

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Nurse)

*VENUE: Low MR unit

*DATE:

*ID: BCN042

*INTERVIEWER: DJW

INT: THANKS VERY MUCH FOR BEING INTERVIEWED, OK. I UNDERSTAND YOU'RE VERY BUSY, I SAW THAT YESTERDAY JUST HOW BUSY YOU REALLY WERE. I'D JUST LIKE TO SORT OF START THE INTERVIEW NOW WITH A VERY SIMPLE QUESTION ...

*Q1. HOW LONG HAVE YOU WORKED IN THIS BREAST UNIT?

Nurse: In total, in the actual, in the breast care centre as a breast care nurse I've been in post for 10 months but I've actually been down here for 13 months because I came down originally on a secondment from the breast care ward, so about 13 months in total but 10 months as a breast care nurse. Because while I was down here one of the breast care nurses had moved on before I came down and they were waiting for funding to see whether they could fill her post, so while I was down here I applied for that job and I'm staying permanently now instead of going back to the ward. So, it's great for me.

INT: OH RIGHT, SO YOU DON'T WANT TO GO BACK TO THE WARD AT ALL?

Nurse: No, no. So, because originally, as I say, a secondment, just to, you know, observe, and I was just going to be here purely to shadow somebody for 12 months and observe what was going on down here so that I could take it back up to the ward, so.

INT: NO, THAT'S ALL RIGHT. SO DO YOU PREFER IT DOWN HERE OR ON THE WARD?

Nurse: Very much so, yeah. I mean ...

INT: IT'S VERY DIFFERENT, IS IT?

Nurse: It is, yeah. I mean I've worked on the breast care ward for five years here and I've worked on the breast care ward at, in London, for three years prior to coming to Leicester, so I've had quite an experience from that side of it, but that's only a small part of, like, you know, the journey that the ladies go through, so it's been a real eye-opener to see it from the beginning ...

INT: YEAH, WELL IT WILL BE.

Nurse: ... and, you know, right to the end as well, you know, rather than just seeing that snapshot on the ward.

INT: AH RIGHT, YEAH.

Nurse: So ...

INT: BECAUSE THERE'S ANOTHER NURSE HERE ACTUALLY DOES BOTH, ISN'T THERE, THAT'S RIGHT, YEAH?

Nurse: Yeah.

INT: YEAH, SHE DOES BOTH, I INTERVIEWED HER YESTERDAY. THAT WAS QUITE, IT WAS QUITE INTERESTING TO HEAR HER SORT OF EXPERIENCES HERE. SHE SAID THAT SHE'D DONE A MANUAL OR SOMETHING, A SORT OF BOOKLET OR SOMETHING [???

Nurse: That's right, yes, she has, yeah.

INT: THAT'S REALLY, I THINK THAT'S REALLY GOOD ACTUALLY. OK. I WANT YOU TO THINK ABOUT THINGS LIKES AND DISLIKES, UNIT PHILOSOPHY, DAY TO DAY RUNNING OF THE SERVICE AND STUFF, AND JUST TELL ME, YOU KNOW ...

*Q2. WHAT'S IT LIKE TO WORK AS A SPECIALIST NURSE IN THIS UNIT?

Nurse: I mean, I just absolutely love it, I mean it's just, when I first came down here, just from the point of view that people just said to me, and not that I wasn't unhappy on the ward, but coming down and doing, even when I came to do my secondment, and people just said to me, 'You look so happy,' and I've like, just completely settled into, you know, the job, right from, from coming into post last April, I've just completely settled into it. I've picked it up quite quickly which in some, you know, the day to day running of what goes on in the clinics, and in some respects that kind of has overwhelmed me sometimes, I think, because I think, oh, you know, I've had to stop myself from saying am I going too fast, am I trying to do it too quickly, but from a practical point of view I'm a person that does pick up things very quickly anyway. And it's only just now I was talking to Jane the other day, who's my boss, and saying to her that it's only just now that things are just beginning to fall into place, understanding about breast cancer and the disease and everything else, and that's all just beginning to come into place now because I've got to grips with like the day to day running of the unit. And now it's kind of like, 'Oh my God, I've got so much to learn,' you know, from, you know, understanding about the disease and the process and everything else. But, I mean, I absolutely, I work with a brilliant team, we all work really well as a team, as in the breast care nurses, but I think the whole unit as a whole, you know, it's very, very different from being on the ward, it's, having, I've worked in outpatients before so I kind of like had a grip on how the outpatients system works, but it's certainly different, your relationship with the consultants and the registrars is completely different than on the ward. I didn't ...

