

\*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

\*VENUE: Low MR unit

\*DATE:

\*ID: Patient64

INTERVIEWER: DJW

INT: FIRST OF ALL THANK YOU VERY MUCH FOR AGREEING TO BE INTERVIEWED. I JUST WANT TO 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: Er, well, basically all I knew was that you looked for lumps and you self-examined, which I did but there was just wasn't anything, well they didn't find anything there either, you know, when it was examined, so.

INT: YES, AND HAVE YOU GOT ANY FAMILY HISTORY OF BREAST CANCER, ANY RELATIONS WITH IT?

Patient: Not as far as I know, I mean I had a cousin that doesn't count, does it, really, that had breast cancer?

INT: WHEN WAS THAT THEN?

Patient: Oh, crikey, years ago. And she actually died of breast cancer, but that was, oh crikey, I can't remember how many, it was a long, long while ago.

INT: WAS IT OVER TEN OR FIFTEEN YEARS?

Patient: Yeah, possibly, yes, because my parents were a lot older, both of them, when they had this sort of second family, so of course all my relatives were quite old and a lot of them were a lot older than we were so you're going back a long while.

INT: YEAH, RIGHT, OK. AND DO YOU REMEMBER WHAT OPERATION, DID SHE HAVE AN OPERATION FOR IT?

Patient: I don't know because they lived in Liverpool, so all we ...

INT: OH I SEE, YES.

Patient: ... and I mean we, we weren't very old, so it wasn't something they would have discussed with us, if you know what I mean.

INT: YEAH, SURE. AND HAVE YOU ANY FRIENDS OR COLLEAGUES, ANYTHING LIKE THAT, THAT HAVE GOT BREAST CANCER?

Patient: Er, yes. I've got, erm, sister-in-law's got ... no, sorry, I'm wrong here. Let me see [chuckles] I'm trying to think of the relationship. My sister's husband's sister.

INT: RIGHT, OK. I'M TERRIBLE ON [???

Patient: I am.

INT: I WAS HOPELESS AT THIS [???

Patient: I'm just trying to think what the, it's not sister-in-law, I don't know what it is, but that's who it is anyway.

INT: RIGHT, OK, YEAH.

Patient: She's got it, I think she's got quite a bad one from what I gather because it went...

INT: WAS THAT RECENT THEN, WAS IT?

Patient: It must be five years because my sister said she's just come off, what is it, that I'm on ...

INT: TAMOXAFEN.

Patient: Yeah.

INT: YEAH.

Patient: She's just come off it.

INT: IS THAT IN LEICESTER, IS IT?

Patient: No, that's in Torquay.

INT: RIGHT, OK. AND WHAT, DID SHE HAVE AN OPERATION FOR IT, DID SHE?

Patient: Er, well, yes, I, as far as I know she had some form of op-, I know she had her breast off, I do know that, and then she had radiotherapy which everybody gets, don't they? But then she had chemotherapy as well, and of course the Tamoxafen.

INT: OK. SO CAN YOU TELL ME NOW HOW YOU SORT OF CAME TO FIND OUT THERE WAS SOMETHING WRONG WITH YOUR BREAST?

Patient: Er, yeah, well to start off with, this probably sounds a bit silly, I had a rash. Now I knew that rash, it wasn't anything to do with cancer, I knew that rash was what I'd done because I'd inadvertently put something on, like, 'cos I use body lotions and things, I'd put something on I knew I shouldn't have done, and I came out in a rash. I knew it was a [???] rash, but ... I get over things dead quick and it lasted well over a week and I thought that's not me.

INT: RIGHT, OK.

Patient: So I went to the doctor and I must admit I didn't say I was, so much I was worried, but I just said I'd got this rash and I thought it was a skin rash, and he confirmed it was a skin rash and left it

that. But then, as I said, the next day, I was saying to a friend, something said, sounds daft, but something said in my own mind, 'You need a mammogram.'

INT: YOU SAID IT WAS A RASH ON YOUR BREAST, WAS IT?

Patient: Yeah, it had gone, but something sort of told me I needed one, and luckily, I mean it was just the sheer thing of fate because I don't think it was a [???] I must have been due for one because the next week I got one.

INT: OH RIGHT, OK.

Patient: So that's how ...

INT: THAT WAS A REGULAR ONE, WAS IT?

Patient: Yeah, because, 'cos when you're over 50 anyway you get them fairly - well, I'm saying fairly regularly, I mean not always ...

INT: EVERY THREE YEARS IS IT?

Patient: They're supposed to be every three years, sometimes you might go three and a half, you know, it depends. But for some unknown reason I must have been due for one because it came. So, as I said, when they took the mammogram and then they called me back I was worried then, and then when they were sort of examining the side I was more, I was more than worried.

INT: WAS IT UNDERNEATH THE ARMPIT ?

Patient: Well, they examined all ...

INT: ALL THE BREAST, YEAH.

Patient: ... all of it. They also gave me a biopsy and, you know, they said ...

INT: SO WHEN YOU HAD ALL THESE TESTS AND THINGS WAS THIS ALL ON THE SAME, WAS IT ON THE FIRST VISIT FOR YOUR MAMMOGRAM?

Patient: No, no, you're going through quite a bit of a process. I think that's probably ...

INT: TELL ME ABOUT THE MAMMOGRAM FIRST, WHEN YOU FIRST WENT FOR THE MAMMOGRAM.

Patient: Yeah, I went for the mammogram and then you get, she came back and said, 'You can go now,' and I said to the one of the doctors [???] 'I just knew there was something wrong,' it was something about body language, I don't know what it was, but I knew there was something ...

INT: THIS IS THE BREAST CARE NURSE?

Patient: Yeah. I mean she didn't give anything away, don't get me wrong, she gave nothing away, but I pick up things very easily, and I just, it was a bit of body language, nothing she could have helped,

definitely nothing she could have helped. I just thought there ... and then when, 'cos I normally get them back ever so quick, you know, within ten ... I mean I know sometimes it might be the thing of work, how much they've got, but when it went into the third week I was starting to get really concerned.

INT: SO IT TOOK THREE WEEKS TO GET BACK TO YOU?

Patient: Yeah.

INT: RIGHT, OK.

Patient: And then they called me back for the second ...

INT: DID YOU SEE THE DOCTORS ON THAT VISIT, THE FIRST VISIT?

Patient: Er, no. No, it was just the sheer, it was just the normal, obviously routine mammogram, as I said, that I must have been due to, it was just a normal mammogram.

INT: AND IT WAS THREE WEEKS, DID YOU SAY, BEFORE ...?

Patient: Yeah, it was three weeks and I was called back for a second one. That one they did, er, a blow-up because whatever it was was very small. They did a blow-up and then they did a, oh, what's the other one you have? Er ... where they put a machine all round ... scan.

INT: YEAH, ULTRASCAN.

Patient: Then they did an ultrascan and they said that, er, you know, they still found something and that and she said, 'I'll try and take a biopsy' but they weren't sure if they could get it because whatever it was was very small, but she managed to get the biopsy.

INT: YEAH, OK.

Patient: And, but then I went, what time ... I can't remember if it was a week or a fortnight, er, waiting for the result, I can't remember. And then, as I said, from the biopsy it was pretty quick.

INT: RIGHT, OK, YEAH.

Patient: Yeah, she, the, erm, consultant, you know, said they'd found something that was microscopically small but it had cancer cells, er, but, you know, and then she gave me all the, as much as, they go through everything, don't they? What the thing, and she said at that time, as I said I've had better news since then, but since that time she said that, you know, people with them this small can go seven or ten years before they come back or, er, and then she went through all, all ... I can't remember, she definitely told you everything but when you're in that position you tend to go for the things that are important to you. You don't listen to all the ...

INT: YEAH, YOU'RE PICKING OUT THE INFORMATION.

Patient: Yeah, you pick, you pick at the information.

INT: YEAH, YEAH.

