

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

*VENUE: Low MR unit

*DATE:

*ID: Patient59

INTERVIEWER: DJW

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

Patient: I knew that 1 in 10 women could get breast cancer. Erm, my sister had breast cancer, my eldest sister died from breast cancer. I didn't realise that there were more, there was ... there was variations in that. Erm ... I don't think I'd really given it a great deal of thought. It hadn't affected me, so it was one of those things that I hadn't thought about.

INT: MM. AND, ERM, I THINK, WHEN WE WERE JUST TALKING EARLIER ON, YOU MENTIONED THAT YOU'D HAD BREAST CANCER BEFORE, IS THAT RIGHT?

Patient: Yes.

INT: COULD YOU TELL ME A LITTLE BIT, JUST TELL A LITTLE BIT ABOUT THAT?

Patient: Yes. I had been going backwards and forwards to hospital: I'd had cysts in my breast for quite a few years, and each time my doctor sent me he said, 'I don't think it's cancer, I think it's a cyst, but we must get you checked out,' so I was quite used to this going backwards and forwards and it happened quite regularly. Then I found that, I had a puckering, slight puckering of the nipple, so I went back to my doctor and he said, 'Oh, I think we'd better get you checked out again,' so I went to hospital, had various tests and they said, no, everything was fine, not to worry, no problem. But six months later the nipple had inverted and I went back to my doctor again and he said that time he thought definitely it was breast cancer.

INT: THE DOCTOR SAID, THE GP, YEAH?

Patient: My GP doctor ...

INT: YEAH.

Patient: ... yes, he said to me, 'I would be 99 per cent sure that you've actually got breast cancer.' So he arranged for me to see the specialist and I went to see him and when he looked at me, he said, 'I would say you've got breast cancer,' so again I had various tests and they all came back negative, nothing wrong. So he said, 'Well I'm sure there is,' - this my specialist at the time, Mr [???], because obviously this is his speciality. 'I'm sure there is something wrong, I'm sure you have got breast cancer,' so what he did, he did an open biopsy and the results came back and said, yes, I had got breast cancer. So my body in fact was masking the fact that I'd got cancer.

INT: RIGHT.

Patient: So all the ordinary tests just came back as negative. So the first time I went, six months before, I'd actually got cancer but again they'd done the tests and they all came back negative. And then he said, 'I will have to do a mastectomy,' so I said, 'Well, why a mastectomy? Why can't you do a lumpectomy?' and he explained that, because where the cancer was, which was under my nipple ...

INT: RIGHT.

Patient: ... he would have to take such a big area, because it's quite, by then it was really, the cancer was quite big, erm, he would have to take such a big area with the cancer and the good tissue, that, erm, there wouldn't be very much of the breast left at all.

INT: RIGHT, OK.

Patient: As it happens when I'd actually had the mastectomy and the tissue went to the lab, the cancer had spread into the breast tissue anyway, so I would have had to have gone back in and had the ...

INT: HAD A MASTECTOMY ANYWAY.

Patient: ... had a mastectomy anyway. So, erm, he did the right thing in actual fact ...

INT: MM, OK.

Patient: ... in that case.

INT: AND THAT WAS AT GLENFIELD, WAS IT?

Patient: That was at Glenfield, yes.

INT: RIGHT, OK. [???

Patient: Yes, Mr [???], he isn't there any more.

INT: RIGHT. AND THAT WAS ABOUT SEVEN YEARS AGO, YOU SAID?

Patient: That's seven years ago, yes, yeah.

INT: AND HAVE YOU GOT ANY OTHER FAMILY HISTORY OF BREAST CANCER?

Patient: Yes. My sister next to me, five years older than me, she's had a lumpectomy, but that's ten years ago and she's still fine. My eldest sister died when she was 50 of breast cancer.

INT: RIGHT, OK. AND DO YOU KNOW ANY, ERM, ANY FRIENDS OR WORK COLLEAGUES, ANYTHING LIKE THAT, HAVE GOT BREAST CANCER?

Patient: Not got, but had, yes. I had a colleague at work and she had breast cancer.

INT: MM. AND WHAT DID SHE HAVE?

Patient: She had a lumpectomy.

INT: MM. AND WAS THIS ALL AT GLENFIELD, WAS IT?

Patient: Yes ... yes, I suppose she must have been at Glenfield. Yes, because she comes from, yeah, one of the villages. And my, I have a friend up the road who's also had a lumpectomy at Glenfield.

INT: RIGHT, OK. ERM, SO CAN YOU JUST TELL ME NOW HOW, HOW YOU GOT THIS BREAST CANCER, THIS INCIDENT?

Patient: Yes. I had been going for a mammogram every year until I got for five years, and then they said to me 'You only need to come every two years now,' so it was two years ago that I went for my last mammogram, and it was just the follow-, routine follow-up mammogram, so I didn't expect anything to come of it, just routine.

INT: SO WHO WAS FOLLOWING YOU UP? DID YOU HAVE A PARTICULAR CONSULTANT?

Patient: The clinic ... yes, no I hadn't, I have now, I do see Mr Everson now. Erm, I saw Mr Jamieson before, since Mr [???] left they didn't seem to have any system where you always saw the same person ...

INT: RIGHT, OK, SO YOU JUST SAW SOMEONE ELSE?

Patient: Yes. I mean, when I had my mastectomy I saw Mr [???] every time, he was my specialist and he was the one I saw, but they didn't, they didn't seem to have got themselves into any kind of, erm, routine about that. But I have seen, this time I have seen Mr Everson, so I don't know whether I'll continue to see him [???]

INT: SORRY FOR INTERRUPTING, I JUST WANTED TO [???]

Patient: Yes, yeah. Erm, yes, so I went for the mammogram, and then three weeks later had a letter asking me to come back and see the breast care team, and I thought, 'Oh, crumbs, you know, what's happened now?' So I went back and they explained that they'd found some calcium. Now in ladies of my age that can just be a calcium deposit ...

