

\*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

\*VENUE: Low MR unit

\*DATE:

\*ID: Patient55

INTERVIEWER: DJW

INT: RIGHT. FIRST OF ALL, I'D LIKE TO THANK FOR BEING INTERVIEWED. I'D START WITH QUESTION ONE, WHICH IS CAN YOU TELL ME A BIT ABOUT WHAT YOU KNEW OR UNDERSTOOD ABOUT BREAST CANCER BEFORE YOU REALISED THERE WAS SOMETHING WRONG WITH YOUR BREAST?

Patient: Erm, I didn't know anything, I knew basically what cancer is and what breast cancer is, erm, but as much as any in-depth details, no, didn't know about any, I knew various types of treatment for cancer but not particularly breast cancer.

INT: RIGHT, OK.

Patient: So, like cancers in general.

INT: YEAH, AHA.

Patient: But not, not necessarily the breast cancer itself.

INT: YEAH, OK. AND HAVE YOU GOT ANY PREVIOUS FAMILY HISTORY OF BREAST CANCER?

Patient: I'm not aware of any.

INT: NOT [???

Patient: I'm not aware of any.

INT: OK, THAT'S FINE.

Patient: I'm not a very large, extended family, we're a very small, so my Mum was an only child and, erm, a lot of the family, through circumstances, is not known about because my Gran was orphaned and we don't know much about the family previous to that, so ... yeah.

INT: RIGHT, OK. AND HAVE YOU ANY FRIENDS WHO'VE HAD BREAST CANCER AT ALL?

Patient: I have, yes.

INT: CAN YOU TELL ME ABOUT THEM PLEASE?

Patient: Erm, a friend that I actually work with had breast cancer six years ago.

INT: RIGHT, CAN YOU ...

Patient: And we've, she's been a big support to me really, and, erm, two or three others, two that are no longer with us.

INT: OH RIGHT, I'M SORRY ABOUT THAT.

Patient: That ... yeah, one quite a while ago, the other one more recently. Erm, previous colleagues over the years, yeah, so I ...

INT: SO WHAT OPERATIONS DID YOUR FRIENDS HAVE, THEN?

Patient: Erm, the first one, Audrey, she was 50 and this was way back, this was 10, 12 years ago, she had a full mastectomy, but it came back later on. Erm, she died about four and a half, five years later. And I know Jasmine left it very late before she went to the doctors, she was a very private person, single, still lived at home with her Mum, and erm, from what I understand, I think it had gone too far when she finally went, yeah.

INT: OH RIGHT.

Patient: Erm, my friend that I work with actually, she didn't have any surgery at all.

INT: OH RIGHT.

Patient: Where her lump was position, lumpectomy wasn't an option, she'd got to have full mastectomy because it was at the very back of her breast, almost on her rib cage.

INT: OH RIGHT, OK, YEAH.

Patient: And they said that lumpectomy wouldn't be an option, but she was very, erm, she didn't necessarily want to lose her breast, so they said they'd try chemotherapy to shrink the lump first of all, and with chemo and radiotherapy they cracked her ...

INT: REALLY?

Patient: ... and she didn't have to have any surgery, yes.

INT: OH THAT'S GOOD, YEAH.

Patient: And she's six years down the line now and up to now in the clear. Also another friend that I used to work with, she's now three years down the line. She had lumpectomy and lymph node dissection and she's in the clear up to now, three years down the line.

INT: OH THAT'S GOOD.

Patient: Yeah.

INT: SO CAN YOU TELL ME HOW YOU FIRST DISCOVERED THERE WAS SOMETHING WRONG WITH YOUR BREAST?

Patient: I went to bed one evening, popped, went to bed early because I was tired, popped myself, put the tele on, laid back, went like that ... and felt it basically, just thought, 'Ooh, God, what's that?' you know ...

INT: YEAH.

Patient: I'm not a lumpy, bumpy person, I don't have lumps, and I do, I must admit I don't check as often as I probably should but I do periodically, when I think about it I do. And, erm, probably, probably once a month, once every couple of months but it, I wasn't even looking for anything, it just, just the way that I'd position my hand and sort of gone like that to smooth my top, and I felt it. And, er, just out of the blue. And I went straight to the doctors the next morning because it was so out of the ordinary because I've never had anything like that before. And I'm glad that I did now. [chuckles]

INT: ABSOLUTELY.

Patient: Yeah.

INT: SO WHEN YOU FIRST FOUND IT, WHAT WENT THROUGH YOUR MIND?

Patient: Erm ... when, the first thing that went through my mind was actually quite, I was quite shocked actually because I thought, 'Ooh ...' you know, well, that does come to mind, breast cancer, and then you think, 'Oh no, don't be stupid, it's, you know, it could be anything, it's my age, I'm coming up to probably menopausal age, erm, but it is a change so I'd better go and get it checked out' basically, you know. Bit horrified at first but then played it down a bit in my own mind and, yeah.

INT: AND THEN WHAT, SO YOU WENT TO YOUR GP AND WHAT DID THEY SAY?

Patient: My GP didn't seem to think it was anything to worry about, so she put me through for a [???] but she said, 'We will get it checked out anyway,' and so they put me through for a routine appointment, so I wasn't seen until two months later ...

INT: OH.

