

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

*VENUE: Low MR unit

*DATE:

*ID: Patient57

INTERVIEWER: DJW

INT: WELL FIRST OF ALL THANK YOU VERY MUCH FOR AGREEING BEING INTERVIEWED. I'D LIKE TO START WITH QUESTION ONE WHICH IS 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: Erm, I didn't know very much. I thought I knew things about it, but then I subsequently found that there was a lot more to it that I didn't know.

INT: RIGHT, OK. WHAT SORT OF THINGS DID YOU THINK YOU KNEW?

Patient: Erm, well one hears about lumpectomy and mastectomy and I assumed it was as straightforward as that, but I didn't realise that the node investigation would create a more painful scar than the actual removal of the tumours, you know, that's kind of thing.

INT: OH RIGHT, OK, YEAH.

Patient: So I thought there would be just a little nick under the arm.

INT: OH RIGHT.

Patient: A nick here and there, but in fact it's, you know, it's quite big scars. But, you know, it's a word that you don't know much about except what you hear on the television.

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

Patient: No.

INT: NO? WHAT ABOUT ANY FRIENDS OR COLLEAGUES OR ANYTHING LIKE THAT THAT HAVE HAD BREAST CANCER?

Patient: No, I haven't, no. I've known of people but nobody personally.

INT: RIGHT, OK. AND YOURSELF, I MEAN, YOUR OWN MEDICAL HISTORY, ARE YOU, BEEN A GENERALLY WELL PERSON OVER THE YEARS?

Patient: Yes, always, yes.

INT: OH, THAT'S GOOD. ERM, SO CAN YOU JUST TELL ME HOW YOU FIRST CAME TO FIND OUT THERE WAS SOMETHING WRONG?

Patient: Erm, I went for the routine screening in Leicestershire and was recalled for a second visit to Glenfield and, erm, that's when the tumours showed up on the x-ray and I couldn't feel them, and they were quite small but, erm, I had that done on the Wednesday, and then the next day I had core biopsies done and the result of that in the following week was that the tumours were malignant.

INT: RIGHT, OK. SO WHEN YOU, YOUR FIRST X-RAY MAMMOGRAM, WAS AT THE GLENFIELD OR WAS IT AT A MOBILE UNIT?

Patient: A mobile unit, yes.

INT: OH, IT WAS A MOBILE UNIT, WAS IT? YEAH, RIGHT. AND THEN YOU WERE CALLED BACK TO GLENFIELD?

Patient: Yes.

INT: THAT'S RIGHT, OK. ERM, SO THE FIRST TIME YOU WENT BACK TO THE GLENFIELD FOR YOUR SECOND MAMMOGRAM, YOUR SECOND X-RAY, YEAH, AFTER THE MOBILE UNIT, ERM, CAN YOU JUST TELL ME A LITTLE BIT MORE DETAIL ABOUT WHAT ACTUALLY HAPPENED ON THAT DAY, PLEASE?

Patient: Erm ...

INT: AS MUCH AS YOU CAN REMEMBER, IT'S A BIT DIFFICULT ...

Patient: Yes, I'll just get my little diary [??] ... Yeah, so I went on Wednesday, the 16th, that was the call-back visit and I was given more x-rays, erm, I think that was all on that occasion. Then the next day went for the biopsies, that's right, biopsies ...

INT: ON THAT WEDNESDAY, DID YOU SEE A CONSULTANT AT ALL? DID YOU SPEAK TO ANY OF THE CONSULTANTS?

Patient: No.

INT: RIGHT. DID YOU SEE THE NURSES?

Patient: Yes, and the radiographers and some doctors were in there doing the x-rays.

INT: AND DID THEY SAY ANYTHING AT THE TIME WHEN THEY WERE, YOU KNOW, TAKING THE X-RAYS AND ...

Patient: Did you say see or say?

INT: SAY, DID THEY SAY ANYTHING TO YOU AT ALL? DID THEY INDICATE AT ALL THAT IT COULD BE CANCER OR ANYTHING?

Patient: No.

INT: NO, RIGHT. AND THE SECOND DAY YOU WENT FOR CORE BIOPSIES AND THINGS ...

Patient: Yes.

INT: RIGHT, OK. SO CAN YOU TELL ME A LITTLE BIT WHAT HAPPENED ON THAT DAY?

Patient: Erm, yeah, similarly, I was given the x-rays, erm, and the samples were taken. Erm, and that was all that day.

INT: AND DID YOU SEE A CONSULTANT AT ALL THAT DAY?

Patient: No.

INT: ANY OF THE BREAST CARE NURSES DID YOU SPEAK TO?

Patient: They were around.

INT: THEY WERE AROUND.

Patient: I could have spoken to anybody if I'd needed to, but I didn't feel I wanted to ask any questions until I'd had any information to ask about, you know. So I was waiting for the results really.

INT: RIGHT, OK. DURING THIS TIME, WHAT WAS GOING THROUGH YOUR MIND? WHEN YOU GOT THE CALL BACK AND ...

Patient: Erm, I was still thinking that they might be benign cysts or something like that because a few years I had a mammogram and there were some cysts ...

INT: OH, RIGHT, OK.

