

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

*VENUE: High MR unit

*DATE:

*ID: Patient29

*INTERVIEWER: DJW

INT: THANK YOU FIRST OF ALL FOR BEING INTERVIEWED, AGREEING TO BE INTERVIEWED, I OBVIOUSLY KNOW IT'S OUT OF YOUR OWN TIME. I'D LIKE TO START OFF WITH THE FIRST QUESTION, CAN YOU TELL ME A BIT ABOUT WHAT YOU KNEW OR UNDERSTOOD ABOUT BREAST CANCER BEFORE YOU REALISED THERE WAS ACTUALLY SOMETHING WRONG WITH YOUR BREAST?

Patient: Well, I've always checked regularly because, I mean, that was something you did - not faithfully each month, but it's something I've always done, but had probably stupidly never thought about breast cancer relating to myself particularly because I've very small breasts and I just thought somehow that wasn't something that would affect me. We've actually got cancer in the family in terms of colon cancer and a grandmother who died of ovarian, I had never considered breast cancer for myself, although I subsequently found out that there is some connection between them which I was unaware of.

INT: RIGHT.

Patient: Erm, so, yes I did know that you should check, and in fact I had been checking but I actually think now, in retrospect, I may have felt something but not taken account of it and actually, because I've got small breasts, I could always feel my ribs underneath, and I remember pausing and sort of poking around a bit more, and really probably there was something there but I didn't register that there was. So I knew, erm, I knew you should check, I did check, but still missed something even though I checked. When I did actually see it for myself I was aware that puckering is something that, you know, you should be aware of and I noticed as I got out of the shower on one occasion. And I can't believe that it had been there for any length of time beforehand because I, you know, I do look at myself, so ... yeah ... is that sufficient or is there anything else that ...?

INT: NO, I MEAN, YOU MENTIONED OBVIOUSLY YOUR FAMILY HAVEN'T HAD A HISTORY OF BREAST CANCER BUT THEY'VE HAD OTHER CANCERS ...?

Patient: Yes, I already undergo, because I asked to go, on a screening programme for colon cancer, which is pretty ironic, because my father and my grandfather died from colon cancer, which began when they were in late 50s, early 60s. And at the time when my father died there was a big hoo-ha in the press and everything about you should go and get screened if it's in your family, it can be treated and everything, and I, you know, I asked to be involved in that screening programme, so I've actually had two now, so, you know, I was sort of 41 when I first started that. So in a sense ...

INT: YEAH, I'VE GOT 40 COMING UP PRETTY SOON, LIKE YOU SAY, AND I'M GONNA BE, AND MY DAD'S HAD IT AND WE'RE PRETTY CERTAIN MY GRANDAD ACTUALLY AS WELL, SO I'VE GOT TO SORT OF ...

Patient: That's right, but I mean you know that that's very preventable if you get it early enough, but that's why in a sense I felt when I actually got this, I thought, 'Well damn me, you know, I've sort of tried to be proactive and this just came from nowhere really.' Erm, so, yeah, there's no breast cancer in the family.

INT: SO YOU ACTUALLY FOUND THE LUMP YOURSELF YOU DIDN'T, YOU WORKED PICKED UP...

Patient: I actually, I actually saw it, ...

INT: OH RIGHT, OK.

Patient: I saw before I felt it, and then, erm, I'd actually, I actually, I mean I am extremely healthy as a person normally, I've never had extensive periods of time, except I did have when my father died, I was off some months with stress, but apart from - and that's ten years ago - I've never had any time off, but I actually fell downstairs before Christmas at this house, erm, and broke my foot and I was sort off school for five weeks and the only thing that I wondered is that, when I actually had the biopsy done and they actually took the thing out and examined it, there was the actual cancerous growth and next to it some sort of fibrous something or other, they said, 'Oh, it's nothing at all, you don't bother about that,' and I just wondered whether there was anything that had sort of, you can get those I think when you do bang or fall or something, whether that, that had sort of ...

INT: TRIGGERED SOMETHING ...

Patient: ... had caused it to be noticeable, you see, you know, I don't think that caused the cancer, don't get me wrong, but whether or not that had caused something else, just seemed to be so, such a coincidence, that, you know, the sort of week after I'd gone back to work I noticed this lump. And that was it, and I actually sort of, I saw it, as I'd looked in the mirror and then felt it and thought, 'Oh, right.' So does that take us onto number two ... or not?

INT: I WAS GOING TO SAY, SO YOU'VE GOT TO THIS POINT NOW WHERE YOU'VE OBVIOUSLY FOUND THIS, SAW AND FOUND THIS LUMP, WHAT INITIALLY WENT THROUGH YOUR MIND THEN WHEN YOU FOUND IT?

Patient: Well I straight away thought to myself, 'I think this is ...' I thought it was cancerous, and the reason I say that is, when I was 21, erm, just after I got married, I had a cyst removed from my left breast and I knew, I'd found that during my final year at university, I knew that that felt completely different to the cyst, there was no movement in it, and it was this puckering thing, I knew that was just a classic sign of it being something. And I just immediately that it was something. And I had already got an appointment booked at the doctor the next day because I'd actually, having gone back to school, I'd pick up a throat infection, I'd got no voice whatsoever, so I was going down the next day just to ask him to look at my throat. And of course then had to whisper about the fact that I'd, you know, found this lump. So I was going down the next day, I went immediately the next morning. And then he said basically he would fax immediately to the hospital Derby and would in motion - he examined me and basically said that I was obviously the best guide if I knew that it was something wasn't normally there, then obviously they needed to deal with it. And he said, 'Yeah, you can see it, [???' Erm, so he faxed and I suppose at the time you're obviously very churned up and worried about it and I think I actually misunderstood what he said to me about how soon I would hear about it. I got the impression that he was saying to me I ought to be sort then be seen next week. So in fact that was on a Wednesday morning and on Friday when I came home from work, at the end of the week, there was a letter which I didn't read it properly but, you know, it was a genuine mistake, it said would I go for a mammogram and I read it as being the next Monday, and in actual fact it was a week on Monday. Erm, so I turned up on the wrong day to the unit. I wasn't trying to jump the gun, I just, it was a genuine mistake, I suppose in our panic really. And they were very good and obviously I actually work a considerable distance in the other direction from here so it's a long journey for me to get to Derby and then back to work, and they said that they would fit me in even though it was a week early. So I actually saw, I had a mammogram and a large mammogram, an ultrasound and I saw the consultant within the space of an hour on that morning, which I thought was pretty good service.

INT: WAS THAT LIKE SORT OF A ONE-STEP CLINIC, I THINK, THEY CALL IT?

Patient: Yeah, it was fantastic. Erm, and they took the samples for the biopsy, you know, all within that hour which, again, I'd got no experience of, I've been in the age where I've been called for screening so I'd got no idea what was done anyway. And basically, by the end of that hour, when Mr Holliday spoke to me, he said to me, 'It looks very suspicious,' and in fact I felt that he was saying to me that, unless he was very wrong, that it was in fact cancerous. I mean I realise teaching English you're aware of people's body language, you know, you teach it and I was picking up on that, but I, when I came out of it and said to my husband, I said, 'I don't think it looks good,' because I felt that he was, you know, preparing me for that really, which in effect he was. So ...

INT: SO, JUST TO GET THIS OUT OF THE INTERVIEW, YOU FOUND THE LUMP, WAS IT THE NEXT DAY YOU VISITED THE GP ...

Patient: Yeah ...

INT: ... BECAUSE YOU ALREADY HAD AN APPOINTMENT.

Patient: The next morning, I found it at night and I went the next morning.

INT: YEAH, AND THEN YOU GOT THE LETTER ON FRIDAY ...

Patient: And then I got the letter on Friday ...

INT: AND THEN YOU WENT A WEEK LATER [???

Patient: ... which was in fact for 10 days time but I went mistakenly ...

INT: SO IT'S KIND OF LIKE ALMOST THREE WEEKS REALLY FROM WHEN YOU ACTUALLY FOUND IT TO ACTUALLY GETTING TO CLINIC. IS THAT RIGHT? OR TWO?

Patient: You mean when is it, what do you mean by getting to clinic?

INT: GETTING TO CLINIC TO GET THE BIOPSIES AND THE MAMMOGRAM.

Patient: Er, no, no, I went, so I went on the Wednesday morning to my own GP, the following Monday I went to the one-stop clinic for the mammograms. That Thursday I went for the results, so I went for the results three days later ...

INT: SO IT WAS LIKE, WHAT, LESS THAN 10 DAYS THAT THEN?

Patient: Absolutely, it was eight days, and at the results I was told, yes, it was cancerous. He told me at that point that they didn't it had gone into the lymph nodes, erm, and it was then, like eight days after I'd first seen it in effect, that I was told that I needed surgery and I was, erm, so this like question 3 here, when I went to the clinic and was told I'd breast cancer, it was confirmed then on the Thursday. And basically I had what was really only perhaps, it would be ten minutes at the very maximum of time with the consultant, when he basically told me that, erm, he would have to do surgery, that obviously then they would only know after the biopsy what sort of cancer it definitely was or anything, and that basically I had a choice between a lumpectomy or a mastectomy. He would be able to tell in the size of it, wouldn't he, I think he said it was a grade one at that point as well ...

INT: YES, YES HE WOULD, YEAH.

