

\*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

\*VENUE: High MR unit

\*DATE:

\*ID: Patient27

\*INTERVIEWER: DJW

INT: THANK YOU VERY MUCH FOR BEING INTERVIEWED. I WANT TO START WITH QUESTION ONE WHICH IS, CAN YOU TELL ME A LITTLE BIT ABOUT WHAT YOU KNEW OR UNDERSTOOD ABOUT BREAST CANCER BEFORE YOU REALISED THERE WAS SOMETHING WRONG WITH YOUR BREAST?

Patient: I didn't know anything at all. Erm, I mean, I've read it in magazines and I've seen leaflets in doctor's surgeries about self-examination and making yourself totally aware, when you go in the bath you should do a self-examination regularly. And I thought, well no, it won't happen to me, this kind of thing doesn't happen to me, so I just ignored it. I didn't know anything about breast cancer at all, I didn't even think about learning about breast cancer, because I just thought it would never down my avenue.

INT: RIGHT.

Patient: So it only came to the forefront of my mind there was something wrong when, after falling, well we have this side staircase here, I was running down the staircase and I jumped off the last two and landed with my left breast hooked around the top of the ... and I thought, 'My God, that really did hurt,' so months went by and I just thought it was trauma, I just thought I'd traumatised myself and I could feel this lump. So it then, then I realised there was something not quite right: I kept thinking self-examination, every day, that feel, feel, feel, something was wrong with the palm of my hand, I knew there was something not right. So I said to my husband, 'Just have a feel of this.' He said, 'I can't feel anything,' I said, 'OK, fine,' but in my brain I knew there was something radically wrong because I thought after four months the trauma should have gone by now.

INT: YEAH OF COURSE.

Patient: So then I went to my GP, not to go with the breast because I'm thinking, 'It'll go away,' but my neighbour across, she'd had a total mastectomy and I said, 'Oh,' you know, 'I've got this nagging feeling in my left breast.' 'Please, Yvonne, just do something about it.' 'Ah, it's all ...' you know. But I was going to Barbados for a holiday so when I went to see my GP I said, 'Oh, blah-blah-blah,' you know, 'When I go away if I'm bitten by mosquitoes I react so violently de-de-de ...' and I said, 'And there's nothing worse than somebody [???] to see a GP with a shipping list of ailments,' I said, 'But I'm not very happy.' And he, you know, had a quick feel, and I could see by the expression on this face that, even though he didn't give a lot away, I could see by the tone of his face...

INT: YEAH, THE EXPRESSION.

Patient: ... that, erm, he realised there was something ... yeah, not quite right. So that was the start of it.

INT: SO HAVE YOU EVER HAD ANY HISTORY OF BREAST CANCER IN YOUR FAMILY AT ALL?

Patient: No.

INT: YOU MENTIONED THE FACT THAT YOUR FRIEND HAD BREAST CANCER...

Patient: Just, yeah, it was just purely because my neighbour phoned me up and said, 'Oh,' you know, 'I've got some really sad news.' I said, 'I can't believe it you, I can't believe that you've got, you know, this disease of our time, so to speak.' So, and she kept saying, you know, 'You must, you must go,' but you see I kept pushing it, so about four months I had this, or I was aware there was something wrong, whether there was something there before or not I don't know. It only brought it to the forefront in my mind when I hurt myself and I thought, well ... if I hadn't have hurt myself I wouldn't have done a breast examination, I wouldn't have done it. I just, I've never enjoyed, it's a most strange feeling having to do self-examination (a) because I don't really know what I'm looking for, because like when you've had children you get, the breast changes, and you get like little lumpy thick bits where your milk ducts and where you've fed babies and I've had three children. And, erm, I didn't think, you know, everything would be ... I just thought everything would be fine. And it was just this one, the left breast, that I realised there was something wrong.

INT: AH, RIGHT, OF COURSE, YEAH. AND YOURSELF, YOUR OWN SORT OF HISTORY, YOUR MEDICAL HISTORY, HAVE YOU BEEN FIT AND WELL?

Patient: Absolutely, absolutely fit and well. Abs-, I had, well I had a hysterectomy, erm, oh God, how many years ago now? Erm, 15 years ago. And ... they left the ovaries and I was struggling with early menopause so the doctor put me on HRT, tried various things, patches, and we settled on, erm, it was Premarin [?] the 0.625 conjugated one which is supposed to be the most natural oestrogen one, so, and I settled down on that, so all my sleep pattern resumed and for years I've never been, never been ill, I'm never ill. I, you know, I work, I work here and I also work for a GP as well, funnily enough, but not my GP, I work for another GP. And I've always been a very well person.

INT: RIGHT, OK. ERM, AND YOU SAID, YOU KNOW, OBVIOUSLY WHEN YOU FELT THERE WAS SOMETHING THERE AND THERE WAS SOMETHING [???] DID YOU THINK AT THAT POINT IT WAS GOING TO BE A CANCER OR SOMETHING ELSE?

Patient: Well, I was hoping, I was hoping that the lump that I could feel was, erm, a trauma lump from hurting myself. But I knew, when I went, what I tried to do, little clever me, I tried to do a self-referral because ...

INT: TO THE BREAST UNIT?

Patient: Yeah, to the breast unit, for, erm, because it was, my next mamm test was due November, this November 2004, and I thought, 'I'll try and do a self-referral,' and then she said, 'No, you have to go through your GP,' which would have, and I'm glad really that I didn't leave it until November, I'm glad I decided ...

INT: ABSOLUTELY, YEAH.

Patient: ... to go when I went, so that's how I decided, well, that's, you know, how it came about that it was brought forward rather than leave it 'til November.

INT: RIGHT, OK. SO YOUR MAMMOGRAM WAS BROUGHT FORWARD?

Patient: The mammogram was brought forward because I had one three years ago, since being 50 I've had one every three years.

INT: THAT'S RIGHT, YEAH.

Patient: The only, the ... the worry, no not the worry, the thought I'd had, how long have I had this, have I had it two years and four months since the last mamm test? Or have I had it four months ...

INT: YEAH, YOU DON'T KNOW REALLY.

Patient: ...that's the unknown, that's the unknown. And, erm, I'm glad that really, I suppose I should have acted four months ago rather than leave it but in my brain I'm thinking, oh, it's just like if you knock yourself, you know, sometimes things take ...

INT: YEAH, YOU GET A LUMP, DON'T YOU?

Patient: ... a while to heal, don't they? Yeah.

INT: EXACTLY, YEAH. YEAH, I DON'T THINK YOU REALLY WANT TO KNOW, WOULD YOU, TO BE HONEST, I MEAN?

Patient: No.

INT: SO CAN YOU TELL ME A BIT MORE NOW FROM THE TIME YOU ACTUALLY REALISED THAT YOU HAD THIS LUMP AND YOU'D GONE A COUPLE OF MONTHS TO THE POINT, THE TIME UP TO WHEN YOU GOT YOUR RESULTS, YOUR DIAGNOSIS?

Patient: Right, well, erm, I went within two weeks, which I thought was very efficient, I had an appointment to go to the City, which is the local, as you know, [???] up here. I went for the normal mamm test and I knew there was something wrong because in the little corridor, which is quite a nice little area, 'Mrs Jones and Mrs Brown and Mrs Green - oh, you can go now. Mrs S-, oh, we'll just do this again.' So they did ...