Patient: ... which have subsequently cleared. That was on the right side, but thi time it was the left side that was being investigated, and, erm, I still felt at that point that it was going to be something harmless.

INT: AND DID YOU AT ANY POINT THINK IT MIGHT BE A CANCER?

Patient: Not really, because there wasn't any history of it in my family and I was so healthy, and I couldn't feel them. So, you know, I thought it was going to be all right. [chuckles]

INT: AND THEN YOU, DID YOU GO, WAS IT A WEEK LATER YOU WENT BACK FOR YOUR RESULTS? IS THAT CORRECT?

Patient: That was the Thursday and I went on the Monday, so it wasn't too long.

INT: OH RIGHT, NOT AT ALL, THAT'S QUITE QUICK THAT.

Patient: Yeah.

INT: AND CAN YOU JUST TELL ME ABOUT WHAT HAPPENED ON THAT PARTICULAR DAY?

Patient: Yes. Erm, we went in to see Mr Windle [?] and ... erm, he said, within about half a minute he had given me the information more or less straight in. 'Hello,' you know, 'How are you?' and all that sort of thing, [???] 'Right, this is what we've found,' and he drew it on a piece of paper for me to see the two tumours, and he wrote a little word at the side with an arrow that said 'cancer'. [chuckles] And he said 'This one is malignant. We think this one is but we're not sure, so, you know, we need to investigate that further. So ...' and then he said, 'So, it's up to you whether you'd like to have a wide excision or a mastectomy.' Just like that, you know.

INT: RIGHT, OK.

Patient: So, my initial thought was, 'Oh, I want a mastectomy, get rid of it all.' That was my first thought, you know, cosmetically or anything like that doesn't matter, just go for the healthy option.

INT: RIGHT, OF COURSE, YEAH.

Patient: And I felt I was floundering a bit because the breast care nurse was there, Mr Windle was there, but my other daughter was with me, but there was no information on which to make a choice. I wasn't being forced to make a choice on the spot, but it was put to me that I was going to have a choice, and I could come in the following week and have the operation. Only a week, they offered me a date which I didn't take, erm, so then I was told, 'Well, you know, you think about it.' And Mr Windle examined me and said he couldn't really feel them. Erm, so, I wouldn't say I was in a state of shock but I was very surprised, you know, at the result because I had been thinking it would be a positive outcome, so it was something to assimilate. Erm, so then I tried to research it a bit, you know, sort of had a look on the internet and things, discussed it with breast care nurse at various points on the telephone ...

INT: OH, OK.

Patient: ... so they were very helpful, but at no point did anybody say to me, 'Because you've got this kind of condition you need to have that operation.'

INT: NO, SURE.

Patient: Nobody ever said that to me. And nobody said to me, 'This operation will cure it, or that operation will cure it.' I more had the impression that neither operation would guarantee a cure, erm, so, you know, it wasn't that one was going to be, solve the problem.

INT: YEAH, OK. AND WHEN YOU WERE IN THE CONSULTING ROOM, WHEN YOU FIRST WENT, WHO WAS IN THERE? THERE WAS YOURSELF, MR WINDLE ...

Patient: A breast care nurse, and my other daughter, she was with me.

INT: NOBODY ELSE. WAS ANYBODY ELSE THERE?

Patient: No.

INT: OK, RIGHT. ERM ... AND WHEN HE TOLD YOU ABOUT, YOU HAD YOUR CANCER, AND THE OPTIONS, WERE YOU SURPRISED OR SHOCKED THAT YOU HAD ANY KIND OF CHOICE IN THE SURGERY?

Patient: Yes, I was, yes. Because all my life if I've needed to go to a doctor, I've followed instructions: 'Take these tablets' or 'Do nothing' and whatever I've been advised I've always followed those directions. But here I am with something sounding serious and no advice really, no ...

INT: RIGHT, OK.

Patient: ... and I couldn't understand why. Although subsequently I do ...

INT: YES, YEAH.

Patient: .. but at the time I was just so mystified, why am I not being told 'This operation is suitable for your condition'?

INT: RIGHT, YEAH, OK. ERM, AND WHEN YOU WERE, WHEN IT WAS CONFIRMED THAT YOU HAD A CANCER, WHAT SORT OF WENT THROUGH YOUR MIND AT THAT POINT?

Patient: Erm, surprise. I wouldn't say I was in a state of shock: I was surprised, erm, and then I worried that the biopsies that disturbed the tumours [chuckles] and caused them to move around in my system because it was described as an invasive cancer, which to me meant it was on the march if it was allowed to get out, you know. [chuckles] So, it was just a kind of layman's interpretation of what you hear. But that concerned me, that it might have disturbed something that's sitting there quite happily doing nothing, so I mean that was a bit of anxiety over that.

INT: RIGHT, OK. ERM, SO YOU SPOKE TO MR WINDLE, HE GAVE YOU SOME OPTIONS, HE DREW SOME DIAGRAMS ...

Patient: Yes.

INT: AND DID YOU FIND THOSE DIAGRAMS HELPFUL IN ANY SORT OF WAY?

Patient: Erm, yes, I did show, yes. I've still got it actually.

INT: OH RIGHT, OK.

