

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

*VENUE: High MR unit

*DATE:

* Patient_Patient21

*INTERVIEWER: DJW

INT: WELL FIRST OF ALL THANKS VERY MUCH FOR AGREEING TO BE INTERVIEWED, I KNOW IT'S YOUR OWN PERSONAL TIME YOU'RE GIVING HERE. I'D LIKE TO START OFF WITH, THE FIRST QUESTION HERE 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: I think like everybody the word cancer frightens you to death, doesn't it, and it means death I think, and I know that's old-fashioned, but I still think that's stands today. And, yes, I probably did have quite a bit of knowledge about breast cancer because my mother died of breast cancer, my auntie died of breast cancer, and I also work for the Health Service, I'm a Clinical Coder.

INT: YOU'RE A CLINICAL CODER?

Patient: Yeah, do you know what that is?

INT: ERM, I COULD PROBABLY GUESS BUT, GO ON, TELL ME.

Patient: Well when somebody comes in and has an operation or a procedure their notes come down to us and we code them, obviously we've got books and we take the code from there, and it's all to do with the statistics, your waiting lists and all that, and your money, you know, what they're gonna pay you, your government budget and everything. So that's what I do. So, although I've not done breasts, they do them at the City, so you know we've sort of covered it in our training. But I did surgery, bowels and that sort of thing, so I suppose I did have a bit of an insight into it. Erm, so I suppose, you know, like people in the street, you know, what you hear on the television, every time you pick up the paper, there's always something about breast cancer, isn't there? It seems to be in your face all the time. So, yes, I knew quite a bit about it.

INT: OK. AND YOU SAY THAT YOU'RE MUM AND YOUR ...

Patient: My Mum ...

INT: YOUR MUM AND YOUR AUNTIE, WAS THAT RIGHT?

Patient: Yeah.

INT: BOTH DIED.

Patient: Both died of it, yeah.

INT: AND WAS THAT A LONG TIME AGO?

Patient: My Mum was 72, she's been dead about 10, 11 years now. But my Auntie she died in her early 30s and I mean that was 40, 50 years ago, she was just a young girl. But I mean in those days, obviously, you didn't have the treatment.

INT: NO, NO, IT'S ALL [???

Patient: And I suppose it was the secondaries that killed them both, my auntie's went up into her brain from her lymphs, and my Mum, she had had her breast off

20 years and it just came in the lymphs, in her bones, and that's what killed her at 72.

INT: OH DEAR.

Patient: Somebody told me a long time ago, when I worked at the [??] in Northallerton, they had a breast care nurse then, and it was when my Mum was poorly, and she said it's the one cancer that always recurs. Not necessarily in the breast but somewhere else. So, I don't know whether, how true that is, but ...

INT: OH IT'S, WELL I DON'T KNOW, I MEAN I'VE HEARD VARIOUS SORT OF STORIES WITH THAT, I SUPPOSE IT'S QUITE DIFFICULT UNLESS YOU ACTUALLY LOOK AT THE, YOU'VE GOT SOMEONE LOOKING AT THE BIGGER PICTURE, SORT OF THING. I WAS SPEAKING TO A LADY YESTERDAY AND ... SHE SAID THAT SHE KNEW SOMEBODY WHO DOES A LOT OF AUDIT WORK IN ONE OF THE BIG HEALTH AUTHORITIES, AND SHE WAS ASKING HER INFORMATION ABOUT, YOU KNOW, STUFF LIKE THAT REALLY, THE AMOUNT IT RECORDS AND ALL THIS KIND OF THING, AND SHE SAID SHE WAS THE ONE THAT REALLY CONVINCED HER TO HAVE A CERTAIN TYPE OF OPERATION, WHICH I SUPPOSE IS FINE. AND SHE SAID SHE FOUND THAT INFORMATION USEFUL ALTHOUGH I SUPPOSE A LOT OF OTHER PEOPLE WOULDN'T, BUT I DON'T KNOW. SO, WHEN YOU ACTUALLY REALISED, SORRY WERE YOU PICKED UP ON SCREENING OR WERE YOU ...?

Patient: No, er, because of my history, since my early 40s I've been screened every two years, and then obviously when I got to 50 you go on the programme, don't you? So, but I was breast aware, if you like. I mean I couldn't say I check my breast every third week of the month or something, because I'd had a hysterectomy so I don't have a period, so they don't really change, erm, and I think I was probably knew ... well I don't know, I sort of had a feel and thought there might be something about this time last year really, but then my daughter, who's 31, found a lump in her breast, and that made me think, 'Ooh, hang on a minute,' and I did find this quite large lump in mine. So I found it myself.

INT: AND WHEN WAS THAT THEN?

Patient: September last year, beginning of September. And then that was sort of on the Sunday night really and I mean I saw my GP on the Monday and it just went from there really.

INT: RIGHT, OK. SO WHAT WENT THROUGH YOUR MIND THEN WHEN YOU ACTUALLY FOUND THE LUMP?

Patient: Oh, straight away, this is it. Because I think always in the back of my mind, because of my family history, I've always thought, 'Oh well when's my turn?' and I think my Mum was first diagnosed about 53, 54, about my age you see. So I just straight away thought, 'This is it.'

INT: SO WHERE'S YOUR GP?

Patient:[??] Did you come through [??]? Maybe you didn't, just a little village just there ...

INT: OH, NO, I'VE MISSED THAT ONE, SORRY, I CAME IN OFF THE M1, THE A50 I THINK IT WAS.

Patient: Yeah, no, well it's just, as you come down into the village, if you turn left and follow the road round, just about 2 minutes away, not far.