Patient: ... when, as I say, and I don't know, initially when I found out what it was I was quite annoyed about that, the fact that I'd been left that amount of time. But then, it's one of those things, isn't it? It's very hard for any GP I suppose to ... I'm relatively young, I suppose really, erm, I don't know, I've still got mixed feelings about that one.

INT: RIGHT, OK, THAT'S OK. ERM, SO YOU WENT TWO MONTHS LATER TO THE, IS THAT WHEN YOU FIRST [???]

Patient: Yeah, I found the lump in March ...

INT: AND THAT WAS AT GLENFIELD, WAS IT?

Patient: ... and I went to Glenfield, my appointment was the 25th May.

INT: RIGHT, OK.

Patient: Erm ...

INT: COULD YOU TELL ME ABOUT THAT APPOINTMENT, WHAT HAPPENED ON THE DAY?

Patient: Er, it was actually quite nice. We weren't left hanging around too long. A friend actually came with me because I wasn't expecting it to be anything untoward, and I said, my partner rather, and he, I says, 'Oh no,' I says, 'It'll be fine, they'll just do a mammogram and ...'

INT: HAD YOU NOTICED ANY CHANGE AT ALL IN THE LUMP?

Patient: No, I had sort of kept an eye on it, and odd days it almost felt as though it wasn't as bad, it wasn't quite ... I think if it had have, if I'd have noticed it growing or getting a lot bigger, then I'd have gone back to my GP but because I didn't feel any change really, and some days it didn't feel quite as big.

INT: RIGHT, OK.

Patient: I'd have, I'd have been concerned otherwise, but that was fine. But at that appointment I had my mammogram, ultrasound, then they called me in for a

needle biopsy. I had the needle biopsy and was told to get dressed and went back out and sit in the waiting room, but then they called me back in again and said that the, the biopsy was inconclusive and they wanted to do a core under ultrasound, and they did that there and then. But by then it was getting on very late in the day, so I had to go back the following week for the results.

INT: RIGHT, OK.

Patient: And I was told then that it was a small cancer.

INT: MM, OK. SO ON THAT FIRST VISIT, WHEN THEY WERE DOING THE BIOPSIES AND STUFF LIKE THAT, I MEAN, WHAT WERE YOUR FEELINGS AND THOUGHTS ON THAT DAY?

Patient: Erm, I just more or less presumed this was what happened when you'd got lump.

INT: RIGHT, THIS IS THE PROCEDURE, SORT OF THING.

Patient: This is the procedure, this is what happens. Erm, to be honest, when it came to sort of the core biopsy, I was, I was quite suspicious that they thought it was something more than just a cyst or something like that. I mean she'd done the needle biopsy, and I would have thought that from that, erm, they'd have probably been able to tell and obviously they wanted it confirming, but I didn't push it, and I let that week go by and sort of, you know, and I'd almost resigned myself to the fact that they were going to tell me that it was ..

INT: YEAH, OK.

Patient: This is my partner coming.

INT: YEAH, OK. SO, YEAH, SO YOU SAID YOU WERE SUSPICIOUS ABOUT THE, YOU KNOW, WHEN YOU GOT TO THE CORE BIOPSY AND STUFF ...

Patient: Yeah, I thought, 'Ooh, this is ...' you know.

INT: DID ANYBODY ACTUALLY SAY ANYTHING DURING THE DAY, YOU KNOW THE CONSULTANTS, DID THEY SAY ANYTHING?

Patient: Erm, I didn't see a consultant. Now I'm not sure ... I saw somebody fairly senior on the day, erm, I'm trying to think how ... had my [???] ultrasound, I did see a doctor, but it was lady doctor and I've not seen her since, and I can't for the life of me remember her name.

INT: RIGHT, OK.

Patient: But she did the needle ..

INT: WAS IT A YOUNG GIRL?

Patient: No, she was a middle-aged lady, short, grey hair, glasses.

INT: ELIZABETH?

Patient: It does slightly ring a bell.

INT: I KNOW THERE'S A COUPLE OF, WAS SHE, YEAH, I MEAN I MIGHT BE WRONG, THERE'S A COUPLE OF GP ASSISTANTS THERE LIKE ...

PATIENT: Yeah, it could have been ...

INT: ELIZABETH EATON AND ELIZABETH DENTON, AND I THINK THEY'RE GP ASSISTANTS.

Patient: Yes, I'm not, I really am not sure. It went, it went in a bit of a blur to be honest that day./ Well it didn't at the time but looking back on it it seems a bit of a blur [chuckles] yeah.

INT: YEAH, OF COURSE, IT CAN DO.

Patient: Yeah, and, er, but she actually did the needle biopsy and, erm, then called me back in to say that they'd found that it was in-, it was inconclusive and that she wanted me to have the core biopsy and that I'd be called back in for that. And, erm, I spoke to, one of the breast care nurses was in the room with me, erm, it wasn't Sue and I'm not sure, I only saw this breast care nurse once.

INT: RIGHT, OK.

Patient: ... Yeah, and then I went back into the waiting room, then went in to have my core biopsy. But, erm, and then I was told, yeah that was it, before I went in I was told that we wouldn't get the result back that particular day because obviously it had got on, I mean I didn't leave there until getting, it must have been getting on for half five, and I should imagine probably the labs were probably closed or whatever by then, or they couldn't do it. Yeah, so I had to come back the following week.