Patient: On a paper towel. [chuckles]

INT: ON A PAPER TOWEL? IS THAT WHAT HE DREW IT ON?

Patient: On a paper towel, yes.

INT: OH RIGHT. OH, YOU'VE GOT IT THERE, CAN I HAVE A QUICK LOOK?

Patient: Somehow it diminished my illness, in some way to see it on a paper towel. I think it's still here. I'm still getting rid of all these things.

INT: [???] OK, HERE WE GO. [???] RIGHT, OK. THERE IT IS. I SEE, RIGHT OK. THERE WAS TWO LUMPS QUITE, FAIRLY CLOSE TOGETHER, THEN, IS THAT RIGHT?

Patient: Yes.

INT: YEAH? OK.

Patient: So .. you know, I'm not saying Mr Windle as belittling my ...

INT: OH NO, NO, [??] AT ALL. BUT I MEAN, JUST WHEN YOU SAID IT WAS A PAPER TOWEL [CHUCKLES] YEAH ... RIGHT THEN. SO ... [??] ERM, DID HE USE ANY OTHER VISUAL AIDS OR TOOLS APART FROM THE DIAGRAM?

Patient: No.

INT: NO? OK. NO MAMMOGRAMS OR ANYTHING AT THAT PARTICULAR TIME?

Patient: I can't remember that they were there. Maybe they were up on the wall but I certainly couldn't see them, I didn't like to go very close to them to see.

INT: RIGHT, OK.

Patient: I think I had seen, at that stage I had seen the mark on the x-ray at some point, maybe when it was being taken and the doctors were looking at it, the radiographers or something. I can remember seeing a picture of my breast and this little mark, but, erm, at the time Mr Windle told me, no, he didn't give me any other visual aids.

INT: OH RIGHT, OK THEN. ERM, AND WHEN HE WAS TALKING TO YOU ABOUT YOUR, THE CANCER AND ITS TREATMENT, HOW MUCH DO YOU FEEL YOU UNDERSTOOD ABOUT WHAT HE WAS TALKING ABOUT?

Patient: Erm, there was so little that, erm, that wasn't a problem.

INT: RIGHT, OK.

Patient: And leaflets were given to me at every stage to help me understand what was happening, like there's a leaflet about the Tamoxafen, About your Core Biopsy, About your Second Visit, you know, there's, there seemed to be a leaflet of information to cover every stage I was going through. So that was helpful.

INT: YEAH, RIGHT, OK. SO YOU SAW MR WINDLE AND HE GAVE YOU YOUR OPTIONS AND TOLD YOU ABOUT YOUR TREATMENT, WHAT HAPPENED AFTER THAT?

Patient: I decided that I wouldn't take the offer of the early operation which was going to be the next week because I just felt I wasn't ready to make a decision about what operation I wanted.

INT: RIGHT, OK.

Patient: So I declined that one and then Mr Windle was going on holiday and so was I, so then I was anxious about leaving it, whether any harm would be done and I did get some reassurance from one of the breast care nurses on the phone, who said, 'If Mr Windle thought that you ought to have the

operation early he would have aid so,' so on that basis I then had the later date for the operation, which was several week later.

INT: OK. SO, JUST FOR AN IDEA OF THE TIME, THE TIMES .. YOU HAD YOUR FIRST MAMMOGRAM, WHAT, A WEEK OR TWO WEEKS BEFORE YOU WENT TO THE GLENFIELD, IS THAT RIGHT?

Patient: Erm ... just have a look. Ah, May 25th was the first screening mammogram, and then one ... two ... three weeks later ...

INT: THAT'S THE GLENFIELD, YEAH.

Patient: ... was the Glenfield second appointment call-back.

INT: YEAH, AND THEN ...

Patient: And then ... the biopsies were the next day.

INT: FOUR WEEKS LATER OR SOMETHING, WAS IT? FOUR DAYS TILL YOU HEAR YOUR DIAGNOSIS, IS THAT RIGHT? WAS IT THE MONDAY?

Patient: My diagnosis, I thought it was Monday, it wasn't, it was the Wednesday.

INT: SO IT WAS A WEEK.

Patient: So it was just under a week, yes, that's right. I had the result of the biopsy. Then I had the operation one ... two ... three ... four ... five ... six weeks later.

INT: SIX WEEKS LATER, YEAH, OK. BUT YOU DECLINED THE EARLY OPTION ANYHOW.

Patient: because I wasn't' ready, mm.

INT: YOU WEREN'T READY, YEAH. THAT'S RIGHT, YEAH.

Patient: It was just all too knew and I didn't have any information so I couldn't make a decision. And once I'd been told that Mr Windle would have said if I'd had to have it immediately, then I felt it was better to wait.

INT: YEAH, SURE. AND AFTER MR WINDLE, DID YOU SEE THE BREAST CARE NURSE?

Patient: Erm ... when is this now?

INT: ON ... SORRY, WHEN YOU HEARD YOUR DIAGNOSIS AND YOU RECEIVED YOUR TREATMENT ...

Patient: Yes, I did, yes.

INT: CAN YOU TELL ME WHAT HAPPENED THERE, PLEASE?

