

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

*VENUE: Medium MR unit

*DATE:

*ID: Patient13

INTERVIEWER: DJW

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

Patient: Not a great deal. I'd come across a couple of people who'd had it but only sort of second-hand, so I really didn't know a great deal about it myself.

INT: RIGHT. AND THE PEOPLE YOU SAID, YOU SAY SORT OF SECOND-HAND, WHO WERE THEY? WERE THEY FRIENDS, RELATIVES, COLLEAGUES?

Patient: Colleagues or colleagues' wives.

INT: OH, RIGHT, OH I SEE, YEAH.

Patient: Yeah, so it was ...

INT: DID YOU KNOW WHAT OPERATION THEY'D HAD?

Patient: Mastectomies.

INT: THEY'D HAD MASTECTOMIES?

Patient: Yeah, mm.

INT: AND YOU, YOURSELF, HAVE YOU HAD ANY PERSONAL FAMILY HISTORY OF BREAST CANCER OR ANYTHING LIKE THAT?

Patient: No.

INT: AND WHAT ABOUT YOUR SORT OF OWN MEDICAL HISTORY, ARE YOU A GENERALLY FIT, WELL PERSON?

Patient: Yep, we were talking about anaesthetics in the hospital and the anaesthetist said, 'Well have you had any operations?' And I said, 'Yes, I had a hysterectomy 30-odd years ago in 1965,' and that was after my second daughter was born. We were out in Germany and there was a problem and they thought a D and C would cure it and they took me down to do a D and C and I haemorrhaged even faster and all they could do was send for Derek and then get permission to carry on and do a hysterectomy. But it was only a partial, they didn't take my ovaries away, it was just my womb they took. And, apart from c olds and 'flu and, you know, odd thing, no, I've had very good health.

INT: OH RIGHT, THAT'S GOOD. AND THE COLLEAGUES YOU SAID THAT HAD BREAST CANCER, THEY HAD MASTECTOMIES, ERM, HOW LONG AGO WAS THAT, DO YOU HAVE ANY IDEA?

Patient: Oh, we had two of them on the go at the same time ... it would be about four or five years ago, yeah and ...

INT: AND HOW THEY ARE NOW?

Patient: As far as I know they're OK.

INT: OH, RIGHT.

Patient: But they were colleagues on the Community Health Council, so of course we don't have any contact with them any more so I really don't know, erm, you know, how they are. The only other one that I've come across is not first-hand, but it's a colleague of my daughter's up in Edinburgh who has had, who went through exactly the same route that I've gone through, and has kept my daughter well-informed. [chuckles]

INT: OH, RIGHT, OK. WORKING UP THERE?

Patient: About what goes on and ... mm?

INT: IS SHE WORKING UP THERE OR AT UNIVERSITY OR WHAT?

Patient: She went up to Edinburgh University and never came home, she lives up there. She teaches, teaches chemistry, and it was one of her colleagues who Rebecca knew what had happened to her and sort of was, talked to her about it and, you know, she's been kept well-informed and then phoned me and said, 'Hey, Mum, de-de-de-de'.

INT: OH, RIGHT.

Patient: You know, so ...

INT: AND WHAT DID SHE HAVE? YOU SAID A MASTECTOMY?

Patient: She had a mastectomy as well, yeah. Much younger than I am, she was only, I think she was only in her forties.

INT: AND I THINK YOU SAID YOU WERE SELF-REFERRED, WEREN'T YOU, AT THIS TIME?

Patient: I self-referred, yeah.

INT: YEAH, [???] MAMMOGRAM.

Patient: Yeah.

INT: THAT'S RIGHT. SO CAN YOU JUST TALK ME THROUGH THAT, PLEASE, WHAT HAPPENED THERE?

Patient: Nothing. Erm, I went to the doctors and I didn't go for that, I went with pain down my thumbs and he got my hand and pressed there and he said, 'Sorry, Miss [???] that's osteoarthritis and there's nothing we can do about it, I'll give you painkillers,' so I said, 'Thank you very much.' And I was there talking to him, I remembered about that I hadn't had a mammogram or quite some time and asked him what to do. And he said, 'Oh, just phone them up and, you know, just go,' and it was as simple as that. I just went, there was nothing there, no lumps, nothing, but I knew I hadn't been for quite some time so I decided that it was time I went. And that was that.

INT: AND IS THAT AT THE ROYAL, YEAH? YOU HAD A ...

Patient: No, they're doing them now at Scarsdale, you know ...

INT: IS IT A MOBILE UNIT OR ...?

Patient: No, it's a proper, full-scale unit, at the back of what was the old Health Authority and is now the Primary Care Trust, they've got this, sort of taken a session of the building and put in clinics there, and this is one of the ones they've put in.

INT: OH, RIGHT.

Patient: A breast screening clinic. Erm, and they've got all the equipment down there.

INT: AND WHEN WAS THAT THEN?

Patient: Oh, it goes back to May. If you want exact dates I can get my diary out.

INT: WHEN YOU HAD THE MAMMOGRAM.

Patient: Yeah, yeah. And then they wrote to me and said, 'We'd like you to come back,' and the date they gave me we were going to be away anyway so I phoned them up and said, 'Look, I can't come that week, can I ... can you re-arrange it?' So I went the following week, er, and it sort of all becomes a blur after that because I can't remember whether they did the biopsy and the scan and the other mammogram again or whether they just did a mammogram and then sent for me again.

INT: OH, YOU'RE OK.

Patient: And I thi-, I've got a feeling they did another mammogram and it was left at that and then they sent for me again and we went through all the things. I can't really remember which ...

INT: BUT WAS THAT BIT ALL AT THE ROYAL, WAS IT?

Patient: No. Yes, it was, yes it was at the Royal.

INT: YES, SO THE FIRST MAMMOGRAM WAS AT THE SCARSDALE ...

Patient: Yeah.

INT: ... AND THEN THEY CALLED YOU BACK TO THE ROYAL TO DO THAT, YEAH.

Patient: Yeah, to do the second one.

INT: SO WHEN YOU GOT THE LETTER TO ASK YOU TO COME BACK, I MEAN, WHAT WENT THROUGH YOUR MIND?

Patient: Well, like I said earlier on, nothing really because I'd had the same experience the time before ...

INT: OH, RIGHT, YEAH, OF COURSE.

Patient: ... and panicked, but this time I didn't, and I just thought, 'Oh well,' you know, 'obviously there'...

INT: [???) AGAIN.

Patient: Yeah. It hadn't quite worked, we'll have another go. Erm, and then the rot set in.

INT: YEAH, YOU SORT OF, YOU WENT FOR YOUR SECOND MAMMOGRAM, AND YOU SAY YOU CAN'T REMEMBER IF THEY DID THE TESTS ...