INT: THIS WAS YOUR MAMMOGRAM?

Patient: This is the mamm test, yes, and then they took me in and did something again and 'Just sit here,' and then, 'Oh, Mrs S-, Mr Sibbering would like to see you.' I thought, 'He's the consultant and I know there's something wrong.' So all my [???] my defence system was kicking in and I mean I feel a bit like sick, I thought, 'God, here we go, this is gonna be really bad news.' Then he said, 'We're going to try, we're gonna do, put this on a sort of piece of machinery, but they just want to like bring up this particular area ...' so then 'But just will you take another seat aside,' so I was in and out of this room like ... then I finally got on the bed and he finally had this little computer thing that you have and he was scanning onto this particular area. He said, 'We have found a mass with a grey mass behind it. So what we're going to do today' he said, 'we're going to do a biopsy.' So he did two biopsies, just little plugs of skin. And then he said, 'You will know in a week's time what the result's going to be.' And ... I was not convinced it was going to be cancer, I was convinced it was just going to be something benign that is just through this little traumatise, not ... but no, the week, having to wait a week was like waiting a year. It was just, I was disappointed really, I mean I know you have to, with biopsies they have to go to be looked at and what-have-you, I don't know how it ...

INT: AND ANALYSED, YEAH.

Patient: Yeah, analysed, but because, because it was so speedy the realisation that I had, there was some radically wrong with me, it's a pity that they hadn't got the expertise to be able to say thee and then, 'You have cancer.'

INT: [??]

Patient: And the week, having to wait one whole week was ...

INT: I WAS JUST GOING TO SAY ...

Patient: ... was so, so traumatic.

INT: YEAH, WHAT WAS GOING THROUGH YOUR MIND AT THAT TIME BECAUSE, I MEAN ... I MEAN FIRST OF ALL YOU HAD THAT LITTLE SORT OF THING IN THE CLINIC WHERE YOU KEPT GOING BACK AND GETTING DIFFERENT TESTS AND STUFF ...

Patient: That's right.

INT: I MEAN THAT MUST HAVE BEEN A BIT ANXIOUS [???

Patient: What I realised, I knew there was something wrong because everybody else had gone and I was still there. I thought, 'This is bad news.' But Mr Sibbering and the other chap, the radiographer I think he was, very, very lovely, made me feel totally, totally at ease, even though he was delivering some bad message: he didn't say it badly but I knew, he said it with a smile on his face and I could see he was trying to, erm, make me feel easy, but I knew there was something.

INT: WHO IS THIS, MR SIBBERING OR THE RADIO- ?

Patient: Mr Sibbering.

INT: AND YOU SAID THE RADIOGRAPHER ...

Patient: And the radiographer, I can't remember the name of the radiographer, he was a senior radiographer, but, erm, Mr Sibbering was very nice. The other guy'd do the biopsy. But the week it was just, having to wait a whole week was ... really painful, mentally painful, you know, so ... And then ...

INT: DID YOU TALK ABOUT ANY OF THESE INITIAL THOUGHT TO ANYONE - YOUR HUSBAND, FAMILY?

Patient: Yeah, of course. Erm, well, when I went for the mamm test I said to Michael, 'Don't bother coming with me,' I said, 'because at the City it's just a nightmare to park because they're rebuilding for the new hospital.'

INT: IT'S [???

Patient: It's terrible. So I said, 'I'll go up on my own and I'll come back on the bus.' So I came back up on the bus, he said, 'You've been a long time,' I said, 'Well unfortunately ...' well, then again, I started to cry, I said, 'It's not very good news actually.' So he said, 'Well, you've not got the results yet, let's wait for the results,' but, phew, I said, 'Well, I feel so negative about this.' He said, 'Well you always are negative,' but I said, 'But I feel doubly negative this time because, you know, it just ...' And so, yeah, I talked to my daughters and I've got a daughter in America; I talked to my neighbour, you know, went over to her and we both had a chit-chat and then she showed me her battle wounds and I said, 'Oh well, you know, at the end of the day I'm gonna look like that.' So, and I said, 'Well, so be it,' you know. But it was, I was hoping that the results were gonna be positive, as say there's nothing wrong, you know. But the week dragged on. I couldn't wait, you know, my husband came with me down to the hospital and we had to park in Car Park 2 at the City and it was the longest walk of my life, I felt sick, I felt physically sick having to walk the length of the hospital. It wasn't the walk, it only took about 15 minutes which, all down these little wobbly corridors. And, erm, I was anxious,

I was sweating and everything was going against me and then ... tch ... we arrived at the destination.

INT: AND, ERM, IF YOU, DID YOU HAVE ANY THOUGHTS ABOUT WHAT YOU MIGHT DO ABOUT IT IF IT WAS GONNA BE BREAST CANCER? DID YOU HAVE ANY THOUGHTS AT ALL ABOUT WHAT TREATMENT YOU MIGHT BE GOING THROUGH OR ...?

Patient: Well I didn't, I didn't know, I knew that they treated cancer, breast cancer with Tamoxafen, only because having worked, we've got patients at our surgery with vari-, you know, one particular lady and then she's been on, there's another lady on it [??] and I knew that it would be treated, or it is treated with Tamoxafen, one of the drugs. Erm, but I've never, I didn't really think about the treatment because I was hoping that I wouldn't need treatment.

INT: YEAH, IT WAS JUST GONNA BE BENIGN, YEAH.

Patient: A-ha, yeah.

INT: SO WHEN YOU GOT TO THE CLINIC, ERM, WHAT HAPPENED THEN WHEN YOU WENT INTO THE ACTUAL ROOM FOR THE CONSULTATION?

Patient: Well, erm, I had, we had to sit on the same little chairs that, where the consultant's little consulting rooms were, and this nurse/secretary came out, said, 'Mrs S-, Mr Holliday would like to see you.'

INT: OH SO YOU DIDN'T SEE THE SAME CONSULTANT, THE ONE YOU SAW [??] MR HOLLIDAY.

Patient: No, I saw, yeah, yeah, Mr Holliday. I didn't know I was going to see Mr Holliday, erm, I was quite surprised, I thought it might have been Miss Wahedna or Mr Sibbering. So we went into the consulting room and Mr Holliday ... reminded me of a cardboard cut-out, totally ... unfeeling ... totally ... he irritated me because he showed no ... expression at all.

INT: MM, A VERY FACTUAL MAN, VERY FACTUAL.

Patient: Yes, and I think he's the wrong consultant to deliver bad news, quite honestly, because I was quite, I was really, really fed up. So I made a point of shaking his hand, said, you know, 'Pleased to meet you,' but his ... total blank cardboard expression, really, I found quite daunting. So he said to me, he just kind of moved slightly, looked at me with his cardboard face, erm, ... he said, 'Mrs S-, I have to give you the results of your biopsy,' no expression on his face, no smile, no turned down mouth, or nothing, just a ... a blank ... irritating face. He said, erm, 'You are a borderline case.' That was the expression he used, 'a borderline case.' I said, 'What do you mean, a borderline case?' He said, 'Well you have two choices, two choices,' he said, 'You have cancer, you can have total mastectomy or deep wide local excision with lymph node sampling.' Well I felt as though I'd just been hit on the head with baseball bat.