Patient: But she went through, I'm pretty sure she went through all the ins and outs and, you know, and she said 'We'd have you back in seven days for the operation.' And, as I said, the, then the breast care nurse took me back into a room and she said, 'Did you understand that?' and I went through, you know, what I more or less knew she'd said. And she said, 'Yes, you obviously understand what she said,' and then, as I said, I just waited for the oper-. As I said, it was very, very quick and, as I said to my husband, really everybody was wonderful. I mean I've got ... I mean I've called the NHS I must admit in the past over different things - not to do with me because I never go, but for relatives and things, not thinking it were fast enough, but the treatment I got, as far as I know anyway, couldn't have been better. You know, they were all really good and, er, well, as I said, they were all lovely, you know, and, as I said, when I went back after the operation, 'cos, well she kept me in for 24 hours but I think that's because I did have my ovaries done when I was very young - well, not very young, younger than I am now, about early 20s, early 20s. And, erm, you know, I had a bad time because the ... for 10 days ... the only way I could describe it was like I was drunk for 10 days. I was, every time I got up I was giddy, I was feeling sick, and I said I didn't know if it was the anaesthetic or it was the, erm, painkillers, because somebody had told me at that time it was the anaesthetic, another person had told me it was the painkillers, so I was never dead sure what, because as I said, you had a lot of juniors in them days, so, of course, they try to help I suppose but they didn't seem to know, if you know what I mean. But, as I said, I wasn't looking forward to the operation at all, but she said, 'Oh well, the anaesthetic's a lot different now than they were then, I'm sure you'll be all right.' Anyway when they did the operation they gave me a thing for sickness, they said it might help, you know, if you are sick. But I'd no trouble at all. The only thing the nurse, in fact it was over dead quick really, the thing the nurse said is that I was out a lot longer than I should have been and it was something to do with the morphine. Do they give you morphine in operations? I'm sure she said morphine.

INT: I THINK THEY GIVE YOU MORPHINE SOMETIME, I'M NOT SURE ...

Patient; Yeah, I'm not sure, but it must have been ...

INT: WHEN THEY ACTUALLY DO IT.

Patient: Yeah, it must have been something either during or after when you 're in the recovery room, I don't know ... but I know she mentioned mor- ...

INT: [???] FROM MORPHINE ANYHOW.

Patient: Pardon.

INT: THERE'S A FEW PATIENTS I'VE INTERVIEWED HAVE ACTUALLY HAD SICKNESS [???] AFTERWARDS AS WELL.

Patient: Yeah, well, as I said, I was just out for the count, 'cos it should have took an hour and a half to come back to my room and it was about two and a half hours or something like that, because my husband was doing wobblies at the, you know, wondering what was going on 'cos he kept coming back and I wasn't there, but I know she me-, I said to my husband, I'm 99 per cent sure, you know how you're a little bit groggy, I'm 99 per cent sure she mentioned morphine, so that was probably what had done it years ago until they found out, 'cos they'll probably, 'cos ...

INT: [???

Patient: ... they might still give it you, you know, afterwards and, you know, they probably kept giving it me and that's why I kept ...

INT: I'M NOT SURE BUT I'VE KIND OF HEARD AROUND THAT, LIKE, OBVIOUSLY YEARS AGO THEY GAVE YOU A LOT MORE ANAESTHETIC THAN YOU NEED AND STUFF.

Patient: Yeah, yeah, as I said ...

INT: [???

Patient: ... it was horrible, it was, I said to my daughter, I said, 'To be honest I wanted to die I felt that bad,' I said, and the only thing I can - not that I've been drunk very often but, certainly in my younger days occasions [???] but that's the only thing I can think, that horrible feeling when you're dizzy, you get up and your head spins, you've been sick, you know.

INT: MM, YOU OPEN YOUR EYES [???

Patient: That's right, oh ...

INT: CLOSE YOUR EYES AND IT [???] [CHUCKLES]

Patient: ... and that was for ten days, it was horrible. I mean my bladder and everything stopped working and that, and, as I said, obviously when it had got out of my system they'd put me on a bag, I said, 'I want to go to the loo,' they said, 'You can't.' So I said, 'I do.' And they said, 'Oh well we'll take you then,' and I did, so obviously it was out of my system then.

INT: YEAH, SURE.

Patient: So, but, as I said, I had no problems this time, you know.

INT: SO THINKING ABOUT IN BETWEEN YOUR FIRST MAMMOGRAM AND WHEN YOU WENT BACK FOR YOUR RESULTS, IS THAT RIGHT? ... YEAH, YEAH, IN BETWEEN YOUR FIRST MAMMOGRAM AND GOING BACK FOR YOUR RESULTS, I MEAN WHAT WAS KIND OF GOING THROUGH YOUR MIND AT THAT PERIOD?

Patient: I think, I mean they tell you not to worry but I don't think you'd be human if you didn't worry - you're bound to worry. Whatever anybody says to you, until you know the ins ... I mean you even worry when you know the ins and outs, but until you know that, because even they don't know, do they? They know the size of it but they don't know what type it is; they don't know if it's invaded any more of your, you know, your organs or whatever it is, until they get that biopsy after they've taken it out. So they can't help you, I mean they always say, 'Do you want to know anything?' Well obviously you do, but you know darned well they can't give you the answers yet ...

INT: YEAH.

Patient: ... because they don't know.

INT: YEAH, SURE.

Patient: I mean they would if they could, but they don't know. But, as I said, you know, touch wood, I've - oh that's not wood, that's marble [chuckles] - but touch wood, as I said, apparently I've been very lucky because it was minutely [?] small, it hadn't even invaded any of the tissue they'd taken out; it hadn't gone into the lymph glands; and it was a class one.

INT: RIGHT, OK.

Patient: So, according to the radiotherapist that means you're 95 per cent sure of getting cured and 90-a few more percentage if I take the Tamoxafen.

INT: [???] YEAH, TAMOXAFEN, YEAH.

Patient: Yeah, yeah. So, I'll be very unlucky if ... if it doesn't get cured hopefully, so ...

INT: DID ANYBODY, WHEN YOU WENT FOR YOUR FIRST MAMMOGRAM, DID ANYBODY GO WITH YOU?

Patient: My husband.

INT: HE WENT WITH YOU, OK.

Patient: Yeah.

INT: AND WHEN YOU WENT BACK, SO YOU GO TO THE FIRST MAMMOGRAM, YOU DIDN'T GET ANY TESTS THAT DAY, DID YOU?

Patient: No.

INT: YOU WENT BACK LATER ON AND THEY DID SOME MORE TESTS, IS THAT RIGHT?

Patient: Yeah, at three weeks they sent you back for the second time because somebody had noticed something ...

INT: RIGHT, OK. AND THEN YOU HAD MORE TESTS?

Patient: You had, I had more tests.

INT: DID YOU SEE A CONSULTANT THEN?

Patient: Er, did I see a consultant then ... I don't think so, no.

INT: AH, JUST THE DOCTOR ...

Patient: No, I saw a doc-, there was about three, well, whether there was a consultant in that room I wouldn't know ...

INT: RIGHT, OK.

Patient: ... 'cos there was about three or four people in that room and they were all talking amongst themselves.

INT: BUT YOU DIDN'T HAVE A CONSULTATION WITH ANYONE?

Patient: No, no. I mean they ask did you want to know anything or, but at that stage, you know, I might have asked a few questions, I can't remember.

INT: RIGHT, OK.

Patient: Oh, I think I did. Like, 'What's the worst thing that could happen?' which is me all over, I want to know what's worst before I want to know what's the best side of it. But, er, otherwise, you know, as I said, they all, they all do right the way through ask 'Have you got any questions?' and, as I said, I did ask what I needed to know, you know, and they answered me, as well as they could.

INT: DID ANY OF THE DOCTORS GIVE YOU AN INDICATION THAT IT COULD HAVE BEEN CANCER, [???] OR ...?

Patient: Yes, in a way. I can't remember ... they didn't say it was and they didn't say it wasn't, but they did say that they'd found something on the scan that was small and it could be, that's, I think that's basically what it could be, 'It could be ...'. I don't think they said it definitely was at that stage.

INT: RIGHT, OK.

Patient: As I said, until the biopsy was checked. I think like all these things, there's always that little bit of caution, isn't there? There is with everything.

INT: YEAH, SURE.