Patient: ... it was 15, 1.5 cm, whatever, it was. Erm, so he knew it was, he knew it was grade one in terms of its size, erm, and said I could have a lumpectomy or a mastectomy. Now obviously it's a terrible sort of shock, my husband was with me then, and what I really wanted to know was which of those I should opt for, and basically he said to me that it was my choice and that they really couldn't say that one outcome would be any better than the other, they couldn't choose between them, I think for the size of tumour that it was. And that was all really he would say. Now we actually left there and he said, 'Would you now like to go and talk to the breast care nurse about it?' and that's what we did, we went and spoke to her and the breast care nurses have been superb, and I've dealt with three of them actually, erm, and on that occasion she sort of just talked to us about it. I asked her to briefly give me some idea of the difference between a lumpectomy and mastectomy and I asked her to show me some pictures. Erm, she showed me a picture of a mastectomy - she hadn't got a picture of a lumpectomy I don't think that she could show me at the time. Erm, she talked about the fact that reconstruction, some people have afterwards, which I didn't even realise was an option. We had about 10 minutes, 10 to 15 minutes just talking to her there. I mean I think my husband was very shocked and upset as well, and she was basically trying to reassure us, erm, I mean one's reaction is immediately 'I'm going to die,' and she said, you know, 'People don't die of breast cancer in the way that they used to,' and we should realised that it was a small tumour and we should feel extremely positive, and I found all that very helpful actually. Because not knowing anything about the situation, I mean you know now because actually following me having it diagnosed there's been a lot about breast care, breast cancer, it has been Breast Cancer Week and the Cancer Reports and everything, it's just everywhere. And obviously the success rates are extremely high with breast cancer, but I wasn't aware of that before. And she sort of just said, you know, 'Don't think that you're going to die.' So we went away and, thinking that, erm ... and my first reaction just, I suppose really just think as I felt myself that I would probably opt for a mastectomy. The fact that I am small-breasted made me think two things - one is that I can understand if somebody has, you know, a large bosom, it's a massive thing to lose a breast and there's a great inequality about it and all sorts of things and the way that you look. I don't think that's an issue for me. And I also thought that, you know, taking a lump out of what little I'd got would probably not leave me with anything that was particularly manageable anyway. I've also got, you know, a very strong marriage and for me I felt that the issue of what I looked like may not be, you know, so serious for me as it might for some women. And I'm also ... not embarrassed about my body in any way, I never have been, just, it doesn't, just doesn't worry me. So that, again, you know, I would probably deal with people seeing me in a way that other people wouldn't. So I went away thinking that a mastectomy is what I was veering towards. Now, bear in mind this is half past three Thursday afternoon, OK? This is about eight days after I'd gone to the doctor to start with. Came home and in fact none of my family knew at this point because I wasn't going to tell anybody until then. I've got two daughters: I phoned one of them that night, my other daughter who's [??] I didn't even phone 'til the next morning, on Friday morning because she'd got a big event on Thursday night. And on Friday morning the hospital phoned me to tell me I could have a cancellation and have surgery on the Monday. So I had the space between 3.30 on Thursday and 10 o'clock Friday morning to actually think about, you know, in one sense what I wanted to do. I mean I did have longer in a sense that they said I didn't have to decide 'til I went in, but I actually was, you know, was asked did I want to go in.

INT: THIS WAS THE NEXT DAY?

Patient: The Monday.

INT: OH YEAH, JUST OVER THE WEEKEND.

Patient: So in actual fact, from when I first discovered my lump and I had a mastectomy it was less than two weeks, it was a day under two weeks, which is not typical, you know, I realise.

INT: WELL I THINK THEY'VE GOT A TWO-WEEK WAITING LIST JUST TO GET TO SEE A CONSULTANT ...

Patient: I know, I know.

INT: ... AND THAT'S NOT ALWAYS, NOT ALWAYS THE CASE. I MEAN I'VE SPOKE TO SOME PEOPLE WHO'RE WAITING SIX WEEKS.

Patient: And that, that stress factor must be terrible.

INT: OH YEAH, I MEAN, IT'S SORT OF BEEN VERY RAPID FOR YOU.

Patient: Yeah, erm, and I mean I'd got somebody with me actually who sort of fortunately just said to me, 'Well, why are you hesitating?' because you know you just think, 'Gosh, Monday!' I mean I was arranging by then even for the family to come up and obviously people wanted to come and see me straight away, my other daughter. But I said, 'Well, yes, I'll have it, you know, I'll go for that.' Erm ... do you want to go on to four and five?

INT: I WAS JUST GONNA SORT OF STOP YOU JUST TO BACK-TRACK A BIT BECAUSE YOU'VE MENTIONED AN AWFUL LOT OF INFORMATION ... I CAN'T [???

Patient: I'm talking ... I'm sorry, yeah.

INT: I THINK ONE OF THE THING I WANTED TO SORT OF GET AT REALLY WAS DURING THIS SORT OF TIME, IT'S BEEN VERY, VERY, IT'S BEEN A VERY, VERY QUICK TIME FOR YOU, WHAT WERE YOUR FEELINGS AND THAT OVER THIS PARTICULAR TIME, YOU KNOW, ONCE YOU'D ...

Patient: Erm ... gosh! I mean obviously it's very stressful. From the point when I actually discovered it until when I went and got the, you know, seven days later or whatever and was told it was breast cancer, I mean obviously I was living with feeling that it was and being pretty certain that it was. I have a job where I'm teaching but I'm actually head of special needs and I'm also a year tutor, so I have a stressful job where I'm dealing one to one with lots of people, and obviously, you know, you're carrying on as if there is nothing wrong. By the end of the first week there was certain senior members of staff who I had to tell because, erm, they knew I was going for tests, and I have to say, I mean I just was certain that it was, you know, from that, I felt sure it was. And I was sort of getting my house in order in terms of my job and making sure that I was leaving things so that people knew what they were doing. But I was trying not to panic: I was trying to be positive and from the time when I'd spoken to the breast cancer nurse who said, you know, you must be, erm, positive about this and not feel that you're going to die, from that point onwards that was what I have tried to do - and I think that's what I have done, haven't I really, Becky?

B: Yeah, [???

Patient: I mean on the Friday morning which I did speak to Becky, er, obviously, being a medical student, she doesn't know much yet about anything much, do you? But you did happen to ...

B: [???

Patient: No, but you had actually cancer, hadn't you?

B: Yeah.

Patient: I mean just say what you told me about what you'd learnt about [???

B: [???

Patient: Well you were saying, you reaffirmed, didn't you, straight away that you thought that people sort of died and you'd realised that wasn't the case any more, and that, you also talked about the fact that cancers are all very different, so you know, all I've got in my mind is colon cancer and you know what that's like and you've seen somebody die from that and it's horrible, er, or, you know, bowel cancer. And obviously, I mean, when my grandmother died you're talking about it was 1959 which is a hell of a long time ago, you know, ovarian cancer is still a very serious thing. But you just said, 'Breast cancer ... even breast cancer isn't all the same,' things like that, and you just, you said to me, I don't know whether you believed it or not, but you just said, you know, 'You're not going to die, you're going to be all right,' and I found that extremely helpful. Now the other thing that needs to come in, I need to explain, that comes into play here, which again is probably unique to my situation, which was extremely beneficial to me, but in a way impinges on what you're talking about, one of my colleagues from work, who's a librarian, who's next to me, who works with me in a team situation, some classes and things, she happens to have a daughter who was an ex-pupil of mine who works with the Norwich Health Authority, she's, whatever that is, and she is to do with cancer services. Now she, she was a research person but she now works, she monitors the cancer system and whatever, and she has worked with tumours to do with the head, she's done something else, and she'd done a time in part of her training to do with breast cancer, she's involved with breast cancer care now. Now she's not a medic but she's sort of, I think she's sort of ... she looks at the processes and makes sure that people are being given what they should be and that consultants are doing what they should and monitors processes and things.

INT: LIKE DOES AUDIT AND STUFF, DO YOU MEAN?

Patient: Yeah, I don't quite know what she, but she sort of, she's obviously deals with patient and sees that they are getting the care that they should do. So, her mum said straight away, 'Would you like Janina to speak to you?' and Janina is, she's a very, bubbly, buoyant sort of person anyway and, erm, I think she's sort of late 20s now Janina is, and I found it tremendously helpful to talk to her. Here was somebody who actually worked with loads of people who were in my situation and who'd got an, I talked to her for an hour on the phone, and the thing, I mean she was really positive again and just kept say, 'Oh ...' you know, 'people are expected to live for a long time [???] people have reconstruction, because they expect them to live ...' and she said, you know, 'If it's early, if it's not gone into the lymph nodes, you know, everything's fine.' And she, the thing that she said to me that I did find particularly helpful is that, you know, we talked about the fact that, a fact that when I talked to the breast care nurse I had been given quite a lot of, or given some information about things to do with breast cancer, but she'd ... I've forgotten what I was going to say to you now ... what did she say?

INT: YOU WERE TALKING TO JANINA AND YOU SAID VERY HELPFUL ...

Patient: What was it she said about ...

INT: OH RIGHT, SO YES.

B: Reconstruction?

Patient: No, it was to do with ... let me stop and just go back. Yeah, she was talking about the chances of getting better, she was talking about ... that's it, she was the only person really who talked about prognosis, the first time they'd talked to me about prognosis in terms of, you know, the different types of tumour - ones, twos, threes and things like that - and, but she said there are people who are even, they've got twos or even threes, and we see that they're getting better and that, you know, they'll be expected to live many years. That's it, the breast care nurse had already talked to me - that's what I was going to say to you - at that first meeting that we had when my husband and she, when we were given the diagnosis, she said that because I was under 50 I was likely to undergo chemotherapy and Tamoxafen, radiotherapy as a matter of course in terms of a preventative measure because of, you know, because I was under 50. And again Janina talked about that and said, 'Yes, you know, with younger women that's what they were doing because it was a way of preventing it,' and she talked, talked to me a bit about, you know, what it was like to undergo those things, said people are not as ill as they used to be, and all sorts of things like that. So that was really helpful, but what she did say to me, you know, I said, 'Well, you know, lumpectomy, mastectomy, you know, what do you think?' and I appreciate it was only her opinion, but she said, 'Well let me put it this way, if you were my Mum I would say to you "Go for the mastectomy" and she said "And if you're getting chemotherapy and radiotherapy after that it's almost like belt and braces, you know, you're removing everything you can, you're taking away, if you think you might worry about the fact that you've left something, that's gone in that sense, and if you're having those other things as well ..." she was saying you really should feel confident about what's happening to you.' And I found for me that was really important.

INT: RIGHT, MM.

Patient: Now there's a personal dimension there I appreciated, you know, and I wouldn't expect any consultant to be able to say that to you, but I have to say and in terms of your study I would imagine that there are probably a lot of women who would have liked somebody to be able to say to them, 'Well if I were you ... seeing loads of women who this happens to ... this is what, you know, I would think.' Because one of the things I wanted to sort of bring up within the terms of the study is that the breast cancer nurse gave me, I mean you can have a look at the [??] I think it's [??] given, there's a breast cancer support group and she gave me this pink leaflet when we first went and said, you know, there were ladies on here who I could phone. Now I felt that, to be honest, I mean I'm quite happy with phoning strangers, an awful lot of people wouldn't be, but I thought if I phoned these people, if they've had a mastectomy they'll be keen about having a mastectomy probably - some might not be; if I phone who's had a lumpectomy chances are that they'll be just as enthusiastic about a lumpectomy, because you know, generally speaking, if you're talking to individuals and that where you've got largely anecdotal evidence of what either happens to work for you and not me. I wanted somebody, at least with Janina, I mean, obviously, she's still got her subjective point of view, I still felt I was talking to somebody who dealt with a whole range of individuals and who'd got some sort of overview, and that's what I personally felt I wanted, rather than approaching individuals who would have what their particular experience was. And I just, and it was admittedly somebody who I felt I could trust, but it was somebody I thought had got some sort of overview, and that for me was what swayed it. Now also I know that she, she spoke to my other daughter who, you know, was very anxious, she's a very anxious person anyway, but how helpful it was for somebody to talk to her and say to her the things that had been said to me, you know, 'Don't worry.' So that, really from that we just, we were just positive as a family. My husband found it hardest I think because I think he was just worrying about what the future would hold and ...