Patient: Well, I asked the same questions that I'd asked Mr Windle and she'd been there, and of course she gave me the same answers which was, it was going to be my decision. But she said that, erm, I needn't rush into the decision and I needed to think about what I wanted to do.

INT: RIGHT. AND DID THEY GIVE ANY WRITTEN INFORMATION TO YOU, THE BREAST CARE NURSES, ANY LEAFLETS AT THAT TIME?

Patient: I think so ... I think ... yes, they gave me the leaflet about each type of operation that was available. That's it. I had that one before the wide excision.

INT: OH, OK.

Patient: And there's another called Mastectomy. Given those two which explained it.

INT: RIGHT, OK, YEAH. AND DID YOU READ THOSE, DID YOU?

Patient: Oh yes.

INT: AND DID YOU FIND THEM HELPFUL AT ALL.

Patient: Yes.

INT: YEAH?

Patient: Yes.

INT: AND, ERM, YOU SAW THE BREAST CARE NURSE AND THEN THEY GAVE YOU THE INFORMATION AND YOU CAME HOME, YEAH? IS THAT RIGHT? AFTER YOU'D SPOKE TO THE BREAST CARE NURSE DID YOU HAVE ANY FURTHER TESTS OR ANYTHING?

Patient: No, nothing else.

INT: THAT'S RIGHT, OK. ERM, WHEN YOU CAME HOME, IN BETWEEN THAT AND THE OPERATION, DID YOU GO BACK AT ALL TO THE GLENFIELD?

Patient: No.

INT: NO? NO FURTHER VISITS BACK.

Patient: No.

INT: OK.

Patient: Oh, except for the week before, the pre-assessment.

INT: OH, THE PRE-ASSESSMENT CLINIC, YEAH. CAN YOU JUST TELL ME WHAT HAPPENED THEN PLEASE?

Patient: Erm ... so much has happened it's hard to remember.

INT: YEAH, IT IS [???

Patient: Erm ... well obviously I had blood tests and heart and things checked. I can't remember.

INT: DID YOU SEE A BREAST CARE NURSE AT ALL, DO YOU REMEMBER?

Patient: Probably, I seem to have seen one of them every time I've gone. They've always been available.

INT: RIGHT, OK.

Patient: It might come back to me later on.

INT: AND WHEN YOU WERE AT HOME, AFTER YOU HEARD YOUR DIAGNOSIS, SAW THE BREAST CARE NURSES, CAME HOME, IN BETWEEN THAT AND THE OPERATION YOU SAID THAT YOU LOOKED, AW DIFFERENT TYPES OF INFORMATION, IS THAT RIGHT?

Patient: Yes.

INT: CAN YOU TELL ME WHAT YOU LOOKED FOR AND WHERE YOU LOOKED FOR IT AND WHAT YOU FOUND?

Patient: Yes, there was, it was all internet stuff.

INT: RIGHT, OK.

Patient: Erm, of breastcancer.org I think is one, and there was a Cambridge one ...

INT: ARE THERE WEBSITES YOU GOT FROM THE LEAFLETS OR ONES WHICH YOU FOUND THROUGH SEARCHING?

Patient: No, I just found those out, yes. I mean that's ... published by BUPA, that one, and then I had this breastcancer.org, which is a very informative site which has actual information about drugs and everything. And then this was a, I think this might have been a Canadian one, I'm not sure, and it was about the guide wire insertions which I knew I was going to have, which mark, the markers to mark where the tumours were. So, this was some ladies' experiences of what had happened to them and one had not had her anaesthetic and one had, you know. So at least I had an idea of what to expect with that then. And I also looked at this Cambridge one, which is ...

INT: CAMBRIDGE BREAST UNIT, YEAH.

Patient: Yes, there's quite a bit in there, which gave me information about what would happen to me, the procedure, you know, along the way, with the operation and everything. And then there was this Steering Committee [chuckles] ...

INT: OH WHAT'S THIS ONE? THIS IS [???] CHOICE OF OPERATION FOR CLINICAL [???], CANADIAN MEDICAL ASSOCIATION. OK. OH RIGHT. [???] OK.

Patient: Then there was this one. All of them were, you know, similar but there was just a little in each one which gave me, you know, a bigger picture of everything.

INT: YEAH. IS THAT, WHICH ONE'S THAT ONE? IS THAT A ... [???

Patient: I'm not quite sure where I got that one from.

INT: YEAH, [???] AC.UK ... RIGHT, OK. OH RIGHT.

Patient: So I just, didn't spend hours and hours trailing through things, I just found a few that answered my questions and stayed with it, and I felt that that breastcancer.org might be a good one to look at for things that I, you know, needed to know as I went along. So I've tuned into that one a few times.

INT: AND YOU FOUND THAT INFORMATION HELPFUL, IT ANSWERED YOUR QUESTIONS, DID IT?

Patient: Yes, yes. There's quite a lot there about Tamoxafen too, which I'm glad to know. And since then I've been looking for some exercises, extra exercises, so I found that one. I had some exercises from the hospital but these were just slightly different so I added those to my routine. [chuckles]

INT: OH, OK. HOW DO YOU FOUND THE EXERCISES? ARE THEY OK?

