but anyway ... but I just felt from her indication that it was sort of in the early stages.

INT: RIGHT, OK. ERM, AND HOW DO YOU FEEL YOU GOT ON WITH MISS STOTTER?

Patient: Well I found her quite good. I had, I did hear various things from various people, but I found the straightforward approach quite good. I mean there was something afterwards which I could, I mean, are we going through this ...

INT: YES, WE'LL COVER IT YES.

Patient: ... chronologically, because there is something that I felt was quite important that she said afterwards, in a positive way. But I'll, if you want to leave that till later.

INT: YES, YEAH, OK. WE CAN COME TO THAT.

Patient: Yes, I mean I, she was very direct, very straightforward, and personally, for me anyway, I found that, you know, I've had various experiences with, er, the NHS and in some ways I'd rather people were straightforward about things than sort of waffle round the point.

INT: RIGHT, OK. AND, ERM, YEAH, I MEAN, SHE GAVE YOU YOUR DIAGNOSIS AND WHAT YOUR FEELING AT THAT POINT THEN, HAVING IT CONFIRMED THAT YOU HAD CANCER?

Patient: I know it sounds a strange thing, but the word 'cancer', I've never really had a problem with.

INT: RIGHT.

Patient: I know a lot of people do, and in fact even now, I don't know whether it's a, I'm, hopefully I'm not in denial or anything, but I see it more of a lump that obviously would grow and become obviously more difficult, erm ... so, erm, sorry - can you ask me the question again?

INT: YES. IT WAS JUST SAYING HOW, WHAT WERE YOUR FEELINGS KNOWING THAT YOU HAD BREAST CANCER THEN?

Patient: I think, and, you know, I know this is confidential [chuckles] that I was more concerned about the breast as a ... appendage, as it were, than the actual word cancer. I know that sounds - well I don't know if it does sound awful - but it is an area that, well, you know, I haven't got many good attributes, but it was one of my better attributes [chuckles]

INT: YEAH, WELL WE'VE ALL GOT THEM [???

Patient: and I mean, you know, ... [???] experiences in life, but, you know, I know that ... anyway. Er, and that was really, yeah, quite a blow really.

INT: OF COURSE.

Patient: I think, I think that was the thing as much as anything. I mean, plus, you know, the thought of a mastectomy was quite daunting, although a lumpectomy, I don't know, I've seen horrible pictures in magazines and things, so I've never perhaps seen an ordinary one where it wasn't too bad before, you know, perhaps more deformed, and I wondered if that even be worse than a mastectomy.

INT: RIGHT, OK.

Patient; But, you know, I mean, it sort of obviously dominates your head ...

INT: AHA, YEAH.

Patient: ... for that time till I went back for the, what would be the third time.

INT: YEAH, OF COURSE. AND YOU HAD SOME TIME WITH THE BREAST CARE NURSE ...

Patient: Yes.

INT: ... AFTERWARDS, ERM ...

Patient: Yes.

INT: DO YOU KNOW WHO IT WAS? WHO WAS IT, THE BREAST CARE NURSE?

Patient: Do you know any names? Oh there was, was there a Maureen?

INT: MARLENE.

Patient: Marlene. Yes, I think that some, I definitely at one point saw Marlene. Oh, in between, talking of breast care nurses, in between the first visit and the second, I phone them because after the first visit they gave me a card with the number on to say I could phone if I'd got any questions, and I think that's when I actually phoned to ask about the driving and the length of time.

INT: THIS IS AFTER YOU SAW THE, THE INDIAN DOCTOR, AND THEN ... ?

Patient: Yes, that's right, sorry, yes it is. Yes, there were one or two sort of queries I'd got and so I did phone and they were very, they very good, very understanding.

INT: OK. AND THEY GAVE YOU, DID THEY GIVE YOU A PACK OR ANYTHING TO TAKE AWAY ON THE SECOND VISIT? ANY INFORMATION? ANY WRITTEN ... YOU SAID THEY'D ...

Patient: They gave me two leaflets ...

INT: OH RIGHT, YEAH, YEAH.

Patient: ... erm, about, one about the wide excision /lumpectomy, and one about a mastectomy, just explaining the difference between the two.

INT: AND DID YOU READ THEM?

Patient: Well I did read them, yes. Erm, in some ways for me they didn't particularly say an awful lot that I perhaps didn't know, but then again this is for everybody and like, you know, I was saying about the literacy. But I suppose in my head I was going more by what Miss Stotter said really.

INT: RIGHT, WHICH WAS ...

Patient: That she, her actual words were she felt there was nothing to be gained by a full mastectomy in this case, but I had the choice, and I mean I do know that there are people who've got nothing wrong with the breast but sort of, because it's in the family, you know, have it removed anyway, which ...

INT: RIGHT, YEAH.

Patient: ... sounds quite daunting, but, erm, but ... er ... yeah, I think I went perhaps more by what she said ...

INT: OK.

Patient: ... than ... I mean the leaflets just explained little bit about the technicalities.

INT: SO IN BETW-, HOW LONG WAS IT AFTER YOU HAD THAT CONSULTATION AND YOU WENT BACK, WAS IT A WEEK LATER?

Patient: That was, yes, that was, yes, probably a week, yes.

INT: OH, OK.

Patient: Yes, it wasn't very long that one.

INT: SO IN BETWEEN THOSE TWO VISITS, DID YOU DISCUSS ANY OF THESE SORT OF ISSUES WITH YOUR FRIENDS, FAMILIES, ANYTHING LIKE THAT?

Patient: Yes. Yes, I did. Erm, I have got a friend who had a mastectomy about eight years ago. In her case she had to have one because, erm, it was peppered cells that was the problem, you know ...