Patient: It's like, as I said to my husband, they'd never say, and they couldn't say, 'You'll definitely be cured,' because nobody dares say that these days, you short of give percentages, don't you?

INT: MM, YEAH.

Patient: Because that is something nobody, even years ago when they might have dared say it, these days they're a little bit more cautious, [chuckles] aren't they? They might get sued or something.

INT: AND THEN DID YOU SEE A BREAST CARE NURSE WHEN YOU WENT TO GET THOSE TESTS?

Patient: I've always seen a breast care ...

INT: DO YOU REMEMBER WHO IT WAS?

Patient: I can't, I saw quite a few.

INT: OH YOU SAW DIFFERENT ONES EACH TIME.

Patient: I saw different ones each time, except the one I saw at the, before I came out of the hospital was the one I saw when I come back for my results and the doctor then told me them, the results. He came in, just examined the scar and the scar tissue and he told me the results and I remember her saying, you know, when to come back, because I wasn't very keen on taking Tamoxafen, to be honest.

INT: OK.

Patient: Yeah, for the simple reason, I don't take any medicines.

INT: RIGHT.

Patient: I mean I've had a thing of, even Paracetamol in, and I tend to throw them out because they never get used 'cos, touch wood, if I do have anything it's so minor and I won't take anything ...

INT: SO ARE YOU FAIRLY, YOU KNOW, YOUR MEDICAL HISTORY ITSELF HAS BEEN FAIRLY GOOD, I MEAN?

Patient: Yeah.

INT: YOU ARE A FIT PERSON?

Patient: Yeah, well as far as I know.

INT: YEAH.

Patient: I mean I've, the few times that, if I go to a doctor there's a reason.

INT: YEAH, SURE.

Patient: You know, I mean, I mean, as I said, I'll probably tell you, the amount of time, I mean, when I go, used to go for smear tests and that and the nurses used to say, 'Don't you like us?' [chuckles] I used to say, 'Why?' they used to say, "Cos you never come,' you know, 'cos I just don't. If I get a cold, I get a cold, but it's never, you know, bad enough to really take it. If I got a temperature I'd take a paracetamol to bring my temperature down, but otherwise I just wait till it goes, a few days it's gone.

INT: YEAH.

Patient: That's why I knew with this rash, as I said ...

INT: YEAH, I SEE.

Patient: ... it wasn't right for me. For somebody else it might have been pretty normal, but it wasn't right for me, 'cos if I have a rash the next day it's gone.

INT: YEAH.

Patient: I just, you know, you know yourself, don't you?

INT: YES, YEAH, YOU KNOW YOUR OWN BODY AND THAT.

Patient: You know your own body and you know what it is, as I said, and that is the reason I'm not happy about taking this. I mean the breast care nurse, I mean I didn't tell them I wasn't happy, but the breast care nurse did say to me, erm, with the Tamoxafen, she said, 'If you have any side effects whatsoever you don't like, take yourself off it.' I mean, I'm hoping I should I can say this, 'cos I don't want to get anybody into trouble ...

INT: NO, NO, OF COURSE.

Patient: 'Cos that's what, yeah, yeah.

INT: IT'S ALL CONFIDENTIAL.

Patient: Yeah, you know, she says, you know, 'Take yourself off it,' she said, 'Because the, it's ...' what she said, 'the chances of it coming back are so, so, so small, microscopically small that,' you know, she more or less said 'Your side effects might be worse than the risk that you're taking ...'

INT: OF IT COMING BACK, YEAH, SURE.

Patient: ... than it coming back,' she said. Er ...

INT: AND THIS WAS?

Patient: This was the breast care nurse, well the doctor more or less said the same thing anyway, the ...

INT: THE CONSULTANT, YEAH.

Patient: Well, the consul-, the only time I saw the consultant was in the hospital when she came round to check me out.

INT: RIGHT, OK.

Patient: Af-, except the first time. And she said that they'd got it all and they'd took a, an x-ray is it? They must take an x-ray somewhere along the line ...

INT: RIGHT, OK.

Patient: And they'd got it all.

INT: RIGHT, OK.

Patient: And she was quite, erm, you know, chirpy, if you know what I mean. You know, you can always tell if something's bad 'cos people tend to get dead serious, don't they? But if it's better news they tend to be pretty normal, if you know what I mean. So, that's the only two times I've seen the consultant. But there again she probably thinks there's no need for me to see her, you know, there's probably other people that it's more, need to see her, so ...

INT: SO GOING BACK TO WHEN YOU ACTUALLY HAD YOUR TESTS, YOUR BIOPSIES AND THINGS, YEAH? AND YOU SAW A BREAST CARE NURSE, DID YOU, AT THE TIME?

Patient: Yes, yes. Yeah, the breast care nurse was with me all the ti-, my husband could have come in but I didn't want him in at that particular time.

INT: RIGHT, OK. DID ANYBODY ELSE GO WITH YOU?

Patient: Er, no, just my husband.

INT: RIGHT, OK.

Patient: As I said, he would have come in with me but I couldn't see the point, you know. You know, something, whatever it was, I'd rather tell him myself than, you know, have other people tell him, sort of thing. So that's the only reason. But there was a breast care nurse with me and, as I said, I had a few different ones and they were all the same, they were all really nice and helpful, you know, they'd tell you anything you wanted to ... and they were, as I said, lovely's the only word you can say for them. Same as the doctors, they were all really nice.

INT: SO WHEN YOU HAD YOUR TESTS, HOW LONG DID YOU, AFTER YOU'D SEEN THE BREAST CARE NURSE YOU WENT HOME?

Patient: Mm.

INT: HOW LONG WAS IT AFTER THAT TILL YOU HEARD YOUR RESULTS OF YOUR TESTS?

Patient: I think it was a fortnight.

INT: ABOUT A FORTNIGHT.

Patient: After the operation you're talking about, are you?

INT: NO, NO, NOT AFTER THE OPERATION.

Patient: Oh, sorry, I beg your pardon.

INT: AFTER THE FIRST TESTS.

Patient: My first test, it was three ...

INT: AND YOUR BIOPSIES.

Patient: Oh, my first test, not the mammogram?

INT: NOT THE MAMMOGRAM.

Patient: The best ...

INT: THE BIOPSY.

Patient: The biopsy ...

INT: YEAH.

Patient: Er ... I can't remember if that was a week or a fortnight. I can't remember. It was either a week or a fortnight. I just can't remember. I know they're the worst times ...

INT: YEAH.

Patient: ... personally. I mean I know it can't be helped, they have to go through all these things, I mean, but obviously if it was in a wonderful world the best thing would be to be told right from beginning to end all in one go, but that ...

INT: YEAH, SURE.

Patient: ... you know, it isn't possible.

INT: NO, SURE.

Patient: But that would be the best because I don't think I'm unusual in this - it is a worrying time.

INT: OH ABSOLUTELY, YEAH.

Patient: And through all of it, I mean, even after, I mean I knew they'd, well they said it's gone now, I knew it had all gone, but waiting for that other, the second biopsy was bad because until you've got that you don't know what sort of, 'cos I mean I didn't even know till they explained to me there's three different sorts of breast cancers: the first is the best one, if you like, if it's, you can call it a best one; the second is the mediocre one; and, as the radiotherapist said to me, and the third one's the nasty one.

INT: RIGHT.

Patient: So I didn't even know there was that.

INT: YEAH, THREE GRADES OF CANCER, ISN'T IT? YEAH.

Patient: There's three grades of cancer. But, as I said, as the breast care nurse said to me, er, when I went back for the biopsy, you know, 'cos I mean, for the first time I did break down in tears, which I hadn't done all the way through, but I think, I mean, 'cos I've obviously I knew I'd got it, it was the relief to know and, you know, she couldn't, she couldn't under-, she said, 'You did understand what he said to you, didn't you?' But I think it was relief that, if I had to have it, I'd had the best ... you know, diagnosis you could have ...

INT: YEAH, THE BEST ...

Patient: ... you know, you couldn't have one better.

INT: THE BEST SCENARIO ...