INT: RIGHT, YEAH.

Patient: ... could be nothing to worry about at all, but because of my history they asked if they could do a core biopsy, just to be on the safe side. And I went back a week later and I knew she was going to say something that I wasn't going to like because was, had got into a gown and I'd sat on the bed and my husband was sat, was kind of sat perhaps over there, at that side of the room, and the doctor came in, Dr [???] came in and she said to my husband, 'Would you like to come a bit closer please?' or 'would you like to come and sit a bit closer?' and I thought, 'Oh, crumbs, she's going to tell me something I don't want to know ...'

INT: RIGHT.

Patient: ... because why would she move my husband from where he was to, you know, come, kind of come in to sit close to me? And she said that they'd found some pre-cancerous cells and that some of the area round the cancerous cells wasn't very good either - they didn't exactly know what was wrong but it wasn't very good either. Erm, and she said, then she offered me either a mastectomy if I wished or a lumpectomy. Erm, she said, 'We're offering you the mastectomy, not because you particularly need it, but we find that some ladies in your position who've already had cancer and they've had a mastectomy, prefer then to have the other breast removed as well.'

INT: RIGHT.

Patient: So I said, no, I would like to save my breast if I possibly could, so she said, 'Well that's fine by me but I'll go and see Mr Everson and ask him to come and talk to you.' So then he came in and he talked to me and he said, he repeated really more or less what she had said, that some ladies would prefer to have their breast removed and I said, no, I really didn't want my breast removed and he said, 'That's fine, whatever's, whatever you want is fine by me.' So we

decided that we'd go with the lumpectomy - or I decided to go with lumpectomy. And that's where we are today. So they did the lumpectomy and of course they took the lymph nodes from under my arm.

INT: SO, AND I THINK THE FIRST TIME YOU HAD, YOU SAID THE FIRST TIME YOU HAD BREAST CANCER YOU'D ASKED THEN ABOUT THE LUMPECTOMY BUT HE COULDN'T DO IT BECAUSE OF THE POSITION OF THE CANCER AND STUFF AND WHAT-HAVE-YOU.

Patient: Yes.

INT: ERM, SO, AND THAT WAS THE FIRST TIME YOU'D BEEN BACK TO THE CLINIC SINCE YOU'D HAD MAMMOGRAMS, IS THAT RIGHT, WHEN YOU SAW DR [???] AND THEN DR EVERSON?

Patient: Yes.

INT: OK. ERM ... WHEN YOU'D BEEN ASKED TO GO BACK TO THE CLINIC, YOU GOT A LETTER TO GO BACK TO THE CLINIC, WHAT WENT THROUGH YOUR MIND AT THAT POINT?

Patient: I thought that they'd found something because for five years, or the, each time before that, I'd just had a letter which said, 'Thank you for attending your mammogram. We're pleased to tell you at the moment there's no problems ...' or words to that effect.

INT: YEAH.

Patient: But this one said, erm, that ... sometimes, the mammograms were in two parts and needed to be followed up and please would I come back and see the breast care team ... and I just thought, well funnily enough, erm, a lady at church, a friend at church, she's had a mastectomy, she had a mastectomy a year ago - all these people, when you think about it - erm, a year ago and she went to her mammogram, follow-up mammogram the same time as me, so I phoned her and I said, 'Have you had a letter, Margaret?' and she said, 'Yes.' And I said, 'Has your letter asked you to come back?' She said, 'Oh no,' she said, 'it's telling me everything, you know, at the moment everything is fine.' So again I had this feeling that they'd found something, and there was something wrong.

INT: MM, AND THAT SOMETHING WRONG, DID YOU THINK IT WAS CANCER? DID YOU THINK IT WAS GOING TO BE CANCER AGAIN?

Patient: Yes, yes, because I have this ... because now I've had cancer, and it's very irrational but you very often think things can be cancer. I've had a gall bladder operation in January and I was very pleased when I was told afterwards that everything, as far as they could see internally, was fine. Because you always, you have this in the back of your mind, if you've got it ... I know now, because obviously after I had it I read up a lot more about it and I know now that it can manifest itself anywhere in the body. It can start off as breast cancer but it can, it can be anywhere else.

INT: MM, IT CAN SPREAD, YEAH.

Patient: It can spread. And even if they've taken the breast off and so in effect taken the cancer away from that area, it doesn't mean to say that the cancer is totally gone, and I mean obviously I know that from the fact that I've got it now - whether it's, whether that's related I don't know, whether it's totally a different thing because it's in this breast, or whether it's in the body, I don't know.

INT: RIGHT. ERM, AND SO YOU WENT BACK TO, SO YOU GOT YOUR LETTER TO GO BACK AND THEY DID YOUR TESTS AND STUFF, AND DID YOU SEE THE DOCTOR THE SAME DAY? IS THAT RIGHT, DID YOU SEE THE ... DID YOU ...?

Patient: I saw, when I went back, I went back ... I had the letter and it was for me to go to clinic the next week, and that's when I saw Dr [???] and she said to me that they wanted to do the core biopsy but they couldn't, they couldn't do it that week because it needed two radiographers and a doctor, and they couldn't actually fit me, there wasn't time to fit me in. So they did me the next week.

INT: RIGHT, OK.

Patient: And I saw Dr [???] again then.

INT: THEN DR EVERSON THE SAME DAY? IS THAT RIGHT?

Patient: And, no ... then it was another week because after they'd done that it takes a week for the results to come back again.

INT: RIGHT, OK.

Patient: So that was one week I went back, the next week I had the core biopsy and the next week I saw Dr [???] and Mr Everson ...

INT: RIGHT, OK.

Patient: ... to discuss the outcome.

INT: RIGHT, OK. I WAS JUST TRYING TO GET, TRYING TO GET MY TIMELINE RIGHT. [CHUCKLES] ERM, SO WHEN YOU FIRST SAW DR [???] AND SHE SAID THAT YOU WANTED, SHE WANTED TO DO A CORE BIOPSY, DID YOU SEE ANYBODY ELSE THAT DAY?