INT: OH, RIGHT, YEAH.

Patient: ... rather than one lump, so she had no choice. But she, erm, she's done a lot of work for Breakthrough to Breast Cancer, of which ironically I was part of a ladies' choir, I really did a lot of work for that, so I was quite aware that there were a lot of people, she does a lot of fundraising now and knows a lot of people who've had some form or other, and, you know, they'd had lumpectomies and they were fine. Obviously she knew other people as well who'd had mastectomies and they were fine. So, yes, it's amazing, once you talk about a subject, because I feel in all case, whatever it is, it's important to sort of say what you've got. I haven't got a problem with that, some people do. And once

you say that, you know, it' amazing the people who either have had something themselves ...

INT: OR KNOW SOMEBODY, YES.

Patient: ... or knew somebody. It's just almost like an epidemic, it seems to me.

INT: WELL, YEAH.

Patient: And that's what, you know, that' what a lot of people are saying that, either there's more of it about or, I hope, that it's being, because it's being diagnosed quicker, really that that's the reason, not that there's more of it. I don't know.

INT: AND, ERM, WHEN YOU WERE BEING, WHEN YOU WERE DISCUSSING WITH MISS STOTTER AND THE BREAST CARE NURSES ABOUT YOUR CANCER AND YOUR TREATMENT OPTIONS ...

Patient: Yes.

INT: ... WAS ANYTHING, HOW MUCH DID YOU UNDERSTAND ABOUT WHAT YOU WERE BEING TOLD?

Patient: Well, yes, I understood what they were saying all right. I didn't have a problem at all with that.

INT: RIGHT.

Patient: I mean when you're sitting there and your head's a bit scrambled - I mean that's why it's good to have somebody else there, because I think my husband asked one question, I've forgotten quite what it was, whether it was to do with radiotherapy ... erm, mm ... but the fact that he was there, or somebody else was there, it sort of, you know, they could sort of remember perhaps parts that I might not have done when your head's split ...

INT: RIGHT, YEAH, OF COURSE.

Patient: ... yeah.

INT: AND, ERM, AND WHILE YOU WERE TALKING ABOUT YOUR DIAGNOSIS AND WHAT OPERATIONS YOU COULD HAVE, ERM, WHO DO YOU THINK ASKED MOST OF THE QUESTIONS AND WHO DO YOU THINK DID MOST OF THE ACTUAL EXPLAINING AND TALKING?

Patient: Well I asked, I asked, definitely asked most of the questions.

INT: RIGHT, YEAH.

Patient: Erm, Miss Stotter did most of that rather than the breast care nurses at the time when they were all in there together.

INT: RIGHT, OK. AND THEN WHEN YOU WENT BACK THE THIRD TIME TO SEE MISS STOTTER ...

Patient: Yes.

INT: I THINK, YEAH, THE SECOND TIME YOU SAW HER BUT THE THIRD VISIT TO THE CLINIC ...

Patient: Yes.

INT: CAN YOU TELL ME WHAT HAPPENED THEN?

Patient: Right, yes. Er, I went in and she said, you know, 'What have you decided?' so I said to go for the lumpectomy but perhaps stupidly, I thought, I didn't quite understand the full possibilities, that, erm, I thought like, when you got in there and you got stuck in, if you found a bigger problem ...

INT: RIGHT, MM.

Patient: ... that you could possibly do the full mastectomy there and then because what I wanted to say, if it was possible and they found something worse, then go ahead, I'd rather wake up without a breast if it was necessary than have to have another operation, but of course physically that doesn't work like that because of the, when they take away the area around the lump it has to go off to be tested ...

INT: YEAH.

Patient: ... which doesn't come back, till afterwards.

INT: RIGHT, YEAH.

Patient: So I said, all right, fair enough. But I mean I still went for the lumpectomy.

INT: RIGHT, OK.

Patient: So, yes, she, erm, really then it was just a question of setting the date.

INT: RIGHT, OK.

Patient: So literally she got out her diary and said, I think it was like two weeks.

INT: RIGHT, OK.

Patient: So I said, 'Great.' Erm ...

INT: SO WHAT'S THIS, THIS IS LIKE, UP UNTIL THIS POINT'S BEEN ABOUT A MONTH OR SOMETHING NOW, IS IT, YEAH?

Patient: Yes.

INT: [???] ALL IN ALL ABOUT SIX WEEKS FROM THE START TO FINISH ... WELL NOT FINISHED, TO THE OPERATION.

Patient: Yes, yes, that's right, it was.

INT: OK. AND, ERM ... DID YOU AT ANY, ANY POINT GET THE IMPRESSION THAT THERE WAS A PREFERENCE FROM EITHER THE NURSES OR THE SURGEONS ABOUT ANY PARTICULAR TYPE OF OPERATION?

Patient: Well, like I said, just quoting Miss Stotter, she felt 'in this case' were her actual words so it didn't sound as though she would perhaps necessarily advise it every time, it would obviously depend. Because certainly when I was in the ward I met, you know, quite a few ladies who'd had mastectomies with Miss Stotter, and so I don't, obviously it's very much on the individual case. And she said they always took away the lymph nodes as well, as a matter of course, whereas I think possibly some surgeons don't always.

INT: RIGHT.

Patient: I believe. Erm, and of course I've radiotherapy to follow up. Again she explained it was all very much a sort of belt and braces situation, to make sure that there was nothing else. So ...

INT: AND THEN YOU HAD THE OPERATION AFTER THAT ...

Patient: yes.

INT: TWO WEEKS.

Patient: Erm, the 30th June I actually went in and I had the operation the same day.

INT: WHEN DID YOU SIGN THE CONSENT FORM?