INT: IN WHAT WAY, IN WHAT WAY?

Nurse: Well I found it quite strange because, when I was up on the ward, you're seen as a ward nurse, and I've been a nurse for a long time, I've been a nurse for 23 years this year, so it's been a long time, you know, I've got lots of experience, and when I was up on the ward, although, you know, you know that people, you know, I had a ... I'm trying to think of the words I want to say ... you know that your colleagues around you respect the fact that you've, you know, that you've got that experience and respect you for what you know, but I was quite, but you never think about the doctors, but when I came down here, although, and I think that what I know about, you know, sort of like what's, I know the day to day running as I say of what's going down here, I still think my knowledge is quite limited as far as breast cancer's concerned, but, erm, what I know about the ward, that experience, I know a lot about that, you know, like, so, I mean, I've been able to bring that down here. But it's just the fact that my relationship I think with them, I'm just surprised that, you know, the relationship that I've got with the consultants - because all of a sudden you feel like, you know, you're totally, you know, you're very respected. Erm, and for me I found that, when I first came down here, after I'd been here a few months, it was a bit scary for me because I thought, I remember talking to Sue about it and saying that I felt as if, 'Oh my God, we've got another specialist nurse here, and I don't feel like I'm a specialist nurse yet, I think, you know, that's further down the line,' and you know like, 'Ooh she's got a wealth of knowledge,' and I feel like I don't, what I know is on the head of a pin really at this moment in time, you know, so that's changed I think. And I think, you know, erm, people expect that you, people expect you to know things as well, you know. And not so much the staff around you but the patients, you know, like the ladies that come in and when I came, and you, like you're answering the phone and people are asking you things, and you think, you know, and if you don't you

have to go and ask somebody else, you know, but from that point of view it's been different. It's been demanding, it's emotional, it's a lot more emotional than I, you know, because I mean it's emotional on the ward because, but the ladies have, you find that most of the ladies, by the time they come in to have their surgery, have adjusted, you know, like to their situation and coping with it. I mean, and there were, when I was on, when I was on the ward, you could have, when I was on nights, you could have nights when you could sit and talk to somebody for hours, but that was, you know, not very often. But down here when you see somebody at diag-, you know, I've never been with somebody at diagnosis and the ladies tell you a little bit on the ward, but they kind, by the time they come in for their surgery they've put that behind them and they've got, you know, they've got a grip on what's going on and they just want to get on with their surgery. So from the point of view of, being down here when they're diagnosed can be, you know, it's, well, it is, not all the time but it can be emotional because, you know, you, erm, you know, especially if you see somebody over a couple of weeks as well and you get that contact with them, and some people, you know, get to you sometimes, you know ...

INT: OH ABSOLUTELY, YEAH.

Nurse: You know ...

INT: INTERVIEWING'S THE SAME THING.

Nurse: And you see the families, you know ...

INT: IT'S EXACTLY THE SAME THING, I INTERVIEW PATIENTS IN THEIR HOMES AND YOU DON'T KNOW HOW AN INTERVIEW'S GONNA GO, ERM, YOU GO IN THER AND SOME PEOPLE ARE FINE, THEY'VE DEALT WITH THINGS, 'AH YEAH, YEAH' AND YOU ASK THE QUEITONS AND ALL THE REST OF IT, AND YOU ALWAYS SORT OF SAY AT THE BEGINNING, YOU KNOW, 'IT'S NOT OUR INTENTION TO UPSET YOU BUT SOME OF THE THINGS I TALK MAY UPSET SOME PEOPLE AND IT MIGHT UPSET YOU, WE DON'T KNOW,' AND YOU HAVE TO TRY AND PREPARE FOR THAT. AND THEN OTHER PEOPLE, YOU KNOW, YOU FIND YOU'RE GETTING THROUGH ... I MEAN I'VE INTERVIEWED MEN AND WOMEN SO I MEAN, YOU KNOW, FOR DIFFERENT CANCERS, AND, YOU KNOW, YOU'LL JUST ON A PARTICULAR TOPIC WHICH, IT SOUNDS SILLY BUT TO ME I WOULDN'T REALLY THINK IT'S THAT EMOTIONAL, YOU KNOW, THAT ACTUALLY THE EMOTIONAL QUESTIONS HAVE GONE, YOU KNOW, ASKING YOU ABOUT YOUR DIAGNOSIS AND [???] AND YOU'LL HIT ON SOMETHING VERY, VERY, JUST TALKING ABOUT LIKE YOU KNOW A FINANCIAL SITUATION OR SOMETHING, AND THAT COULD BE REALLY IMPORTANT TO SOMEBODY OR TALKING OF THE FAMILY OR SOMETHING, AND THEY'LL START CRYING AND YOU THINK, 'OH,' YOU KNOW, 'I DIDN'T EXPECT THAT TO HAPPEN.' YOU KNOW? AND EVERYBODY'S DIFFEENT I SUPPOSE.