INT: YEAH, I CAN IMAGINE.

Patient: I said, 'What do you mean, I've got two choices?' and then I cried, Michael cried, he was with me. I said, 'Two choices?' I said, 'Can you tell me which is the best choice to have, because,' I said, 'I don't know.' I said, 'You're giving me ...' I said, 'Total mastectomy,' I said, 'That's so radical, that's gone,' I said, 'Can you tell me what you mean?' He said, 'Well, obviously your total mastectomy is all the breast comes off,' still with his steely chin and his steely face, 'And the other one is we just cut out the bad bit and we take out your lymph nodes, some of your lymph nodes, sample if it's invaded into

your system,' so I said, 'Well what will happen then if it has?' 'Oh we'll have to re-think, maybe the breast will have to come off.' So I said, 'Well can you,' I said, 'Can you advise me?' He said, 'No, your decision,' and I said, 'Have I got to decide now?' I couldn't think, I could not think, and I thought, 'God, how'm I, what am I gonna do?' So I just sat and gathered my thoughts very quickly, thought, 'Well if I have my breast off it's going to be total, just so radical, maybe it's not invaded all my system ...' and I had to try and get my head all round that these medical things that he was going on with. And I was so irritated with him, I was so, he showed me no comfort at all, none at all. And, erm, I said, 'Right, I will have deep wide local excision, lymph node sampling,' I said, 'Then if so be it, if it's invaded my system, if it's gone beyond the breast into my body, we'll just go for the breast off and we'll down that ...' I thought, well, he wouldn't advise me, he said, 'I can't advise you, it's your choice. Oh, I said, 'Well I'll tell you what then, whoever chops me up, when you get me on the operating theatre, table, if you can see that it's all over the place can you just cut it off, the lot off?' He said, 'No, I can't do that.'

INT: NO, [??] THEY USED TO BE ABLE TO DO THAT BUT NOT NOW.

Patient: So I said to him, 'Well I've booked ...' and he looked at his calendar, he looked briefly away from me and then looked at his calendar, he said, 'I can do it in 12 days' time.'

INT: IN TWELVE ?

Patient: 12 days' time.

INT: TWELVE DAYS TIME./

Patient: So I said to him, 'Right, I'm going to Barbados on 4th February, would it be detrimental if I cancelled this holiday, or sorry, if I go on this holiday?' He said, 'No,' he says, 'Go on holiday and come back.' So I said, 'Can you tell me what ...' I said to him, 'Can you tell me how long I've got to live?' He said do once we've taken the tumour away, if you want to know, I can tell you.' And my husband looked at me and, you know, but you see that's the kind of person I am, I thought, 'Well, you know, if this thing's invaded my system to the point where, you know, I don't know how long I've had it and it's one of these grade three cancers that, is it three that just goes wild around your body?'

INT: MM, YEAH, IT'S WHY THE HIGHER THEY GO, YES.

Patient: Yes, so I said, 'I think I'd like to know how long I've got to live 'cos I've got things to do,' you know, 'I've got plans to make.' No expression on the face when he said, 'If you wanna know, you know, you'll be able to know.' And then it's when, obviously, when they, he said it, on the clinical findings, on the dimensions on the scans it looks like it's approximately 3cm. So that's what I decided to go for, the less radical.

INT: MM, THE LESS RADICAL OPERATION.

Patient: Yeah.

INT: OK. CAN WE JUST BACKTRACK A LITTLE BIT. SO YOU WENT, YOU HAD YOUR HUSBAND WITH YOU, IS THAT RIGHT?

Patient: Yeah.

INT: WAS ANYBODY ELSE IN THE ROOM AT THE TIME?

Patient: There was ...

[Interruption]

Patient: Yeah, there was, erm, I think there was a breast care nurse standing in the corner, erm, Mr Holliday's desk was facing the wall, I was like and I remember she was in the corner, which was to an adjoining door ...

INT: WAS SHE THE [???] DID SHE HAVE A ...

Patient: A navy blue ...

INT: UNIFORM, THAT'S A CLINIC NURSE.

Patient: Yeah it was, I don't know what she was, it looked like navy blue.

INT: YEAH, IT'S A CLINIC NURSE. BREAST CARE NURSES I DON'T THINK THEY WEAR A UNIFORM.

Patient: No they don't, they wear like very smart things, yeah. Oh when I obviously started to blubber, 'cos she offered me a tissue.

[Interruption]

INT: AND IT WAS MR HOLLIDAY OBVOIUSLY THAT BROKE THE NEWS TO YOU.

Patient: Yeah.

INT: DID HE USE ANYTHING LIKE DIAGRAMS OR DID HE SHOW YOU YOUR MAMMOGRAM OR ANYTHING SORT?

Patient: [???] had all the paperwork where, you know, where they've got little pictures of the breast with a cross on it and what-have-you. He didn't put anything up on the screen, he didn't put any x-rays up or any results or scans, no, he was working purely from the desk, and he just showed me, you know, this is where, he said, 'This is where it's located, and this is what it's, you know, we're going to do,' when I'd gone for that, the deep wide local excision.

INT: WERE YOU TOLD AT THE TIME THAT YOU COULD, YOU DIDN'T HAVE TO MAKE A DECISION NOW, OR DID YOU FEEL THAT YOU HAD TO?

Patient: No, yeah, I felt that I had to make the decision then. He didn't say, you know, go away and think about what decision, I felt I had to make the decision then.

INT: RIGHT, OK. HE'S A BIT ABRUPT, WELL NOT YOU KNOW ABRUPT, HE'S SORT OF ...

Patient: Yeah, his bedside manner, I'm sure he can't be like a cardboard cut-out all the time, he's got to be, show some sign of being human, but I was ...

INT: [???]

Patient: I ... to me I would have preferred to have heard the news from Mr Sibbering because I could have handled it in a jocular manner.

INT: YEAHM, MM.

Patient: But because Mr Holliday delivered it with a steely face, it made me feel very, erm, uneasy.

INT: YEAH, MM, THAT'S RIGHT.

Patient: And, erm, if you are going to be given bad news I think it's got to be given by somebody who has [???

INT: MM, READS THE PATIENT A BIT BETTER.

Patient: Yeah.

INT: YEAH. ALL PATIENTS ARE DIFFERENT. SOME PEOPLE APPRECIATE THAT APPROACH JUST THAT'S IT, GET IT OVER WITH IT, AND OTHER PEOPLE DON'T.

Patient: Yeah, but I think ...

INT: YOU'VE GOT TO READ THE PATIENT WHEN THEY COME IN TO A CERTAIN EXTENT.

Patient: Exactly, and I think Mr Holliday, I mean he must have been doing this for years now, he must have, he should be able to read a patient and think, 'Right, with this patient I can smile; with this patient I have to ...; you know. But I was very, very frustrated with Mr Holliday.

INT: YEAH, ERM, ANYTHING ELSE I NEED TO ASK [???] SO NOW, OBVIOUSLY, AT THIS POINT YOU KNEW THAT YOU DID HAVE CANCER, WHAT WERE YOUR FEELINGS AT THAT POINT?

Patient: Erm, sick, I felt ... I just, erm, 'They've got it wrong, Are you sure, are you sure I've got cancer? Are you ...' 'There is no doubt at all, you have cancer.' And they, I said, 'What kind is it?' and he said, 'We will only be able to tell you once we've done the operation.'