INT: THAT'S QUITE COMMON, THOUGH, WITH SPOUSES, I MEAN QUITE OFTEN, ERM, WHEN I'VE DONE RESEARCH AND STUFF LIKE THAT, I'VE OFTEN, I STARTED OFF DOING SOME BREAST CANCER PATIENTS INTERVIEWS, AND ONE OF THEM I USED TO LEAVE A QUESTIONNAIRE FOR THEM AT THE END, AND IT WAS LIKE A QUALITY OF LIFE QUESTIONNAIRE. IT WAS TWO PARTS, IT WAS LIKE A GENERAL QUALITY OF LIFE THEN IT WAS A QUALITY OF LIFE QUESTIONNAIRE SPECIFICALLY FOR PEOPLE WHO'VE GOT BREAST CANCER, AND THERE'S DIFFERENT MODULES FOR DIFFERENT TYPES OF CANCERS. AND, YOU KNOW, QUITE OFTEN WHEN I WENT BACK THE SECOND TIME TO INTERVIEW THEM THE HUSBAND WOULD SAY, SORT OF SAY, 'I READ THAT QUESTIONNAIRE YOU LEFT' AND THEN SAY, LIKE, 'I DIDN'T REALISE JUST EXACTLY WHAT MY WIFE WAS GOING THROUGH,' BECAUSE THIS REALLY GOT INTO THE PSYCHOLOGICAL AND PHYSICAL AND SEXUAL FUNCTIONING, AND ALL THIS KIND OF THING, AND HE SAID 'I DIDN'T REALISE IT WAS SO, SUCH A COMPLEX THING.' HE SAID, YOU KNOW, 'WE'VE TALKED ABOUT CERTAIN THINGS ...'

Patient: Well, yeah, I mean, I mean, I think that's it. I mean from my husband's point of view, I think, because we're the people that we are and the marriage that we have, I mean I think he was very aware of all those things and in that sense, you know, the pain is knowing that you're going through all the physically things you go through and they can't do anything, but you know you're aware of all of those things. And you are, I mean, the way your husband is going to feel about the way you look or the way that that will affect your sexual relationship, you know, is inevitably something that's going to go through your mind. And I know, I mean I can think, when we'd had it diagnosed and, erm, and in fact it was the Friday before I went into hospital on the Monday, because I had to literally fly round getting suitable nightwear and things because, you know, I haven't got anything that I could appear in public in. But you go round places and suddenly it hits you, as you think, anyway, all these, this beautiful underwear that, you know, for years, I mean, Keith'd say, 'Oh, you know, go out and buy some really nice underwear,' and it's, 'Oh, I'm not wasting my money on that.' You think, you know, now you haven't even got the opportunity to do that any more, though I mean I realise now that's not the case, you still can, but suddenly all that, you think of all that dimension of sort of will I ever look sexy again is threatened and it probably isn't threatened as much as you think but, you know, and for a younger woman that must be dreadful, I mean it must be awful. But yeah, so there was all, there is all that that's going on. But I think it's, I think it's the fear of dying that is the biggest issue and, as I say, my husband, after I'd had the surgery and perhaps two or three weeks after, and he did look, he looked, he looked ten years older for two or three weeks, he really looked, he did ... you didn't see him, did you, [??] but he looked ...

B: No, I didn't see him then.

Patient: ... he looked bad, and he said he felt as though somebody had just pulled the rug out from under his feet in terms of his whole future, and he felt just old, suddenly old, and all the things that you thought you might do, etc, and you just feel totally threatened. You know hopefully they won't be, but that's how you feel. And even though your statistics of, you know, three out of four people are gonna this, that and the other ... you still think, 'Well there's still only three out of four ...'

INT: YOU'D JUST LIKE SOMEONE TO TELL YOU WHAT'S GONNA HAPPEN, IT'S GONNA BE THIS ...

Patient: Yeah, and nobody did actually talk about the specific figures, you know, [??] your diagnosis, just that it was just a small-grade tumour and stuff.

INT: SO YOU'D HAD YOUR, YOU'D HAD THIS CALL ON THE FRIDAY ...?

Patient: The Friday morning.

INT: ... TO SORT OF SAY THAT YOU COULD GO IN MONDAY ...

Patient: Yeah.

INT: AND IS THAT, AND PREVIOUS TO THAT YOU WERE THINKING, DID YOU INITIALLY THINK IT WAS GOING TO BE A MASTECTOMY?

Patient: Yeah, Yeah. And I never really wavered from that though I don't actually think I ever, I didn't read up any information about it, I mean I know there are loads of things on the internet, I didn't feel, I didn't feel I could face just looking stuff up really. I didn't ... and I mean I've got a friend who, she was going on things and looking things up, because I just felt in a way that whatever, whatever was presented to me in a way that it was still so individual to what you as a person were like and how you would respond. I felt as if all I'd got to think about is how I would feel about, with no breast, and for me I think the over-riding thing was that, I mean I, I do tend to worry - I worry less than I did, I think, but I just thought will I always be mithering about the fact - to use a dialect word - erm, about the fact that there's still some tissue there and will it flare up again where it was? And for me I just thought, 'Just get rid of it all,' basically, get rid of as much as possible. And I thought, you know, it's not going to be any less complicated to have a prosthesis, and also as well I was thinking then, well, you know, 'I'll have a reconstruction and I'll have the other side made bigger,' [chuckles] which you can do, and I just thought, instead of wearing booster bras I'll do something to ... that was what was in the mind, I mean I don't know about that now but that's what I considered. So I started to sort of like think positive about it and think, well, you know, 'OK, well I'll have a mastectomy and then look at what's the best option for that for the rest of my life.' And I didn't look up statistics, I didn't look up then about what the results of them were or anything, erm, we didn't, did we? We didn't actually talk about ... did you look up anything to do with mastectomy?

B: No, but we didn't have much time either, did we, really?

Patient: No, not really, and you didn't get back, did you, from Uni until Saturday night and [chuckles] it was strange, Sunday was the most peculiar day. We didn't but, erm, I don't know, I don't know where I would have looked, I suppose there'd be something on the internet. So really, where are we up to on this? Erm ... I've said about five, 'How much did you understand of what you were told about cancer?'

INT: YEAH, I WAS JUST GONNA SORT OF GO THROUGH THE, YOU KNOW, WHEN YOU, JUST TO BACK-TRACK A LITTLE BIT TO ACTUALLY IN THE,

*Q2. YOU'RE ACTUALLY AT THE CLINIC ITSELF, NOW YOU'RE GETTING YOUR DIAGNOSIS.

Patient: Well I got 10 minutes, up to 10 minutes with the guy ...

INT: AND WHO WAS IN THE ROOM WITH YOU AT THE TIME?

Patient: There was my husband, a nurse and Mr Holliday.

INT: NOT A BREAST CARE NURSE WAS IT? IT WAS A ...

Patient: She was outside. Yes, she wasn't in the room with me I don't think, I think it was another nurse. Erm, and - though I might be wrong actually - and he just basically just sort confirmed what he thought and said that it was the size

that it was, said that he couldn't really, well that I had a choice between a lumpectomy and a mastectomy, and he didn't give me any guidance about which of those options in terms of prognosis, it was identically basically is what he was saying.

INT: HOW DO YOU FEEL YOU GOT ON WITH MR HOLLIDAY? WAS HE ALL RIGHT?

Patient: Mr Holliday, yeah, I was very impressed with him, and he had a very pleasant manner but I mean obviously in the world in which he operates you can't afford to get involved in conversations with people, because I realised that, you know, the time limits so, but he was very gracious and, but I also felt in a sense that I, it was better to me to know, if he really did think it was cancer, and let's be honest, you know, he must have known when he looked at the mammogram initially 'cos he knows what he's doing. So I felt I liked the way he'd made me feel unless he was wrong it was cancerous because, you know, I don't want to be jollied along if it wasn't. And I also want, I mean I wasn't definitely in my mind saying, 'Oh, it definitely is,' I'll wait until he told me, but I felt he was telling me, and for me I found that was helpful because I suppose I'd had seven or eight days anyway, well, no, three days since seeing, just getting used to the idea that it was going to be. But then I went to the breast care nurse and as I say I probably had 15 ... actually we haven't had that actually, that was the second time. Following that I was also, I asked if I could then go and talk to somebody.

INT: OH RIGHT, WHEN WAS THIS?

Patient: Erm ... no, I'm sorry, I'm getting mixed up, I beg your pardon, that was still the first occasion, I'm getting confused. That was the first occasion, so now, yes, we're up to the point when I've had the weekend and then going for the surgery. So the breast care nurse, yes, I did spend that 10 minutes with them after seeing, er, because like I spent some time on a later occasion, but we're up to now, we're on 7 'What happened while you were talking about what operation you could have, well I've said to, haven't I, there, that he really didn't, he just said ...

INT: YEAH, YOU SAID YOU WENT FOR THAT THING ON THE MONEY, THEY WENT FOR THE MASTECTOMY ON THE MONDAY ...

Patient: So I went on the Monday, erm, again on the Monday, I mean really taking up to question 7, on the Monday when I actually went to the hospital, I mean I hadn't even you see, been able to go in for the pre-assessment things that you normally have. Now it may be that that there's some discussion at that pre-assessment clinic, I mean I wouldn't know that, I'd have to ask, but I think you do see the breast care nurse on that occasion as well as actually having the normal ECG and the blood tests and things that you would have done, or whatever. Now because I'd literally made a decision on the Friday to go on the Monday, none of that happened to me, so I went in at half past seven in the morning, I think it was. Or I phoned up, no I phoned up at seven, that's it, to find out if [??] bed, and got in at half past seven. The breast care nurse did come just to speak to me but he was still actually confirming what sort of surgery I wanted, so I just said, 'Yes, I'm having a mastectomy' again, and not really had any discussion about that. I think on that occasion - you see I can't, now, I can't remember, I was given quite large amounts of information, er, to do with, er, breast unit treatment diary record and that gave me everything to expect in terms of treatment. Now, you know I really ought to tell you that I don't know when I was given this. Erm, I don't know if it was when I went in ... it may have been the first time I met her, so I had some information about what to expect. It would have either been on the Thursday it was diagnosed or the Monday ... I'm really not certain about that to be honest. Let me just think, because it is relative to this ... maybe I was given, maybe I was given this when I

actually was given the diagnosis and saw the breast cancer nurse she gave me some information about, yes, that's right, because I did know what exercises I was going to be expected to do, so I must have been given some information when I first saw the breast care nurse after the diagnosis. There were other things I was given later, but I was given some information about what would be involved in terms of the post-operative process, and that was very good. Yes, you do need to know that, I was given that booklet. So obviously I'd take that into hospital with me, that's right, because I'd got the exercise I needed to do. Now I was told I would see a physiotherapist as well beforehand to go through those exercises. Now again I think patients who maybe went to that pre-assessment thing were and I wasn't because I missed that process.