Patient: Yes, yes, they're good and there's my stick there that I do them with. [chuckles]

INT: OH RIGHT, OK.

Patient: And if I don't, if I haven't done them for a few hours I can feel that I need to, so, and then afterwards it's easier then when I've done them, so they obviously are good.

INT: AND DID YOU FIND ANY INFORMATION FROM ANYWHERE ELSE? DID ANYONE GIVE YOU MAGAZINES, VIDEOS, BOOKS? DID YOU SPEAK TO YOUR GP, RELATIVES, ANYTHING?

Patient: Erm, no. None of those, but, oh, I did speak to my GP. Yes, I had a talk with my GP. She was very helpful and she gave me a lot of time, which was very kind of her, considering the time GPs have, so I was grateful for that, and she was extremely sympathetic. Erm, but also a friend of my daughter's said, 'Would you like to talk to my cousin, Janet, because she's had a lot of things done,' you know, it might help you to talk to her.' So thi very nice girl came to see me and showed me her reconstruction, all that kind of thing.

INT: OH DID SHE HAVE A MASTECTOMY AND RECONSTRUCTION?

Patient: Yes, she'd had a different process, you know, a different history and a different ... she was erm, and she looked healthy, and it was encouraging to see after all she'd been through she was living a normal life and was coping with this reconstruction.

INT: WAS SHE AT THE GLENFIELD HOSPITAL OR WAS IT A DIFFERENT REA?

Patient: No, she was at Derby.

INT: OK, RIGHT.

Patient: Yes. [chuckles]

INT: ERM, CAN YOU JUST TELL ME NOW WHAT HAPPENED ON THE DAY OF THE OPERATION, WHEN YOU WENT FOR THE OPERATION?

Patient: I went in the day before and I had, erm, a chance to settle down really, it was good that I went in the day before in fact. Erm, I can't remember anything specific happening that day, and then the next morning went down to have the markers put in, which was really awkward because of the position of the tumours and, erm, that they had really difficulty. So then they took me into the next x-ray room where I was able to lie down and they sort of turned me into the machine so that my breast was, sort of fell into the machine more. And then they were able to mark them then, so it was a very long-drawn out process, one arm up here and one arm up there ... [chuckles] but, you know, they were all very nice and kind and, erm, I just co-operated the best I could so that I'd have the best outcome really of the markers going in. Erm, eventually they were happy with the position and they marked them and that was done. I felt a bit knocked up with that one. [chuckles]

INT: MANHANDLED, PUMMELED AROUND A BIT ...

Patient: But, the nurse who took me down, she said, 'Would you like some fresh air on your way back? We could go round the outside.' So we went round the outside past the flower gardens and that was nice.

INT: RIGHT, OK. AND WHAT TIME DID YOU HAVE YOUR OPERATION?

Patient: I think it was about 5 o'clock in the afternoon, late afternoon, I was last on the list which a bit hard but somebody's got to be last.

INT: AND DID MR WINDLE PERFORM THE OPERATION?

Patient: He did.

INT: RIGHT OK.

Patient: And some ...

INT: DID HE COME AND SEE YOU BEFORE THE OPERATION AT ALL?

Patient: Erm ... he may have done, I think he did. But also I saw one of his team, who was very helpful and gave me all the information that I'd already had but very straight and, you know, 'Had I understood?' erm, and 'You've chosen to have this, haven't you?' and I said, 'Yes, that's my decision.' Erm, and then I had a small discussion with him about whether it was the right decision and he said, 'At this point, the night before the operation, it may not be a good idea for you to change your mind.' [chuckles]

INT: WAS THIS LIKE, WAS THIS AN SpR OR SOMETHING OR ... WAS IT A NURSE [???

Patient: He was a doctor, I think.

INT: OH RIGHT, OK. AND DID THE BREAST CARE NURSES SEE YOU AT ALL ON THE WARD BEFORE YOUR OPERATION?

Patient: Mm ... probably. They were around quite a lot.

INT: MM. AND YOU ALSO MENTIONED THAT YOU'D CALLED THE BREAST CARE A COUPLE OF TIMES, IS THAT CORRECT?

Patient: Yes, I did, yes.

INT: AND CAN YOU TELL ME THE REASONS WHY YOU CALLED AND THE KIND OF QUESTIONS YOU ASKED?

Patient: Yes. I was anxious about, erm, waiting for the operation, that was one reason. I called them this week because I'd had a bad day a few days ago and I was really in pain and worried and, you know, is it going wrong or is this normal? That kind of situation, and got some good advice and settled down again. And my daughter phoned one of them initially too, when we first had the diagnosis, and had a little chat. So they have been very helpful. They seem to have a lot of information and it's up to the patients to ask for it, I think.

INT: RIGHT, OK. AND, ERM, SO YOU'VE HAD YOUR OPERATION, HOW WERE YOU WHEN YOU CAME ROUND?

Patient: I don't think I was very co-operative and was sitting up all the time apparently and clutching at myself and saying 'It hurts, it really hurts,' and, you know, my daughters were worried, 'It shouldn't hurt, she's had painkillers.' I can remember them saying, 'Mum, you've got to lie down, you've got to lie down. Oh, I just wanted to sit up for a minute, and of course I was falling asleep sitting up. I was really ...