Patient: No.

INT: NO, OK. SO IN BETWEEN AND THE WEEK WHEN YOU HAD YOUR CORE BIOPSY, I MEAN WHAT WAS GOING THROUGH YOUR MIND AT THAT POINT?

Patient: I was hoping that it was just going to be a calcium deposit.

INT: MM.

Patient: But in my back, in the back of my mind I thought they might find cancer.

INT: MM, OK. AND DID YOU DISCUSS YOUR THOUGHTS AND YOUR FEELINGS WITH ANYBODY AT THE TIME?

Patient: Yes, with, my husband and I talked about it and, erm, the lady up the road, my friend up the road, Anne, I talked about it with her as well because obviously she's been through the same thing. And my friend at church [???].

INT: RIGHT. AND AT THAT POINT, DID YOU, IF YOU THOUGHT IT WAS GOING TO BE CANCER, DID YOU HAVE ANY THOUGHTS ABOUT WHAT YOU WERE GONNA DO ABOUT IN TERMS OF TREATMENT AND [???] ?

Patient: Yes, yes, I'd already started thinking about that because I really did not want to lose the breast that I've got. I've got one breast and I really didn't want to lose that one. Erm, so in my mind I'd thought that, unless they said I'd absolutely got to have a mastectomy, then that wasn't what I wanted at all.

INT: MM, RIGHT.

Patient: Erm, I mean I made a joke of it to the girls. I said, 'Oh,' I said, 'Do you know, for one minute it went through my mind, well if I have a mastectomy then I can have a bigger bust ...' you know, 'because I can have any size [chuckles] I like ...' But, no, it was a joke and ...

INT: YEAH, RIGHT, OK. AND THEN YOU WENT BACK THE FOLLOWING WEEK TO SEE, ERM, DR [???] AGAIN ...

Patient: yes.

INT: AND SHE CON-, YEAH, THAT'S WHEN YOU, SORRY THAT'S WHEN YOU ACTUALLY HAD THE CORE BIOPSY?

Patient: Mm.

INT: RIGHT, OK. SO JUST TELL ME A LITTLE BIT ABOUT WHAT HAPPENED ON THAT DAY, PLEASE.

Patient: Yes, erm, they explained to me what they were going to do, that they were going to take samples of the tissue and the calcium and, and what they did first of all they put me into the x-ray machine and fortunately didn't me clamp me as tight as they do when they do a mammogram [chuckles] I'm very pleased to say ...

INT: OH RIGHT.

Patient: ... so, because it took rather a long time, it must have taken about half an hour, 35, 40 minutes to do. Erm, and it's a long time to sit with your breast between two plates. Erm, and all the time she was, as I say there was two radiographers and a doctor and she was talking to me about what she was doing. They froze the breast and she told me that she would be putting the thingy in and, like a little pincer like that, very fine, and would be taking samples each time, and warned me that each time that she did it that I would hear a click, which is the pincers going together. Erm, it was uncomfortable but ... as I say, they'd frozen the breast so I didn't really feel much else. It was a bit like, I explained to one of the girls, erm, when we had our, when we have our ears pierced, it's that kind of 'click' and that kind of pinching, erm, feeling that I had. Erm ... and then she just said that they were going to send it off to the lab and that I would know the results in a week's time.

INT: MM. AND THEN YOU WENT BACK A WEEK LATER TO GET YOUR RESULTS, YEAH, OF COURSE, HOW WAS THAT WEEK WAITING FOR YOUR RESULTS.

Patient: [chuckles] It wasn't very good. Fortunately I was busy at work and, erm, for a lot of the time I could forget about it, put it into the back of my mind. I work as a teaching assistant at school, so with the children, we're very busy and you don't have time to think about much else really.

INT: YEAH.

Patient: Erm, I didn't sleep very well, that was one of the problems, and of course when you're awake in the middle of the night or in the early hours of the morning and you've got nothing else, it just goes round and round in your head what's going to happen, what are they going to find, what are they going to tell me and that kind of thing. So I tried to put it to the back of my mind, but you can't, it's not possible. For a good time you can forget about it but it's always there at the back of your mind.

INT: AND THEN YOU WENT TO HEAR ABOUT THE ACTUAL RESULTS ...

Patient: Yes.

INT: ... ERM, SO, WAS ANYTHING WITH YOU?

Patient: My husband.

INT: RIGHT, OK. AND, ERM, WHAT WERE YOUR FEELINGS IMMEDIATELY YOU WENT INTO THE CLINIC TO GET YOUR RESULTS?

Patient: My stomach was very screwed up and I'd been to the toilet about three times [chuckles]

INT: OH RIGHT, OK. AND DID YOU HAVE ANY EXPECTATIONS ABOUT WHAT YOU, WHAT THEY WERE GONNA SAY?

Patient: I ... I really feel, I hoped that they would say it was calcium, but I really thought that they would say it was cancer.

INT: MM, AND, ERM, SO YOU WENT TO THE CONSULTATION ROOM AND THERE WAS YOURSELF AND THERE WAS HUSBAND ...

Patient: Yes.

INT: DR [???], IS THAT RIGHT?

Patient: Yes.

INT: ANYBODY ELSE IN THERE?

Patient: Breast care nurse.

INT: BREAST CARE NURSE, RIGHT, OK. ERM, COULD YOU SORT OF JUST TALK ME IN A BIT MORE DETAIL THROUGH THE ACTUAL CONSULTATION, FROM THE MOMENT YOU WENT IN?