INT: RIGHT, OK. AND WAS IT MR HOLLIDAY THAT ACTUALLY DID THE OPERATION, WAS IT?

Patient: Yeah, now again, I was lucky and because he was going to have been away obviously for the normal schedule it was a 10-day gap, it should have been, between my diagnosis and when it was actually done and he was going to be on holiday, but because I had a cancellation, in fact there was only three days between it. So, yeah, I went in at half past seven, I saw a breast care nurse, and in actual fact I was expecting to go in later in the afternoon and I was taken down to theatre about half past eleven, so it was just incredibly quick. [chuckles] It was just amazing. So, I mean ...

INT: [???

Patient: I know, my husband and daughter came in, you know, expecting just to spend the morning with me, and, you know, I was whisked away at half past eleven, it was just incredible.

INT: IT'S INCREDIBLE.

Patient: During that proc-, that time, I saw the anaesthetist, I saw, erm, house officer as they're called now, but they just look like sort of 'A' level students or something because nobody dresses like doctors any more, er, and she did the normal checks that she's supposed to. And I saw Mr Holliday, he came and spoke to me about what he was going to do, you know, ensure what was happening, you know, did his cross on the appropriate place. And he was, that was nice, it was encouraging that was, to actually just, you know, see him, and he was, got a very relaxed, friendly, erm, you know smiling perhaps more than he'd seen me before, and that was encouraging. And then I went down at half past eleven and I was back again about quarter past one. They just about had time to go for a cup of coffee, I think, and something to eat and I was back on the ward. So, really, before I'd had time to worry about anything in on sense.

INT: YOU KNOW WHEN YOU WERE ACTUALLY IN THE CONSULTATION, ERM, WHEN YOU WERE ACTUALLY HEARING YOUR DIAGNOSIS AND TREATMENT OPTIONS, WAS THERE ANYTHING YOU DIDN'T UNDERSTAND THAT WAS BEING TOLD TO YOU, OR ANYTHING YOU FOUND DIDN'T MEET UP WITH ANY EXPECTATIONS YOU MIGHT HAVE HAD, OR ANYTHING LIKE THAT?

Patient: No, erm, I mean, obviously, the sort of terminology that they use in terms of grade one and all that, I mean, just from the more general level of reading or understanding I would already understand that. So, no, I mean, I don't, there was nothing I asked for clarification on. I mean I did, I would have, this is the thing as I say relating to your particular study, I would have, even then I would have liked him just as a professional to say, you know, 'In my opinion, I'd probably go for this,' but I appreciate, you know, you probably can't do that. I mean, when we get further down I'll go into some depth of one thing I've thought about, just to talk about, but [???] say that later on.

INT: SO WHERE ARE WE?

Patient: So we're sort of seven [???

INT: I THINK WE ARE, YES.

Patient: Yeah, yeah, I mean, I've said, you know, who was in the room. We were asked if there were any questions, we just clarified that there wasn't anything in terms of prognosis to choose between lumpectomy or mastectomy, that was what was clarified on that meeting, and therefore when I then we went to talk to the breast care nurses, she sort of said, you know, 'You're not going to die,' is what she was saying to me and she showed me a picture. But then thee wasn't really then, it was sort of, you know, you could, she gave me the information about these people I could phone up who'd gone through the process but then, you know, I felt myself when I came home that I just didn't that would be particularly pertinent to me because they would have just their experience. And then really for me it was over that weekend talking to Janina who worked with another Health Trust and, you know, just trusting that she's as good at her job or she seems to be, who I had a hour's discussion with that I found extremely helpful. And I was able to ask her sort of questions about - now probably, if I hadn't had Janina, I'm sure I could have phone up the breast care nurses, local, I'm sure that they would have done that, but I was just fortunate enough to have somebody I felt I could talk to for an hour without any problem. So that was where we were up to, and then I went in on Monday, as I say, I was seen by the breast care nurse who told me that she, I would be seen post-operation, erm, and that was it really then, you know. I came back from theatre, erm, I saw Mr Holliday the next day, he just came round and checked that he was happy with what he'd done and, erm, I spoke to him for a bit longer then actually, but we were talking the book I was ready actually to do with the left side of the brain [chuckles]. But, yeah, I mean I couldn't fault him, I was extremely impressed with him. I had no, I'd got no pre-knowledge of him whatsoever though everybody who just, when people within the hospital there, or women I spoke to in the community or elsewhere, Mr Holliday I believe he's the head of the team there ...

INT: HE IS, YEAH HE'S [???

Patient: and 'Oh, he's really good,' you know, straight away, it was just, he's, you know, he's exceptionally good and in my experience I would have to say, you know, he was extremely professional and I was happy with that. I didn't see him again, I saw somebody else after that.

INT: YOU AID THAT THE BREAST CARE NURSE SHOWED YOU SOME PHOTOGRAPHS OF, I THINK IT WAS A MASTECTOMY, IS THAT RIGHT?

Patient: Yeah.

INT: DID THE, DID ANY OF THE TEAM EVER USE ANY OTHER KIND OF TOOLS IN THAT RESPECT, LIKE DID THEY DRAW DIAGRAMS, SHOW YOU OTHER PICTURES, ANYTHING LIKE THAT?

Patient: No, I don't think so.

INT: NO? DID MR HOLLIDAY DRAW ANY PICTURES OR ANYTHING?

Patient: No.

INT: DIAGRAMS?

Patient: No, I don't think so.

INT: NOT SHOW YOU MAMMOGRAMS?

Patient: Erm, no, no. I suppose if I'd have asked him, I could have asked to see it, but, erm, no, he didn't.

INT: OK, I JUST WONDERED JUST WHEN YOU MENTIONED THAT SOMEONE HAD SHOWN YOU, YOU KNOW ...

Patient: It was a photograph. It was a not very good black and white photograph. I mean I would say that personally that would have been helped, if you'd have got, like they've got in these wonderful leaflets, I mean they've obviously got a large book about breast care I would imagine, if there'd been two or three examples of ... if you could have seen a variety of people who'd had mastectomies. I mean obviously some people have all the lymph glands taken out and that's different to what I've had. And people who'd had ... you know, again, for me, if I'd have seen somebody who'd had, somebody with small breasts [chuckles] somebody with large, 'cos I think, I do think that is relative, 'cos you're physique after you've had a breast removed ...

INT: YEAH OF COURSE.

Patient: ... is totally different if you're larger, I mean, you know, my family, teasing me, 'Oh you look as though you've had a double mastectomy anyway,' you know, because if I haven't got a bra on I'm practically flat-chested, and that is something, you do need to be able to see that range I think. And if you were asking what could you have, I would say just having something that's a very brief booklet that just gives people immediate sightings, if you like. Because again I would have thought that maybe husbands would need to see that because they must be, that must be something that they are concerned about and, you know, just, 'cos otherwise they're gonna worry about what it's gonna look like, aren't they, as well, before it happens. And I've heard about people since who've said that, one woman who somebody knew about, who said to me that she'd sort of sat with a flannel over herself for months because she just couldn't face what she looked like. Well that must be appalling. But maybe if you've actually looked at somebody else other than yourself on an initial occasion at least you've had to face it or you've looked at it, because how do you imagine it? I mean I'd actually no idea it would be such a long scar running right under your arm - I suppose if you think about it logically it's obvious, but, er, and you don't actually think about the fact that because they go across the nipple, I suppose the only thing women have generally seen is breast enlargements or reduction, and of course that's underneath isn't it, you know? And they just, I suppose I would have imagined that if I hadn't seen it. So I think that is something that would be beneficial, just so, and in colour rather than black and white, because that's the reality of it.

INT: YEAH, THAT'S TRUE, BECAUSE I MEAN OBVIOUSLY YOUR SCAR DOES HAVE A CERTAIN COLOUR AND TEXTURE WHICH PROBABLY WON'T COME OUT REALLY IN A BLACK AND WHITE PHOTOGRAPH?

Patient: No, and again, you know, if we're gonna do that, why don't we have somebody who's just had the surgery and somebody two years down the line, because I think that would be helpful, to say, 'Well, OK, it'll look like that then,' but I mean I'm imagining that by the time, you know, I'm sure mine'll be a lot different, I had seroma and things afterwards, you know, so it's still quite puffy, but two years down the line I'm sure it will look a lot different. Erm ... that would have been useful really, if you've got, comparing a lumpectomy and a mastectomy, erm, I would have had something. And then maybe it would have also prompted questions, because what do you ask about it in one sense if it's a vacuum in your mind anyway?

INT: YES, IT'S HARD TO ASK QUESTIONS WHEN YOU DON'T KNOW WHAT QUESTIONS TO ASK, I SUPPOSE, YES, RIGHT?

Patient: Yes, that's right. So I think that would be a good idea.

INT: OH, THAT'S INTERESTING THAT.

Patient: I'll volunteer to model if nobody else will [chuckles] [???

INT: SO WHEN DID THEY, YOU SAID YOU WERE ON A TRIAL OR SOMETHING, IS THAT RIGHT?

Patient: That's a trial to do with, yeah, that's to do with chemotherapy, that is, that's happened since.

INT: OK, SO THIS IS AFTER YOUR OPERATION, YEAH.

Patient: Yeah, yeah. Yeah, I mean, what are we on, eight? I mean we've got one other treatment in terms of, one other appointment 'cos I went afterwards of course to get the results of the biopsy and stuff like that.

INT: AND THIS AGAIN WITH MR HOLLIDAY?

Patient: Well, no it wasn't, I mean when do you want to talk about that? Do you want to talk about that next ...

INT: WELL I'M JUST SORT OF, ERM, WE'RE KIND OF UP TO EIGHT, I DON'T THINK THERE'S ANYTHING ELSE SORT OF I NEED TO ASK REALLY. IT'S SORT OF ...

Patient: Because I talked with the doctor on a further occasion you see.

INT: RIGHT. BUT THIS IS NOT MR HOLLIDAY.

Patient: No, it was one of his team because by the time I came for my 10-day follow-up to the operation he was on holiday so I spoke to somebody else, and there's a team [???

INT: BECAUSE I THINK, YOU KNOW, YOU SAID YOU WENT, YOU WENT FIRST OF ALL THE WRONG WEEK ...

Patient: I know, yes. I mean ...