Patient: I can't remember whether they did the biopsy. I truly can't remember how it went.

INT: MM, DID YOU SEE A CONSULTANT BEFORE YOU WENT FOR [???)

Patient: Yes, Mr Holt.

INT: SO WAS IT MR HOLT YOU SAW ALL THE TIME?

Patient: Yeah. But he didn't do the mastectomy, Mr Chadwick did the operation ...

INT: MR CHADWICK DID THE OPERATION, YEAH.

Patient: ... because Mr Holt was away on holiday.

INT: RIGHT, OK.

Patient: Erm, but I truly can't really remember the scale of what happened from going for the first mammogram, going for the second one ... in a matter of days that I was in, so I think they must have done all the tests. Whether they did the mammogram and checked it and said, you know, 'We want to check for more,' do you know I can't remember for the life of me. I really can't remember, er, how it worked, but I know when we went back for the results Derek came with me and that was when Mr Holt said, 'Sorry, my dear, but there is something there and we need to do something about it.' He said it was entirely up to you, erm, 'You can do nothing or you can have a lumpectomy' and told me all about that, or, he said, 'You can have a mastectomy,' and you know, sort of have the breast removed completely. And I must admit I was a bit taken aback at that stage: didn't really want a mastectomy, erm, so we opted for the lumpectomy and to see where that would lead us. But then, erm, they took one lymph node and this chunk, and it was so ... as they say, I've never been in such pain as I was in. It really was very painful. Er, when I went back for a check-up to be told by Mr Holt that it hadn't worked and what they were going to do, and that was when we were giving the options of having a

second go at the lumpectomy or going on a mastectomy, and then I said, 'Well, no, I really can't face that. I really can't face it again and still not know what it was going to work.'

INT: YEAH, OF COURSE, YEAH.

Patient: You know, and then have to have the mastectomy. I really couldn't face it. So he left me to think about it, he said, 'Well, you go away and think about it, but you've got to come in on Wednesday ...' three weeks ago. I've got my diary, I can give you the dates, '... and it will be Mr Chadwick, but by then you've got to have decided what you want to do.' And we talked about it, said, 'No, what's the point?'

INT: RIGHT. SO, WHEN YOU'D ACTUALLY GONE BACK TO, HAD THE BIOPSIES AND THINGS, DID ANYBODY, WHEN THEY WERE DOING THE TESTS, DID THEY GIVE YOU ANY INDICATION AS TO WHAT IT MIGHT BE IN THE END OR DID THEY MENTION IT COULD BE A CANCER OR ANYTHING LIKE THAT OR ...?

Patient: Oh yeah, yeah.

INT: WHEN THEY WERE ACTUALLY DOING THE TESTS?

Patient: Yeah, yeah.

INT: WHO WAS THAT THEN, DO YOU REMEMBER? WAS IT THE ...?

Patient: Phew, the x-ray people or somebody did the biopsy, then one of the doctors - I presume, or he might have been a technician - did an ultrascan, and then they did another mammogram ... I don't know which order it comes in. It's gone.

INT: RIGHT, OK.

Patient: And, you know, sort of, there was always the possibility and Mr Holt said straight off that it was a possibility that there was something there.

INT: RIGHT, IS THAT BEFORE YOU HAD THE TESTS, WHEN YOU WENT TO SEE HIM?

Patient: Mm.

INT: YEAH?

Patient: Mm. So he said, 'We'll do some more tests and then we'll ...'

INT: RIGHT, OK.

Patient: ... 'we'll see.' Erm, so it started at the end of May and that took us then into the beginning of July. No, it didn't, June. You see it all gets hazy. And then, within another three weeks, I was in again having the mastectomy. Erm ...

INT: SO SORT OF, IT'LL BE ABOUT TWO MONTHS OR SOMETHING, IS IT, FROM START TO FINISH?

Patient: Yeah, yeah.

INT: [??] SO WHEN YOU FIRST, YOU KNOW, WHEN YOU FIRST STARTED TO GET AN INDICATION THAT IT WAS, IT COULD BE CANCER, BEFORE IT WAS ACTUALLY DIAGNOSED OR YOU'D START TO GET AN INDICATION THAT IT COULD BE SOMETHING A BIT MORE SERIOUS THAN LAST TIME, AM I RIGHT IN THINKING ...?

Patient: Mm, mm.

INT: DID YOU HAVE ANY THOUGHTS AT THAT TIME ABOUT WHAT YOU MIGHT DO ABOUT IT IN TERMS OF TREATMENT?

Patient: No. Erm, because I didn't know sort of what the treatment was. I had no idea and I think if I'd known what the lumpectomy consisted of I would have gone for a mastectomy straight away. Erm, ... er, yeah, because, you know ...

INT: BECAUSE IT WAS VERY PAINFUL.

Patient: Yeah.

INT: MM. SO, THINKING ABOUT THE TIME YOU ACTUALLY WENT BACK TO HEAR ABOUT YOUR DIAGNOSIS FROM MR HOLT, CAN YOU JUST TELL ME A BIT MORE DETAIL WHAT HAPPENED ON THAT DAY YOU WENT TO CLINIC AND ...?

Patient: And it hadn't worked? Erm, he just said, you know ...

INT: NO, SORRY, I MEAN WHEN YOU FIRST HAD IT CONFIRMED THAT IT WAS CANCER, THE ACTUAL DIAGNOSIS.

Patient: Oh shell-shocked, I think. I mean we talked in general terms and I had a few tears and just went ... bmmph ... the shutters came down a bit. Erm, and he said, 'Well, you know, go and think about it and when you've thought about it we'll talk about it again.' And I went off into another room with Derek and one of the breast screen nurses.

INT: BREAST CARE NURSES, YEAH. WAS IT DONNA OR MARY?

Patient: Donna.

INT: DONNA.

Patient. And ... we said, you know, there's no point in not doing anything. I mean if you're going to go and have mammograms and then totally ignore it, you're just being ridiculous, to me, I mean, it was just pointless. You've got to do something. So we talked about it and decided on having the lumpectomy, because I thought, you know, to have a mastectomy straight off was a bit ... much and hard, and I didn't really want to face that. Erm, very difficult to face that one, you know.

INT: MM. SO, AND DEREK WENT WITH YOU, IS THAT RIGHT?

Patient: Yeah.

INT: AND THERE WAS, WAS THERE A BREAST CARE NURSE IN THE ROOM AT THE SAME TIME, YEAH?

Patient: Mm.

INT: AND, ERM ...

Patient: [???

INT: SORRY>?

Patient: ... go on.

INT: TAKE A FEW MINUTES.

Patient: I'm all right.