INT: VERY DROWSY.

Patient: ... awkward for them to handle, I think. I think eventually I lay down but ... I'd been fighting a bit, you know.

INT: RIGHT, YEAH.

Patient: And then, erm, accepted what had happened and had such a lot of painkillers and some morphine injections and was not really very aware for a few hours. But the next day, erm, I started feeling it a bit more then, a bit uncomfortable and ... erm, what happened? As the, couple of days after the operation, the painkilling drugs were causing me to have nausea and sickness and I hadn't realised it then about the side-effects and, you know, 'The doctor has prescribed this for you,' 'Right.' 'Oh yes, you're on so-and-so and so-and-so, and here you are,' and you sort of take them, you know, thinking this is what's been set for me to take. So I did take them for several days but I had a couple of bouts of sickness in hospital and then again when I got home a week later and the GP came up and said that, you know, it was the side-effects of the [???] and Triamadol.

INT: RIGHT, OK.

Patient: Tramadol. And that I could probably at that stage manage on paracetamol, which I have.

INT: RIGHT, OK.

Patient: So it was just unfortunate that I got that as well when I was starting to feel better and this was holding me back..

INT: YEAH, OF COURSE.

Patient: And every time I shut my eyes I felt as if the bed was moving or the floor was moving and ... [chuckles] so it was just unfortunate that those side-effects made my initial recovery a bit more difficult.

INT: HOW LONG DID YOU SAY YOU WERE IN HOSPITAL? WAS IT A WEEK?

Patient: Six days.

INT: SIX DAYS, OK, RIGHT.

Patient: In the heat wave.

INT: OH RIGHT. AND HAVE YOU BEEN BACK SINCE, [???] HAVE YOU BEEN BACK TO SEE MR WINDLE AT ALL?

Patient: Yes.

INT: COULD YOU TELL ME ABOUT THAT, PLEASE?

Patient: Yeah, I went back this week on Monday ... yeah, erm ... oh yes, there were no x-rays or anything, thank goodness, I was dreading that there might be because I was so sore, but obviously there weren't. And went into Mr Windle and he told that the scars were looking good, they were OK, they were improving. He suggested to the nurse I had the fluid aspirated, which I did, and he told me that they had found the two tumours and they were small, one was 11 cms I think, so they were small ...

INT: ELEVEN MILLIMETRES? MILLIMETRES [???] YES?

Patient: Yes, millimetres. Erm, and they both were malignant cells, had malignant cells. They'd looked at the nodes and there were no cancer cells in the nodes.

INT: MM, RIGHT.

Patient: So, see him in six months and five weeks of radiotherapy to come, in September.

INT: IN SEPTEMBER. SO HAVE YOU GOT A DATE FOR THAT, HAVE YOU NOW?

Patient: I've got the initial date to see a Dr [???] September.

INT: AND THAT'LL BE DOWN AT THE ROYAL, IS IT?

Patient: Yeah.

INT: YEAH. BAD CAR PARK. [CHUCKLES]

Patient: Yes. My kind daughters have organised friends and themselves to shuttle me down and back, so it's taken the worry of that away from me.

INT: OH, YOU'VE GOT SOME SUPPORT THERE, [???] YEAH, OK. ERM, OK. I WANT TO GO BACK A LITTLE BIT NOW, THINKING BACK TO WHEN YOU GOT YOUR DIAGNOSIS AND YOU TALKED ABOUT YOUR TREATMENT OPTIONS, HOW LONG DID IT TAKE YOU TO MAKE UP YOUR MIND WHAT OPERATION YOU WERE GONNA GO FOR, FROM THAT DAY TO WHEN YOU MADE UP YOUR MIND, HOW LONG DO YOU THINK IT WAS?

Patient: ... I think it was just a few days.

INT: A FEW DAYS, YEAH, MM, AND WHAT DID YOU EVENTUALLY CHOOSE?

Patient: I chose the wide excision.

INT: WIDE EXCISION, YEAH.

Patient: Based on the fact that the tumours were small.

INT: RIGHT, YEAH, MM. AND ...

Patient: And I felt they had been detected early.

INT: RIGHT, OK. AND THINKING ABOUT THE TIMES YOU SPOKE WITH MR WINDLE, HOW DO YOU FEEL YOU GOT ON WITH MR WINDLE?

Patient: Er, fine, yes. Erm, at first I thought he wasn't giving me information that I felt I needed but I realise now that he couldn't, you know, he couldn't say because he doesn't know what the outcome will be.

INT: NO, OF COURSE.

Patient: Erm, at the time I felt I wanted more from him but, erm, it's just an awkward situation where nobody knows.

INT: DO YOU FEEL THAT HE WAS LISTENING TO YOU AND THAT HE UNDERSTOOD YOUR NEEDS AND YOUR CONCERNS?

Patient: Erm, probably, but my encounters with him have always been very brief.

INT: RIGHT, OK.

Patient: He's not a chatting man, you know ...

INT: RIGHT, OK.

Patient: ... or a joke or anything. He, erm, takes it all very seriously. He's very pleasant.