Patient: Yes, right. I signed a consent form on that third visit.

INT: RIGHT.

Patient: Because again that was the second time when, that was with the breast care nurse. She gave me the form and a leaflet to go with it, again in that little sort of room. And when away and said, 'Read that,' and come back, she'll come back and, to make sure that I'd got any questions before signing it, to make sure I understood, erm, you know, what it was all about. And, that's right, she said, 'Well don't sign it, just, I'll come back, but be ready to sort of sign, but if you've got any questions then ...' then she'd deal with them then. And I hadn't, it was all quite straightforward. And again it actually ruled, well it emphasised all the things that could go wrong, which quite rightly so, and I have noticed that on this particular visit to hospital - and I haven't had many dealing for a long time - that they are obviously much more careful these days to put forward every conceivable thing that might go wrong so, because obviously it's such a litigious society, unfortunately. And then plus the fact that you want to make they don't make a mistake ...

INT: YEAH.

Patient: ... erm, and so, yes, she came back and then I signed it. Yes, and it was quite a, the form itself, certainly from my memory of other consent forms, there was a lot more detail these days than there used to be.

INT: RIGHT, OK.

Patient: So I signed the form.

INT: AND THEN, WHAT HAPPENED AFTER THAT? YOU CAME BACK FOR ... WHEN IS IT, A WEEK, TWO WEEKS LATER?

Patient: Two weeks later. Yes, on that visit as well I had to go for a chest x-ray and a blood test.

INT: ON RIGHT.

Patient: In preparation for the operation.

INT: RIGHT, OK. SO A PRE-ASSESSMENT SORT OF THING.

Patient: Yes, that's right, yes, yes. So that, you know, for whatever, anyway, yes, because it was two weeks later, that's right, that I went into the hospital.

INT: MM. SO JUST TELL ME WHAT HAPPENED ON THAT DAY YOU WENT TO HOSPITAL FOR OPERATION.

Patient: Well, well I got up at 7 o'clock and had quick breakfast. They said you could have a bit o breakfast and then down there or 8 o'clock. Oh, they followed, Miss Stotter, erm, Miss Stotter's last interviewed where we set the date, that was followed up by paperwork from the hospital which was standard paperwork, and I did phone the breast care nurses again because I just had the question that hadn't occurred to me before that, obviously with something like this, partly psychological, partly physical, you psyche yourself up and, you know, I didn't want to phone on the morning and there might not be a bed. And, but anyway they explained that in fact that are certain, there's so many beds reserved in this particular ward for this, and unless there was some dire emergency, then it would be available. But they have to go through the usual procedure of phoning up to make sure and everything, but it was fine. And, er, my husband took me down and sort of they took more particulars, the nurses on the ward. And then he went off and, er, I sat there [chuckles] and I waited. And it shouldn't have been till half past three but fortunately it was put back, put forward, earlier, till about one-ish or something, so that was good in a way, not so long time about. Miss Stotter herself popped in, er, one of her, I presume it's, I don't know what they call them, underlings ...

INT: OH, SPECIALIST REGISTRARS.

Patient: Yes, again, an Indian girl, she was very nice, and she said she would be there during the operation but it would be Miss Stotter mostly doing it. She said there's always two. And this, everything had been all right, the chest x-ray, the blood test, everything was fine for that. Erm, and, yes, she was quite reassuring and said, well, sort of see you later, or something to that effect. And then the anaesthetist came round, very pleasant young man and he was very reassuring and, erm, explained again what would be happening in detail. I mean I must say I was impressed all along with the way they talked about each procedure, whatever they were doing, why they were doing it, what it was for. And, you know, he just took particulars, just sort of checked what obviously information he'd got already, you know, weight, height and blood pressure, things like that. And then he said, erm, see you later as well and so I just sort of sat there.

INT: SO YOU WENT DOWN ABOUT ONE O'CLOCK.

Patient: Erm, I was actually in the anaesthetic room at ten to one, I looked at the clock before I conked out. Yeah, I wanted to get my head round it. Oh another thing that I thought was quite good which I forgot to mention in those leaflets, it talked about the length of time of the operations ...

INT: RIGHT.

Patient: An hour an a half for the lumpectomy and two hours for the mastectomy. And I think that was quite good in a way, probably more for the relatives I suppose than the patient, just to know what sort of timescale it would be. So ...

INT: AND HOW WERE YOU WHEN YOU'D COME ROUND?

Patient: Erm, well fine, erm, at first. I was in a long ward somewhere with a mask on, oxygen mask, but I felt all right, it wasn't a problem. And that seemed

fine. He said, oh he said about the drugs and things, the anaesthetist, he said it, it was expression, he said, 'I like my girls to be comfortable when they come round,' was his expression, so it was quite nice really.

INT: OH, I SEE, THAT'S GOOD, ISN'T IT?

Patient: So, yeah, it was quite reassuring. And then I was in there I don't know how long it would be, I've no idea about the timescale, and then I just remember being trolleyed back sort of vaguely into the ward, erm, still with the oxygen mask and drip and things like that. Erm, and, yeah, I mean I felt fine then. And my husband and daughter came in actually to see me and I felt quite chatty, and had a terrible sore throat, really [???] but, erm, they said I think I must have been on some high on morphine or something, you know, because just as they left, I thought, 'Oh, I'm going to be sick,' and I was sick all night.

INT: YEAH.

Patient: It was horrendous.

INT: WAS THAT BECAUSE OF THE MORPHINE DO YOU THINK?

Patient: I think the anaesthetic of some sort, yes. I felt so sorry for the old ladies, I tried, oh it's horrible when there's nothing in side you.

INT: I KNOW.