INT: ARE YOU SURE? IF YOU NEED TO, JUST LET ME KNOW AND I CAN STOP THE TAPE, IT' NOT A PROBLEM. ERM ... WHEN HE WAS ACTUALLY EXPLAINING YOUR DIAGNOSIS AND YOUR TREATMENT OPTIONS, DID HE USE ANY VISUAL TOOLS OR AIDS? DID HE DRAW ANY DIAGRAMS, DRAW YOU ANY PICTURES?

Patient: Yes, yes, he showed me where it was and told me about the lymph nodes and, erm, because it was only small and we'd got it early we could probably get away with the lumpectomy, but it was only when they did it they realised that it was deeper-seated than they thought.

INT: OH, YEAH.

Patient: And they found some calcium which I didn't really understand that bit, I have to say. I'm not a medical person, I don't know about these things. Er, and that one of the lymph nodes was suspect.

INT: RIGHT.

Patient: That was when I went back for the check-up. But he did describe it, he drew it all for me and he showed me the x-ray, which really didn't make, erm, a lot of sense to me. I mean he knew what he was looking at, but, you know, if you imagine that's a breast and then sort of, it was sort of down here in the bottom corner. And he said, 'You would never have found it,' you know, even though you do checks ...

INT: [???

Patient: ... yeah, yourself.

INT: BUT HE, DID HE ...?

Patient: You wouldn't have found it, it was too deep-seated.

INT: DID HE FIND IT WHEN HE CHECKED YOU?

Patient: No.

INT: NO, SO OBVIOUSLY YOU WOULDN'T HAVE, YEAH. AND, HOW DO YOU FEEL YOU GOT ON WITH MR HOLT?

Patient: Oh, he was lovely.

INT: YEAH.

Patient: A lovely, gentle man.

INT: RIGHT, OK.

Patient: And you could say thing to him. I mean when I went back, I tell you one day I went back and that was when I had the biopsies and I went, and that was on June 9th and it was our wedding anniversary, and I said to hi, you know, went back in the room and said, 'You know, this isn't right.' I said, 'this is my 48th wedding anniversary,' I said, 'and I shouldn't be faffing around having all these things done to me, it's all your fault.' 'Oh,' he said, 'I'm sorry,' and, you know, sort of jollied you, jollied us on, you know. I said, 'It's not right,' I said, 'I'm supposed to be going out for a meal today and I can't be doing with' But he was lovely.

INT: AND DO YOU FEEL THAT HE LISTENED TO YOU ...

Patient: Oh yeah.

INT: ... AND UNDERSTOOD YOUR NEEDS AND CONCERNS?

Patient: Yeah, yeah. Erm, I think ... I don't know about other people but I think at first you don't take it all in because you're just so shell-shocked.

INT: YEAH, OF COURSE, THAT STOPS YOU IN YOUR TRACKS, DOESN'T IT, REALLY?

Patient: But it stops you in your tracks and you don't always ask, erm, questions, and you don't know anyway unless you're in the medical profession. I'm not a medical person, we don't even keep a medical book in the house, we don't even keep a thermometer in the house, so, you know, ...

INT: SOUNDS LIKE MY HOUSE.

Patient: Our some total of medical knowledge is what I've gleaned from the CHC over the years, you know, and that's helping people ...

INT: I WORK IN A HOSPITAL, I DON'T KNOW THE FIRST THING ABOUT FIRST AID.

Patient: Yeah, yeah. Erm, so you don't really always know what questions to ask, it's only when you think about it later. Er, you know.

INT: YEAH IT'S HARD TO KNOW WHAT TO ASK WHEN YOU DON'T KNOW EVEN WHAT, LIKE, WHAT THE TREATMENTS ARE [???] MEDICAL TERMS ARE. ERM, AND DONNA, I MEAN, YOU MENTIONED DONNA, HOW DID YOU GET ON WITH DONNA ASHLEY?

Patient: Oh she was lovely, she was lovely, she came and cuddled me and brought me my tissues and dried my eyes and said, 'Come on ... it'll be all right, it'll be all right.' So, yes, she was lovely. And so was Mary, Mary was nice too.

INT: OH DID YOU GET TO MEET MARY A WELL, YEAH?

Patient: Yeah, she came up to me on the ward and talked to me up there and I saw her down at one of the clinics because I have had to go back to have it drained - because that was one of the biggest problems I've had, the drain wasn't working properly, and I had a couple of do's there, sort of I'm wandering around with this bottle in my hand, nothing happening in the bottle but me I'm soaked, you know, and all my clothes were soaked, and it was going everywhere. And had to have the bed changed in the middle of the night ... yuk [chuckles]

INT: OH, THAT WAS [???]

Patient: So that was a bit difficult. So that was when they said, 'Well you might as well go home because this isn't working, er, but we'll keep an eye on it and if you need it, if it starts to swell and gets uncomfortable, give u a ring and come back up and we'll ...

INT: RIGHT, OK.

Patient: 'we'll drain it.'

INT: AND THE NURSES, DID YOU FEEL THAT THEY WERE LISTENING TO YOU AND UNDERSTOOD YOUR NEEDS, YOUR CONCERNS, ANYTHING ON YOUR MIND?

Patient: Yeah, yeah. I phoned up and they aid, 'Oh, come up. How long will you be?' I said, 'Ten minutes,' and Donna said, 'Why, where are you?' I said, 'I only live in Walton.' 'Oh right,' she said, 'OK, fair enough.'

INT: [???]

Patient: ... you see it's just up the road. So we went and I think it was Mary said to me over the telephone, 'Do you know what they do?' and I said, 'No, don't tell me, I don't want to know, just do it, just make it more comfortable than it is now,' and it was absolutely painless, there was no problem. And I think I've been back three times and debated whether to go back on Monday. My daughter came with me last Wednesday, which was the last time it was done, and debated whether to go back on Monday and then thought, 'Oh, no, they've said that, you know, it'll drain itself through your body,' and it's not too uncomfortable so I've just ignored it, and it's been OK. Erm ...

INT: SO, ERM, WE'VE GOT TO THE POINT WHERE YOU RECEIVED, YOU'D HEARD YOUR DIAGNOSIS AND THEN YOU'D GONE OFF WITH THE BREAST CARE NURSE - IS THAT RIGHT?

Patient: Yeah.

INT: AND WHAT SORT OF THING DID YOU TALK ABOUT WITH THE BREAST CARE NURSE, DO YOU REMEMBER?

Patient: Not a great deal. Erm, just more reassurance than anything, you know, 'You'll be all right ...' Just more assurance than anything but not, I think because, I go back to being shell-shocked, you know.

INT: AND DID SHE GIVE YOU ANY FURTHER INFORMATION?