*Q1. RIGHT, SO CAN YOU TELL ME A BIT ABOUT THE TIME FROM WHEN YOU ACTUALLY REALISED THERE WAS SOMETHING WRONG WITH YOUR BREAST UP UNTIL THE TIME WHEN YOU WENT TO HEAR ABOUT YOUR RESULTS?

Patient: Well, obviously, I saw a locum at the GPs, not my proper GP, and she said obviously anybody that comes with something like that they refer them, and here in Derby it's a two-week cancer appointment, and so you're supposed to be seen within two weeks. So she said they'd either ring me or send me an appointment, and I think by the Wednesday I'd had an appointment for the following week. And I saw ...

INT: SO YOU WENT ON THE MONDAY AND THE FOLLOWING WEDNESDAY YOU HAD AN APPOINTMENT?

Patient: Mm, a week on the Wednesday I had an appointment at the hospital, I think it was, and I saw, I went to the Breast Screening Unit at the City, had a mammogram, had an ultrasound, and I saw Mr Holliday, and they took some [???] biopsies and I said to him, 'Well, come on then, you know, tell me.' 'Well I don't know this early' he said, 'I could tell you it's cancer and,' he said, 'results'll come back and say it's not.' And he said, 'I could tell you the other way.' 'Come on,' I said, 'I'm not stupid,' I said, 'You know, I work, I've got an idea ...' 'Well,' he said, 'To be honest,' he said, 'It was highly suspicious,' and left it at that. And I waited a week I think.

INT: WAS THAT ON THE SAME DAY, ON THE WEDNESDAY?

Patient: That's when I had the biopsies, aha. So then I went back in a week for the results and I saw Miss Wahedna and she said it'd come back as breast tissue. They weren't happy with that, so they were going to do some more biopsies under the ultrasound, so they did that and they said it was hard, they couldn't get into it, so he did a fine needle in the end. And I said, 'Does that mean I've got another week's wait?' Anyway a few days later I went back and they had the result and they said they didn't know what it was. It was a cancer but, no, she didn't say that, she said, what did she say ... I can't remember what she said, but the gist of it was they didn't know whether it was a breast cancer or whether it was a lymphoma.

INT: RIGHT, OK.

Patient: Right. They weren't, so they were gonna bring me in and do an open biopsy. So that was how I went away. Oh, mind, every time I went I saw the breast care nurse as well, Karen. So they gave me a date to come in and Mr, not Mr Holliday, the other bloke ..

INT: MR SIBBERING.

Patient: Sibbering, he did the biopsy, and I said, 'Well are you gonna cut it all out?' and he said, well, he'd take what he thought. So then I went back a week after that [chuckles] ...

INT: WHO, SO HOW LONG HAS THIS BEEN THEN?

Patient: Oh, it went, it went on weeks. I think it was a month, from I think going to the doctors, I think I went in on the 4th October and had the lumpectomy and then I went back for the results after a week and they said it was an aggressive tumour and I saw Mr Holliday - no I didn't, I saw Miss Wahedna again. And ... I don't know who I saw ... it must have been Mr Holliday because he did the op. And he said to me did I, oh I was expecting him to say they would take my breast because obviously my mother'd lost her breast, but he just said to me, 'Right, what do you want, a wide excision or do you want a mastectomy?'

and I said, 'Well, can you not tell me what's best?' But he wouldn't, he said 'The decisions yours.' So I just went for [???] he said they'd do that. So I think I waited about another four weeks and went in and had that. And I think it wasn't really till after that they confirmed it was definitely a breast cancer. And that was it. And then I waited another few weeks and I started my chemo [?].

INT: SO IN THE INITIAL PERIOD LEADING UP TO WHEN YOU FIRST WENT THERE FOR YOUR MAMMOGRAM AND STUFF, AND YOU SAY IT WAS ABOUT THREE OR FOUR WEEKS WHILE THEY WERE DOING DIFFERENT BIOPSIES AND STUFF, WHAT SORT OF THINGS WERE GOING THROUGH YOUR MIND AT THIS POINT?

Patient: I think I just wanted them to come out and say, 'It's this.' Because obviously if it had been a lymphoma the treatment's different, and they explained that to me, she said if it was a lymphoma obviously they treat it different to a breast cancer. But Mr Sibbering didn't tell me a lot: Miss Wahedna, it was Mr Sibbering, when he came on the Friday to do the biopsy ...

INT: THE OPEN BIOPSY, YEAH?

Patient: ... yeah, he sort of sat on the bed and said, 'Well we think it could be this or we think it could be that, and this is why they're doing it this way,' and he said, which I already knew that the treatment would be different, which we, but I think when they final histology came back it was a definite breast cancer. And that was it really. I think what worried me most was because, after I'd had the lumpectomy and I went back a week after for the results, I waited another month, and I thin in that time, and I think I probably did say to Mr Holliday [???] 'Is that gonna make a difference?' because when they tell you you've got an aggressive tumour and every time they've looked at it it had changed, I thought, 'My God, I'll be dead in a month,' but he said it wouldn't make any difference. And I mean they did say they'd taken it all, the second time, you know, when they went in obviously you have clear margins, don't you, [???]

INT: SO, ERM,

Patient: And the lymph nodes were clear, so that was good.

INT: SO ONCE YOU REALISED THAT IT WAS PROBABLY GOING TO BE A CANCER, DID YOU HAVE ANY THOUGHTS ABOUT WHAT YOU MIGHT DO ABOUT, DO ABOUT IT IN TERMS OF SURGERY AND THINGS LIKE THAT, WHAT WAS YOUR INITIAL SORT OF THOUGHTS?

Patient: I think I just thought right from the beginning that I would lose my breast, and I think that was just because of my family history and because how, you know, it had been with my Mum, because I don't think that my Mum was ever given a choice, you know, they just said, 'We'll do a mastectomy, lymph glands,' and that was it.