INT: AND DURING THAT WEEK, I MEAN, HOW WAS THAT?

Patient: Erm ...

INT: IN BETWEEN THAT AND GETTING THE DIAGNOSIS?

Patient: I wasn't too bad actually. I think I was sort of ... probably a bit in denial really, even though, I'd almost, I've been pretty calm about it all the way through, to be quite honest. I think I've just got the attitude that what will be will be, and if that's what it is, well then there's nothing, no stressing out about it is gonna make it go away. If that's what it is, well that's what it is and it's got to be dealt with. And that's more or less been my philosophy [chuckles] a lot of the time all the way through. Yeah. And, erm, ...

INT: DID YOU SPEAK TO ANYONE ABOUT IT OR ... AT THAT TIME?

Patient: I spoke to friends. I spoke to the girls at work. Everyone reassured me that I'd be fine, it wouldn't be anything, you know, and it was, but I'd just spoke in general about it. And my friend two doors away, she's come with me to my appointments, and, apart from the time I was actually admitted, when Rob came in for my pre-assessment. Erm, it was actually her when I was told that broke down into tears [chuckles] because she was so shocked. And I just turned round and said to her, 'Kim, I'm not surprised.' I really did, I expected it.

INT: MM, SO IT WAS THE SECOND TIME YOU WENT BACK THERE TO GET YOUR RESULTS?

Patient: That was the week after the core biopsy.

INT: SO CAN YOU TELL ME ABOUT THAT FROM SORT OF START TO FINISH IF YOU WILL?

Patient: Erm, well just a case really of getting in and sitting and waiting. Erm ... er, I got there, waited, and I actually saw Dr Everson, or Mr Everson, and saw him on that day, was called in to like the side room, the consultation room. Erm, I undressed to the waist and he came in and examined the lump with a student, erm, asked me what I'd actually been told about this lump. Erm, I told

him exactly what I had been told, that I'd had the nee-, it had shown up on the mammogram and the ultrasound scan, and that I'd had the needle biopsy and I'd been told that was inconclusive so I'd had the core biopsy, but hadn't yet had my result. To which he then asked me to get dressed and then he'd see me through in the consulting room. And it was almost, as I went through into the consulting room, it was full: the breast care nurse was there, and there was another doctor there; there was somebody else there, and it was almost, as I walked in, it more or less confirmed my suspicions.

INT: RIGHT, OK.

Patient: There wouldn't be that many people there if there was nothing to worry about.

INT: SO WERE YOU STARTING TO GET SOME KIND OF SUSPICION THERE THAT THIS WASN'T [???] ...

Patient: Yeah, and that's when, like, when I sat down and Kim, my friend, she sat at the side of me, and he, he explained things to me, erm, he actually went over what I'd been told again I think, and he said that, he told me that it was actually a small cancer and, I don't know what my ... I was almost expecting it, I wasn't shocked ... erm, and then he went on to explain how we'd, how best to deal with it, gave, erm, explained the lumpectomy, lymph node dissection, or the fact that, you know, it was my choice if I wanted a full mastectomy. Some women say they prefer to get ... get it off and, you know, but, yeah, but explained the two options ...

INT: RIGHT, YEAH.

Patient: ... the lumpectomy / lymph node dissection, the fact that I'd probably need a bit of radiotherapy, well I would have to have radiotherapy afterwards, depending on what they found and once it was analysed what they'd taken away, would depend on any further treatment that I'd need. Erm, but I had got the option of having full mastectomy if that's what I wanted, if I felt that I'd feel, I'd feel safer having that done. And I just really said to him, 'Well, you know, do you think that is necessary?' and he didn't think so, he thought that we'd manage it. He said there was no evidence to prove that the result would be any better, or any different basically ...

INT: IF YOU HAD A MASTECTOMY.

Patient: ... if I had the mastectomy, so I opted for the lumpectomy, yeah.

INT: RIGHT, OK. MM. SO WHAT WERE YOUR INITIAL FEELINGS THEN WHEN YOU WERE ACTUALLY, WHEN IT WAS CONFIRMED NOW THAT YOU ACTUALLY HAD IT? I MEAN YOU'D BEEN SUSPICIOUS AT THIS POINT BUT ...

Patient: Almost relief that I knew.

INT: RIGHT.

Patient: It was almost, 'Well, yeah, OK then, let's get on with it.'

INT: RIGHT. OK.

Patient: Yeah, get it done and out the way. Yeah.

INT: AND, ERM ...

Patient: I mean nobody chooses to be in that position but if you are, you know, you've got to deal with it. Yeah.

INT: AND WHILE MR EVERSON WAS DESCRIBING YOUR DIAGNOSIS AND YOUR TREATMENT OPTIONS, DID HE USE ANY VISUAL AIDS? DID HE DRAW ANY DIAGRAMS, THE MAMMOGRAM, ANY PICTURE, ANYTHING LIKE THAT?

Patient: No, nothing at all.

INT: NOTHING AT ALL, RIGHT.

Patient: Not that I'm aware of. I can't remember anything, yeah.

INT: OK. AND HOW DID YOU ...

Patient: He did explain that he thought it looked as though it was about 2 cms.

INT: RIGHT, IN SIZE?

Patient: In size, yeah, yeah.

INT: ERM, AND HOW DO YOU THINK YOU GOT ON WITH MR EVERSON?