Patient: She gave me ...

INT: I SAW A LEAFLET THERE WITH MASTECTOMY ...

Patient: That's the mastectomy, that didn't come until the second time around. Erm, yeah, she gave me some bits and pieces.

INT: OH THERE'S A LITTLE PACK THERE, YEAH.

Patient: Yeah, erm, and I've kept it all together because it seemed easier to do that.

INT: YES. YEAH, SO YOU GOT, YOU GOT, SHE GAVE YOU SOME INFORMATION. DID YOU READ THE INFORMATION?

Patient: Yes.

INT: YEAH. DID YOU FIND ANY OF IT USEFUL?

Patient: Yes, er, but it still doesn't ... it's the old story, you can talk till the cows come home but it's experience that counts, and it doesn't tell you what you're really in for.

INT: RIGHT.

Patient: And, you know, everybody's experience is different and everybody's pain level is different.

INT: OF COURSE, [???

Patient: I have discovered that my pain level's very low. [chuckles] Oh dear. So, yeah ...

INT: HOW SOON AFTER THAT, THEN DID YOU GO FOR YOUR FIRST OPERATION, THE WIDE LOCAL EXCISION, THE LUMPECTOMY?

Patient: We go from June 9th to ten days, and I've got all the in [???] ... that's my appointment, there was that one, that's the last one ... that was when it was, the mastectomy was done. So if you count from June 9th, ten days, erm, that was when they did the lumpectomy.

INT: RIGHT, MM. AND DID YOU HAVE ANY FURTHER CONTACTS WITH THE BREAST ...

Patient: No ... it wasn't then. You see, as I say, it all becomes a blur. It wasn't, it was after June 9th I went back again ... on ... the following Wednesday I think it was, and that was when he told me he was going ...

INT: WAS THAT AT THE ONE THAT CALLED YOU TO ARRANGE THE INTERVIEW AND THEN SAID YOU HAD TO GO FOR ANOTHER OPERATION?

Patient: Yeah, yeah. Erm ... yeah, that was when I had to go back again the second time.

INT: TO HEAR YOUR RESULTS OF THE OPERATION?

Patient: Mm, and that was on the 21st July.

INT: RIGHT.

Patient: So we count from, let me go back about a fortnight, that was when I went back for the check-up, to go back in an other week so it was June 9th plus a week, or plus a few days, might have been a Monday when they told me, and I went in the following Wednesday ... no, following Friday, and I went in on the Friday and he said, 'You might be able to go home on the same day ...'

INT: OH, RIGHT.

Patient: I was too sick, [chuckles] I was too sick. So they kept me in overnight and I came home on the Saturday. And then I went back again, I think it would be about the 10th July, so it's all quite sort, a short period of time. And Mr Holt then said, 'No, this hasn't worked, erm, what do you want to do?' 'What do you think we should do?' Erm, and we agreed that, erm, we would go for a mastectomy. And that was when he said, 'Well I'm very sorry but I won't be able to do it because I shall be on holiday, it will be Mr Holt who does it,' and I went in on the 21st.

INT: MR CHADWICK.

Patient: And Mr Chadwick did it on the 21st.

INT: SO IN BETWEEN HEARING YOUR DIAGNOSIS AND GOING IN FOR YOUR FIRST OPERATION, DID YOU HAVE ANY FURTHER CONTACT WITH THE BREAST CARE NURSES? DID YOU RING THEM ...

Patient: No.

INT: ... FOR ANYTHING, NO?

Patient: No.

INT: AND THEN SORT OF CAN YOU JUST TELL ME WHAT HAPPENED WHEN YOU ACTUALLY WENT IN FOR YOUR OPERATION, THE DAY YOU WERE ADMITTED, WHAT HAPPENED?

Patient: Nothing. I arrived there at quarter to eight in the morning and they checked me over and the anaesthetist came and he talked to me, and then, you know, sort of not a great deal.

INT: WHAT TIME DID YOU GO FOR THE OP, THEN? CAN YOU REMEMBER?

Patient: It would be about lunchtime I think.

INT: RIGHT.

Patient: Erm ... be about 11 o'clock-ish, I would think. Yeah. Erm, and I know I didn't have anything, oh, I did, I had a piece of toast and couldn't get it down, and that was all I ate.

INT: WHAT, BEFORE YOU WENT OR WHEN YOU CAME ROUND?

Patient: When I came round. [???

INT: YEAH, SO HOW DID YOU FEEL WHEN YOU FIRST CAME ROUND AFTER THEN?

Patient: Terrible.

INT: YEAH, FEELING VERY [???

Patient: Absolutely terrible.

INT: OH DEAR.

Patient: Just very sick.

INT: YEAH, RIGHT.

Patient: Well it's just the anaesthetic I suppose.

INT: AND HOW LONG DID YOU STAY IN HOSPITAL, A COUPLE OF DAYS?

Patient: Only overnight, the first time.

INT: YEAH.

Patient: I went in on Friday morning and I came home on Saturday, and the children came and picked me up, erm, Derek had something he'd got to attend to so Rebecca had come down from Edinburgh and she came and picked me up with her husband and brought me home. Mm.

INT: AND THEN YOU WENT ...

Patient: With messages, you know, if you've any problems, ring up, ring up and don't sit worrying about it. And you've all the tablets. I must admit I didn't really fully understand the tablets, mainly because I'm not a tablet-taker, and the thought of taking two codeines, two paracetamols and one of these ... [???] things, whatever they're called, four times a day, erm, didn't sit well with me at all, and I sort of tried very hard not to take quite as many, and I paid the price. [chuckles] I had to take them in the end.

INT: RIGHT, FOR THE PAIN AND STUFF.

Patient: The district nurse came in on the Sunday and changed the dressing and aid, 'If you need us, give us a ring, erm, and that was that.' I didn't see her again. And then we got the appointment to go back for, erm, after the operation for the check, to be told that, you know, it didn't work.

INT: RIGHT, OK. SO GETTING TO THAT POINT, WHERE YOU WENT TO HEAR ABOUT THE RESULTS OF YOUR FIRST OPERATION AND THEY SAID IT DIDN'T WORK, I MEAN WHAT WERE YOUR FEELINGS AT THAT POINT?

Patient: Even more shattered.

INT: AH, RIGHT.

Patient: Even more shell-shocked. Erm ...

INT: THIS IS MR HOLT YOU SAW?

Patient: Mm, yeah. Erm, and we just had to decide what do, I mean, once again, there was no point in going through all of that and then sort of saying, 'Well, that's it, forget all a bout it,' except some people do, erm, some people decided 'That's it, enough's enough, I'm not going for any more,' but I felt that at was being a bit short-sighted and, you know, I didn't think that was a sensible route to take.