Nurse: You don't know, you never know how, sometimes, and you can sometimes think that you know how people are going to react and they can be completely different, you know, because you might have met them the week before and they'll be, you know, they could come along to clinic and they'll be really tearful, and then you think, you know, 'Ooh what are they gonna be like next week?' you know, when you know that they're coming back for their results, and they can be completely different and surprise you because they'll, you know, the coping mechanism comes in. But it can be, I mean, and I think, because sometimes you, when you're listening to people, you know, and you go away and think about their situations you can't, you know, sometimes your own, things that have gone, your own life experiences, it triggers something off in your own life, you know, and you hear people talking, you know, when they've got families, you know, like, and you've got family and sometimes you start to question, you know, I must, in the last 12 months that I've been doing this job, I've ch-, you know, I've changed so much in the way I think about life. I know it's changed me a lot and, you know, even my husband has said to me, you know, like you think about things so much diff-, you know, so differently now.

INT: OF COURSE, YEAH. I MEAN ONE OF MY FIRST JOBS IN THIS, AS A RESEARCHER UP IN SHEFFIELD WAS TO RUN A FOCUS GROUP WITH LUNG PATIENTS WHO WERE ALL PALLIATIVE AND THE GROUP RAN REALLY, REALLY WELL, WE HAD A FANTASTIC RESPONSE AND STUFF, AND THEN SORT OF I SAYS 'IS THERE ANY QUESTIONS' AT THE END, AND THIS LADY OLD LADY RIGHT AT THE END SHE JUST POPPED HER HAND UP AND I SAID, 'YOU NEEDN'T RAISE YOU HAND UP, IT'S OK,' AND SHE SAID 'DO YOU EVER THINK ABOUT DEATH?' 'WELL, NOT REALLY IN THAT RESPECT ...' BUT YOU KNOW YOU DO NOW, YOU KNOW, YOU START WORRYING ABOUT ISSUES. AND YOU SUDDENLY YOU'LL BE AWARE AND THINK, WELL, I WONDER HOW I WOULD COPE IF I WAS LIKE THAT? YOU CANNOT HELP IT, IT'S JUST THE SCENARIO, IT'S THE SITUATION.

Nurse: Yeah, yeah. I don't, I would, you kind of like think, no you don't think about death and I don't think I think about the actual dying, but I think you think about, I think about, you know, because you can be talking to somebody and they'll be talking about their children and I go away and sometimes think about, you know, 'Oh, if that was happ- ...' you know, how I would feel about it, you know, and that can sometimes have an impact on, you know, you know when you know that somebody's coming the following week and you know that they're coming back and their results aren't very good, and that can have an impact on, you know, when you're going in and you have to take a deep breath and step back and then you go in and approach it, you know, and it can be, you know, quite emotional sometimes.

INT: SO THINKING ABOUT THE UNIT AGAIN, YOU BASICALLY GET ON WELL WITH YOUR COLLEAGUES AND STUFF AND THE MEDICAL STAFF?

Nurse: Yeah, oh absolutely, no problem, yeah.

INT: SO THINKING IN TERMS OF THE STRUCTURE OF THINGS HERE, YOU KNOW WHEN A PATIENT COMES IN WHAT SORT OF, WHAT'S A SORT OF TYPICAL, JUST THUMBNAIL SKETHC OF THE PATHWAY AS YOU SEE IT SORT OF THING? BECAUSE YOU GET SCREENING AND SYMPTOMATIC PATIENTS.