Patient: OK. He was very nice, yeah. Felt fairly comfortable with him. Yeah.

INT: YEAH, THAT'S GOOD.

Patient: Yeah, he was fine.

INT: AND WHEN YOU WERE TALKING ABOUT THE CANCER AND ITS TREATMENTS, HOW MUCH DID YOU UNDERSTAND ABOUT WHAT YOU WERE BEING TOLD?

Patient: I understood most of it, with working in a sort of medical environment anyway, there's a lot of things you sort of, you sort of pick up, so, yeah, I was pretty ...

INT: MM. WAS THERE ANYTHING YOU THINK YOU DIDN'T UNDERSTAND, [???

Patient: Erm ... nothing that springs to mind, nothing obvious, no.

INT: OK. AND, ERM, AND THEN, AFTER YOU'D SPENT SOME TIME WITH MR EVERSON, DID YOU SEE THE BREAST CARE NURSE OR ...?

Paint: Yes.

INT: SO WHAT HAPPENED AFTER THAT THEN?

Patient: We went in, we came out of the consulting room and Sue, the breast care nurse, came with us and we went into like the quiet, what they call the quiet room, and, erm, she discussed everything with me, asked how I felt, and I more or less said the same as what I'd said, 'Well, you know, I've just got to get on with it.' you know, 'The soon ... let's just get it done and get it out, that's all I want, just get it out and take it from there.' It's sort of one stage at a time, isn't it really? But she was, she was lovely, Sue, I mean you can, you know, really talk to her. Erm, the main things that I wanted to know was whether it, now I had a great list of things ... I've gone blank now. I mean one of the things was could it be hereditary because of my daughter, she's 21. Erm, was told that normally, they don't normally test for that unless there is ... women in the family, whereas I'm the first one that I know of, erm, and I was led to believe that they don't normally test for that unless there's more incidences in

the family. Erm ... I was, and while I was in the consultation as well we actually made the appointment, actually made the date as well for my operation. I made, actually made that with Dr Everson before we went out.

INT: RIGHT, OK.

Patient: So I knew exactly when I was gonna have my surgery. Erm, ...

INT: DID YOU SIGN A CONSENT FORM THEN OR ...?

Patient: I signed the consent form, now who did ... I'm trying to think which way ... that was it, I had to, on that appointment as well I had to have a chest x-ray and blood tests.

INT: ON THE SAME, ON THAT SAME APPOINTMENT?

Patient: Yeah. And then I went back a week later to have the results of those.

INT: RIGHT, OK.

Patient: And that's when I signed my consent.

INT: OK, YEAH.

Patient: Yeah. I think [???] I'm confused now, 'cos I saw, is it Dr Kenny?

INT: DR FRANCES KENNY.

Patient: Frances Kenny, that was it. And it was Frances Kenny that I signed the consent with, she did the consent form, and that was the following week.

INT: RIGHT.

Patient: Yeah. I'm sure it was. [???] [chuckles] Yeah. Yeah, that was the following week.

INT: RIGHT, OK. YEAH, SO, ERM ...

Patient: Have I confused things now? I've gone from one to another, I'm [???]

INT: THAT'S FINE. SO YOU'VE SEEN THE BREAST CARE NURSE AT THIS POINT ...

Patient: Yeah.

INT: AND DID SHE GIVE YOU ANY INFORMATION TO TAKE AWAY WITH YOU?

Patient: Yes.

INT: WHAT WAS THAT THEN?

Patient: I got the cancer services leaflet, the NHS one, erm, the ... what else did we have? There was the different, leaflets for the different, erm, different care leaflets. The one for lumpectomy and lymph node dissection plus the one for full mastectomy, and just to read up and possible after-effects of the operation, the seroma and that sort of thing, all to read up on. Yeah, information leaflets.

INT: AND YOU READ THEM,, DID YOU?

Patient: I did. [???]

INT: DID YOU FIND THEM USEFUL AT ALL?

Patient: I did find them useful, yeah. I find it better to be informed, yeah.

INT: WAS THERE ANYTHING IN PARTICULAR THAT YOU FOUND USEFUL, ANY INFORMATION?

Patient: Erm, just all of it in general. It was just, yeah, yeah, just the fact that to have that information and to sort of, you just felt as though you were, you were well informed and you knew what was gonna happen and knew the possibilities, the things that could, could possible happen post-op and that sort of thing, what was gonna happen through the op. Yeah.

INT: AND WHEN YOU WERE TALKING WITH MR EVERSON, WHO DO YOU THINK ASKED MOST OF THE QUESTIONS AND WHO DID MOST OF THE TALKING?

Patient: Erm, I'd say Mr Everson did most of the talking.

INT: RIGHT, OK.

Patient: Yeah.

INT: MM. DID YOU HAVE ANY QUESTIONS FOR HIM OR DID YOUR FRIEND HAVE ANY QUESTIONS?

Patient: Erm, my friend didn't say an awful lot really, she does sat there [???] well she wasn't actually, I think she held back in there, it was when we got into the quiet room afterwards, that's when she broke down and we sat down with Sue, and I found that it was me comforting her, [chuckles] more than her comforting me, yeah. Yeah. I did have questions for him, erm, but it was mainly just confirming the type of treatment, and the type of surgery, and I just needed to know really that, erm, just that lumpectomy and lymph node dissection would be OK, that he didn't feel that it needed to be anything more drastic. Yeah. Because I mean obviously if he thought that needed to be done, well then, yeah, I'd have going along with it. [chuckles] Yeah.