INT: WAS THE BREAST CARE NURSE THERE AS WELL?

Patient: Mm?

INT: AS THE BREAST CARE NURSE THERE?

Patient: Yes, yes.

INT: DONNA, WAS IT, AGAIN?

Patient: Yeah. Erm, yes, I think it was Donna. Er, so ... that was all we decided what we were gonna do, except that Mr Holt didn't accept that that was the final decision, although Derek and I had sat there and said 'That's it, decision made for the mastectomy,' erm, and he said, 'No, go away and think about it and come back on the 21st having decided what you want to do.'

INT: RIGHT, OK.

Patient: '... What you want to have done.' But I rang them up and said what I was going to, what we wanted. Erm, so that was that.

INT: THINKING ABOUT YOUR FIRST OPERATION WHEN DID YOU SIGN THE CONSENT FORM FOR THE FIRST OPERATION?

Patient: Erm ... with Mr Holt, I think.

INT: YEAH, WAS THAT ON THE, WHEN YOU WENT TO HEAR YOUR DIAGNOSIS AND ...?

Patient: Mm, mm, yeah.

INT: OK. AND THEN THE SECOND OPERATION WHEN DID YOU SIGN THE CONSENT FORM THAT, THE MASTECTOMY?

Patient: Yes, that's a very good question. Erm ... the day I went in I think, because, you know, sort of it had been left that we would go away and think about it, erm, and though I phoned up and said we'd decided, erm, and I think it was that day, the 21st, I'm nearly sure it was.

INT: ERM, YEAH, WHERE WE? SO, YOU KNOW YOU'VE YOUR SECOND OPERATION, ERM, TELL ME A LITTLE BIT ABOUT WHAT HAPPENED ON THAT DAY WHEN YOU WENT?

Patient: Same procedure really, erm, you arrive, you're checked over, erm, had your stockings and thing and blood pressure taken and all that, and then the anaesthetist came again and we talked about having been so sick the first time and what could we do to prevent it. Erm ... and we, he did try, bless him, he tried all sorts of things but it didn't work, [chuckles] I was still very sick. Erm, but apart from that, no, and I think Mary came to see me that morning and talked to me about, you know, sort of, 'This is what we're going to do,' and about the ... what happens afterwards and the, oh ... the prosthesis thing-y.,

INT: OH, RIGHT.

Patient: Yeah, and said, you know, 'If you want anything, ring. Don't sit and worry about it, if you've got any problems, give us a ring.' And that's it, you know, sort of, and that was that.

INT: AND HOW LONG WERE YOU IN HOSPITAL THAT TIME?

Patient: Did it on Wednesday and I should have come home on the Monday but they let me come home on the Sunday because thi drain thing was not working so we took it out. They'd no idea, they couldn't measure what fluid was being collected because it just kept blocking, so they took the drain out and said, you know, 'Let's see what happens, but if you've got a problem come back and we'll drain it.' So I came home on the Sunday, erm, and apart from that, you know, the district nurse came in on the Tuesday I think and I haven't seen sight nor sound her since then, except to say that they said if I had any problems, give them a ring.

INT: AND THEN DID YOU, YOU'VE GONE BACK AGAIN TO HEAR THE RESULTS OF THAT OPERATION, IS THAT RIGHT? DO YOU GO BACK TO HEAR THE RESULTS OF THE MASTECTOMY?

Patient: I haven't been back. I've got an appointment to go in October.

INT: OH RIGHT, OK.

Patient: But I haven't been back, apart from having it drained, since the mastectomy .

INT: NO, NO, OK. AND YOU'RE ON TAMOXAFEN NOW, IS THAT RIGHT?

Patient: Yes.

INT: YEAH?

Patient: Yeah.

INT: AND YOU ...

Patient: I'm not a happy bunny.

INT: NO.

Patient: I know I've got to take it but I'm a happy bunny.

INT: IS THAT FOR FIVE YEARS?

Patient: Yeah. Erm, shouldn't read the blurb and yet we always do, we always do.

INT: [???] GET STUFF FROM THE CHEMISTS AND JUST TAKE IT [???] ERM, AND NO RADIOTHERAPY OR ANYTHING ELSE?

Patient: No, no.

INT: YOU DON'T HAVE ANYTHING LIKE THAT, THAT'S OK. ERM, WHEN YOU WERE, THINKING ABOUT THE FIRST TIME WHEN YOU WERE TALKING ABOUT YOUR TREATMENT OPTIONS BEFORE THE LUMPECTOMY, YEAH, ERM, WHEN YOU WERE TALKING ABOUT THE TREATMENT OPTIONS AND THINGS, ERM, DID YOU GET THE IMPRESSION THAT THE CONSULTANT OR THE NURSES HAD A PARTICULAR TREATMENT IN MIND FOR YOU, A PREFERENCE IF YOU LIKE, OR FELT ONE WAS BETTER THAN THE OTHER?

Patient: No, but it was a question of if you went down this route, this was the way it went; if you went down that route, this is what would probably happen, so the discussion was basically on those lines.

INT: RIGHT, OK.

Patient: Like, you know, Mr Holt had said that if I went for a lumpectomy, afterwards I would have to have five weeks of radiotherapy, I would, they would wait a few weeks until I'd sort of healed a bit and then I would start going to Weston Park to have the radiotherapy. Erm, but then when I went back again, and he said at the time, 'If you go for a mastectomy, you won't have any of that, you'll just go straight onto Tamoxafen,' and that would be that. And of course that's the way it's worked out and I'm on Tamoxafen, you know, sort of ... we'll wait and see.

INT: AND, ERM, YEAH, THE SECOND TIME YOU WENT BACK, YOU OBVIOUSLY THAT THE FIRST OPERATION HAD BEEN UNSUCCESSFUL SO YOU WERE OPTIONED AGAIN FOR

Patient: Another lumpectomy ...

INT: OR A ...

Patient: The surrounding area.

INT: YEAH, A WIDER, WIDER [??], YEAH,

Patient: Or ...

INT: A MASTECTOMY

Patient: ... a mastectomy, yeah, and, with no guarantees that the second time would work ...

INT: NO, THAT'S RIGHT.

Patient: ... we decided no, no. We talked about it and said no, I couldn't go through that again.

INT: AT THAT POINT DID YOU GET ANY IMPRESSION THAT EITHER THE BREAST CARE NURSES OR THE SURGEON HAD A PARTICULAR TREATMENT THAT THEY FAVOURED FOR THAT OPERATION?

Patient: No, not really. Erm, I think, with hindsight, Mr Holt would have preferred a mastectomy, but that's only how I feel now, but he didn't say. It was the decision that we had to make, erm, but I think he would have preferred the mastectomy routine in the first place.