INT: I THINK SOME OF THE EARLY SORT OF SURGEONS WERE REALLY RADICAL, WEREN'T THEY?

Patient: Oh yes, it was, very..

INT: VERY RADICAL.

Patient: [???] so I just presumed that, I was pleasantly surprised if you like when he said, 'Oh no, you can just have a wider excision or ...' but he said some women do prefer to lose their breast. He [?] said, 'No, just have a lumpectomy,' because I think making the decision, it's very difficult, because I think the first thing you ask them is, 'Right, if I have a lumpectomy, what's the chances in another year, 18 months, it's going to be back' but he said he

didn't think there was a, it would make any difference, you know, it wasn't going to give you a better chance losing all your breast.

INT: YEAH, THAT'S TRUE, I MEAN, IN TERMS OF SURVIVAL, LONG-TERM SURVIVAL, THERE DOESN'T APPEAR TO BE ANY DIFFERENCE BETWEEN THE TWO OPERATIONS.

Patient: No, that's what they [???] yeah.

INT: YOU KNOW, ONE'S OBVIOUSLY LESS RADICAL THAN THE OTHER, AND THEN IT COMES DOWN TO, SORT OF, YOU KNOW, SOME PEOPLE WANT TO KEEP THEIR BREAST AND ALL THIS KIND OF THING. SOMETIMES DON'T WANT SO MUCH SURGERY, OTHER PEOPLE I THINK ARE WORRIED THAT IF THEY HAVE THE LUMPECTOMY AND IT COMES BACK [???] SECOND SURGERY AND ...

Patient: That's right, and have your breast again, yeah.

*Q2. SO IT'S, ERM, YEAH. SO WHEN YOU ACTUALLY WENT TO THE CLINIC THIS TIME AND THINK ABOUT THE TIME YOU WERE ACTUALLY TOLD FINALLY YOU HAD BREAST CANCER, THAT PARTICULAR TIME, CAN YOU TELL ME WHAT HAPPENED FROM THE MOMENT YOU SORT OF WENT INTO THE ROOM.

Patient: Well, Karen, the breast nurse was there, and I saw Mr Holliday because he'd done the op, and he just said obviously I mean, he was gonna, I think they call it [???] don't they? I'd had the chemo because obviously if there was any seedlings or anything because it had been so aggressive, that that would get rid of them, and then after that I'd have radiotherapy.

INT: SO YOU DIDN'T ACTUALLY KNOW IT WAS A BREAST CANCER UNTIL THEY'D ACTUALLY DONE THE OPERATION?

Patient: No. I knew it was definitely a cancer.

INT: CANCER BUT NOT EXACTLY SURE WHAT CANCER?

Patient: I think at the back of your mind you're thinking all the time, because, I don't know, I just felt it in my own self that that's what it could be. I mean it did frighten me. That was it, the first time I went back and I saw Miss Wahedna, that's right, after I'd had the open biopsy I went back, they thought I might have a primary somewhere else, so I had to have a load more tests.

INT: OH, RIGHT, SO THEY THOUGHT THIS WAS A SECONDARY?

Patient: They thought ... they said it was an unusual type of cancer to find in the breast so I had a bone scan, an ultrasound, to check really I think all my vital organs, erm, and that was before I went in for the op, wide excision. So really ...

INT: THAT MUST HAVE BEEN A BIT ...

Patient: It was very hairy, I've got to say, you just wondered what was, you know, I really thought that was it, I thought I was a gonner to be honest. I thought this was it. And, no, it wasn't until I'd had the wider excision that they definitely said, 'Yes, it is a breast cancer.' But I think that's [???] a primary, it was aggressive and every time they'd looked at it, it was different, apparently, because it was changing so quickly.

INT: SO WHEN THEY TOLD YOU IT WAS A PRIMARY, HOW DID YOU FEEL ABOUT THAT?

Patient: Relieved.

INT: MM, PROBABLY WOULD BE.

Patient: Yes, and particularly when they said it wasn't in my lymph nodes.

INT: AH, RIGHT, SO YOU DIDN'T HAVE IT IN THE LYMPH ...?

Patient: I didn't have it in the lymph nodes, because I think that's what I was bothered about, you know, like when they leave it and, all right, I mean I did say something, well, you know, to Karen I think, [???] you know, it's the waiting, isn't it? I mean four weeks seems like four years when you're waiting to go in to find out exactly what's going on. And you think, you know, 'Well, where it have spread to by then?' But it hadn't, it stayed, well as far as I'm aware, in the breast.

*Q3.SO WHEN YOU WERE ACTUALLY TOLD ABOUT YOUR, THE CONSULTATION WHRE YOU WERE TALKING ABOUT TREATMENT OPTIONS, IF WE CAN CONCENTRATE ON THAT ONE JUST FOR A LITTLE BIT, CAN YOU TELL ME EXACTLY WHAT HAPPENED AS YOU REMEMBER WHEN YOU WENT IN? YOU'LL HAVE COME IN THE ROOM AND WHO TOLD YOU, IT WAS MR HOLLIDAY THAT DISCUSSED YOUR TRAEMTNET OPTIONS AND STUFF?