INT: ERM, AND WHEN YOU WERE TALKING TO MR EVERSON, DO YOU FEEL THAT HE WAS LISTENING TO YOU, THAT HE UNDERSTOOD YOUR NEEDS AND CONCERNS?

Patient: Yeah.

INT: MM?

Patient: Yeah. He didn't ... yeah, you feel with some doctors that you're sort of on a treadmill and they just want you out the door, but he didn't, he wasn't like that, he didn't seem ... and he did give me plenty of opportunity to ask him questions. He asked me if there was anything more that I wanted to know, so, yeah, he was, he was fine.

INT: RIGHT. AND WHEN YOU WERE SPEAKING WITH SUE, THE BREAST CARE NURSE, DO YOU FEEL THAT SHE WAS LISTENING TO YOU, AND THAT SHE UNDERSTOOD YOUR NEEDS AND CONCERNS?

Patient: Yes. Oh, definitely, yeah, yeah.

INT: DID YOU GET ANY IMPRESSION FROM EITHER ONE OF THOSE PROFESSIONALS THAT THEY HAD A PARTICULAR TREATMENT IN MIND?

Patient: Erm ...

INT: OR A PARTICULAR PREFERENCE OR A TREATMENT?

Patient: Only that they felt that the lumpectomy would be sufficient ...

INT: RIGHT, MM.

Patient: ... to treat ...

INT: YOUR CANCER [?]

Patient: ... to treat my ... yeah.

INT: OK.

Patient: To treat what they'd found, yeah.

INT: RIGHT.

Patient: Erm ... if they, I just take it that if they'd have thought more drastic surgery was needed they'd have said so.

INT: RIGHT, MM.

Patient: They, they're the professionals, they deal with it day in and day out, week in week out, and they must get to know more or less what they're dealing with. Yeah, yeah.

INT: AND, ERM, FROM HEARING HOUR DIAGNOSIS AND YOU HAD IT CONFIRMED THAT IT WAS CANCER, HOW LONG DO YOU THINK IT TOOK YOU TO MAKE UP YOUR MIND WHAT TYPE OF SURGERY YOU WERE GOING TO HAVE?

Patient: Almost instantly.

INT: ALMOST INSTANTLY, YEAH.

Patient: At that consultation. I was told to go away and, they did, we did discuss it further afterwards with Sue and, erm, she did say to think about it. I wasn't pushed to make my mind up then but I had made my mind up then. But I was, had still got, that was it, I'd still got that week, I had chest x-ray and blood test taken, and I still, that, I had that week to think about it and then when I went back I signed the paperwork. Yeah.

INT: AND BEFORE YOU WENT TO THE CONSULTATION WHEN YOU GOT YOUR DIAGNOSIS, HAD YOU ANY THOUGHTS ABOUT WHAT YOU MIGHT DO ABOUT IT IF IT WAS A BREAST CANCER IN TERMS OF TREATMENT?

Patient: Erm, my thoughts were that I would do whatever they felt necessary.

INT: OH, OK.

Patient: Yeah.

INT: MM?

Patient: Yeah. They're the experts.

INT: OK. AND ONCE YOU'D MADE YOUR MIND UP, DID YOU AT ANY POINT CHANGE YOUR MIND OR HAVE ANY SECOND THOUGHTS ABOUT WHAT YOU WERE GONNA HAVE?

Patient: No.

INT: OK.

Patient: Not at all.

INT: ERM, SO, HOW SOON AFTER, SO YOU HAD YOUR DIAGNOSIS, SAW THE BREAST CARE NURSE, YOU HAD SOME CHEST X-RAYS AND SOME BLOOD TESTS ...

Patient: Yeah.

INT: AND THEN YOU HAD A WEEK TO GO BACK FOR YOUR ...

Patient: For my chest x-ray and blood test results.

INT: CAN YOU JUST TELL ME A LITTLE BIT ABOUT WHAT HAPPENED AT THAT CONSULTATION?

Patient: Erm, I went in to see Miss Kenny [?] or Mrs Kenny, Dr Kenny [chuckles] [???], yeah, and she actually told me that the tests were clear, that there was no evidence that it had spread, which was a relief.

INT: IT MUST HAVE BEEN, YEAH.

Patient: Erm, I think that week was probably the worst week, the finding out whether it had spread or not.

INT: RIGHT, YEAH.

Patient: Erm, I didn't get unduly stressed out about it, but obviously there is concern there, that is something that ... well that does predominantly, erm, decide on your treatment really, doesn't it?

INT: MM, EXACTLY.

Patient: Your final decision on treatment is whether it's spread or not, I should imagine, yeah. And if it hadn't, I think, erm, the fact that it hadn't just made it more clear that that was it, that was the lumpectomy and that, that was fine, that's what I was going along with [???] yeah.

INT: AND I MEAN OBVIOUSLY WHEN YOU CAME BACK FROM THAT CONSULTATION WHERE YOU JUST GOT YOUR DIAGNOSIS, DID YOU TELL YOUR FRIENDS, YOUR FAMILY AND ...?