Patient: Yes, erm, the breast care nurse and met us and she said, she asked me to undress from, the top half, and put a gown on, and said that Dr [???] would be with me in a minute, she was just reading my notes. Erm, and then she went to tell Dr [???] that I was ready and a few minutes later Dr [???] came in and I was sat on the bed and she came, Dr [???] came and sat beside me and my husband, as I say, my husband was sat over the other side of the room and Dr [???] asked him to come and sit a bit closer. And then she said that, erm, 'I'm sorry to tell you that, you know, there's pre-cancerous cells in what we found and some of the area around isn't looking very good either,' erm ... and then she said about, said about the options I had for treatment, and then ... then I said, 'Well I prefer to have a lumpectomy,' and she said, well, she would go and consult with Mr Everson. So she went out and left the cancer nurse there and that's when I burst into tears, I couldn't hold on any more, so I had a little cry on my husband's shoulder and, erm, ...

INT: WHAT WERE YOUR FEELINGS NOW, BECAUSE, I MEAN, NOW ACTUALLY HAVING IT SORT OF DIAGNOSED AND CONFIRMED? HOW WERE YOUR FEELINGS AT THAT POINT?

Patient: Erm, I really thought when they did the mastectomy that that was it although I'd got it in the back of my mind that it could come back. And I just thought, 'Oh no, I'm not gonna, I'm not gonna have to go through that again,' erm, and 'Will I survive?' Now I don't know why I thought that because the first time I never had, I always thought I would survive. But I'm just thinking, 'It's come back again, will I survive this time?' you know, 'Is it gonna be, that this isn't gonna be the only thing that they find?'

INT: RIGHT, YEAH.

Patient: And I still feel like that now. I haven't told my husband because he's been through so much. I mean I get all the sympathy and, as you can see, I've got ...

INT: YEAH, YOU'VE GOT A LOT OF CARDS HERE, HAVEN'T YOU? IT'S GREAT.

Patient: ... loads of beautiful cards, yes, and I've got loads, I've got, my church family are all praying for me and I've got my family and my colleagues, and I get a lot of sympathy. But he doesn't get the support that I get but he's supporting me.

INT: YEAH.

Patient: And ... I feel sometimes that he's having a raw deal, that he's always there for me but there isn't anybody there for him.

INT: YEAH, RIGHT. IT'S, THAT'S QUITE COMMON ACTUALLY, THAT'S QUITE COMMON.

Patient: So, but ... yes, so I did, I, the emotions that went through my head were, was ... 'Has it gone anywhere else? Is it just in my breast or has it gone anywhere else?' Since then I've kind of thought about it and prayed about it and, erm, I'm on a more even keel. I think, 'No, we'll take one day as it comes, we'll sort out today what today's problem is and leave tomorrow, sort that out.'

INT: AND, ERM, THEN MR EVERSON CAME IN?

Patient: Yes, then Mr Everson came in and he sat down beside me and he said, erm, that, again, he said, well, these were the options and I could either have a mastectomy and why, if I wanted one, or a lumpectomy if I would prefer, and I said, again, I would really like to have a lumpectomy, I didn't want to lose my breast, and he said, 'That's fine,' he would, he was quite happy to do whatever I wanted.

INT: MM, WERE YOU [???] WERE YOU STILL IN THE, WERE YOU IN THE GOWN OR WERE YOU ...?

Patient: I was still in, I was still in the gown. He then asked could he examine me ...

INT: RIGHT, OK.

Patient: ... and I said yes. He said, 'I want to see if I can feel it,' but the, Dr [???] had said to me, 'I don't think that you'll be able to feel it,' she said, 'cos I can't.' And he couldn't feel it.

INT: RIGHT, OK. AND, ER ... THEN WHAT HAPPENED, DID YOU SEE THE BREAST CARE NURSE AFTER THAT, DID YOU?

Patient: Then, erm, Mr Everson said he would, he got his diary out and was looking to see when he could operate, so he actually fixed the date of the operation there and then so I knew when I was going in.

INT: AND WHEN EITHER DR EVERSON OR DR [???] WERE DESCRIBING YOUR DIAGNOSIS OR YOUR TREATMENT OPTIONS TO YOU, DID THEY USE ANY VISUAL AIDS, DID THEY DRAW ANY DIAGRAMS OR SHOW YOU ANY MAMMOGRAMS, ANY PICTURES, ANYTHING LIKE THAT?

Patient: No.

INT: NOTHING? OK. AND, ERM, SO THEN YOU SET A DATE, IS THAT RIGHT, FOR THE OPERATION?

Patient: Yes, yes.

INT: AND THEN WHAT HAPPENED AFTER THAT?

Patient: Then, erm, Mr Everson went and Dr [???] said, said for me to get dressed, and then she said, 'Now, I'd like you to go with the breast care nurse and she can talk to you about what's been said, what's happened, and give you information about what's going to happen to you from, you know, till you go into hospital and what happens when you go into [???]' So I got dressed and we, she, the breast care nurse took us into a nice little room, nicely furnished, private, and said, 'Is there anything that you want to talk about? Is there anything you want to ask me? Anything you're not sure of?' and then she gave me some leaflets about the lumpectomy and what would be happening since, you know, that could go wrong, though she said 'They very, very rarely do but we have to say to you these things could go wrong, just so that you know,' the kinds of things I could do and I couldn't do, that kind of thing. They actually did that as well, I forgot to say, when I had the core mammogram, erm, the core biopsy, they gave me a leaflet all about it and explained exactly what they were going to do and how I would feel afterwards and what I could and couldn't do afterwards. So I'd got it all written down as well as what they told me, I'd got it all written down as well.

INT: ERM, DO YOU KNOW WHO THE BREAST CARE NURSE WAS THAT YOU SAW?

Patient: No, I can't remember her name.

INT: RIGHT, OK. ERM, AND ... DID YOU HAVE ANY QUESTIONS THAT YOU ASKED?

Patient: No, I didn't, because I'd already, I'd already gone through it once and, you know, all the questions that I could have wanted to ask, I think I already knew really.

INT: RIGHT, OK. AND WHEN YOU WERE TALKING TO DR [???] AND MR EVERSON ABOUT YOUR DIAGNOSIS AND TREATMENT OPTIONS, DID YOU, HOW MUCH DID YOU UNDERSTAND ABOUT WHAT YOU WERE BEING TOLD?