INT: YES, A-HA.

Patient: But he doesn't waste any time, and always he gave me the option of asking questions but I didn't know what questions to ask. [chuckles]

INT: MM, IT'S A BAIT DIFFICULT, ISN'T IT, REALLY. YEAH. AND THINKING ABOUT THE TIME YOU SPENT WITH THE BREAST CARE NURSE, DID YOU SEE THE SAME BREAST CARE NURSE EVERY TIME OR DIFFERENT ONES?

Patient: No, I saw, I've seen three altogether.

INT: RIGHT, OK.

Patient: I saw someone called Pat initially. That was when I got the diagnosis, and then I spoke on the phone to Sue. When I was in hospital after the operation somebody called Angie came to see me and so did Sue. Erm, and then this week I've phoned Sue - oh I saw her on Monday and she aspirated the swelling, erm, and I've phoned her since for reassurance and advice. And so, yes, I've had a lot of contact with them.

INT: MM. AND THE TIMES YOU'VE BEEN SPEAKING WITH THE NURSES, HOW DO YOU FEEL YOU GOT ON WITH THEM?

Patient: Fine. Erm, I always felt that they would gauge how much information they gave, depending on the patient's questions and, you know, comprehension of what was going on. I didn't feel it was dumbed down but I just felt that they would, erm, give information if it was asked for.

INT: RIGHT, MM.

Patient: So it was up to me really to ask for things and, erm, I'm the sort of person who does like facts and, you know, and I'd rather work on what is the case, get the information and then act on it. So I was glad to have any information at all really.

INT: AND DID YOU FEEL THAT THEY WERE LISTENING TO YOU AND UNDERSTOOD YOUR NEEDS, YOUR CONCERNS, THOSE SORTS OF THINGS?

Patient: Yes, definitely, yes.

INT: AT ANY POINT DID YOU FEEL THAT EITHER MR WINDLE OR ANY OF THE NURSES HAD A PARTICULAR PREFERENCE FOR A TYPE OF TREATMENT IN TERMS OF SURGERY?

Patient: Mm ... no.

INT: NO?

Patient: No.

INT: OK.

Patient: Unfortunately. [chuckles]

INT: WOULD YOU HAVE LIKED THEM TO? [???

Patient: Yes, as I said, I always wanted to take advice on medical matters, if anything's happened to me in my life, and it was just really strange not to have that given to me.

INT: MM. AND THINKING ABOUT YOUR DECISION TO HAVE THE OPERATION THAT YOU HAD, THE WIDE LOCAL EXCISION, HOW LONG, SORRY, I'VE ASKED THAT QUESTION. WHEN YOU MADE THE CHOICE, DID YOU EVER AT ANY POINT CHANGE YOUR MIND OR HAVE ANY SECOND THOUGHTS ABOUT WHAT YOU WERE GOING TO HAVE?

Patient: No.

INT: NO, OK, RIGHT. THAT'S GOOD. ERM ... DO YOU FEEL THAT YOU HAD THE AMOUNT OF CHOICE THAT YOU WANTED IN TERMS OF SURGERY?

Patient: Yes.

INT: YEAH? YEAH? ERM, AND THINKING ABOUT YOUR DECISION, YOU MIGHT HAVE MENTIONED THIS BEFORE, I'M NOT SURE, WHAT WAS THE MOST IMPORTANT THING THAT YOU WERE TOLD OR THAT YOU READ OR THAT YOU HEARD THAT HELPED YOU MAKE YOUR DECISION TO HAVE THE WIDE LOCAL DECISION?

Patient: Erm, the size of the tumours being small and that, that the type of operation I chose would not influence the eventual outcome, whether there would be a recurrence of tumours or any further cancer, the type of operation would not affect that.

INT: OH RIGHT, OK. AND WHERE DO YOU THINK THAT YOU GOT ALL THAT INFORMATION FROM?

Patient: I think from reading information from the internet.,

INT: RIGHT, FROM THE WEBSITES YOU VISITED AND THINGS, YES.

Patient: Yes, mm.

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

Patient: I'm quite happy about it, yes.

INT: YEAH?

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

Patient: Yes.

INT: MM?

Patient: Yes.

INT: WAS THERE ANYTHING ABOUT THAT PATHWAY, JOURNEY, OR CARE, WHATEVER, THAT DIDN'T MEET YOUR EXPECTATIONS?

Patient: I think, erm, it's hard to say that I had expectations really, it was a completely new situation for me and I was just learning as I went along, all the jargon - not jargon - the names of things and everything associated with breast cancer was new to me, so I couldn't really say I had expectations.

INT: MM. RIGHT, OK. AND 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 IT BE?

Patient: Air conditioning. [chuckles]

INT: OH, YEAH, IT WAS QUITE WARM ON THE WARDS [???

Patient: Oh, it was dreadful, erm, that particular week. Erm ... well, the only negative aspects were very small niggles really.

INT: RIGHT, OK.

Patient: So ... I really feel they're doing their best, and I think they are using the latest techniques, and I felt that they were well up in the research and, you know, I was happy that they were, not the cutting edge, but do you know what I mean, they were always bearing in mind what was going on generally in breast cancer research and passing that on to me. I felt I was benefiting from their expertise.