Patient: Yes, that's when I had to tell them. I mean I hadn't said anything to anybody: I hadn't told my children because the day, the day I found, the day I found the lump is actually the day before my ex-husband's father's funeral, my children's grandfather's funeral, and I couldn't tell them. They were going, because they were going, they're very close, very close to the grandparents on that side. And they were absolutely devastated and there was just absolutely no way I could tell them that I'd found this lump, so I was just waiting to find out what it was. And that was my worst time, was when I actually found out that it was cancer. Those next two or three days trying to pluck up the courage to tell them, find a way how to tell them without stressing them out, because they're not babies, the youngest is just turned 21 ...

INT: RIGHT, OK.

Patient: ... and my eldest is almost 24 and Stuart, in between, will be 23 this year. Erm, my date for surgery was actually two days before my eldest was going to Miami on a holiday he'd planned for months.

INT: OH ...

Patient: I know. And I just, that two or three days just trying to get the right time to tell them. I wanted to get them all together, and I couldn't because they all work at different times, my middle one does nights, so he's [???] you know, he's asleep in the day, and I've only got Nicola that lives at home still, my youngest, and it was her I told. I got the diagnosis on the Tuesday ... I stressed myself out over it the Tuesday night and all day on the Wednesday, trying to figure out a way to tell them how I was gonna tell them. Obviously when I came home I told Rob. Erm, then it was actually on the Thursday morning, we were getting ready to go to work and Nic was getting ready to go to work and I couldn't leave it any longer. I woke her up at 6 o'clock in the morning and went and sat on the bed and told her. [telephone rings] I'll ignore that. Yeah, I actually sat on the bed.

INT: THAT'S JUST A VERY FUNKY MOBILE PHONE RING TONE, ISN'T IT?

Patient: It is, isn't it, it's my daughter. [chuckles] Yeah. And, erm, yes, actually sat on her bed and told her ... and told her that, I just told her it was only a lump and they were gonna take it out and I'd be fine and ... [chuckles] ... you know, that's, yeah, that's it. And the lads one by one over the next two days and I think from the Tuesday to the Saturday, that's the most stressed out I've been, and it wasn't the fact that I'd been diagnosed with it, it was how to tell the kids. And that was the main worry.

INT: RIGHT.

Patient: And that they weren't gonna hear it from somebody else before they heard it from me. [chuckles] Yeah, yeah.

INT: YEAH, ABSOLUTELY. AND THEN OF COURSE YOU WENT BACK AND YOU HAD THE CONSULTATION WITH MISS KENNY, AND THEN HOW SOON AFTER THAT WAS, DID YOU HAVE THE OPERATION?

Patient: Erm ... I had the operation on the 2nd June, so it would be ... I think it was about, I don't know if it was a week, week, two weeks. A week, I think it was about a week after, if I remember rightly. I've not got my appointment cards with me [???] because it just, looking back on it, it all sort of went in a bit of a blur, but I'm sure ... it may have been two, may have been two weeks, I think it probably was, yeah.

INT: RIGHT, OK.

Patient: Yeah. It couldn't have been that far after because of ... 25th May ...

INT: WHEN DID YOU, SORRY, WHEN DID YOU SAY [???]

Patient: And my operation was the 22nd June.

INT: AND WHEN DID YOUR ELDEST GO ON HOLIDAY OR SOMETHING YOU SAID?

Patient: Yeah, my son went on hol-, my son went on holiday two days after my op on the 22nd, he went on the 24th. He was gonna cancel it and I said, 'Look, there's no way,' and it was actually, when I woke up after the operation, it was him that was sat at the side of me. [chuckles] So I'd got to be absolutely fine, so I made this miraculous recovery.

INT: SO WHAT HAPPENED ON THE DAY WHEN YOU WENT FOR OPERATION, THEN, JUST ...?

Patient: I was first down luckily, yeah.

INT: WHAT TIME DID YOU GO IN?

Patient: I went in the previous day, I had to go for my pre-assessment, erm, I had to be there for 3 o'clock in the pre-assessment clinic, and then went straight up to the ward, I was on the ward at about five-ish, and just took it from there. And I was first down in the morning, they said about round half-eight, I went down at quarter to nine, and the next thing I remember I was back on the ward, it was all done and dusted.

INT: RIGHT, OK. WERE YOU ALL RIGHT WHEN YOU CAME ROUND DO YOU THINK?

Patient: I was absolutely fine, I didn't have any, any untoward effect from the anaesthetic, I felt fine. Just like I'd woken up. I wasn't in any great pain. In fact within a couple of hours of actually coming up I was actually on my feet.

INT: RIGHT, OK.

Patient: Yeah.

INT: AND HOW LONG WERE YOU IN HOSPITAL FOR, THEN?

Patient: I was in until the Friday, I came home on the Friday. I had the operation Tuesday morning.

INT: SO FOUR OR FIVE DAYS, MM.

Patient: Yeah. I came home with a drain in because I was still losing quite a bit of fluid.

INT: RIGHT, OK.

Patient: Yeah, and had that taken out the following Tuesday.

INT: MM. AND THEN HOW SOON DID YOU GO BACK TO GET YOUR RESULTS AND HISTOLOGY?

Patient: Erm ... I had it done on the 22nd, the 6th, 6th June I went.

INT: RIGHT, OK.

Patient: I went back for the histology. Yeah, and that's when I was told that everything was, everything was fine, they'd got all the perimeter and there was no evidence that it had gone to the lymph nodes, it was all clear. Yeah.