INT: THAT'S ACTUALLY BEEN VERY GOOD FOR YOU.

Patient: I mean, yeah, I mean I ...

INT: IT'S WORKED OUT VERY NICELY REALLY.

Patient: Yeah, I mean, I'm obviously, I mean in some senses, you know, I've cheated the system but I mean it was genuine, the initial mistake was a genuine one, it was my panic, you just see Monday and you think, 'Oh, Monday,' I mean when you think about it logically afterwards, nobody's gonna get a letter Friday afternoon saying go in Monday, but you're not thinking straight anyway. And I think, if they had sent me home on that Monday the stress would have been terrible really, having gone then, and they were very good, they just fitted me in as an extra person. You see, and that plus the actual cancellation, I mean I realise it's absolutely phenomenally quick.

INT: OH YEAH, COURSE.

Patient: If I'd have gone privately anywhere in the country I'm sure I could not have anything done quicker than I have actually ...

INT: WELL I DON'T KNOW ABOUT THAT, BUT, ERM ...

Patient: Well I can't imagine that you possible would have even had an operation ...

INT: IT WAS INCREDIBLY FAST, YEAH.

Patient: But ... to move on, you see, when I actually got the result of the biopsy I'm very glad what happened happened. I mean, do you want me to talk about what happened in terms of the results of the follow-up then.

INT: IN A SECOND, I WAS JUST GONNA SAY, I MEAN, YOU WENT THROUGH IT VERY QUICKLY, I MEAN, I MEAN, LOOKING BACK AND BEING RELECTIVE ABOUT IT NOW, I MEAN, ERM, HOW DO YOU THINK, THE WAY YOU FEEL NOW, HOW DO YOU THINK THAT HELPED OR DIDN'T HELP YOU ...

Patient: For me that, I'm sure, helped considerably because you don't have time to sit and worry about it, and that is, you know, that's what I would have done, I'm sure about that, because also from the point when you get that diagnosis, I mean the Thursday afternoon I got that diagnosis, erm, I wasn't going to, I wasn't at that point going to go in 'til a week on the Tuesday. Now it happened to be half-term the next week - how I would have coped with going and doing my every day job for the next eight days or so I just don't know, I don't know whether I would have, would, I just don't know whether I would have coped or not. And I obviously was going to have a week off anyway. But I didn't even go in the next day, I mean I felt I just couldn't, I just couldn't do that. And actually I, I mean I, the staff were informed about what had happened to me, they were obviously extremely shocked because there was only like three of them knew anything about it so, suddenly, you know, I'm bouncing around and the next minute you're told somebody's got cancer and everybody was really shocked and of course my classes were even more shocked [chuckles] to find out they're not going to see me for the rest of the year. But from my point of view, I just didn't really have time to think about it, and from my point of view that was great because I think I would have possibly got down about it or worried more about what my prognosis were and thinking about, 'Well, you know, the longer I'm waiting the more damage it's doing,' which may be ridiculous because it may not work like that, how cancer develops, but I'm sure that's how I would have felt. So, yeah, it was all done and dusted, as you would say, without me having a chance to worry about it. Of course on the other hand I suppose you could say I also hadn't had time to think about what a mastectomy would result in or how I would deal with that. And I suspect, I don't know, but I would imagine that the breast care nurse could not have phoned just anybody up to say, 'Do you want to come in on Monday?' She must have seen how my husband and I had reacted to the initial news. I can't imagine just phoning anybody up and say ... there must be some people who would be in such a state that perhaps they wouldn't cope with that in the space of two days. So I assume that she maybe gave me the opportunity because she thought I perhaps could cope with it. But I haven't seen her since to be able to ask her that.

INT: SO, GOING TO THE POINT WHEE YOU'VE HAD YOUR OPERATION AND YOU'VE COME ROUND, WHAT HAPPENED AFTER THAT THEN?

Patient: Well, as I say, I was, basically saw Mr Holliday the next day and that fine, I didn't see him again. So I had it Monday lunchtime and I began the, erm, breast care physiotherapy exercises the next day, erm, and to be honest the most trouble I had is I had a lot of pain with a drain that was resting on a nerve in my shoulder and that was the most trouble I had, that started immediately and

every time I moved it was, it hurt even then, and of course as the anaesthetics and things wore off over the week it hurt even more. But I was actually discharged on Wednesday lunchtime, so I had it Monday lunchtime and I was out of hospital Wednesday lunchtime. I'd still got one drain in at that point which I carried round in a very nice little gold foil bag, but I came home and basically that was it. And I mean the district nurse came out, I think she came out two days and then actually I was in some considerable pain on the Friday which was these damn drains that as the swelling went down, as it got less and less flesh, it became excruciating on the Friday, although Mr Holliday had warned me as he put it, he said, 'The trouble with skin,' he says, 'is that you tend to have trouble with drains and with seroma,' and I'd also got a whacking seroma by then which was very painful. So on Friday, that was the worst day of the whole thing, I was in bed and I couldn't move that day, I couldn't breathe without it hurting. I was really hunched up and the worst thing, the only thing that was a pain to me really is that I knew, because you have to phone up all the time and track how much stuff is coming into these damn bottles, and I knew that on Thursday night at nine o'clock at night, I'd looked how much had come out of it and on Friday when I phoned the surgical assessment unit, I knew that nothing had come out in the twelve hours between, but because total amount that had come out the day before exceeded whatever they're, you know, levels wee, they wouldn't let me remove this drain. And I was in agony, real agony, for the whole of Friday and Saturday, and they would not let me take this drain out. And I couldn't get access to the breast care nurse when the district nurse came. Now if I could have contacted her the district nurse said, well in fact the surgical assessment unit said, they could have over-ridden their authority and given permission to take it out. And that was the, when I say criticism, it's not a criticism because they've got lots of things to do, but if I could have actually accessed somebody they could have taken them out and I was really, I was, I had to take so many painkillers, it was terrible that day. As soon as the drains came out Saturday morning it was much better. And that was it really, stitches came out on their own, took the stoma strips out and that was it really.

INT: MM. AND THEN WHEN YOU, SO WHEN DID YOU NEXT GO BACK TO CLINIC?

Patient: So I next went to see the doctor, that was 10 days after I'd the surgery, everybody has a standard follow-up I think and in Derby it was ten days afterwards. Now that was a further disappointment to me in that I been told ... yes, now, actually I don't know whether I've mentioned that, but when I actually saw the doctor who told me I'd got breast cancer, he told me at that initial thing that I was given the choice of the mastectomy or lumpectomy, that he did not think it had gone into the lymph nodes. Now obviously he wouldn't have said that unless he didn't think it had, you now, I realise that. But when I actually went I found, and the results of the biopsy, it in fact, out of the six lymph nodes he'd taken, it had gone into one lymph node, which they were surprised about and obviously I was ... really upset about. Well I say upset, I mean I was very disappointed because, you know, what I did know from what people tell me is that, 'Oh, if it's not in the lymph nodes, it's wonderful, you know, jamboree time, no worry, no worry at all.' So that was a set-back, I have to say that, you know, I was expecting them to say it wasn't. On the other hand the person who ... and he was emphasising this and stressing this but I think at the time I couldn't get past the fact it was a lymph node and I had been expecting it not to be, but he was saying it was a slow-growing cancer, and that was excellent, you know, and that it was grade one, so all that was really good, that was excellent, so that, in that sense, the prognosis was very good. And he kept emphasising that because I kept saying, 'But, you know, it's in the lymph node.' So I felt shaken by that, and he again just informed me, he said, 'So you will be having chemotherapy, you will be having radiotherapy, you will be having Tamoxafen,' he made me feel as though he thought I was going to feel more upset by that than I was, but I wasn't because I was actually expecting that whatever the outcome was because the breast care nurse had sort of prepared me by saying

that she expected that they would do that anyway because I was under 50. Obviously they would definitely do it given what they'd found. Now we left the room, there again we probably had 7 or 8 minutes. My husband asked a question there, er, what did he ask? He asked ... I can't remember what he asked but he did ask for some clarification to do with it being in the lymph nodes because again that's all we could think about because we were upset about that. I then asked if I could go, if I could see a breast care nurse. It wasn't offered to me on that second occasion, but I said could I talk to somebody about this, and they said yes straight away and they made arrangements for the person who'd been in the room with me to go and take me somewhere else, so somebody relieved her. And then I went to spoke to her for another 15 or 20 minutes again, and if you like had the chance to sort of investigate and explore what it meant to be in one lymph node. Now she put my mind at rest there again by saying, 'Well, yes, it is in a lymph node but ...' she talked about the way the lymph nodes are and the way that they sort of stack up across before they spread out and things, and she sort of stressed to me that I shouldn't get too upset, there wasn't a huge difference between it not being in any lymph node and being in one lymph node. I mean and I assume she's right in saying that, you know, I have to believe that's the case. I mean obviously it's still not as good as not being anywhere. Now again, subsequent to leaving her, so again I felt better, I wouldn't have felt as good if I hadn't have had that 15 to 20 minutes with her because I would just have been obsessing with the fact it was in a lymph node. Now again I came back and I spoke to Janina again and she went away and talked to people that she works with and they just talked to her again about this, you know, the mapping, the way they, like, intersections and everything, that it obviously is much more serious if they are in four or five lymph nodes and it suggests it's spread, you know, everywhere, and that it may well be that it being in one, and also given the fact that it obviously wasn't clearly obvious on the mammogram because he'd made the statement that he didn't think, well they sort of gave to indicate that if it was definitely in the lymph nodes he would have able to see something from that initial mammogram. I don't know, is that the case as far as you know?

INT: YEAH, I THINK YOU'D BE RIGHT, YEAH.

Patient: You know if it was, you know, developed to a particular stage ...

INT: YEAH, MM.

Patient: And that you wouldn't, you know you'd be a bit daft, wouldn't you, saying 'We don't think it's spread,' if you'd really got in your mind any idea that it had.

INT: YEAH, OF COURSE.

Patient: So putting together the fact he'd made that statement and the fact of it being in one, I suppose I sort of deduced to myself that it may well be that it had just got there in a sense that, you know, it was just starting to stack up. Now again, with that being the case, the fact that I'd fast-tracked myself made me feel a lot better the fact that I had. It was chance obviously but you think, well, thank heavens that I hadn't ...

INT: YEAH, THAT YOU DID BECAUSE [???

Patient: ... been hanging around for another couple of weeks because ...

INT: IT MIGHT HAVE GONE TO MORE.