Patient: My head ached and they, I couldn't, they tried to give me tablets but I knew they'd come straight back, I couldn't even keep a sip of water down at one point. But they were wonderful, they were so good and patient and ... so ...

INT: AND HOW LONG WERE YOU IN HOSPITAL THEN?

Patient: A week. They had said it would be about a week. Erm, I'd spoken to one or two people who'd already been in as well and they basically, they talked about the drains as much as anything, the drains [???] not in the sewers. And, erm, what one person said, 'Don't let them send you home with a drain in,' because apparently some people when she was in went home with the drains in and it was all a bit horrendous. I said, 'Well, no, I don't fancy that.' There was no pressure though in any way to do that. They said it's usually about seven days because on the seventh day they have to take the drain out apparently anyway, whether or not it's still leaking.

INT: YEAH. I MEAN IT GETS TO A CERTAIN LEVEL OR SOMETHING ...

Patient: Yes, that's right.

INT: THEN YOU CAN GO HOME OR SOMETHING.

Patient: Yes, yes.

INT: I'VE PICKED THAT UP FROM PREVIOUS INTERVIEWS.

Patient: Yes. Yes, it's sort of, they test, they measure it each day and they remove one fairly quickly, I think that was the one, I don't know, where, went from the breast wound or what, but I was dreading having the drain removed because I've never had that before and I thought ... and it was fine, no problem. And I must say all the nurses, you know, whatever the different levels were, they are really very, very patient, very nice. I don't know whether they've been trained, and I presume I suppose they must have had some sort of training in breast care on that ward, as well as obviously the ordinary nurses,

but you know the whole, particularly the attitude, and I noticed that with other patients, some of them got upset from time to time occasionally and, yeah, very impressed.

INT: AND THEN [??] GO BACK TO SEE MISS STOTTER?

Patient: I had to go back to the outpatients because that was the results, to get the results of the tests...

INT: OF THE HISTOLOGY, YEAH.

Patient: ... yes that's right, the histology. Erm, which, that was, I felt really quite hairy about that because during the time we were in hospital there was another couple of ladies like me, very similar, who'd just had it picked up on the mammogram, no lump, and we did encounter a few people who'd had to come back for different things - quite, well one, only a few, well, within a few weeks and, you know, I thought, 'Oh dear,' especially after the anaesthetic. And we were quite anxious about that, but I believe the other lady asked the nurses about it and she said apparently that was really unusual, it just happened that by coincidence the week we were in there were a few. She said it's really quite rare. But, erm, you know, I didn't really hear that until just after, so we, I must say, the thought of waiting to see if there was anything in the area around was really quite daunting, and almost as bad as the first waiting, I think.

INT: YEAH, YEAH.

Patient: So, anyway, at least I didn't have long to wait and I think I didn't really relax properly till after that.

INT: MM. SO HOW DID THAT CONSULTATION GO?

Patient: Well fine, erm, yes, Miss Stotter was very pleased. She looked at the wound everything and, you know, said that that'll be, you know, it's doing fine, everything was going all right physically, erm, and straight away she said, erm, you know, she said, 'You look worried to death.' I said, 'Well I am ...' [chuckles] and she said, 'well, you know, the results are fine. Everything's clear' and she said, you know, 'If you've got to have a sort of cancer then this is about the best you can.' So ... you know, you can't say fairer than that.

INT: YEAH.

Patient: Erm, yeah, she said it was great. And she didn't want to see me again until November, made an appointment. She said they will be in touch from the radiology department at the Royal Infirmary, because that's the only trouble, I have to go to the Royal Infirmary in Leicester from here which is more of a trek. Erm, and, erm, they would be sending me a letter in due course to go for a planning meeting to plan the, what would happen for the radiology.

INT: RIGHT, OK.

Patient: Radiotherapy. And, erm, and that was it. The point I was going to make before was, while I was in the hospital I was speaking to another patient who was into a lot of alternative medicine things, and she said, 'Oh, you won't be able to have a massage again, you'll never be able to have a massage, because it pushed the cancer round the body,' this is what this lady said. I did wonder myself, [??] and I actually do have massages because I've got arthritis in my neck and shoulder ...

INT: RIGHT, OK.

Patient: ... and I go to a sort of physiotherapist person, and I was a bit sort of anxious and I thought 'Well, I'll ask Miss Stotter.' So, erm, you know, I said this, and she said, she said, 'Who told you that?' So I said, 'Well another patient.' She said, 'Absolute crap!' she said, [chuckles] and it was just the way she said it, I thought, 'Great' you know, it was just so, that was it, you know, reassuring really.

INT: YES, YEAH.

Patient: So, you know, I thought well, that's fair enough, that'll do me. So, yeah, I mean I wasn't in very long.

INT: NO.

Patient: But it was long enough to get the information I needed and to feel a lot better.

INT: MM. THINKING BACK ABOUT YOUR TIME, JUST, YOU KNOW, WITH MISS STOTTER ...

Patient: Yes.

INT: ... DO YOU FEEL THAT SHE LISTENED TO YOU AND UNDERSTOOD YOUR NEEDS AND CONCERNS?

Patient: Yes. Yes, I think so. Erm ... I can't remember. I mean I think one visit, and I can't quite remember which, I had written a few questions down because I find that, erm, in these circumstances sometimes your mind goes blank ...

INT: ABSOLUTELY, YEAH.

Patient: ... and things that you'd thought of, erm, I mean I've done that before on visits to doctors and things. Erm, but yes, yes, I think she did. And then again, each time the breast care nurses were there then too and so I suppose if there'd been anything else they could have probably answered it, you know, afterwards, if there'd been anything that was going to be taken too long, because obviously I realise their time is limited. But, yeah, I felt quite happy with that.