INT: RIGHT, OK.

Patient: I don't know that that's ...

INT: IN THE FIRST OPERATION?

Patient: Yeah.

INT: YEAH?

Patient: Yeah.

INT: IS THERE ANYTHING GIVES YOU AN INDICATION WHY THAT WOULD BE?

Patient: No, except that he aid, you know, sort of 'This is what you can do: you can either have a lumpectomy or a mastectomy,' and we sort of discussed the pros and cons of both, and he said, you know, 'If you have a mastectomy ...' that was the second time I went, he said, 'You know a mastectomy is not nearly as painful as a lumpectomy,' and I, you know, that was the impression I was left with. You know, he said, 'You'd be surprised, ladies come back and tell me, you know, that it hadn't been nearly so painful.' I'm not inclined to agree totally, but never mind. As I say, my pain levels are my pain levels, [chuckles] yeah.

INT: AND THIS WAS THE SECOND OPERATION WAS THIS?

Patient: Mm, mm.

INT: OK. WHEN, IN ALL OF THIS, WHEN YOU'RE TALKING ABOUT YOUR TREATMENT AND YOUR OPTIONS, HOW MUCH DO YOU THINK YOU UNDERSTOOD ABOUT WHAT YOU WERE BEING TOLD ABOUT THE OPTIONS AND THE CANCER AND THINGS?

Patient: Second time around I understood, erm, first time, no, I didn't really, but I think the second time I understood what was involved.

INT: IS THAT BECAUSE YOU FELT YOU WERE A BIT SHOCKED TO TAKE INFORMATION IN OR ...?

Patient: Yes, yeah, but I did understand what was going on, because we'd discussed it the first time when we went for the lumpectomy or mastectomy, and then when we said that's it. I know I was a bit upset about the whole thing to say the least, erm, no I did understand.

INT: RIGHT. ERM, I THINK WE'VE MOVED ON QUITE A BIT NOW. ERM, YES, WHEN THE FIRST TIME YOU CHOSE THE WIDE LOCAL EXCISION, THE LUMPECTOMY, DID AT ANY POINT AFTER MAKING YOUR MIND UP DID YOU CHANGE YOUR MIND OR HAVE ANY SECOND THOUGHTS?

Patient: No, no.

INT: OK. AND, ONCE YOU'D HEARD ABOUT THE OPTIONS, WHAT THEY WERE THE FIRST TIME, HOW LONG DO YOU THINK IT TOOK YOU TO MAKE UP YOUR MIND WHICH OPTION YOU WERE GONNA GO FOR?

Patient: We'd made it up straight away, yeah.

INT: AND WHAT DO YOU THINK WAS THE MOST IMPORTANT THING THAT YOU HEARD OR WERE TOLD OR WHATEVER, THAT HELPED YOU COME TO A DECISION?

Patient: The fact that it was, erm, it had been caught early, because it had been caught through the mammogram, and it, it could only be, it would only be a small one. But it gave me the impression that to go that route ... the first time, but not the second time.

INT: AND THINKING ABOUT THE SECOND TIME, YU KNOW, YOU HAD TO CHOOSE BETWEEN A WIDER LOCAL OR A MASTECTOMY, AND YOU CHOSE THE MASTECTOMY, DID YOU EVER CHANGE YOUR MIND AT ANY POINT AFTER THAT ...?

Patient: No.

INT: ANY SECOND THOUGHTS?

Patient: No.

INT: OK.

Patient: No, once we'd decided.

INT: AND HOW LONG DID IT TAKE YOU TO MAKE YOUR MIND UP ABOUT THAT PARTICULAR SURGERY?

Patient: Almost straight away, erm, almost straight away. We sat and talked about it in, with Mr Holt, and we said, 'Well we've tried plan A, this is plan B and this is plan C: we'll skip plan B and just forget

plan B and go to plan C.' And he aid, 'Well, then I still want you to go away and think about it, and when you've thought about it give us a ring or tell us when you come in what you want to do.' But we didn't, we didn't change.

INT: RIGHT, OK. AND WHAT WAS THE MOST IMPORTANT THING THAT YOU HEARD OR TOLD OR READ OR ANYTHING LIKE THAT THAT MADE YOU GO FOR THE MASTECTOMY? WHAT DO YOU THINK WAS THE DECIDING FACTOR?

Patient: Just the fact that, if I went down the, through plan B, it wasn't necessarily going to work, and I couldn't face going through all that again for it not to work and then still have to have a mastectomy at the end of it. I just couldn't face it.

INT: AND IN ALL THIS TIME, YOU'VE HAD THE, BOTH OPERATIONS, HAVE YOU - I MEAN I KNOW YOU'VE GOT PACKS AND INFORMATION FROM THE BREAST CARE NURSES - DID YOU YOURSELF LOOK UP ANY FURTHER INFORMATION ...

Patient: No.

INT: NO? DID ANYBODY GIVE YOU INFORMATION?

Patient: Oh, I've had information from all sorts of people. [chuckles]

INT: OH, TELL ME A LITTLE BIT ABOUT THEM, THEN.

Patient: Oh yeah, from all sorts of people. Yeah, most of it encouraging I have to say, all of it encouraging, especially from up in Scotland.

INT: OH YES.

Patient: This is somebody I've never met, no idea who she is, but she's a colleague of my daughters, and Rebecca knows her very well and we've talked about this before, and some of it was partly to say, you know, she phoned up Becky and said, 'Is your Mum going to have breast reconstruction?' and she aid, 'I've no idea. Hang on a minute I'll phone my Mother,' [chuckles]

INT: [???] TALK BETWEEN THE TWO OF YOU.

Patient: No. She said, 'Oh that's all right, because I didn't either,' she said, and she was only 40-odd, which surprised me, I thought she would have done. But she aid, no, it had never been a problem, so that was that. But I decided at the age of 70, really, you know, come on [chuckles] it hardly matters any more. I'm never gonna look like one of these cover girls, whatever happens, so, no, it didn't really matter.

INT: [???] HAVE YOU SEEN CALENDAR GIRLS ?

Patient: You're joking. I'm in the WI, so I know. But even so [chuckles]

INT: [???]

Patient: But apart from that, you know, you see these young girls on, stars, or whatever they care to call themselves, wondering round with hardly any clothes on and [chuckles] their bosoms sort of stuck out like ... yes ... never mind. I'm never gonna look like that whatever happens, so ...

INT: AND THAT INFORMATION THAT YOU GOT, WAS IT, DID YOU FIND IT USEFUL IN ANY SORT OF WAY? HOW DID YOU FEEL WHEN YOU GOT THAT INFORMATION FROM ...?