Patient: The best scenario in the circumstance you could have and, as the breast care nurse said to me, she said, you know, 'It's lovely to be able to give somebody this news because ...' she said, 'I'll be honest with you, it doesn't happen very often,' which surprised me, 'cos you always think, if you've got something small, it's bound to be all right, but obviously it isn't always.

INT: YEAH. SO WHEN YOU WENT BACK TO HEAR ABOUT YOUR, THE RESULTS OF YOUR BIOPSY ...

Patient: Yeah.

INT: AND WHEN THE CONFIRMATION OF THE DIAGNOSIS OF CANCER WAS MADE, CAN YOU TELL ME ABOUT WHAT HAPPENED THAT DAY? WHO, DID ANYONE GO WITH YOU THAT DAY?

Patient: Er, yes, I went, my husband went with me but, then again, I didn't want him in with me.

INT: IN THE ACTUAL CONSULTATION?

Patient: No.

INT: DID HE SIT OUTSIDE?

Patient: He sat outside.

INT: SO WHEN YOU WENT IN, CAN YOU TELL ME WHAT HAPPENED THEN?

Patient: Yes. The consultant, you know, explained that they'd found something that was microscopically small, she showed me how small, about like a pea or something like that, but very small anyway. Er, they'd found something and that it had cancer cells, and then at that time, I mean, if she did mention cure[?] - I'm not going to say she didn't because, as I said, I can't, they go through so much, I can't remember everything she said. But I know she said normally with something like the size of this one, they usually don't come back for 7-10 years. But at that time, as I said, I never, I mean I know people that have been cured of cancer, and bad ones, but they, as far as I know, she might have done in the end ...

INT: RIGHT.

Patient: ... but I don't think she did, but then again I wouldn't like to swear on it. But she did go through nearly every-, 'cos I thought to myself, 'If you get over that stage then you go to this stage, and if you get over this stage you go to that stage ...' and you think to yourself, 'Oh, flipping hell, will I get through the first stage?' you know. I mean obviously they've got to tell you all this but that's, that's how, you know, you think. You think to yourself, 'There's so many stages to go through,' and, as I said, it can't be helped but I think it's all the examining and all that, and, well, if you're like me, and I don't think I'm unusual, you think to yourself, 'I hope they don't find, find something else,' 'cos I always thought I was dead healthy.

INT: MM, YEAH.

Patient: But then again, as far as I'm concerned I was because, as I said, there was nothing you could feel.

INT: NO.

Patient: I couldn't feel it, the doctors couldn't feel it. So, I mean, I, as I said, self-examine all the time, or on a regular basis. I'd never found anything and, but as I said, the doctors, as they said, right the way through they all said, 'There's nothing there to feel,' and there wasn't.

INT: MM.

Patient: So, I suppose that's being so small.

INT: WHICH CONSULTANT WAS IT?

Patient: Er ...

INT: IT WAS A FOREIGN LADY, WAS IT?

Patient: Yes.

INT: MISS [???

Patient: Yes, yes.

INT: WAS THERE A BREAST CARE NURSE IN THE ROOM WITH YOU?

Patient: Erm, was there?

INT: WHO ELSE WAS IN THERE, DO YOU REMEMBER?

Patient: I can't remember. I think there was. I couldn't swear on it. I know I definitely saw a breast care nurse ...

INT: AFTERWARDS, YEAH.

Patient: ... yeah, 'cos a breast care nurse took me out and, I think there was. As I said, it, when you're going for those things you, you know, whether it's the way nature does it, but your mind cuts off to a certain ... you hear everything ...

INT: OH YEAH.

Patient: ... well I do, but that's what happens to me, same as, well, as I say, the same thing happens when I lose anybody that's very dear to me: I never cry, my brain sort of cuts off ...

INT: RIGHT.

Patient: ... and it's about, you know, a week or something like that.

[INTERRUPTION IN RECORDING]

INT: YOU WERE SAYING THAT SORT OF YOUR BRAIN KIND OF CUT OFF.

Patient: Yeah, it cuts off, it does that with every, everything that ... I mean I know what's going on ...

INT: [???

Patient: ... I know what's going on and I know what people are saying to me, but it's like probably a shocked state, you know what's going on and you hear everything but your brain cuts off.

INT: YEAH, [???] BUT YOU'RE NOT REALLY TAKING IT IN, ARE YOU?

Patient: Well, you do take it in, I take it in, I know exactly what they're saying but, because I'm an emotional person, normally my emotions get the better of me.

INT: RIGHT.

Patient: But when anything like that happens, something sort of cuts off.

INT: RIGHT.

Patient: It's unusual. I can't explain it, but it just cuts off.

INT: RIGHT.

Patient: And I know what's going on, I know exactly what you're saying to me and, you know, if you ask me what I'm doing and I take it all in, but my emotions don't come out. It just cuts off, just like that. It's odd but it does. And as I said, and that's why, as I said, when I have good news I sort of come back to normal and that's when all my emotions sort of, like I did with the nurse when they've given me, actually given me very good news. That's the only time the emotions ever ...

INT: RIGHT, YEAH, SURE.

Patient: ... came out.

INT: SO WHEN SHE CONFIRMED THIS, THE DIAGNOSIS THAT IT WAS CANCER, I MEAN HOW DID YOU FEEL THAT, KNOWING THAT YOU ACTUALLY HAD BEEN CONFIRMED THEN?

Patient: Er ... shocked and not shocked: I wasn't shocked because I'd a feeling, but shocked because I'm health fanatic number one. I do every-, always have done. I eat the right foods, I drink the right, I don't over-drink, I don't smoke, I do loads of exercise, and I'm very rarely ill. So, you know, although you know it's, there's something wrong, you can't believe that that's what it is, if you know what I mean.

INT: YES, YEAH.

Patient: You know, 'cos I said, the first thing I said to the doctor when the doctor examined me, was, you know, she says, 'Are you healthy?' I says, 'I thought I was,' but it puts all the things that you

believed in, you think to yourself, 'Well ... probably what I think isn't right ...' do you know what I mean?

INT: RIGHT, YEAH.

Patient: You know, you start mistrusting what you, you think, you know.

INT: YEAH, AHA.

Patient: But then again, as I said to my husband, possibly because I've been so healthy might have helped the fact that I've got this type of cancer and not another type, but you don't know, do you?

INT: WELL, YEAH, YEAH, THAT COULD BE. ERM, UP UNTIL THIS POINT, UNTIL YOU HEARD YOUR DIAGNOSIS, HAD YOU ANY THOUGHTS IN YOUR HEAD ABOUT WHAT YOU MIGHT DO ABOUT THE CANCER IF IT WAS CONFIRMED, IN TERMS OF LIKE, YOU KNOW, AN OPERATION OR TREATMENT OR ANYTHING LIKE THAT?

Patient: Er, well, I was hoping, well she did, the surgeon did go through that, and that's something I'd forgotten, she did said, oh something incision ...

INT: WIDE LOCAL EXCISION?

Patient: Yes. She said, you know, she said, 'Normally people with one that's as small as you have have this incision ...' and at the end she did say, mentioned mastectomy, but she didn't, you got the impression she didn't sort of think you should go along that line, but she didn't actually say that, you know what I mean?

INT: RIGHT, YEAH.

Patient: And she gave me a leaflet to bring home and read that she'd done, and in it it did say that, you know, the taking, the small, well I think even if they're larger it said, taking them out and having radiotherapy is just as good as having a mastectomy.

INT: A MASTECTOMY, MM.

Patient: And I wouldn't think anybody'd go through a mastectomy unless they thought they had a better chance with a mastectomy. I can't see why you would, but that's just my opinion.

INT: RIGHT, YEAH.

Patient: But unless you actually thought that that was gonna help you, that's the last resort I should have thought anybody would go for. You know, if she'd said, you know, 'You could definitely be cured if you have a mastectomy,' I think people would have a mastectomy but if, as I said, it said, 'Well you could go down that line,' you might not have to have any radiotherapy but then again you might anyway, depending on where, what they found, you know.

INT: YES, EXACTLY.

Patient: Erm, I can't see why anybody would go down that ...

INT: RIGHT, YEAH.

Patient: ... that line, because nobody wants to be deformed, do they? It is, I mean I know you can have reconstruction which I suppose if I had to have it that's what I would.