INT: AND WHEN YOU THINK ABOUT THE TIMES YOU WERE SPEAKING WITH THE BREAST CARE NURSES, DO YOU FEEL THAT THEY WERE LISTENING TO YOU AND THAT THEY UNDERSTOOD YOUR NEEDS AND CONCERNS?

Patient: Yes, I think so, yes. I think, one thing in that department that I think would have been slightly better, they were fine in the clinic situation, I think in the ward, 'cos actually somebody else did have a visit from a breast care nurse, but I don't know if I did, while I was in, to talk about perhaps future concerns or things maybe afterwards. I mean the actual general nurse were so good that it didn't really matter ...

INT: RIGHT, YEAH.

Patient: ... really, each time there was perhaps a query or something ...

INT: YEAH.

Patient: ... but I mean there was this very much awareness that they were available because in fact I did phone - when did I phone? Once or twice I think I did phone them, I used the number that they'd given me, and they always got back to me if they weren't there straight away.

INT: MM, RIGHT, OK. CAN YOU REMEMBER WHAT IT WAS YOU PHONED ABOUT? I KNOW YOU'VE SAID

Patient: Well one of them was the driving thing. Ooh, oh ... oh, then, of course, yes, something else I forgot to mention was this seroma clinic business, that's what that's fluid's called apparently, erm, which they gave me a leaflet about. I think, now, that could have been ... no I think it was the ordinary nurses on the ward, not the ones in the clinic. Yes, if there's a build-up sort of of fluid under the arm, after the drains were taken out, then there was a, there's a clinic on a Monday, Wednesday and Friday to have it drained, and you just, it gave details about phoning a number. Yes, she talked about that and I think she talked about the, erm, how, what it would build up to. They talked about it building up to the size of a tangerine. I have been back twice and it wasn't actually as big as a tangerine but it was uncomfortable, and on both the times I thought, 'Oh dear, am I wasting their time?' but on both occasions they said, no, I was right to go back.

INT: AHA.

Patient: But that was ... now that was a breast care nurse assisted by one of the nurses off the ward who did it. And they, she also said about using some E45 cream on the wound, rub it in, just to soften it, things like that. So that was, yes, that was the breast care nurse who said that.

INT: OK. ERM, JUST GET MY QUESTIONS HERE BECAUSE WE'VE MOVED ON QUITE A BIT.

Patient: Oh ...

INT: ERM, SO WHEN YOU'D, YOU'D HAD YOUR FIRST CONSULTATION WITH MISS STOTTER AND SHE TALKED ABOUT TREATMENT OPTIONS ETC ...

Patient: Yes.

INT: ERM, HOW SOON DO YOU THINK IT WAS FROM HEARING THAT YOU HAD YOUR DIAGNOSIS OF CANCER BEEN CONFIRMED TO THE POINT WHEN YOU MADE YOUR DECISION ABOUT WHAT SURGERY TO HAVE? HOW LONG DO YOU THINK [???] [???]

Patient: Probably the next thing day, I think.

INT: RIGHT, OK.

Patient: I mean I possibly could have even said there and then, but it was nice not to feel to be pressured, I must say. Yeah, I mean, yeah, partly because, as I say, I had this feeling, the way she put it, that she felt that, and I thought, well I would take, in a way I suppose it was a gamble, as I've said before, it could have looked worse or not from the full mastectomy, but, erm, I thought, well, in the end, I thought I will take the gamble. And in fact, fortunately, the actual shape is no different. And, erm, seeing other people in hospital, that was similar too, we all showed each other our boobs. [chuckles] You get very basic in these places.

INT: YES. [CHUCKLES] DID YOU AT ANY POINT, DID YOU EVER, ONCE YOU'D MADE YOUR MIND UP, DID YOU EVER CHANGE YOUR MIND OR ...?

Patient: No. No, I didn't, no, I felt reasonably happy with it. Erm, yeah, you know, except for I suppose the underlying just slight possibility if, you know, there might be the need for further surgery, you know, the actual hassle of going through all that again. But I decided anyway to take the gamble, partly -

well in fact mainly because of the way she had put it. I mean I still had the choice, but, yeah, I decided to go with it.

INT: AND IN BETWEEN HEARING, YOU KNOW, GETTING THE CONFIRMATION OF YOUR DIAGNOSIS TO THE ACTUAL DATE YOU HAD THE SURGERY, ERM, DID YOU LOOK FOR ANY OTHER INFORMATION EITHER FROM A GP, RELATIVES, FRIENDS, NEIGHBOURS, SUPPORT GROUPS, BOOKS, MAGAZINES, VIDEO, INTERNET - ANYTHING LIKE THAT?

Patient: Yes. Well, as I say, when you start talking to people, you know, the number of people who were, [???] who've either had it or had something to do with it, that was very useful. My daughter, actually I was quite touched by this, my daughter had a friend who said there's a really must-read book, and it's called 'Your life in your hands' by somebody Plant, I don't know if you've heard of that.

INT: I THINK I HAVE, YEAH, [???]

Patient: It was quite interesting and I did get it from the library. And I also got some leaflets. Oh, a friend happened to be, yes, actually a friend [???] some event where they had got breast care leaflets and gave me a pile. Erm, and, erm, and so I read those. Erm, I mean I discussed it with friends and relatives. I mean I haven't got anybody in the immediate family who'd had the experience of it.

INT: NO.

Patient: Erm, but sort of, it did seem everywhere you looked, even in the papers, there was something. I mean the articles in the papers actually weren't a lot of use but it just showed the ...

INT: YEAH.

Patient: ... enormity of it.

INT: YES.