Patient: Mm, he just said, erm, I mean I think originally, right, going right back to the very first appointment I had and the first biopsies, I saw Karen, the breast, nurse, and she went through everything then, you know, what, you might need chemotherapy, you might need radiotherapy, and I think they did say if I lost, if I had my breast my off, I'd probably not need the chemo but just the radio. But then I might not need chemo anyway. Do you know what I mean? Even if I'd had the lumpectomy. I think it was all depending on the results that you got. But Karen covered everything, I mean they give you brochures and, you know, everything really to read through right from the beginning. And ever visit I'd had, and the very last time when I saw Mr Holliday for the results, Karen was there, and then obviously when he'd finished telling me he said, 'You know we're gonna go for the chemo and the radiotherapy,' and then Karen always takes you to one side and explains it in more detail, if you like, and 'Have you got any questions?' and I think at the end of the day you just, you just, you know, you listen to what they say and you think, 'Well he's the one that knows what he's doing,' and you sort of go with him really, you can only be advised. Unless you're dead set against it. I mean with hindsight now, and even with hindsight there I've got to say I didn't want the chemo. Er, but my family weren't having any of that, they thought I should go with it. And I won't have it again, I won't go through it again, if it comes back. But then that's my decision and I think I'd have to go with that now, but I've given it my all and I've done it.

INT: HOW LONG HAVE YOU BEEN ON CHEMO THEN?

Patient: I've got one more to go on Tuesday.

INT: AND HOW LONG HAVE YOU BEEN ON SO FAR?

Patient: December I started, I had one every third week.

INT: IT'S QUITE A ...

Patient: It's been awful.

INT: IT'S A STRONG TREATMENT REALLY. EVERYBODY YOU SPEAK TO SAYS THE SAME THING.

Patient: Yeah, he said it would hit me hard and by God it has, but the first, the first treatment you have you don't know what to expect, and I happened to

have a chest infection just after I started with that at Christmas, and I was really poorly, but the drugs that they give you, I've obviously had a reaction to one of them and I mean it literally sent me out of my mind. I think I spent the first seven days in bed. It was awful. And I just thought, well I'd had the chest infection and that made it worse. You go the second time and Geoff will tell you, I mean he sat on the bed with me, I was frightened [chuckles] I think I'd everybody I'd known dead in the bed with me. I was just absolutely out of it, and it's the most horrible experience, and I rang them at the chemo suite and she said straight away, 'It's the drugs, we'll change them for you.' But you don't know that at the time.

INT: NO, OF COURSE, OF COURSE.

Patient: And all the other side effects that go, I mean I think my digestive tract is wrecked, you know, I mean I'm feeling a bit better today but I've not come up as quick this time. And then I've got one more to do, but I've had five really shitty ones.

INT: I CAN IMAGINE.

Patient: Oh, they've been hell. And the time before last time, because my veins aren't very good, the stuff went into my hand so that was all panic. They had to take photographs, I was in a sling for three days. We were ice packs every six hours ... you know, I think everything's just ...

INT: IT SOUNDS AS IF YOU'VE HAD A RIGHT OLD TIME.

Patient: I had, I have, I've had awful ones. I wouldn't go through it again, and of course I lost all my hair with the first one. So ... not all, I won't have it again.

INT: SO WHEN YOU WERE IN THIS, JUST GOING BACK TO THIS CONSULTATION FOR A SECOND WHERE YOU HEARD ABOUT YOUR TREATMENT OPTIOBNS, WHO WENT WITH YOU? DID ANYONE GO WITH YOU?

Patient: Yes. Geoff's been with me every time.

INT: OK, AND WHO ELSE WAS IN THE ROOM AT THE TIME WHEN YOU WERE ACTUALLY DISCUSSING THE ...

Patient: Just Karen, Mr Holliday and the breast nurse, yeah.

INT: AND DID YOU HAVE ANY EXPECTATIONS ABOUT WHAT YOU WERE GOING TO BE TOLD?

Patient: Well I expect, well I was hoping because when I went for that final result I was hoping that it was a breast cancer because there's a good chance that you're gonna survive a few years if you go from what people say. So, I suppose I was relieved, if that's the word, when he said, 'Yes, it was a breast cancer.' And, yes, you know, he said they'd taken it away, and they'd just back it up with chemo [???] They're never gonna come out say, 'That's it, you've got 20 more years,' are they?

INT: SO WHEN YOU, YOU KNOW, ERM, WHEN THEY WERE TALKING ABOUT YOUR TREATKMENT OPTIONS, WHAT SURGERY YOU WERE GOING TO HAVE, DID MR HOLLIDAY OR THE BREAST CARE NURSES USE ANY KIND OF TOOLS SUCH AS MAMMOGRAMS OR DID THEY DRAW DIAGRAMS, ANYTHING LIKE THAT?

Patient: No.

INT: ANY PICTURES?

Patient: No.

INT: OK. AND I MEAN HOW DID YOU FEEL YOU GOT ON WITH MR HOLLIDAY AND KAREN?

Patient: Oh Karen was lovely, you know, anything you wanted to know, she was there for you. I mean once or twice I did have queries and once or twice I was very down because it's, you can't explain it to anybody because, how can I say, you feel not bitter, but you feel annoyed because you think, 'Why me?' and you like to be in control of things, but it's there and you're not in control of it, and it takes over your whole life. It's taken over our life, you know, for months now. You know, you have to live your life by the fact that you've got this treatment and you've got to take each day as it comes because you're feeling so, not just down, but you feel so rotten, poorly rotten, you know. Erm, you just feel so annoy-, I think I felt so annoyed about the whole thing really. And, yes, there's always somebody worse off than you, but that doesn't make you feel any better.

INT: NO, OF COURSE, IT'S ALL VERY RELATIVE [???

Patient: They've been very, Karen's been very supportive, you know, she's been at the end of the phone, any of them, if I've had a query or I've perhaps got a symptom that I hadn't expected, erm, I've just needed to ring really and they'll talk to you. They've been very, very good that way. And a couple of visits ago I see Mr [???], he's my oncologist, and was talking to him, I don't know what about really, because they've been so ... not so clear about the main cancer if you like, and you do think of things, don't you? And I was trying to explain to him that, with this rotten chemo that he's given me, that if there had been something, how long was it going to show its ugly head? Do you know what I mean?