Patient: Erm ... helpful, encouraging, and as I say, you know, I know that if I want to I can phone them up and say 'Here, here, here ...' you know, 'What about this? What about that?' And I'm hoping, I don't know, but next, it's every third Wednesday - I wish they'd call it something else instead of this, I think it's a bit twee to say the least - Bosom Buddies, ugh, it's the ladies who've had the ...

INT: OH, LIKE A SUPPORT GROUP OR SOMETHING?

Patient: Yeah, yeah.

INT: YES, RIGHT, BOSOM BUDDIES.

Patient: I'm going to ring up and see if they've got a meeting next week. I sort of half suspect that being August there might not be one, so I shall check up, and I think I shall probably go and then I can ask Mary or Donna the questions that are buzzing round. Not that I've got very many, I mean, it's over, done with, and that's it. Get on with life.

INT: THINKING ABOUT THE TWO OPERATIONS THAT YOU DID HAVE, DID YOU FEEL THAT YOU HAD THE AMOUNT OF CHOICE THAT YOU WANTED IN THE KIND OF TREATMENTS YOU COULD HAVE HAD?

Patient: ... Yes, in as much as, you know, the choices are there to be made. Yeah, yeah. I mean there's only so much you can sort of do, you either, as I say, it's either plan A, plan B or plan C and, having been given the information, you choose which one you want to go down and we went to plan A first of all and then decided that plan B wasn't a goer, and we went to plan C. But, yes, erm, I can't say that, you know, sort of it was difficult to make a choice because you've got to make a choice. I mean you could totally ignore it if you're that, plan AA if you like, if you choose to ignore it and do nothing. And when I was talking to that daughter up there, she lives in Australia, and we phoned her up and told her what was happening and she said, 'Oh [???' and I was talking to her the other day and I said, you know, 'I almost wish I'd never started this.' She said, 'Oh, don't talk like that, Mum, just think, if you hadn't gone ...' because I said, you know, 'If I hadn't gone for my mammogram I would have to go through any of this.' [chuckles] She said, 'Yes, but just think what the results could have been. Just think.' And she's got a friend who lives across the road who is absolutely riddled with cancers.

INT: AH, NO.

Patient: And she's only a young woman. You know, she said, 'No, Mum, don't talk like that, don't talk like that.' So ...

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

Patient: Very positive. Erm, I think everything that was done that could possibly be done. I was given the information and it was very fast, erm, we had my sister-in-law staying with us a week before we went, I went for my mammography, and, erm, then she went home and of course there was nothing in the pipelines then. And then when we rang up and Derek spoke to her when I was in hospital she couldn't believe, she just could not believe what was happening, and that it had all happened so quickly, you know, she said people wait for months. And I said, 'Well, no ...' I really couldn't complain. And the care that I had, erm, was good. I wouldn't write home about the food but we'll ignore that. [chuckles]

INT: AND THE DISTRICT NURSING? I MEAN YOU MENTIONED THE DISTRICT NURSING ...

Patient: Er ... I had two visits the first time and one visit the second time, erm, and I'd no dressings so, you know, they couldn't do anything. And that was that. Sat and talked to me, the first time, we talked about radiography and I was bothered about my hair coming out, I said, because I don't have a lot going for me, my hair's the only thing I've got, that's naturally curly, and the thought of losing that was bugging me more than somewhat. And she said, 'Well you might,' and that didn't endear her. And then we talked a bout the effects of the radiography and how it could make you very tired and, you know, sort of off-colour for months on end, and that set me back a bit. [chuckles] I didn't want to hear that, I didn't want to hear that then. Erm ... but then we talked to somebody else and said 'Rubbish, rubbish. You will probably feel tired but you, chances are you won't lose your hair, you only lose your hair if you have chemotherapy,' erm, and, do you know, I think that was the biggest thing that bothered me, losing my hair. Isn't that silly?

INT: OH, THAT'S VERY ... NO, NOT SILLY IT ALL, A LOT OF WOMEN, A LOT OF WOMEN THAT'S ONE OF THE BIGGEST FEARS, LOSING THEIR HAIR.

Patient: Yeah, yeah.

INT: YEAH, NOT SILLY AT ALL THAT. MM. YEAH. ERM, HAS THE TREATMENT, OR CARE, IN ANY WAY NOT MET YOUR EXPECTATIONS?

Patient: No, because I didn't have any expectations.

INT: OH, RIGHT.

Patient: Erm ... it sort of, a bit like dream-walking somehow, [chuckles] it just all happens, you know. You start here and you just sort of goes on, and it just all happens, erm, and so, no, I can't say I had any expectations because I wasn't expecting anything in the first place, because I didn't expect to go and have all this done. So, no, I didn't have any expectations. But have been well impressed, well impressed. I liked the ward, I liked the staff, with the odd exception, but, as I say, the food really wasn't much to write home about, but apart from that, we'll ignore the food.

INT: WELL THE NEXT THING I WAS GOING TO ASK YOU WAS IS THERE ANYTHING YOU COULD, YOU COULD CHANGE, IF YOU HAD THE POWER AND MONEY TO CHANGE ONE THING ABOUT THE SERVICE THAT YOU WENT THROUGH, WHAT DO YOU THINK IT WOULD BE?

Patient: Food. Improvement to the food. I think it's the old story. I mean I was in on the CHC and one of our members was in on the committee that sorted out this new food system that they've got up at the Royal, and it was going to be the best thing since sliced bread. Well, it isn't. I mean, (a) if you haven't ordered a meal you have to have what is left and the first time I came round, the first time I

was in I didn't have anything except one piece of toast at night. The following morning I didn't fancy any breakfast at all, so that was that. Erm, on the second time, about the second day, though we hadn't filled in any sheets, erm, we had to have what was left and the only thing that was left that particular day was cauliflower cheese and broccoli, and I quite like cauliflower cheese, but that was disgusting, it was horrible.

INT: YOU TRIED IT, DID YOU?

Patient: Absolutely horrible, and the vegetables - it's the vegetables that always fail them. I mean we had chicken and leak pie one day and that was really nice but the vegetables ...

INT: SOGGY.

Patient: Soggy and wet ... horrible. And it's always the vegetables that let them down and I don't know quite how they get round that. But because they have this cook:chill system and the food comes from Wales somewhere ...

INT: SORRY, PARDON?

Patient: The food comes from Wales.

INT: NO.

Patient: It does, you check up.

INT: OH RIGHT, I'LL [???

Patient: You check up, the food comes from Wales. They don't have, they've got kitchens where they re-heat the meals but they're all brought in from ...