INT: [???) GREAT RELIEF THEN, THEN?

Patient: Yeah, [chuckles] and it was a stage two, which wasn't too bad, not brilliant but not too bad. So, yeah, because two of the girls that I was in with were stage three and another one was worse than that.

INT: OH DEAR.

Patient: Yeah.

INT: AND SO WHAT'S, WHAT'S YOUR TREATMENT SORT OF PLAN NOW?

Patient: Radiotherapy, it was found to be hormone responsive. I had to wait ...

INT: SO YOU'LL BE GETTING TAMOXAFEN.

Patient: ... another week, yeah, I'm on Tamoxafen. I'm having Solidex monthly injections in the stomach, well implants aren't they? I had my first one on Wednesday, my GP did that. Erm, started Tamoxafen on Tuesday, had my implant on Wednesday, and my radiotherapy starts next Thursday, on the 29th for five week.

INT: FIVE WEEKS, FIVE DAYS, YEAH.

Patient: Yeah, yeah. And I've been measured up for all that. I went on Tuesday and been measured up for it. I've got my tattoos. [chuckles]

INT: OK. ERM, NOW IN BETWEEN, ERM, GETTING YOUR DIAGNOSIS, THAT CONSULTATION, AND THE OPERATION, DID YOU LOOK FOR ANY OTHER INFORMATION ABOUT BREAST CANCER AND ITS TREATMENT, SUCH AS SPEAK TO A GP, RELATIVES, FRIENDS AND NEIGHBOURS: DID YOU CONTACT ANY SUPPORT GROUPS ...?

Patient: Search engine.

INT: SEARCH ENGINE ON THE INTERNET?

Patient: Yeah. [chuckles].

INT: AH, OK. SO WHAT DID YOU LOOK FOR THEN?

Patient: Erm, just general information, general information on the different treatments, right from the start I stated looking. I tend to use that quite a lot for [???

INT: WHEN YOU SAY 'START', WHAT START ARE YOU TALKING ABOUT, FROM WHEN YOU ACTUALLY FOUND SOMETHING OR WHEN YOU WENT TO GET THE ...?

Patient: Erm, actually from the start really ...

INT: FROM THE START, RIGHT, OK.

Patient: ... I started looking and seeing the different options and different treatments and if this could be, you know. I put, first of all, when I first found the lump it was 'breast lump'.

INT: RIGHT, OK.

Patient: Yeah, and the different things that it could be. [chuckles] And then when I found out what it was it was the different treatments, yeah.

INT: GOT MORE SPECIFIC, YEAH, OK. HOW DID YOU FIND THAT INFORMATION? WAS IT ANY USEFUL, USE TO YOU OR ...?

Patient: Yeah. I'd rather, yeah, I'd rather know as much as I can. I find that it's better to be informed, and I found that it also gives you questions to ask as well.

INT: MM, RIGHT, OK.

Patient: In some cases, yeah.

INT: 'COS YOU SAID YOU HAD A LIST OF QUESTIONS, DIDN'T YOU? IS THAT WHERE YOU GOT THEM FROM?

Patient: Erm ...

INT: YOU SAID YOU HAD A FEW QUESTIONS OR SOMETHING ...

Patient: I had quite ...

INT: YOU COULDN'T REMEMBER WHAT THEY WERE, BUT ...

Patient: I know, I had no end of questions for when I went back. I'd had the diagnosis and had to have the, erm, the chest x-ray and blood tests, and Sue had said, when she gave me the leaflet, the cancer services leaflet, 'There's a bit in the back, write down any questions,' she says, 'Just write them all down, anything that comes into your head that you want to know about ...' she says, '... just write them all down. There's a section at the back where you can put them all down.' And I did, I had a list. [chuckles] So when I went back ..

INT: RIGHT, OK.

Patient: ... Dr Kenny got the lot. And so, yeah, and it was just general. No, I didn't, I hadn't really, it wasn't things I got off of there, it was just general things that came out of my head, yeah. Erm, it was like the hereditary issues, what type of cancer was it, was it particularly aggressive and obviously she told me that they wouldn't really be able to tell that after surgery. Erm, work related things: how much time would I need off work and ... if I'd got the booklet on me I could have told you the exact questions I asked. [chuckles]

INT: OH IT'S ONLY A GENERAL IMPRESSION OF, YOU KNOW, WHERE YOU GOT YOUR QUESTIONS FROM AND WHAT YOU WERE ASKING.

Patient: Yeah, yeah. And a lot of my questions generally about the cancer itself, I think a lot of them I actually got my results, my answers by going on the internet.

INT: OH RIGHT?

Patient: Yeah. And sort of the information about treatment and things like that, but obviously you want it, you want to hear it out the horse's mouth when it does, 'cos not everybody's gonna be exactly the same, are they? No, no.

INT: AND [???) INFORMATION THAT YOU GOT, DID YOU GET BOOKS, MAGAZINES, VIDEOS, DID YOU PHONE ANY SUPPORT GROUPS OR ANYTHING OR ...?

Patient: No, it was basically friends. I had a lot of information from Alison who I work with who went through it six years ago.

INT: RIGHT, OK.

Patient: She was like my main support really.

INT: DID SHE GO THROUGH THE SYSTEM AT GLENFIELD, DID SHE?