INT: MM, YEAH.

Patient: And he said then, 'You know, if you want to go back and talk to Mr Holliday ...' they'd do anything, you can't, I can't fault the treatment I've had, I think they've been brilliant, you know, they've all been available there if you've wanted to talk to them. I think I've been quite lucky in that respect.

INT: SO HOW DID YOU GET ON WITH MR HOLLIDAY, THEN?

Patient: Fine, he seemed fine. I think he's very to the point, you know, he hasn't got the best bedside manner, I think Mr Sibbering's more bedside manner [chuckles] but ...

INT: YEAH, I'VE INTERVIEWED ALL THE PEOPLE AT DERBY, THEY'RE A VERY NICE BUNCH I THINK.

Patient: Yes, they are a very good bunch, yeah, yes, they're a very nice bunch. But, erm, yes I didn't have any problems with him, and he asked you, I'm the sort of person that I don't want to be, don't give me any bullshit, I want to know. That doesn't always suit everybody, you know, people sometimes don't want to know, but I want to know, you know, I'm interested, I want to know what they're going to do and what they've found and ... and, yes, he is good, he did tell me. In fact I read my own histology ...

INT: YOU WHAT?

Patient: I read my own histology report, yeah. So you couldn't want better than that, could you?

INT: HOW, I MEAN, HOW HAS GEOFF TAKEN ALL THIS THEN?

Patient: Erm ... I think he was devastated at first, I think he's ... he's not known how to take it, I mean, how do you take it? It's very, very difficult, I don't know, I mean, fortunately for me he was made redundant in December and thank God he's been here, because certainly the week I've had my chemo I couldn't have been left on my own. I don't know. I don't know how he's really taken it, you'd have to probably ask him, as I say, he's been very supportive and he's been really helpful, everything's been for me really. I think it, I don't know, it makes you think, doesn't it? I think it definitely changes your attitude to life.

INT: YEAH, IT PROBABLY WOULD, YEAH, I MEAN, I HAVNE'T BEEN THROUGH IT MYSELF PERSONALLY BUT I THINK IT IS TIMES LIKE THAT WHEN YOU START TO RE-EVALUATE THINGS.

Patient: And I think, I mean, I have, I have probably been very moody and there have been down days, I mean there have been down, there's no denying it, and he's obviously had to take all that, you know, the rubbish I've sort of spouted out really, and I've been lucky that he's been there [???

INT: SO WHEN YOU WRE ACTUALLY TALKING ABOUT ALL THESE THINGS, YOU SAID YOU READ YOUR HISTOLOGY AND THAT, SO YOU PRETTY MUCH UNDERSTOOD WHAT YOU WERE BEING TOLD ...?

Patient: Yeah.

INT: ... WITH REGARD TO THINGS LIKE YOUR DIAGNOSIS AND THEN WHEN HE DISCUSSED THINGS LIKE YOUR TREAETMENT IN TERMS OF THE DIFFERENT TYPES OF SURGERY YOU COULD HAVE, YOU WERE ALL RIGHT WITH THEM? YOU KIND OF UNDERSTOOD WHAT THE WIDE LOCAL WAS AND ...?

Patient: Yeah.

INT: OK. WAS THERE ANYTHING YOU DIDN'T UNDERSTAND AT ALL? ANYTHING YOU FOUND, THROUGHOUT ALL THIS EXPERIENCE, ANYTHING YOU DIDN'T UNDERSTAND?

Patient: No, no I don't think there was anything I didn't understand. I mean I think all the time, and I think everybody will tell you this, all they want you to say is, 'Right, go away, Mrs Richardson, you're gonna be fine,' but they're never gonna ... do you know what I mean? They're never gonna pat you on the back and say, 'Right, that's it, you're fine, off you go.' I think it's something you've got to live with for the rest of your life.

INT: DID YOU SPEND ANY OTHER TIME ALONE WITH THE BREAST CARE NURSE AFTER YOU SAW THE DOCTOR? SO THEY OBVIOUSLY TAKE YOU TO ONE SIDE, DON'T THEY?

Patient: No, not since the last time I went and I got my final result and before I started my chemo, Karen has rang me a couple of times: unfortunately both times I've been out but she's left a message on the answer machine. Erm, have I got any problems, is there anything, you know, do I need to talk about anything? But I haven't, I've been fine, as I say, she said she would keep in touch and she has, they have kept in touch. But, no, I haven't seen Karen since that time I got my final diagnosis and like my treatment plan, if you like.

INT: AND WHILE YOU WERE TALKING WITH THE DOCTOR, SUCH AS, WELL THERE'S THREE OF THEM YOU ACTUALLY SPOKE TO, DO YOU FEEL THAT THEY SORT OF LISTENED TO WHAT YOU WERE SAYING? DO YOU THINK THEY UNDERSTOOD YOUR NEEDS AND CONCERNS AND THINGS?

Patient: I think, I've spoken to Mr Ottermeyer [?] more than I probably did with Mr Holliday because when they went for the final results, he's giving you the

final results, he's checking your wound, he's telling you what he's got planned for you, but then he's passing you on, isn't it? And I think you need to come away and you think about things because, and Geoff's said this, when we've been and when we were going through all those different diagnoses and they didn't know, and they were telling you things, I think that's why you need somebody with you because I'll say something to Geoff, and he'll say, 'Well you haven't understood what they've said,' because he has obviously taken more in than I have, because I think you are in like a bit of a shock really, you know, you're trying to take it all in. So perhaps what I haven't missed, you know, he'll say to me, 'No, they said, they've told you this ...' or '... they've told you that,' and so, and I think since I've started my chemo I've probably had more questions. I found another lump at the top of my ribs and so that, I think, brought a lot more questions to Ottermeyer. I think that's what's spurred me to ask if there'd been any seedlings because they did know that this was gonna be the primary, how long they expected to get, you know, something from that. I think like your liver or somewhere, and he said it would be a couple of years after the chemo [???]. So I think that, I came away thinking, 'Oh well, at least I've got two years.'