Patient: I understood, yes, I understood that they were telling me.

INT: RIGHT, ANYTHING YOU DIDN'T UNDERSTAND, ANYTHING YOU FOUND DIFFICULT TO UNDERSTAND?

Patient: No.

INT: NO, OK. AND, ERM, YOU SAW THE BREAST CARE NURSE AND THEN WHAT HAPPENED AFTER THAT?

Patient: Well, then we came home.

INT: OH RIGHT, OK.

Patient: And it was just a case then, that it was, erm, two weeks later when they did the operation.

INT: THE OPERATION, YEAH. DID YOU HAVE ANY FURTHER CONTACT WITH THE BREAST CARE NURSES?

Patient: No, but they gave me a card and they said if at any time I wanted to talk to them, if I thought of any questions I wanted to ask, erm, ring this number and there'd be somebody there available to talk to me.

INT: RIGHT, OK. AND, ERM, IN BETWEEN THOSE TWO WEEKS DID YOU TALK TO ANYBODY ABOUT YOUR DIAGNOSIS AND WHAT WAS GONNA HAPPEN?

Patient: I talked to my colleagues at work and my friend up the road, my friend at church. Yes, because I find personally that it helps if I can talk about it, if other people know and, erm, I know it doesn't work for everybody ...

INT: NO, OF COURSE.

Patient: ... but it does for me to talk, I'm quite happy to talk about it, and I find it helps me if I can talk about it, if I can talk about things that might be worrying me, or what's going to happen, things like that.

INT: YEAH? ERM, WHERE ARE WE? ERM ... AND THEN TWO WEEKS LATER, WHAT SORT OF, WHAT HAPPENED IN BETWEEN, DID YOU GO FOR A PRE-ASSESSMENT?

Patient: Yes.

INT: WHEN WAS THAT?

Patient: Erm, that was a week later, I went for a pre-assessment and ...

INT: WHO DID YOU SEE THEN? [???) WAS THE ...?

Patient: It was a nurse and, oh yes, I did see, erm, it wasn't, it was another doctor, I can't remember his name. The nurse did all the pre-assessment checks, the blood check, the blood pressure and weight and height and tests my heart and things like that. And then ... then I saw, oh, I hadn't seen him before, that was, that was, erm, I saw, erm ... oh ... the person who dispenses the pills ...

INT: I DON'T KNOW ...

Patient: I can't think what they're called [chuckles]

INT: THE PHARMACIST

Patient: Pharmacist, thank you. I've got a friend up the road who's a pharmacist.

INT: OH, I THOUGHT YOU MEANT, I THOUGHT YOU WERE THINKING OF A NAME, OBVIOUSLY, THINKING, 'I DON'T KNOW ANYBODY.' [CHUCKLES]

Patient: No, no ...

INT: AND THEN YOU REALISE, OH, YEAH, PHARMACIST.

Patient: Yeah, pharmacist, yes. I saw her a pharmacist: I hadn't, I hadn't seen the pharmacist before, erm, when I went in six months earlier and had my pre-check [?) I didn't, and he just wanted to know about my general health and was I on any tablets, anything like that. Erm, and then I saw another doctor, I don't know he was and I haven't seen him again since. I didn't see him when I was in hospital [???)], so ... but he just went through again the health thing, was I normally healthy and were there any problems, [???) And then he asked to examine me, so went and got the nurse so he could examine me. Erm, listened to my chest, erm, he had a feel to see if he could feel anything and then he just, 'Oh, we'll see you in a week's time.

INT: AND THEN, WHAT HAPPENED THEN, ON THE DAY OF THE OPERATION, JUST TALK ME THROUGH THAT.

Patient: Yes. I had to be in, I wasn't allowed to eat anything after 12 o'clock, and to drink anything after 12 o'clock, and I had to be in at half past seven, but I had to phone at half past six to see if there was a bed for me before I went in. So we went in for half past seven and the nurse came and she gave me my band and I'd, they'd already told me that I would need to go down to the breast care unit and have a wire inserted so that the doctor, would know where he was going when he actually came to operate, so I knew that some time in that morning before I went down for surgery I'd need to have this done. Erm, the nurse came and said that I was due to go down at half past ten and the anaesthetist would come and see me and then I would go down to the breast care unit and have the wire put in, which would be the same procedure as the core biopsy, they would freeze the breast and put the wire in. The anaesthetist came and he talked to me and said was there any problems and had I been sick after my last operation, looked at my blood pressure, temperature, things like that, and then said he was quite happy and that he would see me down in the anaesthetic room. Erm, then somebody came from the breast care unit and said 'We're ready for you down there,' so I went down there and had the wire inserted. And by the time I got back it was time for me to get into the beautiful operating gown that they supply in hospital [chuckles] that is an all down the back. Erm, so I then got changed into my operating gown and about half past ten somebody came up for me to take me down to surgery.

INT: RIGHT, OK. AND WAS IT MR EVERSON THAT PERFORMED THE SURGERY?

Patient: Yes.

INT: YEAH. WHEN DID YOU SIGN THE CONSENT FORM FOR THE ... WHAT SURGERY YOU WERE GOING TO HAVE?

Patient: Erm, between, when I came back from the, erm, after having the wire put in, the nurse came and sat on the bed and she went through again, went through all the checks, asked, you know, asked the same kind of questions that I had been asked two or three times before, and she was the one who, erm, showed me ... no, she didn't, I beg your pardon, it must have been one of the, it was one of the doctors, he came up with the form, again somebody I hadn't, I hadn't seen before. He'd got the form and he came and explained what he, that's right, he came and explained what was going to happen and ... now what did she say? She said something he hadn't written on the form that he ought to before I signed it ... I can't remember what it was, but he'd, there was something he hadn't written on the form that he should have done, so she made him take it away, the nurse did, until he'd done ... she said, 'Don't sign that because ...' she said he's got to put whatever this was, and I can't remember what it was ... anyway, erm, ... so then she was, she was doing her, all her pre-checks, and then he came back with the form and she looked at it before she gave it to me to make sure that what it was was written in, so that then I signed to consent form, to [??] the operation.