Nurse: Yes, but it depends on the clinic, you know, because like you say there is a screening clinic and a symptomatic clinic. So if it's a screening clinic then I mean you get patients that are coming along who are, because they're coming back for second stage screening so they've already had the mammogram, so you get ladies that are coming along that are very, very anxious, and they come back and they have like further imaging and then if need be they then have to go on and have a needle test, they'll be examined by a doctor, and then, you know, if they've had a needle test they have to come back the following week for the results. So obviously this, you know, need for emotional support for the ladies before they go home and they're given, you know, a contact card and are able to contact us if they've got any queries, you know, in that week that they're waiting. If it's a symptomatic clinic, you know, you've got ladies that are coming along that have been referred from their GP with a lump in their breast equally, you know, anxious. But then that's sometimes, that's different, slightly different in the fact that they could have an actual diagnosis on the day that they come along because they go through the imaging, they might have ...

INT: THE ONE STOP CLINIC, YEAH.

Nurse: Yeah, they might have an FNA which, you know, fine needle aspiration, or a biopsy, and then they get, some get a definite, some can get, have a definite result, some get a provisional result because on whether, you know, they've done, you know, drag cytology or whether they've just done a core and they've got a definite result, you know. And so from that point of view that is, you know, and the ladies can be here for a long time, they can be here for like two

or three hours if not longer sometimes waiting for, you know, waiting to go through that process, and then at the end of it, you know, they're diagnosed with breast cancer. So that is, you know, for the patients it's quite emotional and for us it's, you know, we go in once they've been diagnosed and I think it's a lot for them to take on board in one day, a hell of a lot, I mean I don't know, you know, and I put myself in their shoes sometimes and think, you know, how would I be able to cope with it, and some ladies come along and they've got it in their head because they've got a breast lump, well yes, you know, I probably maybe I have got breast cancer, and seem to cope with it quite well. And then obviously you've got the ladies that you know are absolutely shocked, you know, we had a lady came a few weeks ago who had a breast lump but had been told by her GP that he was 99.9 per cent certain that it was nothing for her to worry about because she was quite young. And she came in, you could tell she was really anxious because she was really giggly and, you know, and the registrar actually didn't cope with it, as in he was absolutely brilliant at giving her the news, but because she'd been so upbeat when she came in, he found that quite difficult when he had to go in and break the news to her that she'd got breast cancer because that was really difficult. And she was just absolutely floored ...

INT: I BET SHE WAS, YEAH.

Nurse: Because, you know, she was just totally convinced that she had nothing to worry about, you know, and because the GP had said to her, 'Well you'll be, you know, it's nothing to worry about.' So then you've got somebody that you're trying to pick up then, you've got to pick up the pieces from that then so it can be extremely difficult.

INT: ONCE THEY'VE GOT THE DIAGNOSIS WHAT IS THE PROCESS, JUST BRIEFLY, THE PROCESS THEY GO THROUGH THE CLINIC THEN.

Nurse: Well once they've got the diagnosis then the consultant will discuss treatment options and from there then, they then go on, we take them away and have a chat to them, go through all the written information, discuss the surgery. They'll then go on to have staging tests if they can, like blood tests, chest x-ray, ECG ... if they're able to cope with it on that day. If they can't cope with it that day or, and they don't want to talk to us, we do give them the opportunity to go away and come back at another time and we always do that, you know, because some ladies just want to just go and they don't want to, you know, they can't cope, you know, so they're given the opportunity to come back and we'll make arrangements for them to come back another time. And then, erm, usually once they've had all that and they've had all the staging tests and they come back the following week, see the consultant and he goes, again goes through what, you know, what they've decided surgery-wise they want to do, and then they're consented for surgery and given a date to come in.

INT: AND YOU DON'T DO ANYTHING LIKE HOME VISITS OR ANYTHING LIKE THAT?

Nurse: No, we don't do home visits, no.

INT: SO THINKING ABOUT WHAT WE'VE BEEN TALKING ABOUT SO FAR, IS THERE ANYTHING YOU THINK HERE THAT SORT OF REALLY SORT OF HELPS YOU TO DO YOUR JOB, ANY KIND OF FACILITATOR THINK IN THE WAY THAT YOU DO THE JOB, ANY SORT OF ...?

Nurse: In coping with, what, you know ...?

INT: JUST ANYTHING, YOU KNOW, JUST THE WAY YOU ACTUALLY DO SOMETHING OR WHATEVER.