INT: THIS IS A LUMP, IS THIS JUST A RECENT THING?

Patient: Yes.

INT: AND WHAT DO THEY ...

Patient: He wasn't bother when I, I've put on an awful lot of weight, I've put on over a stone since I started my chemo, and my abdomen's been really, really swollen. And I had had a bit of pain down here, and I think one night when I was lying in bed, you know, like you do that, I thought, 'Hang on ...'

INT: THERE'S A LUMP THERE.

Patient: It felt like a lump, it's just like at the top of my ribs under my breast.

INT: BUT HE DIDN'T SEEM CONCERNED ABOUT THAT?

Patient: He didn't seem bothered about it, he said, 'Everybody's got two side different,' and he said that he wasn't bothered about it, but they would keep an eye on it. And that was when he said, you know, if there was anything, you know, it could possibly be two years before [???]

INT: AND WHEN YOU WERE TALKING WITH THE NURSES, DID YOU FEEL THAT THEY SORT OF UNDERTOOD YOUR NEEDS AND CONCERNS, DID YOU FEEL THAT THEY WERE LISTENING TO YOU AND STUFF?

Patient: Oh yes, I think Karen was very good. I think as long as you've got the support at the end of the day I think it's something you've got to come, you've got to deal with yourself really, and not, do you know what I mean? Everybody deals with things differently, and I think you've just got to, sort of deal with it yourself. But I think just sometimes you need somebody to talk to and, like I say, they've been brilliant.

INT: AND YOU JUST MENTIONED YOU GOT SOME INFORMATION FROM THE BREAST CARE NURSES, YOU GET A PACK, DON'T YOU?

Patient: Yeah.

INT: I'VE SEEN THAT.

Patient: A little booklet with all the different treatments in.

INT: HOW, I MEAN, HOW WAS THAT, DID YOU READ THROUGH IT ALL?

Patient: Oh yes, definitely.

INT: AND DID YOU THINK IT WAS USEFUL IN ANY WAY?

Patient: Yes, yes, because you do refer back to it, you know, I've referred back to it in the beginning a few times, you know, like what you might expect after your operation, if you get lymphoedema or the chording [?], and, 'cos I did get a bit of chording under my arms, so, yes, I thought that was very helpful, they were very good. Good little book.

INT: SO, WHEN YOU WENT TO THE CONSULTATION AND THEY STARTED, THEY STARTED DISCUSSING TREATMENT OPTIONS, HOW SOON DID IT TAKE YOU TO SORT OF MAKE UP YOUR MIND WHAT YOU WERE GONNA HAVE?

Patient: Well I had to sort of say there and then. Erm, when I saw Mr Holliday and he gave me, erm, when he said it was, they were gonna, either could either have a mastectomy or a wide excision, and I said, 'Well you tell me, what do you recommend?' but he wouldn't. He said, 'Well ...' because I think the size of the lump and the size of the breast, he said, 'You're fortunate you've got a choice,' he said, 'It's up to you.' But then when I was admitted to have the op, he comes to see you, and he asked me again, so I really had had that month ...

INT: AH, RIGHT, OF COURSE, YEAH.

Patient: ... to think about it, and he said to me, you know, 'Are you happy with what you're going with? Have you changed your mind?' So I suppose if I'd had second thoughts I could have said to him there and then, 'No, I want to have my breast off,' and he would have done it, but I said, 'No, I was happy with the decision that I'd made.'

INT: SO WHAT, SO KIND OF WHAT REALLY MADE YOU CHOOSE THAT TYPE OF OPERATION?

Patient: I just think losing your breast's quite traumatic really, and I think because he'd said, and where my lump is at the top, I think it's the most common place, if you like. And Karen said when you put your bra on you probably won't be able to tell, there won't be much of a difference. Although he said he'd had to take more than he thought. So I suppose for cosmetic reasons really I chose to go with that. Oh, and I also know something else that's gone through this, Maureen, my friend, and her lump was in a different place to mine, and she saw Mr Holliday and she just had a lumpectomy like me. So [???

INT: AND ANY SORT OF, HOW DO YOU FEEL ABOUT THAT CHOICE NOW?

Patient: Oh think I've definitely made the right decision, definitely.

INT: AND THE ACTUAL, THE WOUND AND STUFF LIKE THAT AFTERWARDS, HAS IT HEALED OK?

Patient: It seems to be fine, yes, he's made quite a neat job of it, what you could say [chuckles] I've not had, the only bit was I had a bit of chording under the arm, which, I mean, we got some physio and it's gone. But [???

*Q4. JUST TO MOVE ON A LITTLE BIT NOW, SO YOU WENT FOR THE WIDE LOCAL AND YOU OBVIOUSLY YOU DISCUSSED ALL THIS SORT OF STUFF GEOFF AND ...

Patient: Oh yes ...

INT: AND TELL YOUR FAMILY.

Patient: Well I've got two daughters, 29 and 31, so, yes, because I think ...

INT: HOW DID THEY TAKE IT?