INT: RIGHT, YEAH.

Patient: Because I wouldn't like to be, you know ... I know some people don't mind, you know, as I said, the lady I was telling you about, that had already had one, she didn't have a reconstruction. It didn't bother her, I think some people it doesn't probably, I don't know. But it would have done me, I know it would.

INT: RIGHT, OK. AND SO SHE TALKED ABOUT YOUR TREATMENT OPTIONS AND TOLD YOU, GAVE YOU THE LEAFLET, ERM, AND THEN WHAT HAPPENED AFTER THAT? DID YOU JUST GO ...?

Patient: Then the breast care nurse took me into another room and asked me if I understood all that the consultant had said to me.

INT: DO YOU REMEMBER WHO THE BREAST CARE NURSE WAS?

Patient: I can't, honestly, I can't. I saw so many of them.

INT: OH, OK.

Patient: You know, different ones may, I don't, except that one that I saw at the end when I went, at the end of the operation, that came to tell me the last bits that you had to know before I got discharged, and she was the same one as I saw when I went back for my biopsy test. I don't think I saw the same one twice. I might be wrong but I don't think I did.

INT: MM, RIGHT.

Patient: You know, I did see different ones at different times.

INT: RIGHT, OK.

Patient: But, as I said, they were all, as I said, just as nice as one another and all, they're just as helpful as one another.

INT: MM, YEAH. AND DID YOU TALK ABOUT THE TREATMENT OPTIONS AND THINGS WITH THE BREAST CARE NURSE AT THAT TIME?

Patient: Er, possibly, I can't remember because, as I said, once she'd said this, unless I'd read something to say that I'd had a far better chance having a mastectomy, I wouldn't have chosen anything else anyway.

INT: RIGHT, OK, MM.

Patient: I mean I never, all the way along, I've never felt that ...

INT: [???

Patient: The microphone [???

Husband [?]: [???] I just didn't want you to [???] yeah.

Patient: I never felt that they wouldn't, you know, listen to what I said 'cos, to be honest ... well, I know they would anyway, but I wouldn't have stood for that because I'm not the sort of person that you'd, that allows somebody to dictate to me ... I mean, it's me, whatever happens it is me, and I have the right to choose what happens to me, but I never felt like that, all the way through. There was nobody I could say that gave me the feeling that they wouldn't listen to what I ...

INT: RIGHT, OK, YEAH.

Patient: ...would say and what I wanted to do.

INT: MM. SO YOU FELT YOU GOT ON WELL WITH MISS [???], THE SURGEON?

Patient: Yeah, yes, well I definitely did. I mean obviously at the beginning they were very serious, which you can expect them to be, I mean you wouldn't want them smiling, would you? I mean ... it wouldn't be right. But, as I said, when she came back, you know, the second time, you know, you know, she was, you know, talking to you normally.

INT: MM. YOU FELT THAT SHE WAS LISTENING TO YOU AND UNDERSTOOD YOUR NEEDS AND YOUR CONCERNS?

Patient: Yes, I believe she was.

INT: RIGHT.

Patient: You know, I'm sure she, as far as I could see, that she was, you know, you know, she basically gave me the options and she obviously gave, she didn't say her opinion, but you could tell what her opinion was, but I'm positive if I'd have said, 'No, I don't want to go along that route,' she would have listened and she might have, I don't know, 'cos you, I don't know, she might have said, tried to talk me out of it, and she might not, I don't know.

INT: RIGHT, OK.

Patient: But I always felt, I didn't feel as if, you know, 'You do what I say and this ...' I didn't feel like that at all.

INT: RIGHT, OK THEN. SO, AFTER YOU HAD YOUR DIAGNOSIS AND YOU SAW THE BREAST CARE NURSE, HOW LONG WAS IT AFTER THAT TILL THE OPERATION, DO YOU REMEMBER?

Patient: Seven days.

INT: SEVEN DAYS.

Patient: Very quick. And, as I said, I knew it was, I mean you say, 'cos I don't know if they do anything they're not supposed to, so I'm a bit dubious what I say, you know, [chuckles] they did ring me up on the night of the op, 'cos it does say, 'Ring before you come in, there might not be a bed,' ...

INT: RIGHT, YEAH, YEAH.

Patient: ... you know, which worries you, to be honest, because when you've got something like that you want to get everything done ...

INT: ABSOLUTELY.

Patient: ... quick as possible. Erm, but they rang me saying could I go in that night because there was a bed, a bed available, and unfortunately I couldn't because Derek had gone to work, because Derek works nights, and he'd gone to work and I said, 'Ooh, no, I can't, I just can't, there's no way I could, you know, get in tonight,' and that, and she said, 'Oh well, it's just that there's a bed available at the minute,' you know. And that worried me 'cos I said to her, 'That doesn't mean to say I'm gonna lose my bed, does it?' you know. So, she said, 'Don't worry about it,' she said, she said, 'We'll put our name on, just pretend you're here,' you know, and that me think ... I thought, 'Well I'm gonna like these people,' [chuckles] you know what I mean?

INT: OH THAT'S NICE OF THEM, YEAH.

Patient: Yeah. I thought, 'I'm gonna like ...' and, as I said, they were all lovely, you know. There was abs-, you know, if you've got to have hospital treatment and visits, you know, you couldn't have wanted anything better because they were all, as I said, helpful; they gave you, when you asked questions they gave you the answers, you know, they didn't go overboard - 'cos I don't think that it's too good to give people information that they don't always ask for, you know ... you know, sort of, until they know the ins and outs anyway, I don't think anybody should say, er, you know, all, not all the time anyway, 'This could happen ... this might happen ... this sometimes happens.' You know, I don't think it's information people need, that might be my opinion, but I don't think it's information people need to know. If you say, 'Can you tell me this, that and the other ...' you want to know it: if you don't ask it, unless you're very unusual, you don't particularly want to know it.

INT: NO, SURE.

Patient: But, as I said, most people want to know obviously when they know for sure themselves, but you don't want to know the might-be's.

INT: YEAH, YEAH.

Patient: 'You might be this, you might be that' ... because, as I said, they don't know for sure themselves so, you know, it's best not to say anything really unless that person says, 'Can you tell me?' and then - this is just my opinion - just give an honest answer.

INT: YEAH.

Patient: Which, as I said, I ... I think I got all the time. I mean I did ask some of them questions, but they did give me an honest answer, but if I hadn't have asked it then I wouldn't have wanted to know. I

mean, as I said, the neighbour actually has got breast cancer, in the corner, quite a bad one apparently, or so she says, I mean, I wouldn't know. And funnily enough she was in the same place as I was, we met each other waiting for the biop-, well I don't think she was waiting for the biopsy results, I was, she was waiting for something, tests of some sort. And she said the same thing. She said to me, 'I wish they wouldn't give me information that I don't need to know,' 'cos I said to her, 'Well don't worry about it at this stage, they won't even know, so try not to worry about them.' I mean everybody says that, don't they? But you do worry. But, as I said, that just gave me the impression that I'm probably not the only one: unless you ask the question you don't want to know, unless they actually know the answer.

INT: RIGHT, YEAH.

Patient: If they know the answer, then obviously you want to know, you've got ... well they will tell you, won't they?

INT: YEAH.

Patient: But you don't want the might-be's. 'You might be this, you might be that, you might have this or you might ...' I mean I know with the cancer thing they have to say that at the beginning, 'You might have cancer, you might not,' that's fair enough.

INT: YEAH.

Patient: You know that anyway, don't you? They wouldn't be doing these tests ... but it's the bits about, you know, what could happen in your worst scenarios. If you ask that question, which, as I say, ask, I tended to do, you want to know the answers, but if you don't ask it, personally from what I've heard and other people have said to me, I don't they ought to say anything, 'cos it just makes you more worried about something that might not happen.

INT: YEAH. HAD YOU, YOU KNOW, IN BETWEEN HEARING YOUR DIAGNOSIS AND YOUR TREATMENT OPTIONS UP TO THE POINT WHEN YOU HAD YOUR OPERATION, HOW LONG DO YOU THINK IT TOOK YOU TO DECIDE WHICH OF THE OPERATIONS YOU WERE GONNA HAVE, THE BREAST CONSERVATION ...?