INT: AND WHEN YOU CAME ROUND HOW WERE YOU, AFTER THE OPERATION?

Patient: [chuckles] Erm, I wasn't too bad actually, no, no. And because I'd been sick after my, when I had my gall bladder done, the anaesthetist said to me, 'Oh, I'll make sure you're not sick after this,' and I didn't, I felt, didn't feel too bad at all.

INT: AND HOW LONG DID YOU STAY IN HOSPITAL?

Patient: Just overnight [???

INT: DID YOU GO OUT THE NEXT DAY?

Patient: I didn't, I didn't have to have any drains ...

INT: OH RIGHT.

Patient: Now I don't know why, I don't know why, and I shall ask, erm, when I go, I'm going tomorrow actually for the results ...

INT: OH, RIGHT.

Patient: ... tomorrow afternoon. Mm, so, because I didn't have to have any drains in then Mr Everson - well it wasn't him, it must have been his houseman, said, erm, if I felt all right then there was no reason why I shouldn't go home.

INT: OH, RIGHT, OK.

Patient: So I went in one, half past seven one day, came out four o'clock the next.

INT: MM. AND SINCE THEN HOW HAVE YOU BEEN?

Patient: Sore, achy ...

INT: MM.

Patient: Erm, I've had a problem with my, my arm here, but I've been back to see my GP and he just, he thinks it's the nerves, thinks that because they were messing around under my arm here, think they've actually disturbed ...

INT: OH, TAKEN, DID THEY TAKE SOME LYMPH NODES?

Patient: Yeah, they took some lymph nodes ... that they disturbed the nerves and that's what's causing this, the pain that I've got here, so he's given me some anti-inflammatories to see if, erm, it is better than it was, it's not right but I can actually, I couldn't do that before, I couldn't stretch my arm out it hurt so much [chuckles] ...

INT: RIGHT.

Patient: ... so, erm, 'cos first of all I thought it was bruising because I had a, I had a bruise from there down to there, a bruise across here, and I thought, 'Oh, it's probably, you know, internal bruising,' which they'd said to me, 'Even if you can't see it, it will be bruised internally.'

INT: MM, OF COURSE, YEAH.

Patient: Erm, so I thought that's probably internal bruising but when that started to go this was still hurting, that's why, you know, better go see my GP.

INT: MM, SO ... AND, YOU'VE HAD YOUR OPERATION, SO WHAT HAPPENED AFTER THAT IN TERMS OF, HAVE YOU BEEN BACK TO SEE .../

Patient: No, I'm going ...

INT: OH, YOU'RE GOING BACK?

Patient: ... tomorrow.

INT: RIGHT. IS THAT TO SEE MR EVERSON?

Patient: Yes.

INT: AND THAT'LL BE THE RESULTS OF THE HISTOLOGY?

Patient: Yes.

INT: YEAH. WHAT THEY TOOK OUT AND [???

Patient; Yes, yeah.

INT: ERM, OK, THINKING ABOUT THE TIMES YOU SPOKE WITH, ERM, DR [???] AT FIRST, ERM, DO YOU FEEL THAT SHE LISTENED TO YOU, THAT SHE UNDERSTOOD YOUR NEEDS, YOUR CONCERNS, ANSWERED YOUR QUESTIONS AND THINGS?

Patient: Yes, yes, she, they do, she wasn't, wasn't rushed or anything, she didn't, you know, didn't ... I didn't feel as if she was rushing me, she was quite happy to sit there and listen to what I'd got to say.

INT: MM, AND A SIMILAR SORT OF QUESTION ABOUT MR EVERSON, DO YOU FEEL THAT HE LISTENED TO YOU AND UNDERSTOOD YOUR NEEDS AND CONCERNS?

Patient: Yes, yeah. Again, he sat, you know, he sat himself down beside me on the, on the bed and he was listening to what I was saying.

INT: HOW DO YOU FEEL YOU GOT ON WITH DR [???]?

Patient: Very well.

INT: YEAH?

Patient: Mm, yes.

INT: AND WHAT ABOUT MR EVERSON, HOW DID YOU GET ON WITH HIM?

Patient: Yes, I mean, I didn't see, actually seeing her obviously, I've only seen him once, so that's very difficult to tell really, and it was only for a few minutes, just when he came in and confirmed what she'd said. Erm, so, yes ...

INT: WHAT WERE YOUR FIRST IMPRESSIONS OF HIM? YOU'VE OBVIOUSLY ONLY SEEN HIM ONCE SO WHAT WAS YOUR FIRST IMPRESSION?

Patient: Erm, he seemed very nice, very pleasant, yeah.

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

Patient: Yes, the one in the clinic particularly, I thought she was very good. Erm, I saw one in the ward and she was a different one and ...

INT: WHEN WAS THIS, AFTER YOUR OPERATION [???] ?

Patient: Yes. In a way she, [chuckles] I felt she was a bit dismissive, because I'd only had a lumpectomy and ... six of us in the bay, and four of the other ladies had all had mastectomy, erm, and I hadn't got any drains in, you know,

so it was kind 'Well, you're all right, aren't you?' kind of thing. Well I was ...

INT: YEAH, OK.

Patient: But ...

INT: AND THIS WAS A BREAST CARE NURSE WAS IT?

Patient: That was a breast care nurse, yes. Now they might have been turned [?] I mean it obviously wasn't, not intentional, I mean, obviously she didn't intend for that to come over that, but that's how I felt, that I'd only had a lumpectomy and I hadn't got a drain in so, you know, she didn't need to spend the time there with me.

INT: RIGHT, OK.

Patient: Erm, as it happens I didn't need her to. So ... [chuckles]

INT: ERM, THINKING ABOUT THE NURSES AND DR [???] AND MR EVERSON, DO YOU, DID ANY OF THEM SEEM TO HAVE, THINKING ABOUT THE OPERATIONS YOU COULD HAVE, THE TWO OPTIONS, DID ANY OF THEM SEEM TO HAVE A PARTICULAR TREATMENT IN MIND?