INT: SO WHEN YOU WERE ACTUALLY TALKING ABOUT YOUR DIAGNOSIS AND TREATMENT OPTIONS WITH MR HOLLIDAY DURING THIS CONSULTATION, HOW MUCH DID YOU UNDERSTAND ABOUT WHAT WAS BEING TOLD TO YOU?

Patient: None of it.

INT: NONE OF IT, MM. BECAUSE YOU SAID YOU WERE VERY SURPRISED YOU HAD A CHOICE, THAT IT WAS A BIT OF A SHOCK TO YOU.

Patient: Yeah, I ... personally ... I can't understand why I was given a choice. I think I should have been told 'All you need is a deep wide local excision, and then, if after doing the operation there's something we'll rep-think it.' But having to have a choice like a total, just total breast off or just a chunk, cut out a lump, I mean, having to have, to make that choice, is, to me was quite traumatic.

INT: YEAH, OH I CAN IMAGINE IT WOULD BE, YEAH.

Patient: Because I can't understand why. If they, from all the evidence that they've collated, the growth, the size of the growth, they must have realised that they can just ... tch ... cut this away with a good area as well, rather than just say, erm, 'You've got, you can either have this done or that done.' And in my brain I thought, 'Well, if I have a choice, it can't be that bad, it's got to be, I've got to think positively here so I'll just go for the easier route first, and then, if, hopefully, it's not gone beyond.' But I did not want to have to make a choice. I think the choice should have been made for me. I think they should have said to me, 'OK, Yvonne, ... or Mrs S- ... erm, what we're going to do is this: we're going to do a deep wide local excision, we're going to sample your lymph nodes, just let us check that it's not invaded into your system, and if it has we will have to have you back in we'll do a total mastectomy or we'll see what else we can do.'



INT: I THINK THE REASON, WHAT THEY DO IS THEY OFFER A CHOICE IS BECAUSE SOMEONE, EVEN WHEN THEY GET A VERY, IF THEY'RE PICKED UP ON SCREENING, AND THEY GET JUST A VERY SMALL CANCER, LIKE THIS TINY LITTLE THING IT IS, AND AS SOON AS THEY'RE TOLD THEY JUST SAY, 'I WANT A MASTECTOMY' AND SOME PEOPLE, I THINK, THEY THINK IF THEY JUST CUT IT OFF, IT'S GONE, AND THERE'S A LOT LESS CHANCE OF IT COMING BACK. THE REALITY IS THERE'S NO DIFFERENCE IN TERMS OF SURVIVAL WHEN YOU'VE GOT A CHOICE BETWEEN, AS HE SO VERY SORT OF CANDIDLY PUT IT, 'YOU'RE A BORDERLINE CASE.' BUT, ERM, YEAH, SOME PEOPLE DO AND, YOU KNOW, YOU THINK, 'WELL, YOU DON'T ACTUALLY HAVE TO HAVE THIS REALLY, I MEAN YOU CAN GO FOR A WIDE ... NOT CUT IF OFF' SO I THINK THEY TRY TO AVOID NOW SORT OF TRYING TO PUSH YOU IN ONE WAY OR THE OTHER BECAUSE IT MIGHT BE SOMETHING THAT, YOU KNOW, IF, TO HAVE ONE OPERATION YOU MIGHT, TO GO BACK TO YOUR OWN THING, 'ACTUALLY NOW I'VE THOUGHT,' YOU KNOW, SAY IF YOU HAD A MASTECTOMY FOR INSTANCE, THEY'D SAID, 'OH NO, YOU NEED A MASTECTOMY, CUT IF OFF,' YOU MIGHT COME BACK LATER ON AND SAY, 'WELL YOU KNOW NOW I'VE FOUND OUT I COULD HAVE HAD ANOTHER OPERATION, AND I WOULD MUCH PREFER THAT.' SO THEY GIVE YOU THE CHOICE, BUT THE CHOICE IS DIFFICULT BECAUSE THEY'RE [???] OR NOT.

Patient: That's true, and I think, if, with deep wide local excision, and I think the consultant should say 'That is all that's necessary, you don't need total mastectomy, that is all you need.'

INT: YEAH, EXACTLY.

Patient: Because you could see from the scans where, how invasive it looked from the grey area. I know that it's all, you know, histology and all this kind of thing, I know it's very deep and very involved, I know there's a lot more to it than just, you know, taking, I know it's very, very involved. But I would have preferred it if he'd have said to me, 'We'll just do a deep wide local excision and sample of your lymph nodes,' rather than have two choices because I felt like I'd just been run over with train.

INT: AH, WELL, OF COURSE, EXACTLY. I MEAN I THINK IT'S BEEN SORT OF ...

Patient: You see, what ...

INT: THE WAY IT'S BEEN BROKEN HASN'T BEEN VERY [???] TO BE HONEST, THE WAY IT'S BEEN APPROACHED.

Patient: I think the ... because he gave me the choice, total mastectomy immediately conjures up in your mind you are riddled with cancer. Right? Deep wide local excision, it actually contains your thoughts that it's not as bad as your brain's telling you. You see?

INT: YEAH, OF COURSE, ABSOLUTELY.

Patient: So if he'd have said to me, 'Oh, Yvonne, all we need to do here is, from all what we've got, da-da-da-da, and that's all you need. But if the results come back a little bit negative from the lumps, then we'll have to re-think it, Mrs S-,' but my brain was told automatically ... 'Total breast off, damn what's going on here?' you know, but I think he should have just not given me two choices.

INT: MM, RIGHT. JUST MOVING ON A LITTLE BIT. YOU SAID YOU DIDN'T UNDERSTAND CERTAIN THINGS AND WHAT-HAVE-YOU THAT YOU WERE BEING TOLD, DID THE DOCTORS AND NURSES PICK UP ON THE FACT THAT YOU DIDN'T REALLY UNDERSTAND VERY MUCH?

Patient: No.

INT: OK. ERM, ANAD ...

Patient: But they were very, the breast care nurses were marvellous.

INT: YEAH, I WAS JUST GOING TO COME TO THAT NEXT, WAS, DID YOU SPEND ANY TIME ALONE WITH THE BREAST CARE NURSE AFTER SEEING MR HOLLIDAY?

Patient: Yes, I did. Erm, they were wonderful, you know, we went into this little room, but, erm, [sighs] very nice little tranquil room, but the tranquillity made me feel it was sinister.

INT: OH, RIGHT, MM.

Patient: Can you understand where I'm coming from? I've got a very, my mind goes off in directions at tangents other people's mind doesn't do.

INT: YEAH, FOR SOME IT'D BE RELAXING BUT FOR YOU IT'S [???] STRANGE REALLY?

Patient: Yeah, it was like when you're going to the undertakers and when you go into the parlour to arrange a funeral ...

INT: ALL VERY QUIET, YEAH.

Patient: ... the tranquillity, the little bubbling lamp in the corner. I mean there's a coffee pot there and ... it, it felt [chuckles] to me sinister, the quietness of it felt, the tranquillity felt sinister to me - that's how I interpreted it. Because there was no hustle and bustle, the door was shut, the breast care nurse came in, steely face and very concerned obviously. I couldn't detract upon the care and how caring they were, but the way they were made you feel that you were doomed. Do you understand me?