Patient: Er .. my eldest daughter, she's pretty sensible. Erm, obviously she was upset, erm, and I think it sort of rubs off on them because if it's a hereditary tumour ... my other daughter, Debbie, well, she stuck her head in the sand and it's not [??] but she was devastated, I think she's found [??] Because I think immediately you sort of say to them, 'Well I've got a lump and it's a cancer,' you do, I think, especially Debbie, I think she thought I was gonna die, you know [chuckles] that's the immediate reaction.

INT: ARE THEY CLOSE, ARE THEY? DO THEY LIVE CLOSE OR ARE THEY ...?

Patient: Debbie lives in Derby here, so she's quite close and my other daughter's in Ripon in North Yorkshire, but I see her quite a bit. So ... and obviously because my eldest daughter had found this lump originally, she obviously knows about Grandma and my Auntie, she's seeing [??] in Northallerton and he wasn't terribly bothered about her, he said it was just like a fatty lump. But then of course I hadn't said anything until I'd sort of gone, had to go in for my open biopsy, I'd never said anything to the girls. Well I thought there's no point till I know what's happening, I didn't want to worry them. Erm, it put a different light on really her lump, if you like, erm, so she's now, they have like a [??] clinic there and they'll keep an eye on her now every year, as I've been diagnosed. But, erm, as chances are, you know, I asked Mr Ottermeyer if he thought it was an hereditary tumour, or was it just a one-off, but he just said, 'Ooh, we'll refer you, if you ring up Karen'll sort you out with an appointment,' I think Mr Sibbering does a clinic, you know, where you can have the [??] test or something. But Debbie wouldn't, my daughter here. She's not, she's not into that, you know, she'll deal with that if it's gonna happen. But, as I say, Emma's, she's done it all on her own bat really. But, erm, I mean, I've just, [??] I've just got to watch what I'm doing, be aware, you know, and I can't do any more really.

INT: SO, APART FROM THE INFORMATION YOU GOT FROM THE HOSPITAL, DID YOU GET ANY OTHER INFORMATION FROM ANYWHERE ELSE ABOUT TREATMENT OPTIONS AND BREAST CANCER?

Patient: I did, not about the treatment, I think, I did try in the bookshops in Derby to get a book about it, because you know Koo Stark, she's had breast cancer.

INT: YES, SHE'S HAD A DOUBLE MASTECTOMY APPARENTLY.

Patient: I know she has. And she's written one or two articles in the papers which I've read, and you get articles in women's magazines, and you read. And I think she, that Koo Stark, she said, oh, she thought the treatment was barbaric, in one of the articles I read.

INT: REALLY? IN WHAT WAY DID SHE FIND IT BARBARIC?

Patient: I don't know, I don't know whether she was referring to the, you see they messed her around a bit because she went to America in the end, didn't she? I think she was about two years before they diagnosed her [??]

INT: NO, I DON'T KNOW ANYTHING ABOUT IT, I NEVER ACTUALLY HEARD ABOUT IT, TO BE HONEST, I MEAN IT CAME AS A BIT OF A SURPRISE TO ME, IT CAME UP IN ONE OF THE DISCUSSION GROUPS THAT WE HELD, [???] AND I'D KIND OF HEARD BEFORE THAT SHE'D HAD BREAST CANCER, OR SHE'D HAD A SCARE OR SOMETHING LIKE THAT, AND THEN SOMEONE TOLD ME THAT SHE HAD THE WHOLE MASTECTOMY.

Patient: Yeah, but she's chosen to have that second breast off ...

INT: SHE HAS, YES.

Patient: ... because I don't think they'd given her a definite diagnosis on the second breast. I think they'd said there was, I don't know whether they'd said it was abnormal or what, erm, but she'd chosen to have that second breast off, so they wouldn't come back. And in fact, my eldest daughter, she said she would have her breasts off if it meant she wouldn't, you know, wouldn't get breast cancer. I know, I mean, I've, if there's an article in the paper or a magazine, you read it, don't you?

INT: MM, WELL YOU'RE BOUND TO, YEAH.

Patient: You do. And I think October's the month, breast cancer month, isn't it? And it just seemed to be in your face all the time, everywhere you go. I think I knew enough about it. I think I knew enough about the cancer that sometimes you think, 'I don't even want to look at it,' so, no, as I say I looked at a few books in Waterstones, but basically it was just telling you exactly what I'd gone through and what I knew, and so I didn't bother. So, no ...

*Q5. SO JUST THINKING AGAIN ABOUT, YOU KNOW, THE EXPERIENCE YOU'VE BEEN THROUGH, AND THINKING ABOUT THE CHOICE THAT MADE OF THE SURGERY, WHAT DO YOU THINK WAS THE MOST IMPORTANT THING THAT YOU WERE TOLD OR YOU READ OR YOU HEARD THAT HELPED MAKE YOU MAKE THAT DECISION WHAT YOU WANTED TO KIND OF HAVE?

Patient: To me I think the most important thing was having a positive diagnosis. Erm, just, because that was it, wasn't it? It was like closure, 'Well this is it, it's a grade three, it's an aggressive tumour, it's this ...' and then I think from that you move forward. So I think definitely the diagnosis was, because it had took so long for them to get that, if you like. It was, I just wanted them to come and out say, 'Yes, it's this.' And then, er, you know, you get on with it, you deal with it from then. So, yes, that was the most important thing for me. And I think, as I said before, my decision about which, if he'd said, 'You've got to have a mastectomy,' I would have accepted that. I wouldn't have liked it, but, you know, you just accept it because if that's gonna make you better, that's what you go with. I have chosen to go with the other and I'm pleased that I did. I might not say that in another few years [chuckles] but, you know ...

INT: WELL THAT'S PART OF [???

Patient: I haven't had second thoughts, if you like.