Patient: And possible new research that's taking place all the time. Erm, that was about it really. I didn't seek any help from any self-help group at that point.

INT: YEAH, OK. AND THINKING ABOUT THE TYPES OF OPERATION THAT WERE DESCRIBED TO YOU, DO YOU FEEL THAT YOU HAD THE AMOUNT OF CHOICE THAT YOU WANTED?

Patient: Yes, well yes, because there were just the two alternatives, so, yes, I did, yes.

INT: OK. AND THINKING ABOUT THE DECISION THAT YOU MADE, WHAT DO YOU THINK WAS THE MOST IMPORTANT THAT YOU WERE TOLD OR YOU HEARD, THAT YOU READ, OR WHATEVER, THAT HELPED YOU MAKE YOUR DECISION TO GO FOR THE OPERATION YOU DID?

Patient: Well, the number of people who'd had a lump of some sort and had the lump removed and had never had any more problems, you know, and we're talking probably a lot of years in some cases. I think that was, yeah, the positive thing, yeah.

INT: AND JUST TO GET AN IDEA, SO YOU'RE WAITING NOW TO GO AND SEE THE ONCOLOGIST, IS THAT RIGHT?

Patient: Erm, I've been to see, I've been on Tuesday to have my planning meeting ...

INT: OH RIGHT. AND HOW DID THAT GO?

Patient: Well, it went very well. Erm, except I've, came away feeling quite depressed really, far more than I had with the operation, because partly this timescale of this radiotherapy, it's five week ...

INT: FIVE DAYS FOR FIVE WEEKS.

Patient: ... of five days a week, yes. And sort of, I'm perhaps not the sort of person to be pinned down for any length of time, particularly these days with only working part-time.

INT: [???] IT'S AT THE ROYAL AS WELL, ISN'T IT?

Patient: Yes.

INT: SO I DON'T THINK IT'S AS EASY TO GET TO.

Patient: It isn't, it's the parking that's a nightmare: it's not so much getting there physically, it's parking. And ... also, I mean I know this is in confidence as well, I didn't really want to feel too dependent on my husband.

INT: RIGHT, OK.

Patient: For various reasons really.

INT: [??]

Patient: Erm, and ... again, they emphasise all the things, all the bad things, the side effects and things like that. The actual planning in the sense that they take you into ... I mean I don't know if you want to know the details ... they take you into this room [??] that's not ...

INT: YEAH, YOU CAN TELL ME, GO ON, YEAH.

Patient: Yeah, but like an x-ray room and then they have to adjust all the machinery obviously like an ordinary x-ray to fit your part the, you know, the screening, obviously in this case it's the left breast area, and got me positioned in the right position and height, and it all goes onto a computer so that, when you go, presumably each day you go, they can quickly get it into place, because obviously that took time, the actual therapy is about ten minute's which, you know, isn't too long, so it's, obviously a lot of people go through these places because obviously other cancers as well.

INT: OH RIGHT.

Patient: Oh yes, it's not just for breast cancer this, this is the oncology department for anybody, and again my husband had warned me that I might see people obviously not so well as me, which, you know, I did. So, yes, so it was, it's a very busy place and I'd also been warned about the machinery breaking down quite frequently and long delays. In theory you should be in and out within half an hour if everything's all right, but ... I'm not, somebody said take a really good book, not just a magazine, take something you can lose yourself in.

INT: [??]

Patient: So, I didn't, I feel I've not had such positive experiences of that, more because of the inconvenience than the actual treatment. Erm, they were quite keen to point out all the bad things with that. There was another thing

that the doctor at the oncology had got the result of, which was, Miss Stotter hadn't got the results at the time, was to do with the, something to do with hormones and the Tamoxafen, and I have got to take the Tamoxafen, and that plunged me into a depression really because they really, you know, they emphasise the side effects with that, the worst of all, that said, oh, you put weight on and you have to take it for five years, and all sorts of nausea and sickness and ... different things that could occur.

INT: RIGHT, YEAH.

Patient: So, although they were very, they were very good, they were pleasant, very understanding, but they, obviously they had to tell me these things. So I went to see my GP yesterday, partly just to tell him how things were and he'd got the, you know, the report from the hospital, which I'd, on coming out of hospital, the letter that I'd had to take, and he said that was very good, everything had gone very well, very positive, and so I explained about this. And he said, well, he personally - and he said then - that the doctors do have to emphasise, especially these days, all the worst things that could happen. And so he knows loads of people who've had Tamoxafen and never had a twinge, so we shall see. And he also was quite reassuring in that, erm, if it didn't suit and I was really bad or something, there are other things ...

INT: RIGHT, YEAH.

Patient: ... but they tend to use that because it's much more tried and tested than the other.

INT: ABSOLUTELY, YEAH.

Patient: And he said it's, again it's a sort of belt and braces situation.

INT: [???] RIGHT.

Patient: So, I felt, I came out feeling a bit better about it. We shall have to see.

INT: SO WHEN, WHEN DOES ALL THIS START THEN?

Patient: It all starts on the 9th August and through to the 14th September, because there's a couple of days out for bank holidays and a service day for the machine. Erm, so basically I've got to, you know, be around.

INT: WELL IF IT'S BEING SERVICED IT'S LESS LIKELY TO BREAK DOWN.

Patient: Well, hopefully, yes. Yes, that's true, I suppose, yes, actually.

INT: [???]

Patient: No.

INT: [???]

Patient: But I know people have said that, from quite a lot of people who've used that department and said this. Erm, and also from the radiotherapy I've had different report about that. Most people it's just like a bit of sunburn and it's not too bad, it will be perhaps sore, but nothing too horrendous. And some people say you feel tired and some don't emphasise that, so we'll just have to wait and see.