Patient: She did, yeah. She went ... and Sue was actually her breast care nurse and Sue remembered her because I mentioned Alison and she knew her straight away, yeah.

INT: OH, THAT'S NICE.

Patient: Yeah, yeah.

INT: YEAH. AH, RIGHT THEN. AND WHEN YOU WERE AT, ERM, WHEN YOU WENT TO RECEIVE YOUR DIAGNOSIS AND YOU WERE GETTING CHOICE OF TREATMENTS, I MEAN HOW DO YOU FEEL ABOUT GETTING A CHOICE BETWEEN TWO TREATMENTS? WHAT WERE YOUR THOUGHTS ABOUT THAT?

Patient: Erm ... yeah, I think, yeah, it's good that they give you the choice.

INT: MM, RIGHT.

Patient: Yeah, because, I mean I can understand why some women probably do say, 'Yeah, just take it away,' you know, but I, myself personally I couldn't see the point in having that radical surgery if it wasn't really necessary.

INT: RIGHT, OF COURSE, YEAH.

Patient: Yeah.

INT: WERE YOU AT ALL SURPRISED THAT YOU GOT A CHOICE, WAS IT SOMETHING YOU WERE EXPECTING OR ...?

Patient: Erm ... I wasn't expecting to have a choice, to be honest. I thought I'd be told what'd be best.

INT: RIGHT, YEAH.

Patient: Erm, I was, yeah, I was surprised that I'd have the choice, if I wanted to have full mastectomy I could have that. I wasn't expecting that, to be honest, I thought it'd just be they'd advise what they thought would be the best treatment.

INT: RIGHT, OK.

Patient: Yeah.

INT: SO LOOKING BACK NOW, WHAT DO YOU THINK WAS THE MOST IMPORTANT THING THAT YOU WERE TOLD OR HEARD OR THAT YOU READ THAT HELPED YOU MAKE A DECISION TO HAVE THE WIDE LOCAL EXCISION ... THE LUMPECTOMY?

Patient: I think mainly just reassurance from the consultant that he felt that, you know, nothing more drastic was needed, even though I'd got the choice I could have that.

INT: RIGHT, OK.

Patient: Yeah, yeah. As you say, it doesn't matter what you read or, you still, it's actually that, that's eye to eye, face to face contact with a person that knows what they're doing, [chuckles] you know, yeah.

INT: AND WAS IT MR EVERSON THAT PERFORMED THE SURGERY?

Patient: It was Mr Everson, yeah.

INT: MM, OK, THAT'S FINE. ERM, LAST COUPLE OF QUESTIONS NOW. LOOKING BACK FROM WHEN YOU WERE FIRST DIAGNOSED UNTIL NOW, HOW DO YOU FEEL ABOUT THE CARE YOU'VE RECEIVED?

Patient: Brilliant.

INT: YEAH?

Patient: Yeah.

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

Patient: Definitely, yeah. Yeah, very good.

INT: MM. DID YOU HAVE ANY EXPECTATIONS? BECAUSE YOU'RE A MEMBER OF THE HEALTH SERVICE, WHAT WERE YOU EXPECTING?

Patient: Erm, I really don't know. Erm, I'd just been told by everyone that I'd spoken to, and any one, I'm gonna quote Alison again that I work with who's been through it, she just said they're all so nice, so my expectations were that it was, I was gonna get good treatment, and I did. I can't fault any of it, to be honest.

INT: WAS THERE ANYTHING THAT, YOUR TREATMENT OR WHATEVER, THAT DIDN'T MEET YOUR EXPECTATIONS?

Patient: The only thing is the fact that it took so long for me to get ...

INT: REFERRED.

Patient: ... referred.

INT: YEAH, FROM YOUR GP.

Patient: That was from my GP, that wasn't, yeah. Once I was there everything, well everything was so quick. It was just dealt with and, you know, sorted. But that's the only part of it, is the referral process. Yeah.

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

Patient: ... Nothing that springs to mind, to be honest.

INT: OH, OK.

Patient: There's nothing that I can honestly say ... no, I think the service is excellent.

INT: RIGHT, OK.

Patient: Yeah.

INT: AND NOW YOU'VE BEEN THROUGH THIS EXPERIENCE, WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW, FIRSTLY ABOUT THEIR DIAGNOSIS?

[Interruption for telephone call]

INT: YEAH. I'LL JUST REPEAT THE QUESTION. NOW YOU'VE BEEN THROUGH THIS EXPERIENCE, WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT THEIR DIAGNOSIS?

Patient: ... Erm, that, once they've been told that it is breast cancer, for me how far it had gone. Had it ... that was what I needed to know.

INT: MM.

Patient: Yeah.

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

Patient: Erm, they just need to be well-informed about, about the actual surgery itself. Erm ... sorry, I'm losing the ... erm ... sorry, I've lost the gist of the question [chuckles] can you repeat it?

INT: THAT'S OK.

Patient: Yeah, sorry about that.

INT: WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT THE OPERATIONS THAT THEY CAN HAVE?

Patient; Basically what is necessary for their type of cancer.

INT: RIGHT.

Patient: Yeah, they just need to be well-informed about the options and what is best for them really, how radical surgery needs to be, or doesn't need to be, whatever the case. Yeah.

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

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

INT: JUST STOP THE [???) I THINK.

[End of interview]