Nurse: I mean, I think because we're such a, the immediate breast care nursing team, because we're such a close team and we're all people that have worked with each other, you know, away, you know I've worked with some of my colleagues on the breast care ward, so we all know each other quite well, and I think the fact that we know that, you know, if you don't know something you know that you can approach them and you don't feel like, there's no problem about saying 'I don't know this' you know, and never ever problem about that, you know, nobody would ever sort of like think, 'Ooh, why doesn't she know the answer to that?' Everybody's, you know, there's always somebody there to help you and we're able to come away, you know, if you're having a bad time in the clinic, you know, and somebody, you've had a patient that's been quite difficult and emotionally demanding, then there's no problem to go to one of our colleagues and say, 'I just need time out,' you know, to go away and sit and have 10/15 minutes or however long you need out of clinic, somebody'll go over and take over from you. During the course, you know, we know that, you know, if I've, if I've had somebody that's been particularly emotional and, you know, you feel like you're totally drained, I know that I can go to one of my colleagues and say, 'Can I talk to you about this person?' and we do hand over each day so it helps you offload, you know, some of what you've taken on board for that day. And I think that helps with coping.

INT: AND ON THE OTHER SIDE OF THAT, IS THERE ANYTHING HEER THAT YOU THINK SORT OF CONSTRAINS YOU DOING YOUR JOB, ANYTHING THAT SORT OF COULD BE BETTER OR WHATEVER?

Nurse: I think, erm, we could do with some more staff, you know, sometimes, but you know breast care nurses, because sometimes you feel like you're playing, you know on some days you can feel like you're playing catch-up, because you're not only, you're in the clinic, you've got the bleeps, you know, so we're taking, so you can be in with a patient and, you know, or you can be with a doctor, and your bleep goes off and it's an outside call and you know that, particularly on certain days of the week, you know, when the letters for second-stage screening have gone out, you know that it'll be somebody that's on the other end of the phone that's really anxious wanting to know why they've been called back. And it can be, you know, it really demanding and it's, you can feel like you're being pulled in, you know, lots of different directions. So I mean I suppose if there was more staff, if we were a bigger team, that would help, because as I say you just feel like some days you're playing catch-up because, you know, you come out of clinic and there can be things that you've got to do and you know that you've got another clinic to do, and you know that you walk in the office and there's five messages on the answer machine and you can pick up the phone and answer some of the messages and you can be on the phone with somebody for half an hour. So there never seems to be enough hours in the day and there doesn't seem to be enough of us to be able to cope, you know, with the demand workload that we've got. And it would be quite nice to be able to, you know, there are lots of, erm, you know, the services that we would like to expand on to, you know, which might help us. But then again it's staff, like we would like to, you know, we've been looking about having a drop-in clinic; home visits are another thing that we would quite like to do but then there aren't enough of us and it's such a, 'cos it's such a huge area, Leicestershire, to cover.

INT: YEAH, OF COURSE.

Nurse: You know? We would like to do cross-site working because we do have patients that go over to the Royal to have reconstructive surgery and they don't, you know, get the benefit of seeing a breast care nurse. So there's lots of things that, you know, that we can't do and I think that gets a little bit frustrating.

*Q3. DO YOU FEEL THAT PROFESSIONALS HAVE DIFFERENT STYLES OR DIFFERENT WAYS OF WORKING, IF SO, WHAT WAYS HAVE YOU NOTICED?

Nurse: Now, this is the question that had me puzzled as to what you meant by it really as in styles?

INT: IT'S JUST DIFFERENT, JUST DIFFERENT WAYS OF WORKING REALLY, THAT'S ALL IT IS, YOU KNOW?

Nurse: As in the way the clinic's run or the way people ...?

INT: WELL THE WAY THAT PEOPLE DO THEIR JOBS, THE WAY PEOPLE INTERACT WITH PEOPLE, THINGS LIKE THAT, YOU KNOW, JUST GENERALLY THAT, WE'RE ALL INDIVIDUALS KIND OF WORKING IN AN ENVIRONMENT, JUST KIND OF HOW WE SORT OF WORK IN THAT ENVIRONMENT, HOW WE GET ON WITH PEOPLE, HOW WE APPROACH THE JOB AND STUFF.

Nurse: Well I think people, I think, yeah, I mean people do have different styles because I think because everybody's got their own personality so I think, you know, that has a big part to play in it. I'm still not sure what ... I'm still not sure about the answer to that one really. I mean I can think about the way as in styles the way the clinics are, you know, like the consultants run the clinics in slightly different ways, you know, so ...