INT: YEAH, YEAH.

Patient: And I felt ...

INT: I'VE GOT, ANOTHER PATIENT WHO'S HAD BREAST CANCER YEARS AND YEARS AGO AND SHE'S HAD A RECURRENCE IN HER LUNGS UNFORTUNATELY, AND SHE'S A VERY JOVIAL PERSON AND SHE SAID, ERM, WELL, YOU, WHEN YOU'RE SERIOUSLY ILL YOU DON'T WANT MISERABLE PEOPLE AROUND YOU.

Patient: It's true.

INT: AND THAT'S HOW WE'RE DEALING WITH IT, SO WE KNOW THAT WE, WHEN WE TALK TO HER AND WE WORK WITH HER QUITE EXTENSIVELY, THE LAST FEW [???] JUST GONNA MAKE HER FEEL TERRIBLE. SHE WANTS TO LAUGH ABOUT IT, YOU KNOW, AND FEEL THAT PEOPLE ARE NOT TREATING HER AS SOMEBODY WHO'S ABNORMAL IN ANY WAY.

Patient: That's right, yeah, and this is why I felt ... I mean, whether anybody else has said this to you, but it, to me, the tranquillity felt sinister, and I felt ... awkward, I didn't want to be in that room, I didn't want to be told anything. I'd already been told the bad news, I didn't want any more, anybody else talking to me and giving me advice, because my brain was too full of ... pain. I didn't want to listen to anybody else, I just wanted to go home and cry, do you see?

INT: I KNOW A LOT OF PEOPLE FEEL THE SAME THING. SOME PEOPLE DON'T EVEN MAKE THAT FAR, SOME PEOPLE LITERALLY COME OUT THE ROOM AND JUST WALK OFF HOME, IT'S JUST THE LAST THING THEY WANT TO HEAR, THEY DON'T WANT ANY MORE INFORMATION, JUST 'LET ME GO HOME, DEAL WITH IT MYSELF, YOU CAN TELL ME LATER.'

Patient: Yeah, because, they're like, well they're giving you this booklet and that booklet and - don't get me wrong - the care, the way they cared was very good, but it was ... I felt traumatised, there was too much information being given to me. And 'Here's this to read, and here's this to read, and do this and ...' I thought 'Oh God, I've got another booklet, I've got to do this and I've got this to do, ... and I've got this to do ...'

INT: SO CAN YOU JUST TELL ME SOMETHING, WHEN YOU WENT IN THE ROOM AND YOU SAID IT FELT A BIT SORT OF SINISTER, WHAT HAPPENED THEN? WHAT DID YOU TALK ABOUT?

Patient: She was just saying about the, she just said, 'Look, you know, it is ...' she reassured me, whereas I thought the consultant should have reassured me, that it was curable. It was the breast care nurse that told me it was curable, not the consultant, which I thought was wrong. But I thought, 'Well ... who am I to try and change all this lot?' She just talked about the treatment and possibly how long you'll be in hospital and, erm, just basically, you know, 'We're here to support you if you've got any questions or any doubts ...' just given lots of ... a little booklet with, you know, all this thing and it's like your little Bible and so on and so forth. But basically just talked about the, what was going to happen really, which I didn't want to talk to her about it, I wanted to talk to the consultant about it. But obviously the consultants are far too busy to sit chit-chatting about ... you know, extraneous matters which deviate from the clinical side. [???

INT: YEAH, MM, ABSOLUTELY. SO HOW WERE YOU IN THERE THEN WITH THE BREAST CARE NURSE, ROUGHLY, DO YOU KNOW?

Patient: Erm, it was probably about 15 minutes, erm, yeah it was about 15 minutes because I just wanted to go, you know, and, yeah, and I detracted from the chat and said, 'That's a nice necklace you're wearing and ...' [chuckles] things like this.

INT: AND AFTER THAT DID YOU, YOU CAME HOME, YEAH?

Patient: Came home, yeah, with, erm, a very gloomy feeling, but then I came home and told all my friends and da-da-da, 'So this is the outcome, this is what's happened and where I've got this cancer thing and, anyway, but I'm going to Barbados,' so I went off on my holiday, came back. I went on holiday for two weeks, came back on the Wednesday and, which was the 18th ... 18th, yeah, Wednesday the 18th; on the 19th I went in for clinical assessments; on the 20th I went in for the surgery.

INT: RIGHT, OK. AND DID MR HOLLIDAY DO THE SURGERY?

Patient: I'd, well, no, it was a Mr ... not Mr Sibbering, it was a Mr Pan[???], it wasn't him that did it, what was his name? 'Cos this little man came to see me and, erm, he said, 'I'll probably be doing your surgery,' so I said, 'Will Mr Sibbering not be doing it?' erm, Mr ... can't remember his bloody name. Very, very nice, he obviously works hand in hand with him.

INT: WAS HE MR SIBBERING'S UNDERSTUDY?

Patient: I think he might have been his, yeah, I think he must be, I can't really remember his name, sorry.

INT: YEAH, WE DON'T INTERVIEW THOSE BECAUSE THEY, THOSE PEOPLE TEND TO ROTATE AROUND THE DIFFERENT AREAS SO THEY GET DIFFERENT EXPERIENCE AND DIFFERENT CONSULTANTS, SO, WITH THEM BEING TRANSIENT, WE CAN'T REALLY INTERVIEW THEM BECAUSE IT MIGHT BE THAT THEY'RE NOT THERE WHEN WE'RE INTERVIEWING THEY MIGHT

SEE OR THEY MIGHT ONLY SEE THEM FOR A COUPLE OF WEEKS, YOU KNOW, SO I DON'T KNOW THIS GUY'S NAME.

Patient: Erm, he came to see me and he said, 'Oh, I'll be doing the operation for you,' he was quite a nice man actually, you know, he had an air of ... sympathy but not overly sympathetic, and he was, erm, and I said, 'Well, whatever you do, make you cut it, cut a straight line and do the stitching properly otherwise you won't get your sewers badge in the brownies, right!' So, erm, he smiled at that. Then he said, 'Well the anaesthetist's got to come and see you.' Oh, at the clinical assessment, that was what happened at the clinical assessment, the, I'd just come back off holiday and I had this awful cough ... cough, cough, cough, cough ... and I think I must have got some like viral infection off the plane, you know you get recirculated air now, this most horrible dry cough. So anyway the first nurse that [??] 'You're chest sounds terrible.' Oh God, so she said, 'I'll have to the nurse, get a doctor,' so the doctor came and she, the doctor listened to me and she said, 'I'm not quite happy, there's like an area what I'm not happy with, I'm going to send you for a chest x-ray,' so before they'd actually decided whether they were going to do the operation on Friday I had a chest x-ray, and the chest x-ray was fine. And it's, the doctor, she said, 'You've got a viral infection which is like in your throat which is causing you have to have a really ...' I've still not got over it. Anyway, and then the anaesthetist, she came to see me, and she was talking to me and she was a bit concerned about this hoarseness, and then she examined me and she said, 'No, I'm happy to do it,' she said, 'I don't want to leave this operation. I want it done and out the way,' and then Capman [?], Mr Capman was it ... Mr Catton, it was Mr Catton, she said to Mr Catton, 'Right,' she said, 'I'm quite happy to anaesthetise this lady.' 'Right, we'll go ahead with the operation tomorrow morning.' So that was that, 9 o'clock.