Patient: No.

INT: NO?

Patient: No.

INT: RIGHT.

Patient: It was, I had the feeling that Dr [???] thought I might choose to have a mastectomy, erm, but that's just a ...

INT: WHY WAS THAT? WHAT GAVE YOU THAT IMPRESSION?

Patient: ... I don't know really.

INT: WAS IT SOMETHING SHE SAID OR [???] ...?

Patient: I think it probably was, yes, the way, perhaps it was the way she said it. And then when I said I definitely wanted if possible to have a lumpectomy she said, 'Oh, well, I'll go and have a word with Mr Everson,' so I had this feeling - I suppose that, it was a, it was an overall general feeling that she felt that I ought to opt for the mastectomy.

INT: RIGHT, OK. ERM, [???] AND WHEN YOU SAW THE BREAST CARE NURSES, DID THEY GIVE YOU ANY, DID THEY GIVE YOU SOME LEAFLETS [???] ?

Patient: Yes.

INT: DID YOU READ THOSE Leaflets?

Patient: Yes.

INT: YEAH, AND DID YOU FIND THEM USEFUL AT ALL?

Patient: ... I already knew the information that was in them.

INT: MM, OH YEAH, FROM BEFORE [???]

Patient: ... from before [chuckles] so, yes.

INT: RIGHT, OK.

Patient: And the information was more or less the same, but it didn't hurt to go through again to refresh it in my memory.

INT: AND ONCE YOU'D, ONCE YOU'D ACTUALLY HEARD YOUR DIAGNOSIS THIS TIME, IT HAD BEEN CONFIRMED, ERM, FROM THAT POINT, HOW LONG DID IT TAKE YOU TO MAKE UP YOUR MIND ABOUT WHAT SURGERY YOU WERE GONNA HAVE?

Patient: I'd made up my mind straight away, 'cos I'd already been thinking about what they would say ...

INT: RIGHT.

Patient: ... and the options I had, and I'd already thought to myself and I'd actually said to my husband that if possible I would have a lumpectomy, didn't want to have a mastectomy again.

INT: I KNOW YOU MENTIONED, YEAH, THAT LITTLE JOKE EARLIER ON, [???], BUT IN BETWEEN HEARING YOUR DIAGNOSIS AND THE TIME [???] SURGERY, UP TO THE POINT WHEN YOU'D HAD YOUR SURGERY, AT ANY POINT DID YOU CHANGE YOUR MIND?

Patient: No.

INT: NO? [???]

Patient: Yes.

INT: IN BETWEEN HEARING YOUR DIAGNOSIS AND YOUR SURGERY, ERM, YOU OBVIOUSLY GOT THE INFORMATION FROM THE BREAST CARE NURSES AND ALL THAT, ERM, DID YOU LOOK FOR FIND OR WERE GIVEN ANY OTHER INFORMATION ABOUT BREAST CANCER AND ITS TREATMENT, EITHER FROM A GP, RELATIVES, FRIENDS, SUPPORT GROUPS, BOOKS, MAGAZINES, VIDEOS, INTERNET, TELEPHONE HELPLINE - ANYTHING LIKE THAT?

Patient: No.

INT: NO? [???] ERM, AND THINKING ABOUT YOUR SURGICAL CHOICES, YOU KNOW, THE OPTIONS YOU HAD, DO YOU FEEL YOU HAD THE AMOUNT OF CHOICE THAT YOU WANTED [???]

Patient: Yes.

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

Patient: ... I think the most important thing was that it was contained, they were telling me it was contained in a small area and, because of that, because they said it was a just a small area, I felt that the lumpectomy was the best option for me.

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

Patient: I'm very happy with the care I have received.

INT: DO YOU THINK IT'S MET YOUR EXPECT-, ANY EXPECTATIONS YOU HAD?

Patient: Yes. Yes, they're very caring, they'd, everything was done as fast as I'm sure that it was possible to do - I know I've had to wait a week for different things but obviously things like stuff going to the lab is going to take a while to do, it can't be done immediately. Erm, so in that case, you know, I think that everything else has gone very well.

INT: RIGHT, OK.

Patient: Could you stop a minute please ...

INT: YEAH, NO WORRIES.

[Interruption in recording]

INT: YEAH, WAS THERE ANYTHING ABOUT THAT CARE IN THAT TIME THAT DIDN'T MEET YOUR EXPECTATIONS?

Patient: No, no, I have been happy with the treatment that I had in Glenfield, it's a very nice breast care unit and it's ... it's nice that when you have a particular problem, as in breast cancer, that you go to an area that just deals with that one thing, and especially such an intimate part of your body as well, a woman's body particularly, and that you know you're comfortable in the area, and that you know people understand why you're there really, and, yes, it's very good.

INT: THINKING ABOUT THE FIRST TIME YOU HAD A BREAST CANCER AND YOU WENT TO THE SAME CLINIC, WAS THERE ANY CHANGES OR ANY DIFFERENCES IN THE WAY THAT THE SYSTEM WORKED THEN, OR ...?

Patient: Yes, because when I first went they didn't have ...

[Interruption in recording]

INT: RIGHT. ERM, YES, YOU, SEVEN YEARS AGO, I WAS ASKING IF THERE WAS ANY, IF YOU THOUGHT THERE WAS [???] IN THE SERVICE, OR ...?

Patient: Yeah, when I, [???] they didn't have a dedicated breast unit ...

INT: RIGHT.

Patient: ... it was just the normal outpatients, you went into normal outpatients area.

INT: RIGHT, OK.

Patient: Erm, but I apart from that, no, I don't think so because I actually saw Mr [???] all the way through last time, which was nice, because, erm, every time I went into clinic it was Mr [???] I saw, I didn't see anybody else, and, erm, I saw the same breast care nurse as well last time all the way through. It's still, they still had the system, the breast care nurses were there and they still took you off to one side and talked to you, you know, erm, so they did more or less the same things but it was in a general clinic rather than in the breast care unit. So that would be the only difference ...