INT: SO, WELL TELL ME ABOUT THAT THEN.

Nurse: Erm, well I mean one, I suppose it's, that has an impact on the way the rest of the clinic and the way the rest of the doctors because one of the consultants likes to be in total control of the clinic, so she has, she sees all the notes for the patients that are coming to the clinic and then disperses the notes between, you know, the other doctors that are there. So, erm, I suppose that, you know, so then that particular consultant tends to sort of like keep, you know, a lot of the patients back that are potential cancers, so you get the other doctors that get a little bit frustrated because they feel that they're just seeing, erm, you know, ladies that have got benign breast diseases as opposed to the cancers. So that clinic can be difficult, so I suppose that in a way is somebody that's adopted a style and is, that impact, that's having an impact on the way the other doctors, because they sit there and they wait for notes to come through, so you can be sitting waiting for quite some time in the clinic, you know. And then, I don't know, I don't know what else to say really about that one.

INT: I THINK THAT'S FINE. DO YOU THINK THE WAY THAT THESE DIFFERENT SORT OF, THE WAY THAT CONSULTANTS RUN THEIR SORT OF DIFFERENT CLINICS AND THINGS, DO YOU THINK THAT HAS ANY IMPACT UPON THE WAY THE PATIENTS SORT OF GO THOROUGH THE CLINIC?

Nurse: Definitely, because as I say the particular clinic that I've just been talking about, those patients can sit there, that clinic runs on for quite a long time, and those patients can be sitting there for, you know, a long time, because it's a one-stop clinic, so they can be there for hours. And, I think, because you waste, because one doctor's seeing all the notes and is reading all the notes and then, as I say, dispersing them out to the other doctors, so that takes time because, as I say, we can be sitting there waiting. So you do get patients coming through that have been sitting there for a long time waiting for a result, you know, that have been sitting for a long time waiting to come in to see a doctor, then they go on and they've got to have like tests, and then they're sitting waiting again for quite some time, you know, so that does have an impact on, I think it has an impact on how, you know, everybody in the clinic is because, you know, you get the doctors that are frustrated because they're not, you know, they don't feel like they're being challenged; you get the

patients that come in and they're frustrated because they've been waiting for a long time to see a doctor, and it, you know, it has an impact on the clinic and I think and how people feel within the clinic. And, you know, erm, one of the consultants sees, erm, the ladies and, you know, I, which I find difficult, in fact there's two consultants that do it, and I found it quite strange when I first came down here, that the ladies can be diagnosed and consented all on the same day. And I had, and I still, sometimes it still doesn't sit comfortably with me, that I think, you know, that somebody can be diagnosed and be able to make a decision about surgery all on the same day. Erm, it doesn't always happen but it happens quite a lot, and I think that's something that, you know, I think is, and that's, you know, there's two particular consultants that work that way. And I think, you know, that, erm, is quite difficult, and I think it's difficult for us as nurses, you know, the breast care nurses and the patient's advocate, you know, and I do, I have tended to say at that point, you know, 'Well you don't have to make a decision today, you can go away and think about it, and come back.' And some of them will say, 'Oh, no, it's, you know, I'm quite happy,' but it's still, I still don't feel comfortable about that, and that's something that, you know, I probably, and I think we all feel that way that, you know, that can be quite difficult.

INT: OH WELL, ACTUALLY WE'RE GOING TALK ABOUT THAT A LITTLE LATER ON SO ABOUT SORT OF PATIENTS' DECISION MAKING AND STUFF. I'D LIKE TO MOVE ON NOW TO ACTUALLY BEFORE A CONSULTATION WHERE A DIAGNOSIS IS TO BE GIVEN. I'D LIKE YOU TO THINK ABOUT A CLINIC JUST BEFORE A PATIENT'S ABOUT TO HEAR THEIR DIAGNOSIS, AND FROM THIS POINT IN THE INTERVIEW I'D LIKE US ONLY TO FOCUS ON NEWLY-DIAGNOSED BREAST CANCER PATIENTS.

*Q4. WHEN IS YOUR REGULAR BREAST MDT MEETING HELD IN RELATION TO THE CLINIC WHERE PATIENTS ARE GOING TO BE GIVEN A DIAGNOSIS OF BREAST CANCER?