INT: SO FROM THE POINT WHEN YOU ACTUALLY WENT TO THE, TO GET YOUR MAMMOGRAM AND YOU'D GOT THE EARLY MAMMOGRAM TO THE POINT WHEN YOU ACTUALLY GOT YOUR OPERATION, HOW LONG DO YOU THINK THAT WAS?

Patient: From the mammogram to the operation, it was ...

INT: FIVE WEEK?

Patient: It was, it was about ... it was the 20th February I had the operation, two weeks back from that is when I was on holiday, so that's like the 4th ... er ... two weeks before that ... it was about five weeks, about five weeks it would be, yeah. Two weeks, it was less than two weeks I had to wait for the, then I had a week's wait for the results, and then I went on holiday and it was ... it was about five weeks.

INT: FIVE WEEKS, OK. AND JUST THINKING BACK A LITTLE BIT TO THE ACTUAL CONSULTATION BETWEEN YOURSELF AND MR HOLLIDAY AND THEN THE BREAST CARE NURSE AFTERWARDS, WHO DO YOU THINK ASKED MOST OF THE QUESTIONS AND WHO DO YOU THINK DID MOST OF THE TALKING?

Patient: Me.

INT: WHICH ONE, QUESTIONS OR TALKING?

Patient: I did both, questions and talking. I did most, with the consultant, me.

INT: RIGHT, OK. AND WITH THE BREAST CARE NURSE?

Patient: The breast care nurse, I think it was probably about 50:50.

INT: AND WHEN SHE WAS DESCRIBING THINGS, I KNOW SHE HAD THE PACK, DID SHE SHOW YOU ANY PICTURES, DIAGRAMS, DRAWING ...

Patient: No.

INT: NO, OK. ERM, AND JUST THINKING WHEN YOU WERE ACTUALLY SPEAKING TO THE DOCTOR, MR HOLLIDAY, DO YOU FEEL THAT HE LISTENED TO YOU, WHEN YOU WERE TALKING.

Patient: No.

INT: NO, OK. DO YOU THINK HE UNDERSTOOD YOUR NEEDS AND CONCERNS IN ANY WAY?

Patient: No.

INT: OK. DID YOU FEEL THAT WHEN HE WAS TALKING TO YOU HE HAD A PARTICULAR TREATMENT IN MIND?

Patient: No.

INT: OK. AND WHAT ABOUT THE NURSE, DO YOU FEEL THAT THEY LISTENED TO YOU AND UNDERSTOOD YOUR NEEDS AND CONCERNS?

Patient: Yeah, I did actually, yeah. They came across more, more human.

INT: YEAH. AND DO YOU THINK THAT THEY EXPRESSED A PREFERENCE FOR ANY KIND OF TREATMENT, DID YOU FEEL THAT YOU GOT ANYTHING FROM THEM THAT THEY THOUGHT ONE OPERATION WAS BETTER THAN THE OTHER?

Patient: No.

INT: OK.

Patient: They just kept reassuring me that it is curable.

INT: SO. WE'RE AT THE THIS POINT NOW WHERE YOU'VE GONE IN FOR THE OPERATION, HOW WAS THE OPERATION, HOW DID THAT GO?

Patient: Fine, erm, I went down more or less bang on 9 o'clock and I think I vaguely remember coming round about 12 o'clock, 1 o'clock. I think that was down, I must have been in the recovery area for a while, I'm not quite sure, I don't know. It went fine, yeah. I didn't feel very good like, I felt as though I'd been through a ...

INT: YEAH, THIS IS AFTERWARDS [???

Patient: Yeah. But I was fine, I was fine.

INT: SO THEN WHAT HAPPENED AFTER THAT THEN? YOU CAME ROUND, DID THE DOCTOR COME TO SEE YOU OR ...?

Patient: I can't remember how soon after the operation ... actually Mr Catton, it's Mr Catton came round I think later on in the evening, and he said it was bigger than they thought ... and I felt quite OK with that, I just thought, well obviously they've cut away more than they needed. Erm, and then that was that, and then on, and I said, 'Oh well, you know, I haven't had chance to look, I hope your stitching's been good,' [???] so I said, 'Can you tell what you've done because I feel, like, wrecked,' especially my arm, I couldn't lift my arm up because the ...

INT: THE DRAINS AND STUFF?

Patient: Yeah, I've got, I had these awful drains in and one really was right, drain right under here, yeah, and one at the back and they were stitched in place, you see. And I was most, it's just a most awful, awful feeling having those drains in, so I felt really wrecked. But my arm was like, ugh, like a big golf ball [???] I said, 'Can you tell me how many lymph nodes you sampled, I might as well ask?' he said, 'Four,' he said, 'We did four of your lymph nodes.' So that was that, I was just, then I just ... felt OK. The following day I felt wonderful, I felt quite light-hearted, I felt very jocular, but then the day after I felt so sad.

INT: MM, WHAT MADE YOU FEEL SAD?

Patient: I don't know, I felt cry, I felt weepy. Whether it was the anaesthetic that had maybe picked in and made me feel really down, I felt really, really depressed. And on the Sunday about 5 o'clock Mr Sibbering poles along with a laughy face on, because he said to me, 'Oh by the way ...' ...

INT: HE'S [???]

Patient: He's lovely, isn't he?

INT: YEAH, HE IS, YEAH.

Patient: He said, 'By the way, what part of Barbados did you go to?' I said, 'Hang on a minute, I think, I can't remember,' I thought it was Rockley [?] I said, 'Why are you asking?' he said, 'Because I did my training in Barbados.' So I said, 'Mm, very interesting,' I said [chuckles] so, but his, his bedside manner when I went first of all to his consulting room [???] where he examined me, erm, the topical examination, he was just so, erm, amazing, do you know what I mean, he made you feel so, so at ease, even though, you know, he knew what he was feeling for, because with this one he got, that was out the way, I could tell by he [???] something there. Then he got round to here and he said that he was, he was using his little finger, that little tentacle, then I knew that he homed in on exactly the problem area. So on the Sunday he had his son with him and his son had a little car going over the top of the bed, you know. He said, 'I've just got my little helper.' So I said, 'Is the trainee consultant?' Then he got the paperwork and he said, 'Oh, blah-blah-blah. It was bigger than we thought, da-da-da-da.' And that was that. So I didn't realise what this 'bigger than they thought' was until I questioned a nurse at the DRI at the Radiotherapy Department what it was, because they didn't actually tell me that there was two things going on here.

INT: OH RIGHT?

Patient: Apart from the tumour, there's another thing called, is it D-something-something where you've got cell changes that's going to develop into cancer.

INT: MM, OK, I'M NOT REALLY SURE WHAT THAT IS.

Patient: Right, erm, apparently there was two lots of things gone here, but I was never told this at the City. There was, Mr Sibbering said that it was bigger than they thought and they didn't elucidate any more and then when I, and then I didn't question him, I just thought, 'Well, you know, it's, they've done their best,' and that was that. And then ...

INT: SO HOW LONG WERE YOU IN HOSPITAL AFTER?

Patient: Three days.

INT: THREE DAYS.