INT: NO. SO LOOKING BACK NOW, THINKING FROM WHEN YOU WERE SORT OF FIRST, NOT DIAGNOSED, BUT WHEN YOU FIRST WENT TO THE CLINIC FOR YOUR TESTS AND STUFF, UP UNTIL NOW, WHAT DO YOU FEEL ABOUT THE CARE THAT YOU RECEIVED?

Patient: I think I've had really good care really. I mean I know, on the News they say it's regional, isn't it, in some areas you get better than others, but I think as a whole I've not, knowing the health service, I think I've done all right, I'm not into complaining.

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

Patient: I don't think I had any expectations. I would have like it to be, I mean, and I think that goes for everybody, you want it to be quick, like you want to have your biopsy one day and you want to go the next day and get your results. And if they say, 'Right, you got to come in,' you want to come in in a couple of days, you don't want to wait three weeks or four weeks. But then, from what they said, that isn't gonna make any difference. But I know it does, but you can't say that to ... maybe not in my particular case, but I mean I've had notes at work where somebody's had to wait and they've come in and it's spread so much they've just shut them up and sent them home. So I think that bothered me: a little bit of knowledge isn't good.

INT: MM, YEAH.

Patient: . So I think that bothered me: a little bit of knowledge isn't good.

INT: MM, YEAH.

Patient: You've just got to, erm, [??] and certainly when you go, when you go to the chemo suite, when I've see the consultant, they've not rushed you, they've had time for you and they've answered your questions and, no, I think I've been really quite lucky really.

INT: SO IF YOU HAD THE, IF SOMEONE GAVE YOU THE POWER AND MONEY TO CHANGE ONE THING ABOUT THE SYSTEM THERE THAT YOU WENT THROUGH, WHAT WOULD IT BE?

Patient: Erm, what would it be? I think just, but you can't really, I suppose just to get your test results quicker really, but I mean it takes time, doesn't it, for them to do whatever they have to do with them. I don't know, I don't know how you would change it really. Because like I say, one thing goes into another, you know, you've got to have a timescale, haven't you? I suppose if I'd waited longer I might have said, 'Oh, God, just to be seen quicker,' but ...

INT: AND YOU'RE GOING THROUGH YOUR CHEMO NOW, IT'S GOING TO BE COMING TO AN END, DID YOU AY YOU HAD RADIOTERHAPY AS WELL?

Patient: Yes, six ...

INT: HOW WAS THAT?

Patient: I haven't had it yet. He said he gives you about a month's break.

INT: OH, SO YOU GET YOUR CHEMO FIRST THEN YOU GET YOUR ... [??]

Patient: And then I get my radio ... yeah.

INT: AND HOW LONG WILL THAT ...?

Patient: Six weeks I have to do it for six weeks.

INT: SO WHERE ARE YOU GOING FOR THIS TREATMENT, IS IT DERBY? RIGHT, THEY DO IT AT DERBY.

Patient: Oh, to the Infirmary, yeah. See how that goes, but I mean I've had, got a couple of friends, one lady lives in the village, now she's had her breast off and she goes to Burton, and er, she went to Burton, and she's having different chemo altogether from me, erm, and she's going to this, Derby, for her radiotherapy but she's had, I think she had her op and chemo privately: they came home to her house to have her chemo. And so we've sort of been able to talk about things, and I've got another friend, Maureen, who's, where she finished in

November having radiotherapy, one of the girls I work with. So it's been nice because she's been saying, 'Oh well this is what happens, and this is what happens ...' so that's really helped me really, thinking of what I'm going to expect, talking to her and how she's been feeling. So it's been nice really having them.

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

Patient: Well I think that depends on the individual person because, like I said before, some people don't want to know, do they? Some people are just, they're just not, you know, they might know 'Well, I've got breast cancer,' but that's as much as they want to know. And they'll put themselves very much in their consultant's hands. But with me I wanted to know as much as I could now. I mean to somebody in the street they wouldn't know whether they, possibly, if they've got a grade one or a grade two, it wouldn't make any difference to them. Whereas I know I've had a grade three and that's worse than having a grade one, you see. It's quite, I mean, I think that's very much an individual thing. I think people should be told as much as possible, and I think they do tell you now, don't they? They seem to be quite happy to tell you whatever you ask.

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

Patient: Oh I think they need to know everything, as much as they possibly can about that, particularly if, like you, you were given the choice. But even so, if he'd said, 'Right,' you know, 'You need to have your breast off,' I'd want to know exactly, you know, how they'd do it, [chuckles] you know, how long the operation was, what it was gonna be like. And I think you need to know as much as possible, definitely.

*Q6. FINAL QUESTION, IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY? IS THERE ANYTHING YOU THINK WE'VE MISSED OR ANYTHING YOU THINK THAT'S IMPORTANT YOU'D LIKE TO TELL ME?

Patient: I don't think so. I think we've got it just about covered, because I think, talking to Karen, the breast nurse, even if I'd wanted to perhaps meet somebody that was in a similar position, I think they'd have probably arranged that as well. But I mean I've had, I know a couple of people, so we've sort of gone through it together. I think, I think really do think they've got it quite well put together really in Derby: whether it's not like that everywhere, I don't know. But with my experience, I think they've, you know, they cover all your needs really. And it's not as if they've dropped you, once, you know what I mean? They've still kept in touch.

INT: OH RIGHT, YES.

Patient: They've still sort of, you know, as I say she's rang me twice since I started my chemo to see that I was all right and did I have any problems, was there anything I needed. So I don't think you could ask more than that really. Because at the end of the day you've got to deal with it yourself.

INT: OK. THAT'S IT, THANK YOU VERY MUCH FOR THAT.

.....

*Q7. THE REST OF THE TAPE HERE...
Here