Patient: Well I think I'd more or less made my mind up straight away.

INT: RIGHT, OK.

Patient: Because I got the impression that that, although I don't think she said it, but that was the one she would have recommended.

INT: AND WHEN DID YOU FILL IN THE CONSENT FORM?

Patient: Er, when I had the operation.

INT: AH, RIGHT, OK. AND DURING THAT TIME DID YOU EVER CHANGE YOUR MIND OR ...

Patient: No, because ...

INT: ... THINK TWICE ABOUT WHAT YOU WANTED?

Patient: No, because, as I said, I read the leaflet which she'd given me.

INT: RIGHT, OK.

Patient: And they, as I said, they more or less said that there's no difference in the result, whichever route you go, you know, it's just as successful one way as the other, and there's no, there's just the fact that you might not have to go through radiotherapy, but I mean, I don't fancy that, I've got to go soon for that. I don't fancy it at all, but then again you don't fancy things like that, do you?

INT: NO, SURE.

Patient: But from what I gather that isn't too bad, it's only if you have to have chemotherapy that you get a lot ...

INT: YEAH, CHEMO'S DIFFERENT.

Patient: ... pretty nasty, from what I've heard about, from other people, that can be pretty ... but most people that's had the radio- said you don't usually have any problems with that. It's just the fact that you're being 'doctored' if you like again, a thing I'm not used to being, going to doctors and being pulled about and ...

INT: WHEN MISS [??] WAS DESCRIBING YOUR TREATMENT OPTIONS, DID SHE USE ANY, ANY VISUAL AIDS OR TOOLS SUCH AS DIAGRAMS, PICTURES, MAMMOGRAMS, ANYTHING LIKE THAT?

Patient: Er, she used, she drew, all she did was, I think she drew about the size of my tumour, which they'd got, because I'd had a blow-up.

INT: YES, THAT'S RIGHT.

Patient: Because I'd had, 'cos they had to put a, like a little wire ...

INT: AH RIGHT, YES.

Patient: They had to put a wire there. In fact they did, before my operation, they did a mammogram and a scan to make sure they'd got the right place, because, as I said, it was very small, that's presumably why, you know. But before that then they did a blow-up - not at the operation, at one of the previous ...

INT: WHEN THEY DID THE BIOPSIES AND THINGS?

Patient: Yeah.

INT: YEAH.

Patient: They did a blow-up of it, you know, to have a look at. Because when I saw it I thought, 'Oh, crikey, that looks big,' but it was so many times ...

INT: BIGGER, OH RIGHT, YEAH.

Patient: ... ten or whatever it is times bigger than it really was because they did this blow up. But, as I said, they did, you know, they were there a little while, even with the operation, trying to put, finding the place to put the wire, you know, they were there quite a while because obviously they've got to be precise, haven't they ...

INT: MM, YEAH.

Patient: ... in that. But, you know, as I said, everything went fine.

INT: I'VE TOTALLY FORGOTTEN ABOUT THESE QUESTIONS [???] ALL THE ONES SO FAR, I JUST ... GIVE ME A SECOND, I'LL JUST SCAN AND MAKE SURE I HAVEN'T MISSED ANYTHING. ERM ... OK. WHERE ARE WE? WHEN YOU WERE TALKING ABOUT YOUR DIAGNOSIS AND YOUR TREATMENT OPTIONS WITH MISS [???], DO YOU FEEL THAT, WAS THERE ANYTHING YOU DIDN'T UNDERSTAND ...

Patient: Nothing.

INT: YOU FELT YOU WERE OK WITH EVERYTHING?

Patient: No ... yes, absolutely nothing. I mean she did say, 'Have you got any questions?' and if I'd got any questions I would have asked them.

INT: RIGHT.

Patient: I underst-, you know, everything she explain I, you know, I understood. Obviously, as I said, the first time I took in the bits that were important to me. I wouldn't ... I couldn't stand there and go through everything that she'd said to me but I picked out the bits that were important, you know, the bits in between, because a lot of the bits in between are what might happen if ... you know ...

INT: YEAH, IF [???]

Patient: ... if it's so-and-so, so-and-so. And to my way of thinking, until you know, what's the point in knowing about them.

INT: RIGHT, OK.

Patient: There isn't. I mean she did go through it, but there wasn't any point, until she had got the answers and then, as I said, well I didn't have to ask questions when they [???] the biopsy they explained everything anyway, told me everything so there was no questions I needed to ask.

INT: AND IN BETWEEN HEARING YOUR DIAGNOSIS WITH MISS [???] AND ACTUALLY HAVING THE OPERATION, DID YOU AT ANY TIME CONTACT THE BREAST CARE NURSES YOURSELF, DID YOU CALL THEM ...?

Patient: Yes, I did, over different things, minor things.

INT: SUCH AS ...

Patient: Nothing ... I ... oh, the exercise programme, 'cos I wasn't sure, I thought, 'Cancer ... can ...' I don't know much about ... I mean I know what cancer is obviously but I don't know how it works medically.

INT: RIGHT, OK.

Patient: And I thought, well, 'cos I did a lot of using my arms, tops of arms, and that, and I thought, well am I gonna do, make things worse if I, if I do that sort of thing. I mean I know the things I do with my legs are all right, but it was the top half of my body I wasn't sure about. So I did ring and ask and she said, 'Well, it'll make you more healthy, you know, you're all right, just go ahead,' sort of thing. And then when I, I did about a few days ago ring up again 'cos I didn't know who to ask, stupid things, as I said, probably non-important things in a sense, but I could have asked other people but you tend to go for the more serious when you're with doc-, and that was 'Can I wash with soap now?' you know 'cos it's about a month so I presumed I could. 'Can I wash with soap now?' What was the other thing: 'Can I put something on the scar tissue to help with it?' you know, to help it, because I mean there's nothing wrong with it, it's very healthy, but I'd got something that's supposed to help decrease scar tissue - whether it works or not I don't know, I'll soon find out, won't I?

INT: MM, YEAH.

Patient: But 'Can I put that on to try it?' And, er, oh, 'Can I drink soy milk?' which probably sounds a stupid question but, because I know these things have something to do with oestrogen, these tablets, and I know soya is like a vegetable type of, can have that sort of thing of, you know, a vegetable type of oestrogen type of thing ...

INT: I NEVER KNEW THAT ACTUALLY.

Patient: Well I think

INT: [???

Patient: I think it is because, I mean, I'm not saying milk itself, but I think soya is, it is a veg- ... because I know there's certain soyas that they tell you when you're going through the menopause can help with the, erm, flushes. I mean whether they do or not I don't know, but ... and, as I said, I'd got that in my ... I mean I might be completely and utterly wrong, I don't know [chuckles] but I've got that in my mind that it was some for of oestrogen. So I just rang up to say, 'Can I drink soya milk?' because I thought to myself, 'Well it's no good sticking more oestrogen in if they're trying to block it in the first place, you know' [chuckles] But, I mean, she said, 'Oh, yes, certainly you can, you know, drink it if you like.' I said, because I just, I mean my friends think I'm nuts but I happen to like soya milk. [chuckles]

INT: ERM, WHERE ARE WE? ER, OK, AND YOU SAID YOU GOT SOME SUPPORT INFORMATION FROM MISS [???

Patient: Yes, I did, yes.

INT: AND DID YOU GET ANYTHING FROM THE BREAST CARE NURSES? DID THEY GIVE YOU ANY LEAFLETS OR ANYTHING?

Patient: Er, I don't think so. I think it was basically, there was basically most of that on that information that you wanted to know. Oh, yes, they did, they gave me some about if fluid builds up under your arms or something, although they did say they don't think that would apply because ... the ones I'd had taken away were just for testing and they didn't think, but they said if it did, you know, you could go and have it taken away, it's quite usual. And they gave me a lot of things that might happen that were pretty normal, you know, that you might feel tearful and, you know, is quite normal, and things like that. And they gave me, I think they gave me a couple, as I said, one about that ... I think the other one was, I can't remember if they gave, I think it was them that gave it, it might have been the consultant', I'm not sure, but I think it was about the operation I was going to have, in the early days, I think, you know, what sort of ... or something like that. Or was it ... ooh, no, it wasn't, it was about the, erm, what you go before you, the preliminaries you go before your operation, 'cos I had to go, er, ...