INT: YEAH, MM.

Patient: So I couldn't make a [???

INT: AND NIGGLES, DID YOU SAY, WHAT ...

Patient: Oh, like, well like an agency nurse that appeared in the night and was, you know ... you know, and was totally inadequate and left my colleague sitting on the side of the bed swooning and bleeding and went off and didn't come back. And I couldn't move, you know, just staffing, little staffing things.

INT: OK.

Patient: Like the showerhead that kept falling off on us. [chuckles] You know, just all the little niggles, but nothing that ...

INT: WHAT WAS THE FOOD LIKE?

Patient: Well it was all right, I mean, once the nurse put my dinner in front of me and before I'd even looked at it, said, 'Do you want to change your mind?' [chuckles] So she'd obviously thought it didn't look good. I was quite happy, I mean a week in hospital you can not worry too much, but, erm, I ate what I hoped was a healthy diet but it didn't stop me from getting really constipated. [chuckles] I don't know if you want this on your tape, but ... oh dear me.

INT: WE'LL STOP THERE. [CHUCKLES] OK.

Patient: Yeah, a nasty moment. [chuckles] But I had eaten all the, you know, nourishing parts of the menu so ...

INT: OH, RIGHT. OK. ERM, DID YOU SAY THAT, I'M JUST TRYING TO PICK UP SOMETHING NOW, DID YOU SAY THAT THE BREAST CARE NURSE CAME UP TO SEE YOU?

Patient: Yes, yes.

INT: OH, CAN YOU TELL ME ABOUT THAT, BECAUSE ...

Patient: Right. She came and introduced herself because I hadn't met that particular one before.

INT: WHO WAS THIS THEN?

Patient: Angie or Angela.

INT: OH, ANGELA IT IS, YEAH.

Patient: And she pulled the curtains round the bed, so obviously she was giving me the opportunity to have a more private conversation with her if I wanted one, and, erm, gave me, asked me a few questions which gave me the opportunity to talk about any fears or depression I might have about it, and ... I think, you know, to give me some support if I was struggling with anything after the operation psychologically particularly. Erm ..

INT: SO THIS WAS POST-OPERATION?

Patient: Yeah.

INT: YEAH? WAS IT AT HOME, DID YOU SAY? DID THEY COME AND VISIT YOU AT HOME?

Patient: No.

INT: AH, RIGHT, SO, I THOUGHT YOU SAID THEY VISITED YOU AT HOME.

Patient: No.

INT: OK. THIS IS POST-OPERATION?

Patient: Yes. And we had telephone conversations when I was at home.

INT: RIGHT, OK. SORRY, I THOUGHT YOU SAID THEY'D COME AT HOME, SORRY ABOUT THAT. I MISHEARD THAT. NOW YOU'VE BEEN THROUGH THIS EXPERIENCE, WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT, FIRST OF ALL, THEIR DIAGNOSIS?

Patient: Erm, well I think it's, erm, it's important to give people information, even if, I'd say even if they might not understand it. At least it's something to work and something to think about and find out about. I think, er, for myself I'd like to be fully informed. I mean I would have been quite happy if Mr Windle had shown me, you know, pictures of my cells and, you know, 'This is that kind of cell and that margin there ...' you know, I would have been quite happy with all that. But not everybody wants to know that, I appreciate it. So I would have been happy with more information. But I'm also, I also accept that the way it was done was all right, it was all right, because I still had time to find out in other ways. Erm ... I think, er, the ... the horror of hearing that, you know, suddenly you're a person with breast cancer diminishes once you get into that world of appointments and doctors and nurses, who're talking freely about all the aspects of it and, and then you start to hear of ladies with far worse scenarios than oneself and, er, you know, you start to count your blessings a little bit. You think, 'Well I've only got ... at the moment' you know. And you went into a whole world of breast cancer. And I sat here in those weeks and I, the first time I took a Tamoxafen, oh dear, nearly choked up then, I felt, 'This is because I've got breast cancer I'm taking this tablet,' and it was such a big moment it seemed at the time. I mean now I just take one every day, you know. This is ... I've got breast cancer, that's why I'm taking this. It was as if it reinforced it for me and made it real.

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

Patient: Er, I think, erm ... that it would be helpful if it was said that, no it was said that, that neither operation is a cure. I think that was said to me, in fairness. I think that's important.

INT: RIGHT, MM. FINAL QUESTION, IS THERE ANYTHING ELSE YOU'D LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY? ANY IMPORTANT POINTS YOU THINK WE'VE MISSED OR ANYTHING WE HAVEN'T COVERED?

Patient: I don't think so. I think we've pretty well covered it all.

INT: OK. I'M JUST GONNA SKIM BACK THROUGH THE QUESTIONS TO MAKE SURE I HAVEN'T MISSED ANYTHING ... NO, THAT'S IT. I THINK, [???] I THINK I'VE GOT EVERYTHING THAT I ...

Patient: You can always ring me if there's something you want [???] I don't mind.

INT: OK, I THINK THAT'S IT THEN, I'LL SWITCH OFF NOW. OK?

Patient: Right.

[End of interview]