INT: RIGHT, OK.

Patient: ... I think.

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

Patient: ... I think it would be to see the same doctor all the way through.

INT: RIGHT, OK.

Patient: So that you've got continuity. I saw, I have seen Dr [???] actually, I've seen her several times now; I saw Mr Everson once; when I was on the ward I saw different, all the time I saw different doctors, and it's nice to feel that you see somebody who knows a bit about you without having to look at your notes and read your notes up all the time.

INT: RIGHT, OK. ERM, LAST COUPLE OF QUESTIONS. NOW THAT YOU'VE BEEN THROUGH THIS EXPERIENCE, WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW FIRST ABOUT THEIR DIAGNOSIS?

Patient: ... What their options are.

INT: MM.

Patient: What kind of surgery they are going to have or can have ... Yeah, I think that's, that's the most, as far as I'm concerned, it's the most important thing, to really have a good discussion about what kind of cancer, and what kind of surgery you can have, what the options are for that.

INT: MM.

Patient: Erm ... I can't think, it's difficult to think ... I was trying to think how I felt first time because I think that's different from, in a way, how I felt this time because I actually had more idea this time of what was going to happen ...

INT: RIGHT, YEAH OF COURSE.

Patient: ... than the first time, which was totally, erm, totally different.

INT: MM.

Patient: Yes, I think the most important thing is that your options for surgery are spelt out to you, and why, why the doctor feels that, or perhaps if the doctor feels that this one would be better than this one, why. Erm, when I had my mastectomy I did say to Mr [???] 'Have I got to have a mastectomy?' I can remember saying that, and he said, 'Yes, because ...' and then explained why he felt that the mastectomy was the best option for me. So I didn't actually choose a mastectomy with Mr [???], he actually said to me ...

INT: RIGHT, OK.

Patient: ... 'This is what I want to do.'

INT: YEAH, MM.

Patient: I didn't argue, and especially, as I said, apart from when I'd said to him, 'Why?' and then he explained to me while he felt mastectomy was the best option.

INT: AND A SIMILAR SORT OF QUESTION, ERM, NOW YOU'VE BEEN THROUGH THE EXPERIENCE, WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT THE OPERATIONS THAT YOU CAN ACTUALLY HAVE?

Patient: How you are likely to feel afterwards ...

INT: RIGHT.

Patient: ... about it. Now that's difficult because everybody in a way will feel differently, but I think your breast, for a female, is so much part of your femininity that to lose it is a really big shock, and especially when you look at yourself afterwards ...

INT: YEAH, OF COURSE.

Patient: ... and see, just totally nothing there, it's totally flat. So ... it's, that's, yeah, it's, it's difficult.

INT: MM.

Patient: I would say that, if they can, to let you know how you're likely to view it afterwards ...

INT: RIGHT.

Patient: ... but I think that would be a very difficult thing to do.

INT: MM, RIGHT. HAVE YOU ANY IDEA HOW THEY WOULD DO THAT?

Patient: Well, that's it, it's very difficult, isn't it? Erm, one of the things is to ... that you can assure, reassure people, women, that they will get used to it and that, even though at the time - and I'm talking about a mastectomy - you look at it and you think, 'How am I gonna get used to this? How am I gonna get used to looking at me like this? What will my husband think about this? ... partner,' but after a while, after time, you actually do forget about it, and it's when you kind of occasionally get out the shower and look at yourself in the mirror and think, 'I've only got one breast,' but it isn't something that stays there, it is something that evens itself out ...

INT: [???

Patient: Yes.

INT: MM, OF COURSE. ERM, ONE THING I WANTED JUST TO CLARIFY WITH YOU FROM WHEN YOU WENT FOR YOUR INITIAL MAMMOGRAM, AND THEN OF COURSE YOU WERE CALLED BACK, ETC, TO THE POINT WHEN YOU HAD YOUR SURGERY, HOW LONG ARE WE TALKING ABOUT THERE? FOUR OR FIVE WEEKS [???

Patient: It was, I had, it was three weeks till I got my letter back ... so that's three, then I went back to see them the following week, so that's four; they I had my core biopsy ...

INT: THAT'S FIVE.

Patient: ... that was five; then I went back to see them for the results, that's six; and then two weeks later ...

INT: IT'S LIKE EIGHT WEEKS.

Patient: ... it's eight.

INT: EIGHT WEEKS, YEAH, FROM START TO SURGERY. OK. ERM, AND REGARDING, AND REGARDING THE, ERM, THE SURGICAL OPTIONS THAT YOU GOT [???] WAS WHEN YOU WERE GIVEN A CHOICE OF OPTIONS, HOW DID YOU FEEL ABOUT HAVING A CHOICE?

Patient: Erm, I wanted the choice because I actually had decided that's what I wanted, but ... I also felt, I mean I was happy with what Dr Everson said, because, Mr Everson said, because that's what I wanted, but in some ways it would have been nice if he'd said, 'Yes,' he thought that that was the best option as well ...

INT: RIGHT, OK.

Patient: ... rather than he was happy to do whatever I wanted to do.

INT: YEAH.

Patient: So, although that's what I wanted, I felt it would have been nice if he'd agreed that that was the best option for me.

INT: RIGHT, OK.

Patient: Although I didn't need his agreement [chuckles] if you can understand what I mean.

INT: YES, YES. ERM, THE FINAL QUESTION, IS THERE ANYTHING ELSE YOU'D LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY? ANYTHING, IMPORTANT POINT, YOU THINK WE'VE MISSED OR SOMETHING WE HAVEN'T COVERED, OR ...?

Patient: No, I don't think so. I think, erm, you've covered everything that is ... pertaining to the whole procedure.

INT: RIGHT, OK. I'LL TURN OFF.

[End of interview]