INT: OH, FOR YOUR PRE-ASSESSMENT?

Patient: Your pre-assessment ... I think the nurse in there the only one, I mean she was nice as well but not quite as nice as the breast care nurse, the only that gave me information I didn't want to know, because she went through the whole lot. [chuckles]

INT: OH RIGHT, YEAH.

Patient: You know, you might have to have a, oh, what's that other stuff, radio-, ... chemo ... 'You might have to have chemo, you might have to this ...' and, as I said, I don't want to know what I might have to do. I want to know what I have got to do, and that's only, as I said, after, because, as I said, until they've got the results, with the best will in the world they couldn't tell you because they don't know.

INT: YEAH, MM. ERM, IN BETWEEN, YOU KNOW, THINKING BACK UP TO YOUR OPERATION AND THINGS LIKE THAT, DID YOU LOOK FOR OR WERE YOU GIVEN BY ANYBODY ELSE ANY INFORMATION ABOUT BREAST CANCER AND ITS TREATMENT EITHER BY YOUR GP, RELATIVES, FRIENDS, NEIGHBOURS? DID YOU CALL ANY SUPPORT GROUPS, ANY BOOKS, MAGAZINES, VIDEOS, INTERNET, ANYTHING LIKE THAT ... DID YOU LOOK FOR ANY FURTHER INFORMATION?

Patient: Not really, no, 'cos I felt as if I'd had all the information that I felt was relevant really. I mean, as I said, all you basically want to know is what sort it is, has it invaded any of your other tissues, and what's the chances of a cure, or, if not, what else, you know, and what treatment are you gonna have. I can't think of anybody really, and I think you've got to be a bit careful of things like that, because my sister's got calcium deposits, she's under - I mean she hasn't got cancer yet, but it's, apparently it means you can or might - no, not you can, probably is not the word, but you might get it in so many years' time: then again you might not.

INT: RIGHT, YEAH.

Patient: And she looked it up on the internet and she said, 'I wish I hadn't,' she said because, she said, 'It gave me lots of information I didn't know, and it frightened me to death,' so she said, 'I wish I hadn't really.'

INT: YEAH, IT CAN BE SCARY [???] I MEAN THE LADY I WAS SPEAKING TO YESTERDAY AND SHE SAID THAT SHE WAS ON THE INTERNET AND SHE ALMOST, YOU KNOW, WAS DOING IT ALL THE TIME, GOING ON AND GETTING MORE AND MORE INFORMATION, AND THE MORE SHE FOUND THE MORE SCARED SHE WAS REALLY.

Patient: [???] I mean I don't think too, I mean, I think it was on one of the [???] I think too much information is bad. I honestly and truly think too much is bad, especially until they know exactly, you know, what you've got and what ... and then, as I said, I think most consultants, I'm sure the one I have got would have done, would have explained everything I'd have wanted to know.

INT: RIGHT, OK.

Patient: Because I could have asked her then, because, as I said, I didn't need to because the doctor gave me all the information, but, I mean, if, you know, she'd had that information when I'd been in the, she told me she didn't, when I'd come, after my operation, if she'd had it then I would have asked her and I know she would have told me, you know. But she didn't have it. She did say, 'Any more, any more questions?' but how could I ask more questions because she wouldn't have known the answers? The questions I wanted to know she wouldn't have known the answers until she'd had the biopsy herself, so there wasn't any point in asking her anything else. She'd have told me if she'd have known, I know she would, or anything I'd asked her. But there was no point because she hadn't got the, she hadn't got the answers I wanted, or needed to know.

INT: AND WAS IT, THINKING ABOUT YOUR OPERATION, WAS IT MISS [???] CARRIED OUT THE OPERATION?

Patient: I'm sure - well I presume it was.

INT: DID SHE COME ROUND IN THE MORNING AND, BEFOREHAND, DID YOU SEE HER?

Patient: No, no. Well she did, yes, indirectly, because I went home the next day.

INT: OH RIGHT.

Patient: I mean, er, 'cos my husband asked if I'd have gone the same day and they said, 'Well in this ward, no,' but I think the only reason Miss [???] kept me in for more than the one night was the simple reason I'd told her about the bad side effects I'd had with the anaesthetic, and she was taking a precaution.

INT: RIGHT, OK.

Patient: I don't think she probably feel, you know, well I'm pretty sure that if I could, you know, that ward was allowed to release people, which, as a nurse came and said, 'We can't, we don't release anybody from this ward except the next day.'

INT: MM, RIGHT.

Patient: Because otherwise I'm pretty sure I could have gone home, because I had no effects from that operation. I mean as soon as I come round I wanted to drink, I wanted to go to the loo and I wanted something to eat. So [chuckles] you know ...

INT: [???

Patient: And the next, the next morning I wanted to get washed, get dressed and wait to go home.

INT: AH YEAH.

Patient: You know?

INT: DID YOU HAVE ANY DRAINS OR ANYTHING IN?

Patient: No.

INT: NO?

Patient: Nothing, no, nothing. And I also didn't have any pain ...

INT: OH THAT'S GOOD THEN.

Patient: ... which, as I said, 'cos they, they said, 'Do you want any tablets?' I said no, 'cos, as I said, I don't take tablets unless I need them. I said, 'No,' and then next thing she said, 'Well, don't, you know, you might still have the, ooh, morphine in your system, so ...' she said, 'take a paracetamol just in case.' So I had a paracetamol, that was straight after, not long after the operation, or when they'd ever come round with it, and I took a paracetamol, and that's the only tablet I took for the whole time. I felt a bit sore, but that's all you can say I felt, which, you know, expect to feel a bit sore being opened up, wouldn't you?

INT: OH YEAH, MM, SURE.

Patient: But I wasn't uncomfortably sore. I was able, I mean, they gave me two lots of medicines to take back with, both painkillers, didn't use any of them, gave them back and they're sending them to Africa I think [chuckles] you know, went to the Infirmary, I took them back with me 'cos I thought, 'Well somebody might ...' didn't even open them. And I was able to do the exercises and everything. Just didn't have any. Not pain-pain anyway, just a bit of soreness. So ...

INT: AND HOW SOON AFTER THE OPERATION DID YOU THEN GO BACK TO HEAR ABOUT THE RESULTS OF THE OPERATION?

Patient: Er ... I think it was a fortnight.

INT: RIGHT, OK.

Patient: Roughly about a fortnight.

INT: AND WAS IT MISS [???] YOU SAW THEN OR SOMEBODY ELSE?

Patient: No, it was somebody else.

INT: DO YOU REMEMBER WHO IT WAS?

Patient: No, it was a male doctor, I can't remember, I know it was a male doctor.

INT: RIGHT, OK.

Patient: They just came into, they examined, the chap that examined me to see if the scar was all right and no problems with it, was the one that gave me, and he did give me his name but, you know, I can't remember.

INT: WAS A DOCTOR OR A MISTER, DO YOU REMEMBER?

Patient: No, I think it was a doctor.

INT: RIGHT, OK.

Patient: I think it was a doctor.

INT: IT MIGHT HAVE BEEN [???

Patient: Yeah.

INT: A HOUSE OFFICER [???

Patient: Yeah, possibly, yeah.

INT: ERM, AND SO WHAT WAS THE RESULT THERE, THEN?

Patient: Well, as I said earlier on, well it's as good as it possibly could be. AS I said, it was very, microscopically small was their termination for it, microscopically small, they'd got it all - I remember him saying that - and the tissue all around it was normal, the glands under my arms that was analysed were all normal and it was a class one.

INT: GRADE ONE.