INT: OH YOU LEARN SOMETHING NEW EVERY DAY, I JUST THOUGHT THEY DID THEM DOWNSTAIRS IN THE CATERING.

Patient: They used to, they used to have a nice kitchen downstairs.

INT: I WOULD THINK THEY'D BE BETTER [???

Patient: But they decided that this cook:chill ... and there's an awful lot of waste, oh they do have a lot of waste.

INT: OH, THERE WILL BE, YEAH.

Patient: It'd be interesting to see where the food came from for your mother.

INT: I THINK IT MOSTLY CAME FROM MY FRIDGE. [chuckles]

Patient: [chuckles] Yeah, yeah.

INT: OH WELL, I'LL TELL HER THAT ONCE I GET BACK. ERM ...

Patient: So, yeah, that's, for the Royal it comes from Wales. Not at Walton, Walton they still cook their own food, and they all say it's much better at Walton. And I have had meals in their canteen so I know that the meals aren't too bad. Erm, because I go up and do the Jubilee Café up there: when I'm better I shall go back, when I'm feeling up to it I shall go back and do it.

INT: OH, THE HALLAMSHIRE FOOD'S QUITE GOOD. I DON'T KNOW WHAT THE PATIENTS GET BUT I KNOW THE KITCHEN DOWNSTAIRS, THEY PUT TWO DIFFERENT DELI BARS ON AND A PROPER KITCHEN WITH HOT FOOD AND STUFF, AND IT'S GOOD STUFF, I MEAN, I LIKE EATING DOWN THERE. LAST COUPLE OF QUESTIONS ...

Patient: That would be the only thing for me, and I think food is important.

INT: MM, YEAH.

Patient: Erm ... and of course one young lass in [chuckles] and she smoked, and she really was quite poorly was that young girl, and she could never get enough food, she could never get enough food, she was sort of having everybody else's leftovers and all their cheese and biscuits and, you know, there was never enough food to fill her. It was a shame. But there we are. Right, go on.

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

Patient: ... I think that's very difficult. Erm, whichever way you tell it, it is hard. It is hard to take, and it must be just as hard to give the information, and I don't know how you make it any easier. I just don't know how you could possibly make it any easier, except to have people around, kind, like Donna and Mary, and your husband, and your family. Erm, I don't know that there's anything that could soften the blow, because it is a blow.

INT: OH YES.

Patient: And I don't think there's anything.

INT: AND IS THERE ANY PARTICULAR INFORMATION ABOUT YOUR DIAGNOSIS YOU THINK IS IMPORTANT TO HEAR?

Patient: No, because I think unless you've got medical knowledge, you don't know anyway, so, erm, speaking as a complete lay person, erm, no. I think perhaps you could be guided, once you've been told, off to the websites and things like that, which is fine if you've got a computer and you're into that kind of thing, well, yeah, fine, fair enough. Or if you're desperately seeking information you can go down to the library and look up the information. But I think a lot of the time you don't want to face up to it anyway.

INT: RIGHT, YEAH.

Patient: You don't want to face it anyway, so you don't want to be told. A bit like me when I rang up and I spoke to Mary and I said, you know, 'Can I come? I'm getting really very uncomfortable,' and she said, 'Yeah, OK. Do you know what they do?' and I said, 'No, and don't bother telling me.' [chuckles]

INT: ERM IT'S ...

Patient: Ignorance is bliss or something.

INT: ERM, 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 THEY CAN HAVE? WHEN THEY'RE BEING TOLD ABOUT THEIR OPERATIONS.

Patient: That's it's not easy, that there is a lot of ... uncomfortable pain involved. And yet pain levels are so different for everybody. I mean I was in a bed: there were three of us, there was one lady there and one lady there, with me in the middle, and I'd had, erm, a lumpectomy and then a mastectomy. This girl had had, erm, a lumpectomy. This girl had had a lumpectomy. And they were fine. They had, she had, certainly this one had no problems at all. It drained well, she could do all the exercises, she was fit, she was, you know, sort of ... fine. The other girl had quite a few problems and they weren't sure that she wasn't gonna have to come back and, you know, but she didn't want to know, she didn't want to talk about it, you know, and she knew that I'd already had a lumpectomy and I was in having a mastectomy. She didn't want to know ... she didn't want to know that that was possibly a route that she would have to go down.

INT: RIGHT.

Patient: Erm, we'll not talk about it, we talked about anything but not that. And I think that's, the shutters come down.

INT: YEAH, OF COURSE.

Patient: And you don't want to talk about it. Erm, and that's the way it goes. I mean I didn't tell anybody about going until I went to the WI and I'd arranged to go somewhere and had to cancel and normally, if we go on visit and thing and there's a payment to be made, normally if you withdraw you have to pay, and I didn't know quite what the situation was and I went and aw somebody and I said, 'Look, you know, I'm not being difficult but I am going into hospital and I'm not sure that I'm going to be able to go to this visit. What are we going to do?' and she said, 'Well we have paid for it, Kath, so ...' she said, you know, 'leave it with me,' and she checked up and she said, came back and said, 'No, under these circumstances, forget it, forget it.' And then I told somebody else, erm, and I told my next door neighbour what was happening with the proviso that she didn't tell another neighbour, because if you told that neighbour it went ... you know, with the grapevine, went round like a shot. And we proved it actually later because, erm, I had to tell her myself because I met her as I was going out to the hospital and she said, 'You're up early, what are you doing?' and I can't lie, I'm not a good liar, I sort of said what was happening. And she was on the bus and happened to meet one of my other friends who hadn't, had no idea what was going on, and Margaret said, 'Has Kath phoned? Haven't seen her for ages,' 'Oh,' and it was off. So the grapevine was working quite well by that time.

INT: OH RIGHT.

Patient: [chuckles] Not that it mattered by that stage in the day, I mean, it really wasn't that important. But I did want it, when it was only a lumpectomy, I did want it to be personal and it was my problem, you know, didn't want it discussed ...

INT: YEAH, OF COURSE.

Patient: ... all around the place. Erm, as I say, it ended up getting discussed everywhere because from Australia to Edinburgh, friends round about. I mean I have a friend who does community bus driving and she, some of her ladies, she knew a couple of them, and she came back with all sorts of information. 'Talking to So-and-So,' oh God, and I don't know these people from Adam, you know, no idea who they are, but she said, you know, 'So-and-So said, remember this and remember this,' you know. Oh dear. So ...

INT: LAST QUESTION HERE, IS THERE ANYTHING ELSE YOU'D LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY? ANYTHING IMPORTANT YOU THINK WE'VE MISSED OR NOT COVERED?

Patient: No, I don't think so. Erm ... no, I don't think so. I think we've covered everything.

INT: I'LL TURN IT OFF ...

[End of interview]