INT: RIGHT, YEAH. ERM, LOOKING, I'VE JUST GOT A COUPLE OF QUESTIONS LEFT ...

Patient: Yes.

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

Patient: Very, very good. Excellent. Yes, I mean, I really, well that's partly why I wrote that letter, it was partly to sort of emphasise the care and partly to try and make sure ladies go for their mammograms. But, yes, I mean from start to finish I was very impressed. I mean personally I've always been very much a supporter of the NHS. When I mentioned that private thing, I've never had any dealings with that all, my husband suggested [???] you know, did it. But, er, and I, you know, over the years, you used, I've used the NHS with my family for various things. But obviously I haven't had anything myself or anybody for a long time and so, you know, I was a bit daunted from what you hear. But I do feel that it's like news, that people emphasise the bad things and, I mean, I just could not have had - I said I couldn't have had better treatment if I'd gone privately on anything. I really do mean that. And personally I wouldn't have liked to have been in a single room either, erm ...

INT: LIKE A SIDE WARD.

Patient: Yeah, no, I wouldn't have liked that. Oh, I mean in private hospitals you have a single room all the time anyway, as a matter of course, but I would have hated that because part of this particular case was the sort of, the camaraderie of, you know, 'We're all in the same boat, girls,' sort of ... and it's very, very reassuring when, because the people are very supportive of each other, and you know you hear about their experiences and different things, and everybody I spoke to, I mean, you maybe speaking to some of them of course with your research, but certainly nobody'd got any complaints at all or [???]

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

Patient: Oh dear, that's a difficult one. Erm ... mm ... erm, I really don't know, I wouldn't know where to start. I can't think of anything really.

INT: NO?

Patient: Maybe, the only thing that in my particular case was that fortnight wait when I would have preferred less of a wait, but that's partly to do with bank holidays and I don't think that could have ... but no, I mean, like equipment and stuff that I seemed to encounter, it all seemed to be, you know, even the food was really good. Erm, everything. Oh, I'll probably think about something after you've gone but I can't instantly think of anything at all.

INT: RIGHT.

Patient: I mean are there things that I could suggest that I could say yes or no to?

INT: NO.

Patient: Oh right, no, OK.

INT: YOU'VE GOT LIKE TO SAY IT IN YOUR OWN WORDS.

Patient: Oh dear.

INT: YEAH, BUT IF THERE'S NOTHING, THAT'S FINE, THAT'S GREAT. [CHUCKLES]

Patient: I can't, you know, I mean, maybe, you know, sometimes when people suggest something I think, 'Oh ... yes, maybe,' but I mean the waiting really couldn't have been much quicker, I don't think really. Erm, and as I say the treatment by the nurses and everything. I mean the nurse at times were, there was, in fact, just the day before I came out fortunately, it wasn't earlier on, had a real, erm, I mean maybe more nurses in the ward ... not because of anything to do with me, but the last night I was there, there was a lady who'd come in the night before her operation, again you may end up speaking to her, she was younger than me but she was going to have a mastectomy, and she sort of, it was about bedtime and she was getting into bed and the nurse came round to do the blood pressures, and she started to get into a state. They drew the curtains round but of course you could hear. I mean in a way she might have been a candidate for a side ward, possibly, although we were supportive. Erm, and she also had a problem with blood pressure, so in a way one was making the other, you know, she was getting into a state, that was sending her blood pressure up ...

INT: YEAH, OF COURSE.

Patient: ... and it was chicken and egg, and it really was a very hectic night, and the nurse was wonderful, she spent loads of time with her. I mean it was our bedtime, we didn't need it, and I did have earplugs which I put in, and I sort of woke up all of a sudden about one-ish and I could hear all this talking, and they were all up, they'd all, all the rest of them were sitting up, all talking, it was like something like, something in the dorm at a boarding school or something, and this was the other patients supporting her. But, and then the next morning it was really, erm, hectic because the blood pressure was so high that when the anaesthetist came round he went berserk and wouldn't, you know, couldn't operate at the time, and ... she really had got herself into a stage. And perhaps, I mean I felt for the nurses because it was operation day and they'd got all the others to deal with as well, and it was touch and go and they were sort of phoning through her blood pressure every five minutes, and I felt for them, it really was so busy for them at that point. So I don't know whether perhaps more nurses who weren't perhaps so pressured. I mean in no way did they ever, erm, what's the word, dismiss you or, you know, say, 'Go away,' anything like that, ever, they were wonderful. And to listen to them talking with this lady, or one of them in particular, well it brought tears to my eyes really, you know, I just thought, 'Well, there for the grace of God really ...'

INT: YEAH.

Patient: But that's about all. I mean it does make me so angry about, well not just the National Health Service, but it's the same in many organisations. People at the bottom end as it were, or the nursing end, you know, they're so [??] pressure, but that's the [??] many organisation. And they were just brilliant really.

INT: AND 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?

Patient: Erm, [??] well to be, I think to be up-front with you, like Miss Stotter was, erm, and to sort of outline clearly what's, what are the alternatives. Erm, and the timescale of everything. Yes, I mean basically what is going to happen at each stage of the way, I think really, which I feel that I did have, that, you know, it was explained, at least as far as I was concerned, quite clearly, as to what was going to happen.

INT: MM.

Patient: And also the prognosis, I mean one expression Miss Stotter kept using was about me living to be a little old lady or something, which, you know, I mean, that was obviously quite encouraging of course. Yeah, I mean, it was, yes, it sort of ... it was positive, but on the other hand if the news had been worse news, I would have liked to have known that.

INT: RIGHT, OF COURSE, YEAH.