Patient: Grade one. And he said the chances of it coming back are microscopically small, er, 'We'll give you some radiotherapy and put you on Tamoxafen ...' you know, he said two years, the other bloke said fi-, the radiologist said five years. He was a bit put out because I said, 'Well they said two years,' because I don't like taking tablets, but as long as it doesn't affect me I'm not bothered how long I am but I just don't like tablets. But obviously, if I don't have any side-effects, but, as I said, the nurse said to me, and I didn't mention, it was just what she said, I didn't say I didn't like taking tablets, but I don't, she said, 'If you have any problems with it,' she says, 'Take yourself off it,' she said, 'Because the chances of it coming back and so, so small,' she said, 'It's like weighing up scales ...

INT: AH YEAH.

Patient: You know, 'That might do you more harm than ...' she didn't say that but that's the impression you go.

INT: YEAH, YOU GOT, YEAH.

Patient: 'That might do you more harm than the chances are,' as I said, the radiotherapist consultant said it's 95 percent chance of a cure and he said the Tamoxafen puts on another 2 or 3 per cent so, as I said, if I take then that's just a minute thing that they'd have to say, in my way of looking at it anyway, because nobody's going to say, 'You're definitely gonna get cured,' 'cos they can't.

INT: MM, YEAH.

Patient: But, I mean, you know, obviously I've got a very, very good chance of it never coming back again.

INT: THINKING ABOUT THE OPERATION THAT YOU HAD, THE WIDE LOCAL EXCISION, ERM, AND THINKING ABOUT WHEN YOU WERE TALKING TO MISS [???] ABOUT THE OPERATION YOU COULD HAVE, DO YOU FEEL THAT YOU HAD THE AMOUNT OF CHOICE YOU WANTED BETWEEN THE TWO OPERATIONS?

Patient: Er, yes, I mean, as I said, she didn't say a lot about a mastectomy, she did mention it at the end, 'You can go for a mastec-, of course you can go for a mastectomy,' but I got the impression it wouldn't what she would recommend and it's, to be honest, it's not what I would want.

INT: RIGHT, OK.

Patient: Unless, as I said, they'd say, 'You can have a mastectomy and that would mean you would definitely be cured for life.'

INT: RIGHT.

Patient: Then you would think about it. I'm not saying I'd still go for it, but I would have thought about it. But from what I read in what she gave me, it basically said between the two operations of, you know, chances of it coming back, it didn't say that but, you know, that's the impression you got, are more or less the same.

INT: RIGHT, OK. AND, YOU MIGHT HAVE ANSWERED THIS ALREADY BUT I'M NOT SURE, WHAT DO YOU THINK WAS THE MOST IMPORTANT THINK THAT YOU WERE TOLD OR THAT YOU HEARD, THAT YOU READ, WHATEVER, THAT HELPED YOU MAKE YOUR DECISION TO HAVE THE WIDE LOCAL EXCISION?

Patient: I think it was the fact that there's not much difference in your chances of being cured, because, as I said, I can't see the point why anybody would, oh right, you don't have to go for the radiotherapy, but even so, I can't imagine why anybody would go to the degree of having a part of them taken away when it doesn't really give them any better chance.

INT: AND WHEN YOU SAID THAT ABOUT, IS THAT SOMETHING THE CONSULTANT SAID OR IS IT WHAT YOU READ OR ...?

Patient: Well, no, it was what I read, but it was written by the consultant, 'cos her name's at the bottom.

INT: RIGHT, OK.

Patient: So she might as well have said, might she?

INT: YEAH. OK, LAST COUPLE OF QUESTIONS FOR YOU, LOOKING BACK TO WHEN YOU WERE FIRST DIAGNOSED UNTIL NOW, HOW DO YOU FEEL ABOUT THE CARE YOU'VE RECEIVED?

Patient: I think it was absolutely brilliant.

INT: MM, [???

Patient: I mean obviously I've, I don't know about the medical side of it, there's no way of me knowing that, you know, whether you could have better, er, well not better operations, but, you know, better drugs or ... I mean I wouldn't know that, but as far as I'm concerned, if I'd have gone private, I don't think I could have had better treatment. It was quick, everybody was exceedingly nice, everybody was helpful, everybody gave me the information I needed and, as much as you could possibly be, I never felt I was being told what to do.

INT: RIGHT.

Patient: I was informed and given the information and advised, which you expect a doctor or consultant to do, but I never felt as if I was told what to do. I always felt I had that choice that, you know, if I'd have said 'No, I want to go for so-and-so,' I'm not saying they wouldn't try and, if they thought it wasn't your best option they would obviously try and give you their opinion why they didn't think it was your best option, but I never felt that they would sort of try and say, 'Right, you do this because I know best,' you know what I mean? I never felt like that.

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

Patient: The only thing would have been, and it's probably something that isn't possible, is the time between your biopsies and getting your results.

INT: RIGHT, OK.

Patient: I mean ...

INT: YOU MEAN MAKE IT SHORTER?

Patient: Much shorter. I mean, because that is your worrying, I think most people, although they don't want to know what's, deal with what they've got, it's that 'Have I got so-and-so? Could it be so-and-so?' and one minute you think to yourself, 'Oh, no, I'm gonna be all right,' the next minute you think, 'Well it might be ..' You know, it's all that might-be's.

INT: YEAH, THE UNCERTAINTY OF IT.

Patient: That's the uncertainty and if I could change any-, as I said it might not be practical obviously, it might be something to do with how long it takes, 'cos obviously you're not the only one, they've probably got thousands of biopsies going through ...

INT: RIGHT YEAH.

Patient: ... the thing, so, it might be something to do with that. But if I could choose and I could do anything which I think probably if you went private you think might happen - then again it might not - it would be that. It would be the times in between because that is the most worrying part of the whole thing. It's, you know, not knowing and, you know, thinking it might be possibly worse than it is.

INT: ABSOLUTELY, YEAH.

Patient: 'cos, as I said, touch wood, you know, as far as I can see, I was lucky because, if you're gonna have one, as that nurse said, you want one with results like I've got.

INT: RIGHT, YEAH.

Patient: But you don't want one at all really but, you know what I mean.

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

Patient: Well basically I think most people want to know what's the chances of being cured of it, and, if not being cured of it, you know, what can be done to prolong your life. I think that's what most people want to know with any illness that's like that, isn't it? Well any illness really, you want to know how long it's gonna last or, you know, as I said, with something that's life-threatening like cancer is, as I said, the main thing I should think most people is, 'Can I be cured?' I mean I always thought, I must admit, that, you know, if you got one small enough you were bound to be cured, but I'm not quite so sure now. Because the bits of reading, through the system, it might depend on what sort you've got.

INT: RIGHT, YEAH.

Patient: You know, which I never thought that, because, but then again I mean I thought cancer was cancer: I didn't realise there was different sorts of cancer. But I should say it's 'Can I be cured?' Well, three things probably, can I be cured, and if not, you know, what's the likelihood and what, how long would they ... I mean obviously you can't be sure because nobody ever knows, but before it comes back, what's the usual time of it coming back in other words. And if it does come back what's your chances of getting over that? You know, that's sort of thing. And on top of that, with me it would be would I be disfigured? Which probably sounds vain but I don't think I'm particularly vain, it's just I think most people don't want to be disfigured, do they?

INT: YEAH, YEAH.

Patient: So ...

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

Patient: I think they want, they need to know what choice they've got, which is very important, I think they need to be given the choices, but what chance, you know, is there any difference in, you know, your survival rate if you like, on what choice you take, because obviously that matters. It might, you know, you might still decide to go another way, I don't know, it depends on you, but, and, you know, as I said before, and if you do, I don't know if this is part of the question [???] but if you do have a mastectomy, you know, you know, can you automatically get a reconstruction. I mean I don't know them answers because, as I said, I didn't go down that line ...

INT: OH I SEE.

Patient: ... but if I had have done ...

INT: YEAH.

Patient: But as I said, when I read the leaflet and that, and the survival rate, as I said, didn't seem to be any different, I couldn't see the point. I might as well just have the other one and, you know, be done with it.

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

Patient: No, I don't think so. I think we've covered most of the ...

INT: YEAH, I THINK WE'VE GONE THROUGH PRETTY, EVERYTHING, YEAH.

Patient: Everything, yeah.

INT: OK. IF THERE'S NOTHING MORE I SHALL TURN OFF. OK.

[End of interview]