Patient: It might have got into more and then it wouldn't have been the same situation. And even though it was, again, you know, the breast care nurses said, and that was interesting, that you wouldn't expect to see it in a lymph node in

that grade cancer and the slow-growing cancer, you know, etc, but she didn't make, she just threw away the comment that in fact that is something that they are seeing more often, so, you know, I would just be interested to know why that is, that's obviously, you know, they said they had two or three occasions when ... she actually used the phrase, you know, she says, 'It's quite startling, you're not expecting that at all,' and that within their experience it was happening, you know, more often than they'd seen it. So I don't know what that says. I mean in my naiveté, because [??] physiology, I said, you know, 'If you're small-breasted does it mean it's less distance to travel?' you know, which is a ridiculous statement, and Becky said, 'Don't be so stupid [chuckles] but again you've no ...

INT: WELL YES, IT'S [??]

[BOTH TALKING TOGETHER] [??]

INT: IT'S NOT STUPID TO YOU, IS IT?

Patient: It's nearer the [??] so yeah, you know, but I did go away and I suppose I'm at that stage now where, I mean, I'm still at that stage where I know that, if it weren't in the lymph nodes at all the prognosis is better than if it's in them, but I'm hanging on to the thought that it's as good as, you know, not having it in any lymph nodes. I mean you've got to sort of keep positive, haven't you? And it's no good worrying about it, and you've got to say to yourself, it's not the same as having it in three or four, and therefore no point worrying about it in the same way, and that's what I've done really. So that was the situation in terms of talking to the second person. He made it just, he just stated what the situation was ...

INT: WAS IT A HOUSE OFFICER OR AN Spr?

Patient: No, he was another, he's a consultant, he was, I can't remember his name. I think he was, or maybe he ...

INT: WAS HE WELSH?

Patient: No. He'd got, he'd got, I assumed actually, it was something that was an Asian name or something, but, oh, Sibbering his name was.

INT: OH, MARK SIBBERING.

Patient: Yeah.

INT: OH HE'S LOVELY HIM.

Patient: Yeah, he was lovely. I just didn't know the name. Yeah, Mr Sibbering, so he was a consultant, I think there's three in the team. Yah, he was lovely. I'd seen him on the ward actually coming to other patients, and he was, quite sort of jolly and extrovert sort of person comp-, Mr Holliday was much more sort of reserved, as individuals, just different. But he was lovely, yeah, and I say he was, he was matter of fact but very, he was trying to encourage me not to get too bogged down with this lymph node thing that, you know, because I'd just gone, 'I'm not expecting to hear that,' and he was very positive about the sort of cancer and the size of the tumour and sort of said that's what I should be thinking about really. And said he'd made an appointment for oncologist to do the chemotherapy and I would be passed on to them at that point. I also raised with him my concerns about the fact that, erm, I'd got colon cancer within the family and just, I said the one thing I was a bit concerned is that, having transferred from another Health Authority, I had raised with my GP that I had been on the programme there for getting a colonoscopy on one occasion and a

barium on another, I wanted to make sure I was part of that programme, and also I was concerned about this link that people had been mentioning to me. I mean I've no idea what sort of link it was, or, but that I'd got in my mind now that, you know, probably wrong, and Becky says it's stupid to think that, you think, right, one cancer's got you so another's going to be lurking round the corner. That's just how you just feel as though it's out to get you which I'm sure is ridiculous but I wanted to make sure I was on that. And he said he would get me an appointment with a Familial Cancer Unit and in fact I've received an appointment for that, so I will talk to them about my worries about the ovarian thing and the cancer, the colon cancer and, you know ... but as I understood he was then passing me on to the oncologist who would then deal with the chemotherapy aspect of it.

INT: AND IS THE ONCOLOGIST THE PERSON WHO MENTIONED THE CLINICAL TRIAL?

Patient: Yes, that's where I've, yeah. So that was, and that's again, I spoke to the, so the breast care nurse, and then we went away and then waited in effect for the oncology appointments to come through next.

INT: SO WHEN YOU WERE ASKING...

[Interruption in recording]

INT: YEAH, SO DID YOU FEEL THAT THE DOCTOR YOU SPOKE TO, MR HOLLIDAY, DID YOU FEEL THAT HE UNDERSTOOD [???] YOUR CONCERNS?

Patient: Yeah, it was Mr Sibbering the second time, erm, yeah I mean in both situations, yes, they were extremely sympathetic but you are aware, and I was aware on the second occasion, Mr Sibbering, that you were part of the clinic and he has another patient to see in a few minutes. But the fact that you've then got the breast cancer nurse was, to me, the difference, and I was able to just go away with them there and then and talk to them. I'm sure I wouldn't have been able to that with him because he wouldn't have had time.

INT: AND DID YOU FEEL THAT THEY LISTENED TO YOU AND UNDERSTOOD YOUR [???] CONCERNS [???]

Patient: Oh yeah, I mean, I think they were superb: on every contact I've had with them I think the breast care nurses have been superb. They've been ready just to answer or to sort something for you immediately. I mean I had, that was the, I had actually, I had this seroma drained on that occasion of that first time on that ten-day follow-up which was fantastic, when they took our 120ml and it was just wonderful, and then, in fact I made an appointment to have it drained a second time when I saw the [???] so things like that as well, because, you know, they are unpleasant and you're thinking about those because they impede in how you're progressing. So all those things, you know, I had access to having that done straight away. That was important. But, yeah, I felt that when I left, having seen a consultant for the second time, that the questions I wanted to ask about this lymph node thing and what it means, and again, you know, she reiterated, this was a different nurse in fact on the second occasions, you know, 'Don't go away thinking you're going to die, you're not going to die.' I mean I don't know if she thought how long I was going to live, you know, I mean I know, but I do know, you know, that the ten year thing is what they're looking for and we talked about the fact that, you know, basically before I'd actually discovered the cancer, like, I'd gone in as an extremely healthy person and given the fact that the surgery is the major thing for breast cancer, you know, you're removing and away, if they've got rid of it all, you're undergoing chemotherapy and radiotherapy as a healthier person than most people are, aren't you? Which is, you know, so you have to think that to yourself, again, you know, yes, OK, well we've all got a certain amount of cancerous cells

anyway all the time but you're not going into chemotherapy hopefully riddled with cancer in the way that other people sitting doing chemotherapy with you are. So I've tried to focus on those positive things all the time really.

INT: MM, YEAH. AND THE INFORMATION YOU GOT IN THAT PACK THAT YOU SHOWED ME, HOW HELPFUL DO YOU THINK THAT WAS, WAS IT USEFUL?

Patient: I think the information's been really good. I mean, yeah, this booklet's really good and it gave you your exercise regime, what to do. It told you like ...

INT: AND YOU FILLED YOUR LITTLE EXERCISE TICK BOXES IN DID YOU?

Patient: Of course, I'm a teacher. [???

INT: THAT'S WHY I SAID IT ACTUALLY. [???

Patient: More than being a teacher I'm a control freak actually, I am a control freak. That's why I do three jobs at work. But I mean, obviously, well, before I went in I read and highlighted things that I needed - sad, isn't it?

INT: NO, THAT'S THE SORT OF THING I WOULD DO, I READ PAPERS AND I SORT OF HIGHLIGHT [???

Patient: I like to be in control. But I mean it did tell, like, when I got this swelling, it told me what a seroma was and it told me, and for me I need to be in control of things, you know.

INT: MM, ABSOLUTELY, YEAH.

Patient: I know some people don't, some people like to just stick their head in the sand, but I don't. I mean if I weren't in control of things I wouldn't have been at the doctor's the next morning, I wouldn't have had it happened in two weeks, you know, I mean, I just, but that is me as a person. And again with cording [?], I've developed cording, and it's not pleasant but, I mean, at least, you know, this is called cording and, again, Mr Holliday had said to me, with your skin, chances are you'll get it, so at least you know what you're expecting, whereas I think, you know, you get down and miserable about things if [???] and, I mean, like, again, you know, I mean it's not really progressing as it should have done and I've managed to access extra physiotherapy appointments. I've got some at hospital and also got through my GP at a clinic down the road. Because, again, you know, I've just got to take control of things and get some concerted effort so that I can get back to full use, you know, you can't ... and all the cha-, again changes in sensation he'd told me, and I did, I got a loss of feeling as though I'd got permanent sunburn on my skin, but, again, because knew it was all written [???] for three months it'll be like that, you know, and avoiding lymphoedema and ... I've gone out and bought my gardening gloves ... but, you know, for me that's important, you know. I've got, you've got to do everything you can to take control of the situation. I know you can never fully control everything and something like this tells that you can't when it comes down to it ...

INT: WHEN YOU SAY THAT YOU GOT THE INFORMATION OBVIOUSLY FROM A FRIEND, WAS THERE ANYWHERE ELSE? YOU DIDN'T LOOK ON THE INTERNET, DID YOU?

Patient: No, I mean I did have friends actually, I mean, they've actually handed me some stuff, that was later to do with chemotherapy; somebody gave me information to do with wig suppliers; and a friend, I mean a very dear and close friend, really like a sister, she went, I told her I'd got a grade one, I've got this, that and the other, she was going on and finding out what she could about

things. Like when it was in one lymph gland, she was straight on the internet and she was having a look what it means, and she has confirmed with what it says on there, what other professionals have told me, if you like. So that, and again, you know, just saying the success rates are so tremendous, and I do think that's important, I mean in one sense it can be, there are times over the last weeks where every damn advert, there's this huge thing at the moment about, you know, the subsidising, I mean, as giving money each month to Cancer Research, isn't it, and things? And Classic radio I've just stopped listening to because every five minutes there has, but you can only take so much information I think. But on the other hand I do think it is important that there is all this positive message that's going out, because I wasn't aware before I had breast cancer that there is such high success rates now with it. And, again, thinking logically, given that you know there must be go, who have breast cancer diagnosed, and who are a lot further down the road than me because they haven't found it so early, and they're all part of those statistics, you know, it is encouraging then to think you do have every chance. There were a couple of people, well actually, no, that's another thing I should mention, that there are individuals as well who've had breast cancer and been part of the programme who sort of spring up out of the woodwork - I'm a member or I go regularly to the [??] Methodist Church, having only moved recently and there were not many people I knew, but there are two women from Church who I'd never met before, one of whom's just gone through chemotherapy actually for ovarian cancer and who just gave me tremendous sort of individual support in terms of just phone up and saying, you know, 'You're gonna be fine, I'm sure you'll be fine,' and somebody else had had a lumpectomy who talked to me. And the women do support each other like this. And somebody else who's the wife of a colleague and she'd been diagnosed ten years younger than I am but she had hers seven years ago - in fact she went on a trial for [??] which is now standard of course, I mean I'm having, that is part of my chemotherapy as standard now. And she was very encouraging, and you think, well that's seven years ago, you know, and she's ten years younger than me. In fact it was in all her lymph nodes. A canteen lady where I work, she'd had, she was given the all-clear after ten years, and all those things are very encouraging for you when you're at the beginning of the process. And both of them very, you know, positive people. So, erm, that anecdotal information, I suppose having chosen the route, has been encouraging and uplifting. Erm, but I have stopped, I mean I did, was reading something [??] cancer and I actually made the decision on Sunday night, I had a down on Sunday, just went up to bed and was just reading things to do, it was to do with ovarian cancer. And then, you know, I actually, I'm actually worried about that one now, although, you know, Becky says, 'You must stop worrying about 'til you need to know there's a close link' or whatever, but, erm, and I've just made the decision that I'm going to stop reading about it because then you just starting thinking negatively and you start worrying about, 'Right, will that be the thing that I get next?' and obviously that's a silent one. But I've talked to the familial cancer people about that, you know, I suppose a I've got chemotherapy coursing round my body it's worth worrying about it ...