Patient: Yeah, Friday, Saturday, Sunday. Friday, Saturday, Sunday, yeah. It's a pity I couldn't have stayed in four days I could have got a claim off my private health care but ... [chuckles] three days I was in, and I came home and then I had an appointment to see, erm, Mr Holliday, no sorry, Mr Sibbering, so he could explain exactly what they'd done. And Mr Sibbering, I think, yeah, it was about a week later I think. He had got all these papers out and he dew on a piece of paper, 'Now this is da-da-da, and this was ... and we cut all this away, da-da-da-da. But,' he said, 'You have to take Tamoxafen.' He said, 'Have you had any blood clots,' I said, 'Not as I know of, blah-blah.' Erm, you have to take this for five years, it's an oestrogen blocker so, because apparently, they told me it was a grade two cancer, it wasn't the slowest, [chuckles] wasn't the fastest, but it was sensitive to oestrogen.

INT: RIGHT.

Patient: So, which meant that, you know, they had to put me on this Tamoxafen for the next five years.

INT: AND DID YOU HAVE ANY RADIOTHERAPY, DID YOU ...?

Patient: No I didn't, no, because fortunately it hadn't invaded my lymph system.

INT: AH RIGHT, OK.

Patient: But I'm having radiotherapy now - chemotherapy do you mean?

INT: NO, RADIOTHERAPY.

Patient: Oh, no, I'm having radiotherapy now. I'm having it now for fi-, this is my second week, so I go every day.

INT: EVERY WEEK DAY FOR FIVE WEEKS.

Patient: Every week, yeah, so.

INT: AND HOW ARE YOU FINDING THAT?

Patient: It's all right.

INT: IT TIRES YOU A BIT, DOESN'T IT, USUALLY?

Patient: Well, yeah, I'm trying ... you know, it's strange, it says you're going to feel tired and I'm trying to prove that it won't make me feel tired. [???] but at the moment my theory, erm, the theory is OK but she said 'If you get, as you get to the end of the treatment you'll probably feel quite tired.' But the, erm, the Tamoxafen, er, I'm not happy with the Tamoxafen at the moment because I think my sleep is so disrupted and [???] but I'm going to ... the City Hospital prescribe Tamoxafen, which is the generic, and my GP has given me Nolbadex D [?] which is the pharmaceutical make, not the generic one. And I was talking to the radiographer yesterday and she said, 'I think there is a difference in the two drugs, even though there's not supposed to be.' She said, 'People who've been on Nolbadex D find the side-effects less than on the Tamoxafen.' But apparently the Tamoxafen and the Nolbadex D, the chemical composition is supposed to be exact, but she said, 'I believe that there's a difference between the two and the side effects with the Nolbadex D are not as bad.' [???] [chuckles]

INT: RIGHT, OK. JUST RETURNING TO THE INFORMATION THAT THE BREAST CARE NURSE GAVE YOU, DID YOU READ ALL THAT STUFF?

Patient: Yes, I did.

INT: YEAH, AND IS IT USEFUL?

Patient: Oh, well, I don't know, I suppose so, I might have chucked some of it away. Yeah, I found it, I found it quite informative really. I mean it's, there's just loads of it, you know, I kept

[Outside noises]

INT: IT'S GOING TO BE A TREAT TO ANALYSE THIS ONE, I'LL TELL YOU.

Patient: Sorry about the music [chuckles] it's the window-cleaner. Yeah.

INT: DOES HE KNOW HE'S BEING RECORDED. WE OUGHT TO SEND IT TO 'STARS IN THEIR EYES'.

Patient: Do you know, I'm sure they probably think I'm dead and buried, you know, because they haven't seen me for months, the window-cleaners. Yeah, I read it and read it and I did all the exercises and going on, you know, avoiding this, and coming to terms with breast surgery and cording and all the, I've read it and read it ... I found it helpful, I did find it helpful. Erm, it's just, yeah, I did find it all very helpful, and if there's anything you need you can take some of this away with you.

INT: NO, I'VE SEEN PLENTY OF THEM [CHUCKLES]

Patient: Welcome to the breast care [???] I've more information, I mean you're not left in the dark as to what's going to happen to you, but, because you're just bombarded with information and information and information, you think [???]

INT: [???]

Patient: They're climbing through the doors. Sorry about this.

INT: YEAH. DID YOU HAVE ANY CONTACT WITH THE BREAST CARE NURSE FROM WHEN YOU FIRST SAW HER TO WHEN YOU HAD YOUR OPERATION?

Patient: Er, she phoned me.

INT: OH RIGHT.

Patient: She phoned me a couple of times to see how I was coping, er, which I thought was quite sweet because then it did, you know, compound the fact that they do really care, and they, they did come across a quite caring team, you know, they were caring.

INT: AND AFTER YOU'D MADE YOUR INITIAL DECISION IN THE CONSULTATION, DID YOU CHANGE YOUR MIND AT ALL?

Patient: No.

INT: NO. HAPPY WITH THAT DECISION?

Patient: Totally happy.

INT: YEAH, OK.



Patient: Totally happy, because I knew that, if my first decision was wrong, we could go down the next road.

INT: YEAH. A FEW QUESTIONS TO FINISH OFF WITH. ERM, YEAH OK. SO YOU SPOKE TO FAMILY AND FRIENDS, YOU MENTIONED THAT; YOU WERE GIVEN THAT INFORMATION, DID YOU GET INFORMATION FROM ANYWHERE ELSE? DID YOU SPEAK TO YOUR GP? DID YOUR FRIENDS AND NEIGHBOURS GIVE YOU MAGAZINES OR VIDEOS OR ANYTHING LIKE THAT?

Patient: No, no. Erm, I went ... what did I do? Oh no, my GP phoned me ...

INT: OH RIGHT?

Patient: ... erm, because, erm, why did he phone me? Oh I know, yes I know, just come back to me, erm, I wanted a sick note for work, so what I'd done, I'd phoned up my surgery ...

[Interruption]

Patient: I phoned up my surgery and I said could I have possibly a sick note for four weeks, just so I can get over the initial period, get myself back on the road to recovery, erm, and I said if you just put like 'Post-op breast cancer' and I said I want a Med3 form please ... [chuckles] ... so that was that and they were very good because normally at my surgery it's a little bit austere and a bit, 'Ooh ... you know ...' but I think possibly because it's the 'C' word, 'Oh-ho, you know, we've got one with 'C'' dead nice, wonderful, bend over backwards, couldn't you know ... then in the afternoon it was Eisenberg - Dr Eisenberg was the doctor that I first went to who first did me a referral to the City - he phoned me up and he said, 'Oh, Yvonne, erm, you know, what can you tell me about, it's about the sick-note ...' No problem, so I got the sick-note, he gave me three months off work. I said 'I don't want to be off work three months, I'm not ill, I've just got a hiccup in my life.' He said, 'But most people want to be off work,' I said, 'But not me, I have to go back to work,' I said, 'I can't sit here cogitating and pontificating over what's gonna happen.' He said, 'All right then, when do you want to go back to work?' 'I said, four weeks' time just so I can get back the range in my arm,' I said, 'That's all, I can work on my physio.' No problem. But he said, 'I'm so sorry to hear that ...' I said, 'Well,' I said, 'That's just unfortunate.' The surgery were fine, that's the contact I had with the doctor, and I haven't been back since.