Patient: ... Personally, but then again I know that's not perhaps everybody's way, partly from various experiences I've had in my life I prefer to know the facts and what's happening, and what's likely to happen, things like that.

INT: RIGHT. AND NOW YOU'VE BEEN THROUGH THIS EXPERIENCE, WHAT ARE THE MOST IMPORTANT THINGS THAT SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT THE OPERATIONS THAT THEY CAN HAVE?

Patient: Well, I suppose, like I was given a choice, if there is a choice. I mean, if there's not, in the case of my friend, then that's fair enough, and if, I mean I don't know what was said to her but she seemed quite happy with it, but, erm, if there's no choice, then they outline that clearly and why. Again, in my case, because there was a choice, erm, to have it outlined clearly what would be the alternatives.

INT: RIGHT. HOW DID YOU FEEL ABOUT BEING GIVEN A CHOICE?

Patient: ... Well, I mean, particularly now, with hindsight, I'm very glad, because I could have gone for the mastectomy, or they could have said, 'Well, you know, this is what we do.' I should imagine probably in the case of this grandmother of mine, presumably I think they sort of just chopped it off and that was the end of it.

INT: RIGHT.

Patient: But, erm, it's nice to feel that you can still retain a greater part of your body, which obviously it is, erm, unless it's absolutely necessary to lose it.

INT: YEAH, MM.

Patient: Erm ... yeah.

INT: THAT'S FINE, IT'S OK, YEAH.

Patient: OK.

INT: THE FINAL QUESTION IS, IS THERE ANYTHING ELSE YOU'D LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY? ANYTHING YOU THINK I'VE MISSED OR ANYTHING YOU THINK THAT'S IMPORTANT WE HAVEN'T COVERED?

Patient: Well, I mean, I realise sort of your research is particularly about certain aspects, but I do feel, and somebody was telling me, erm, not long ago, it was in the paper, and I wished I'd seen it, I don't suppose it perhaps sunk in or even if I have seen it, they were talking about the mammograms, and I do feel that that is really an essential thing, and perhaps if it could be widened to a greater age group than it is, because there were quite a few people younger than me in. It was an interesting [??] from quite young to, you know, really quite elderly ladies, and I do feel the importance of that service, that it is a wonderful service - as other sort of free testing services are as well. Erm,

that more information perhaps could be available at that stage, to hopefully avoid things getting to a later stage.

INT: YEAH, OF COURSE.

Patient: And that, erm, erm, it was in the paper, this article was saying somewhere, and it was some government minister, was implying there was no evidence that mammograms were of any use. And I wish I'd seen it and I wish I knew who this minister was because I would really [chuckles] feel like writing to him. Erm, because obviously that is something that presumably, that's a financial statement, that they're trying to cut down I should think, although there's talk of extending it beyond 65 now.

INT: THERE IS, IT'S UP TO SEVENTY NOW.

Patient: Yes, is it?

INT: YEAH.

Patient: Well, that's good, but I don't know where this article ...

INT: IT'S UP TO SEVENTY, I THINK IT IS NOW.

Patient: Yes. And possibly at the younger end. Erm, it has been said vaguely and I've never took it up in earlier life, if you'd had somebody in the family who'd had it - you see, the thing is, the trouble was when people asked about my mother she actually died when I was a baby of septicaemia [???] kidney operation, so she never got to that age ...

INT: RIGHT.

Patient: ... and so I'll never know, but I said to my own daughter that perhaps next time she went to the GP about another matter, she could perhaps just mention it. And, because I have heard from certain quarters - and perhaps this is, without being elitist, er, it's perhaps less educated quarters, that 'Oh, it hurts having a mammogram.' And it doesn't hurt. It is a sort of squashed feeling, it isn't ...

INT: IT'S DISCOMFORT.

Patient: Yes, it's, no way is it painful, and this sort of gossip if you like, if that's the word, you know, can get around particularly certain stratas of society, without sort of ... erm, saying anything ...

INT: NO, THAT'S FINE, THAT'S OK.

Patient: And a lot of people in that, the other lady in the hospital, and I hope she does the research, erm, she knew people who didn't go. I mean she would know, she always went, but she said she was really going to campaign, but I mean I don't think there's anybody within my circle of acquaintances that wouldn't, whatever it was like. But I do feel that that's quite a [???] obviously because of my own experience. Erm ...

INT: YEAH, IT'S ONCE EVERY THREE YEARS, ISN'T IT?

Patient: Yes, it is. This was my third time, because I'm 58, just turned 58, and this is the third time I've been and, you know, I gaily went along, quite happily, and there we are. But I'm grateful that it is. So, erm ...

INT: OK. ANYTHING ELSE?

Patient: Erm, I don't suppose, I don't know if this is relevant or not, but while I was in there, particularly amongst the younger ladies I spoke to who had diagnosed a lump, there were one or two people who had gone to the doctor with a lump or something and the doctor – the GP I mean – had been a bit, a bit dismissive at first, erm, where I was always given to understand that if you had a lump go straight to the doctor and then they would refer you. And, I mean, unless the doctor could have diagnosed there and then that it wasn't anything like this for some other reason, it was definitely just a cyst, but I don't know whether he could have done. But there were one or two people who said they actually went two or three times before he would take them seriously. I mean I don't know, I can't speak from experience on that.

INT: NO, I'VE HEARD THAT.

Patient: Yeah, I do think that's an area that might need a bit of education on somebody's part.

INT: YEAH, ABSOLUTELY.

Patient: So ... is that OK.

INT: YES, THAT'S FINE, IT'S OK. ERM, TURN OFF?

Patient: Well, if you want to, I don't mind. I'm OK, yeah

INT: [??] [??]

[End of interview]