INT: SO YOU'VE STARTED CHEMO, HAVE YOU?

Patient: I've started chemo, yeah.

INT: AND HOW IS THAT GOING?

Patient: It was absolutely diabolical the first, I mean the first week, well, no, the first week was bad. I mean people had talked to me and had said, erm, it really is very individual as to how you'll react, so it's actually, it's two weeks tomorrow since I had it. But I went and I really did react, when I say vilely to it straight away, but I do as an individual tend to respond to drugs. As I say, the only time when I've been off work, when I was off with stress, and they tried to put me on antidepressants and I just felt as though you may as

well just kill me first, it was so bad I never went on them, and I probably took me longer to get back to work but I do react to things. And when I came back it was just almost as if I was sort of shock, my teeth were chattering and my pulse was racing and I felt terribly, terribly sick. Now other people who've had it said, 'Oh you'll be all right for the first couple of days, then it really hits you,' but I was really sick, and I was sick, I couldn't keep water down or anything and this terribly headache, it was just, it was, the first 24 hours were dreadful, and then it was slightly better but I still felt sick really Sunday and Monday, and then Monday and Tuesday, which is when people said it would hit, I just felt as though I could not do anything at all [???

INT: IT FLOORS YOU, DOESN'T IT, REALLY?

Patient: It was just like, I'm norm-, I mean I am notorious at work with children running down corridors to keep up with me and, you know, I have boundless energy, and I have never experienced anything like it. Just two 20-minute bursts of energy a day and you're lucky really. And I found that that was it, it just floored me really for a whole week.

INT: AND IS THIS PART OF THE TRIAL OR ... ?

Patient: Well, no, I mean the trial, you know, hasn't affected me really because I'm not receiving ...

INT: NO, YOU SAID YOU WERE [???

Patient: ... as, sorry, and, you know, the control group, I'm just receiving calcium tablets for that, erm, those are just, I mean, the thing about the chemo is that it makes you constipated and this dreadful taste, and so everything's just miserable really. Obviously I realise now, the second week was, I've just coming to the end of the second week, and I'm fine now, I'm probably a bit better than most people, you know, but, er, I'm better now, but still really, like yesterday and the day before I was fighting off a sore throat and, again, I've been told that your infection is, your infection risk is higher during the second week, so I was worried that I might sort of go down with something. But I think I've got a strong immune system [???]. I mean I was worried I was gonna lose my hair and things, so again some people lose their hair straight away, which mine's still growing and getting extremely grey because I can't do anything with it at the moment. So I'm looking forward to that happening next, but that hasn't happened yet.

INT: WHAT DO YOU THINK WAS THE MOST IMPORTANT THING YOU WERE TOLD OR HEARD THAT HELPED YOU MAKE YOUR DECISION ON WHAT TREATMENT TO HAVE?

Patient: The advice from Janina, without any doubt, that's what gave me most comfort and just made me think, yeah, you know, I'll do that. I mean, are we on question 12, [???

INT: THAT, HERE, QUESTION 12. LOOKING BACK NOW, WHEN YOU WERE FIRST DIAGNOSED, WHAT DID YOU FEEL ABOUT CARE YOU RECEIVED?

Patient: I was thinking about this and thinking about what the crux of your research is and trying to think of a parallel from my own life in terms of what I do, and I know in one sense you can't compare what the surgeons do in any way, but I was trying to think, 'Is there any situation in which people look to me to give them a piece of advice that is gonna matter in some way?' And the only think I could think of, and I know it's very trivial in one sense, is that there's a point at which with GCSE candidates you make a decision about whether to put them in for a Higher English GCSE or a Foundation level. And basically, if you put them in for a Higher level they have the opportunity to get a grade

between A or D: if you put them in for Foundation level you have the opportunity to get between a C and a G, so you can't get any higher than C. Now you get a group of candidates who are what you call C/D border: what do you do? What do you advise them? Do you put them in for Higher and sometimes in terms of their own self-esteem they feel better because they're putting in for Higher; do you run the risk of them not getting a C grade which, that's the magic one that everybody wants because, you know, it's not a 'real' GCSE in terms of being able to go onto further things if you don't get a C. Do you put them in for the Foundation so they ... do you put them in for the Higher, knowing that they've may not get the C because quite honestly the competition that they're against on the Higher level they don't look so good. If you're at the bottom end of things your C doesn't look as good compared to other C's, so you may not get the C you may get a D or you may do badly on the day and you may even not get anything at all. Or do you put them in for a Foundation level and know that they can only get the C? And maybe it's a difficult decision because in fact maybe on the course work or in terms of the speaking and listening element that they do, they may have got, you know, a couple of Bs on that, but if you don't think they're gonna do very well in the exam and, you know ... And I know it may sound trivial compared to something like that, but for them at that time, they want you to tell them what should they do. Now I would in that decision be knowing, looking at the range of my experience for 20 years and knowing what's happened to candidates in the past, and knowing the sort of kids who've ended up getting a D where really you want them to get into C. Now really you want them to get that C whatever, whatever ... So I suppose in a parallel you might say you want them to have the best chance of getting better if you've got [???] that, you know, what's their best chance for their best prognosis. But that's the equivalent if you want them to get a C. And I would say to the candidate, 'This is what I think you should do. I think we should put you in for this because, looking at all the things, everything considered, I think that's what you should do.' Now I think in a way I wanted the consultant to say that to me. Now I'm not stupid and I know that a consultant would probably be mad to do that in the present litigation culture, and maybe in the future, maybe as a teacher I will be if somebody sues me because I've made a decision that's prevented them getting a C. So, you know, I've thought about this before you were coming, and I wanted to offer that because I think, I do think it probably sums the way I feel about what I would have liked the consultant to say, and tried to find a parallel from my own experience and my own profession, but I realise it's only an analogy and that it doesn't fit perfectly. And again I, that's the other thing, to develop it, I probably have a greater knowledge you see about the pupil and of their background and what's right for them: a consultant has never seen me before and doesn't have a detailed understanding of my medical history or my psychological state I suppose, so I suppose I couldn't reasonably expect him to make that decision. But maybe somebody needs to talk to people in a way to find out more about that so that you might be able to give them perhaps a little bit more guidance. There must be people who are far less eloquent than I am, far less intelligent or thoughtful than I am, who have to make that decision ...

INT: OH ABSOLUTELY IT AFFECTS EVERYBODY

Patient: ... and I don't know how they [???]

INT: THERE'S A RANGE OF DECISION MAKERS ESSENTIALLY: YOU'VE GOT VERY ACTIVE PEOPLE, AND YOU SOUND VERY ACTIVE TO ME; AND YOU'LL GET PEOPLE WHO'RE WHAT WE CALL COLLABORATIVES WHO WILL HAVE LIKE A TWO-WAY SET OF, YOU KNOW, THEY'LL LISTEN AND THEY'RE PREPARED TO CHANGE THEIR MIND AND WEIGH UP OPTIONS, AND THEN YOU GET PEOPLE WHO [???]

Patient: You just want to be told.

INT: THEY JUST KIND OF LIKE, YOU KNOW, AND YOU'LL OFTEN HEAR PEOPLE SAY IT'S THE ELDERLY PEOPLE WHO'VE VERY PASSIVE AT THE MOMENT ...

Patient: I would think your collaborative group would probably benefit from what I'm saying just the same. I'd still have to go away and make that decision even if he told me, but again in that middle it's just, that is, you want them from their breadth of experience to be able to, because talking to individuals about what they've had personally is still what they had, which in a sense is what I ... but you want somebody with that breadth to say, you know, 'Well from what you're saying to me, from what you seem to be like as a person to me, from what I know about your medical history, this is what I would advise,' but can you do that in the present culture? I don't know if you can.

INT: I MEAN I DO KNOW THAT THEY'VE OBVIOUSLY GOT THE UNIT GUIDELINES WHICH THEY FOLLOW WHICH WILL RECOMMEND THAT SOMEONE COMES IN WITH A 5CM TUMOUR AND AN A CUP BREAST, YOU'RE GONNA THEM A MASTECTOMY ...

Patient: Oh yes, your options are ... yeah, yeah.

INT: BUT THE PATIENT STILL HAS A CHOICE, THEY CAN STILL, THEY CAN STILL TURN ROUND AND SAY, 'NO I WANT A WIDE LOCAL EXCISION ...'

Patient: [???

INT: AND THE SURGEON'S THEN GOT TO SAY, 'WELL, LOOK, YOU KNOW, COSMETICALLY IT'S GONNA LUCK RUBBISH BASICALLY AND, YOU KNOW, IT'S ...

Patient: And the risks are greater.

INT: ... THE RISKS ...

Patient: But I think that's it, because I fell into this category of 1.5, on your list there you have a choice of between the two. Because it's the same, when I went to chemotherapy, you see, erm, I know it's not directly relevant, but then you're given a choice there. I mean the chemotherapy, it was a senior registrar I think I spoke to there, excellent, very detailed understanding of everything that would be involved and again a breast care nurse there who, after, they monitor very much what you're taking in and she says, and you can tell with someone like myself that you're understanding what's been said and I asked some questions, but you were given there, it was, I mean I didn't understand it, I asked him to clarify what he meant, but basically I had the choice of two regimes and it's all worked out statistically and you, one regime in the end gave you a 3 per cent better prognosis over another, you know. And then you sort of, I asked him then to clarify exactly what he meant, you know, [???] but when it came down to it there at least I suppose I was given something, that that's a 3 per cent better rate and he said, really, in your situation, it's very little between it. And then he's saying, 'You know you're going to lose your hair with this one and you won't in that one, but basically you feel a bit worse on that one.' But I then made the decision: I thought, well if I'm putting myself through all this for six months, OK it's 3 per cent but I may as well take my best 3 per cent option even if it means losing my hair or whatever. Well that's me, again, for me losing my hair is not the issue really, I'll just go for my best 3 per cent option. So I was given loads of information there again, but in one sense, in one sense I was given slightly more information because I was given a statistic that, yes, that is slightly better than this one, whereas with the lumpectomy/mastectomy ... and it may be that it isn't, maybe that's why they couldn't give it me, but there was anything else then I'd got to hang my decision on because there wasn't any other parameters, nobody went into the psychology of it with me or ... and I asked to look at the photographs - do you see what I mean? So ...