INT: TALKING A LITTLE BIT ABOUT YOUR DECISION AGAIN NOW, WHAT DO YOU THINK WAS THE MOST IMPORTANT THING THAT YOU WERE TOLD OR THAT YOU READ THAT HELPED YOU MAKE YOUR DECISION TO WHAT TREATMENT YOU WERE GONNA HAVE?

Patient: The most important decision was what I chose. Erm, no that's not right. Yeah, it is, but I think it should have been described to me more clearly as to what was involved and why it was necessary only to do ... [sighs] ... he should have told me that ... having the two choices I was, did not want. He should have just given me that one choice, because they must have known that total mastectomy wasn't necessary. But, as you say, women ...

INT: DIFFERENT WOMEN WANT DIFFERENT, DIFFERENT REACTIONS ...

Patient: ... have, react, yeah, but he should have explained to me, if he'd have explained to me 'It's not necessary to have the breast off but if you want it all off, that's what you can have, but it's not really necessary.' That's what he should have said to me, and he didn't.

INT: YEAH, I THINK THAT'S A FAIR COMMENT, TO BE HONEST. LOOKING BACK NOW FROM WHEN YOU WERE FIRST DIAGNOSED UNTIL NOW, ERM, WHAT DO YOU FEEL ABOUT THE CARE THAT YOU'VE RECEIVED?

Patient: Fabulous, yeah.

INT: DO YOU THINK IT MET YOUR EXPECTATIONS?

Patient: Mm. It's met all my expectations. I am very, erm, I have been impressed and overwhelmed with the support and the professionalism from the breast care nurses right through to the radiotherapy I'm having, their attitudes, I am very, I cannot, erm, be negative at all. I can only but praise, sing their praises, because everybody has been very, very good, except - well Mr Holliday, obviously, is a very professional man, it's just a shame that he presents himself as a cardboard cut-out, which is dead off-putting.

INT: YEAH. IF IT WAS, IF YOU WERE TOLD YOU HAD, YOU KNOW, THINKING ABOUT THE DERBY CITY UNIT YOU WENT TO, THE BREAST CARE UNIT, IF YOU WERE TOLD YOU HAD THE POWER AND MONEY TO CHANGE ONE THING ABOUT THE SERVICE THERE, WHAT WOULD IT BE?

Patient: ...quite a difficult question really because I haven't really thought of that aspect because ... the Department seemed to run quite smoothly. It didn't present any hiccups, it didn't make you feel there was something amiss. I think, I think possibly the little area where the ladies go and they're told to go, 'Oh 'bye Mrs Jones; bye-bye Mrs Brown ...' I think there should be, instead of that person who's sitting there like me knowing full well there's something wrong with all these people going, I think there should be a little area set aside for that person where there's a question mark about the results, just to be able to go into another little room with a television on, you can read a magazine, just to relax. Erm, because I could feel myself getting worked up because I knew all these people were going and I knew there was something wrong with me. Yet if you were put, if you were taken away and put in another room, you wouldn't be aware that Mrs Jones, Mrs Brown, Mrs Green has come and gone, come and gone, and come and gone, and you're still sitting there. Do you know what I mean?

INT: YEAH, IT'S SLIGHTLY DIFFERENT AT THE HALLAMSHIRE WHERE THEY'VE GOT JUST THIS ONE CORRIDOR WHERE EVERYONE SITS, AND THEY'VE ONLY GOT TWO BREAST CARE NURSES, SO OF COURSE WHAT HAPPENS IS IF YOU'RE SITTING THERE WAITING AND OTHER PEOPLE ARE GOING IN BEFORE YOU, YOU STRAIGHT AWAY THINKING, WELL THEY'RE WAITING FOR THE BREAST CARE NURSE [???

Patient: Exactly, so they know, don't they? So there has to be a division really so that you can, erm ... excuse me, this radiotherapy, it makes me itch ...

INT: YEAH, IT DOES SOMETIMES.

Patient: Sorry, so, no, I think that's the only, I think that, thinking about it, you know, would be quite, it would be a bit of a bonus, because you know that, 'Oh, there's something wrong with me, they've all gone and I'm still sitting here,' you know, 'Hello, darling, what's going on here, like?'

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

Patient: I think they should know how invasive it's been, erm, obviously the prognosis, and ... er ... the treatment, the medication that you're going to take is going to make them cancer-free, or, erm, and possibly even told what the chances, percentage-wise, of the cancer returning after, erm, you have maybe chemo and radiotherapy, what is the chances of the cancer returning, which is one of the questions I want to ask the oncologist when I see her next Wednesday.

INT: AH RIGHT, OK, YEAH.

Patient: Yeah, because, erm, I, if there's a very, very small percentage of this breast cancer returning, I don't feel as if I want to take drugs for five years. I feel that ... I don't want to bombard my body with ...

INT: CHEMICALS AND ...

Patient: Yeah. 'Cos I only, if I have a headache, I just, all I take is paracetamol, that's all I've taken for years, that's all I take. And to have to think about five years of drug treatment, like, and after five years when I stop taking Tamoxafen, will it re-occur? Is there a guarantee? That's really, I think people should know.

INT: YOU'VE ACTUALLY ANSWERED THE NEXT QUESTION, I WAS GOING TO ASK YOU ABOUT THE OP, WHAT'S THE MOST IMPORTANT THING SOMEONE WITH BREAST CANCER NEEDS TO KNOW ABOUT THE OPERATIONS THEY CAN HAVE?

Patient: I think for the average lay person, they don't understand when you go to hospital, it's all so clinical and all so scary and you're all so uptight. The average person can be told what's gonna happen but I don't think it really goes in, I don't think it, I think it only just touches the top surface. People I think are confused and they don't know what to ask, they don't know what kind of questions to ask, erm, I think if the person would ask the question I don't think the consultants, erm, would have the time to explain what they're going to do apart from they do briefly say, 'Well, we're gonna do this, we're gonna do, we're gonna cut this, cut this out, do this, cut this out ...' but to go into technicalities, it would be a total waste of their time.

INT: SO YOU THINK JUST LIKE A THUMBNAIL SKETCH SORT OF THING OF WHAT'S GONNA HAPPEN?

Patient: Yeah, I think so, yeah. I think that would probably be sufficient for the majority of people, when you can be reassured that 'This is what we're gonna do, da-da-la-la-la,' and, but to go into, you know ... I think people would like to know, just as you say, a brief sketch, a bit of a potted history of what's gonna happen. This little road leads to absolutely nowhere and the amount of traffic that comes up here ... [chuckles]

INT: FINAL QUESTION. IS THERE ANYTHING ELSE YOU'D LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT TODAY, ANYTHING YOU THINK WE'VE MISSED, ANYTHING YOU THINK IS IMPORTANT THAT YOU MIGHT NOT HAVE MENTIONED YET?

Patient: No, I think, erm, I think I've covered everything, I think, I feel quite ... do you think everything's, anything you can think of I need [???

INT: NO I DON'T THINK SO, I THINK WE'VE BEEN THROUGH EVERYTHING.

Patient: I think I've ... probably ...

INT: WE'VE PRETTY MUCH COVERED FROM START TO FINISH.

Patient: Yeah, quite chatty [???

[End of interview]