INT: YEAH. IF THERE WAS ONE THING YOU COULD, IF YOU HAD THE POWER AND MONEY TO CHANGE ONE THING ABOUT THE SYSTEM THAT YOU WENT THROUGH AT DERBY, WHAT WOULD IT BE?

Patient: Gosh! Well I suppose, I mean, given the sense that I didn't fit the norm, the speed factor of actually getting something done from the moment when you find it must be the most important priority because, I mean, anybody must be in such a stressful situation, and I'm quite sure I would have felt worse if I hadn't have had it dealt with as quickly. I [??] the speed. I mean and I don't know, well do you know how common is that thing of actually having two mammograms, an ultrasound and seeing the consultant all within an hour?

INT: ERM, WELL I DO, THEY DO THE ONE-STOP CLINICS AND THEY ARE VERY FAST, BUT SOMETIMES THEY STILL NEED TO BRING YOU BACK WHEN YOU'VE GOT YOUR BIOPSY RESULTS, SO SOMETIMES THEY CAN ACTUALLY TELL YOU ON THE SAME DAY.

Patient: Well, I mean, I ... I mean did go back then two days later, yeah, but I mean, I don't, I mean, certainly in the past, I'm not sure, you had mammograms and ultrasound but you didn't necessarily see the consultant on the same day as far as I know.

INT: MM, YEAH.

Patient: But from my point of view the fact that you'd seen somebody, he'd look at it and made some initial diagnosis and for me, you know, really made me think, 'Yes, it is something.' That, I would say, would have to be a priority, the speed at whatever stage in terms of from when you first see it to being told, yes, definitely, erm, because again, my mammogram thing would have been longer, you see, wouldn't it? It would have been, er, that initial thing.

INT: THEY'RE USUALLY WITHIN ABOUT A WEEK.

Patient: Yes, so ...

INT: YOU'D HAVE HAD YOUR MAMMOGRAM, YOUR TESTS, AND YOU'D HAVE COME BACK THE FOLLOWING WEEK. IN YOUR CASE YOU'D HAVE, I MEAN, I DON'T KNOW IF YOU'D HAVE ACTUALLY SEEN MR HOLLIDAY BUT ...

Patient: Yeah, I mean, I suppose in a sense, I suppose bringing the mammogram forward and making that quicker would be more important even than the surgery because, OK, I would have had a week longer, but at least, you're a week longer waiting for what you know rather than a week where you're still just worrying and worrying and worrying without knowing anything, because you're still worrying and worrying then without ever having got to the point where you've been diagnosed and somebody tells you, 'You won't die with this,' you know, 'People do survive.' If you're just waiting for the test and everything, you're still going over all that, so I would say probably bringing up, being able to get that mammogram and get that initial diagnosis as quickly as possible, you know, bring it to, you know, within days of first finding it and then getting a mammogram and getting a diagnosis is where I'd put the money, I think, yeah.

*Q5. NOW THAT YOU HAVE BEEN THROUGH THIS EXPERIENCE, WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT THEIR DIAGNOSIS?

Patient: Erm, well certainly with breast cancer the fact that the prognosis for recovery is so good, because I mean I'm an intelligent person and reasonably aware, but I did not know that statistics for breast cancer are so good. And also just being aware, my own experience has been of bowel cancer in terms of,

you know, knowing it, erm, and clearly, you know, it's not the same as bowel cancer and the fact that you can cut out breast cancer makes it different to other cancer. And I just, probably just hadn't thought about that. So being aware that the prognosis is as good, and I think clearly that that is, that is being pushed more, being more aware, people are more aware of it, and the fact that people, there are more and more people who are living for 10 years or more after breast cancer, erm, because obviously you go back to the same chance as anybody else in the population, don't you, after 10 years, as far as I understand? For me that's most important. The points when I start to become negative or feel, you know, less positive about it is if I start thinking, 'Well, you know, will I actually live for 10 years or will?' and it's no good thinking like that really, you've just got to, you've got to grab for yourself, the statistics are good and, you know, what's the point in thinking that it's going to be worse for you or you should be one of the bad ones if there's no reason to think that really? So ...

INT: AND WHAT SORT OF, WHAT DO YOU THINK ARE THE MOST IMPORTANT BITS OF INFORMATION PEOPLE WITH BREAST CANCER NEED TO KNOW ABOUT THE ACTUAL OPERATIONS THAT THEY CAN HAVE?

Patient: Erm, well, I do, I've said before about the photos, but I do think it is important, and I would really advocate if you could do that having access to what it looks like at the very beginning when you're making the decision ...

INT: AH YES, THE PHOTOGRAPHS AND THINGS. [???

Patient: ... would be really important, it would be really, because you have no idea, and I've actually, and I've been showing my scar to people because I'm that sort of person, but, because, well not just to anybody, but, you know, but to my circle of friends and colleagues who say, I say, 'Do you want to look at it?' because I think women would actually. If you have no idea what one looks like, and actually when people look at it they say, 'Ooh, you know, it wasn't like I thought it was going to be.' I mean I've got a particularly [???], flat, good scar, but you know, why not look at it? Why not make it something? And maybe there are loads of men actually who would like to know what it looks like because you just have no idea and it should be something that, if you, I'm not saying you thrust it everywhere, I'm not saying everybody would cope with it, but there must be people who at least that situation where you say, you know, we've actually got some photos, would you like to have a look at what's involved with the two?' Because how do you make a decision about that if you've never even seen what it looks like?

INT: YEAH, MM.

Patient: So, yeah, I do think that would be really important and I mean presumably that wouldn't cost a lot, would it for heaven's sake to reproduce some information like that?

INT: I SHOULDN'T THINK SO, NO ...

Patient: You'd only need one in all those centres, wouldn't you? You wouldn't need to take it away, as it were.

INT: NO, OF COURSE, I MEAN, I SUPPOSE, ERM, BECAUSE I DON'T KNOW, DID YOU GO DOWN TO THE PROSTHESIS ROOM OR SOMETHING OR ...?

Patient: I haven't been there yet, I'm going ...

INT: ER, I THINK THERE'S SOME PEOPLE GO TO THE FITTING ROOM AND STUFF LIKE THAT AND WHAT-HAVE-YOU.

Patient: Beforehand is that?

INT: YEAH, I'M NOT SURE IF THEY GO BEFOREHAND, BUT I'M CERTAIN IN THE BREAST CARE ROOMS, YEAH, BECAUSE YOU'D BE TAKEN INTO THE SECOND ROOM, WOULDN'T YOU, THAT'S RIGHT.

Patient: Yeah, no, well that, you see, in that [???] as far as I know that comes later, erm, you go to be fitted.

INT: I INTERVIEWED ONE OF THE NURSES IN THE PROSTHESIS ROOM.

Patient: Sorry.

INT: I INTERVIEWED ONE OF THE NURSES, NOT IN THIS UNIT, BUT ANOTHER UNIT, IN THE PROSTHESIS ROOM WHICH WAS AN INTERESTING EXPERIENCE. [CHUCKLES]

Patient: Yes, [???] Yeah, I've yet to see that. Yes, because I mean obviously that's a part of what's gonna lie ahead of you in terms of mastectomy and I had some, again people who'd had it sent me some catalogues and things, erm, but again, you know, that's ... but, yeah, nobody showed me and nobody gave me any idea of the whole world of prostheses that would obviously be part of that decision, and perhaps that's more than you could deal with. I don't know, but I mean people might need to know that. I suppose in one sense though you need, you've obviously got to be doing what's best for you medically first of all, but no, it might even be something that people need to think about. But I suspect as well that maybe if people saw what prostheses looked like now and, you know, perhaps people might not be so put off by it. No, I really do think, the more we're talking about that and thinking about it, that that would be really something that ought to be trialled somewhere, the idea of having something photographic that's, that's sensitively and tastefully presented so it doesn't look like a medical textbook, you know, but, I mean, again, show you how peculiar I am perhaps as an individual, but how, again, it's taking control of yourself, isn't it, and it's being proactive and it's me, but I felt, before I actually had it done, and other people would say, 'Well what a macabre thing to do,' but the weekend before I had my mastectomy, so it's like the day before I had it done, I had a photograph taken of me, erm, because, it probably sounds strange but I just felt I wanted some record of what I looked like ...

INT: ABSOLUTELY.

Patient: ... and it's an awfully long time I had a topless photograph taken of myself, it was on a beach years ago, but I, and other people would say, 'Oh I think that's sick, or that's awful,' but for me I just felt that was what I looked like and I wanted some record of it and I wasn't gonna look like that any more but I was gonna look like something different, you know, and you've to deal with that. And that was it, and I mean I'm very fortunate and, you know, my husband wanted, he didn't want to look at it at first because he actually couldn't cope with drains coming out because he's awful with any blood and guts stuff, and actually looking at the drains used to make him feel sick but he, you know, he did, he looked at it from the first time, the day I came home, he said, you know, 'I want to look at it.' And, erm, eventually, you know, he, well the drains were out, you know, it was something that he wanted to make sure he could touch it and things because it was important to him. Erm, I mean, he's, I think he would like for me probably to have reconstruction, which he's said, which I was surprised actually, I didn't, but I'm going off that having talked to some people that have said that, you know, they wished they'd never had it done. Obviously that's something that I shall consider later, but ...

*Q6. OK, LAST QUESTION, IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY, ANYTHING YOU THINK WE'VE MISSED OR WHATEVER?

Patient: It's been comprehensive I think, hasn't it?

INT: I THINK IT HAS BEEN, TO BE HONEST, I THINK WE'VE TRIED TO BE AS COMPREHENSIVE AS POSSIBLE RAISING [???] AND THINGS. IF THERE ISN'T THEN I'LL TURN OFF ...

[End of interview]

Can't place

*Q1. PLEASE TELL ME ABOUT THE TIME FROM WHEN YOU FIRST REALISED THERE WAS SOMETHING WRONG WITH YOUR BREAST TO THE TIME YOU WENT TO HEAR ABOUT YOUR RESULTS?

*Q3. AND WHAT HAPPENED WHILE YOU WERE TALKING ABOUT WHAT TREATMENT YOU COULD HAVE?
Here

*Q4. SO, PLEASE TELL ME WHAT OPERATION(S) YOU HAD FOR YOUR BREAST CANCER?
Here

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