Nurse: Well our MDT meetings are every Monday so it's Monday lunchtime, so and then you've got the patients, the results will have been discussed for the patients that are coming back to a screening clinic that afternoon, and then for the rest of the clinics for that week where the patients will have been on the ward and had surgery, so for the follow-up clinics and the other screening clinic on the Wednesday. So, you know, that takes place as I say at the beginning of the week so you've got all the results through for the week really.

INT: AND ARE PATIENTS DISCUSSED PRE-OPERATIVELY AT THAT MDT?

Nurse: Yes, yeah.

INT: QUESTION 5'S AN INTERESTING ONE ...

*Q5. HOW DO YOU USUALLY FEEL AFTER AN MDT MEETING?

Nurse: It is an interesting one and we all, you know, because we've talked about this, not from this, not from the interview, and I found it, when I first I came down here and I'd been to MDT meetings before on the ward, I've been a couple of times, and then I deliberately didn't go again because it's really difficult when you're on the ward and, you know, you've been and you know somebody's results, erm, and I think, as I say I went a couple of times, and when we're down here we don't always go, I might not go every week because somebody else might go to the MDT, but when you do go, you, it's, it's, I find it really difficult and we've talked about this and Jane said exactly the same and Sue, that they feel that you feel that you've been given privileged information and you, you know, you have to hold on to it and you have to be professional, when you're in the clinics and you know, you're walking up and down the corridor and the ladies are there and you know that they're coming in and you know their results and you have to be, you know, unemotional, you have to be professional

about it. And you almost feel, I sometimes almost feel deceitful because I feel like, and when you go on the ward as well, because you can go up to the ward, you can be at the MDT on a Monday and you might go up to the ward the following day and you know that you're sitting talking to somebody and you know their results, and you know that they're going to be coming back to the clinic at the end of the week and they might have really good results and you, you know, it's really difficult when you know somebody's got really bad results. And ...

INT: DO THEY EVER, DO THEY ASK YOU?

Nurse: No.

INT: [???] ASK YOU?

Nurse: And we don't tell them that we go to, we don't tell them that, because that was one of the things that I asked when I came down here about the MDT and I was told, you know, we don't disclose that we go to the MDT, because I think that, you just, we just couldn't because then the patients would know that we are priv-, you know, privileged to that information, and they would, you know, they would know that we've got those results and I think that would, you know, it's the same as like, erm, we've always said that we don't like the ladies knowing their results on the ward because, you know, it's occasionally happened where somebody's, where one of the consultants has given the lady her results on the ward and it has a huge impact, if it's bad results it has a huge impact on the rest of the ladies on the ward because, you know, like, you know, they know because they go back and you know at some point they discuss it with everybody else, and if they're really bad results, you know, it really brings the ward down. So it's, I find it really difficult. But you just, you know, not so much now, when I first came down here I was going to the MDT but then you just have to just detach yourself from it and, you know, it's part of what you do and, as I say, you just, but there are times when you know that somebody, you know, occasionally, and you think, 'Oh God,' when they awful results, you know, and you just feel, you know ... but you feel, you tend to feel that in the MD-, I tend to think when they're going through the results and you're looking at the PASS slide and they're talking, and you kind of like think, 'Oh no ...' but then once you come out of the MDT you've left it there then because you kind of like, you know, or we come back and we talk about it amongst ourselves and then, you know, we leave it here and then so we don't take it away, you know, up to the ward or into the clinic area. But you do feel a bit ...

INT: AND DOES THAT SORT OF VARY ACCORDING TO THE EXACT WORKLOAD AND WHAT-HAVE-YOU? IF YOU'VE GOT A HEAVY SORT OF CASELOAD THAT DAY OR A LIGHT CASELOAD, DOES IT VARY AT ALL?

Nurse: I don't think it, no, I don't think, you know, what your caseload is. I think it, you know ... and I think it varies on whether you've been involved with that, you know, particular lady as well. You know, if it's somebody that you've been involved with and particularly if you know some of their per-, you know a lot of their personal things that are going on in their life and so you know that, like, you know whatever the results are, good or bad, you know that, what kind of impact it's going to have on them, you know. And particularly if you know, if they're bad results, you know that it's, you know, if you know the personal things, if you know that they, you know, whether they've got physical handicaps or whether they've got, you know, children or whatever, and you just know that that's going, you know, kind of have a huge impact on them.

INT: YEAH.

*Q6. AT A PRIOR CONSULTATION, IF IT WAS SUSPECTED THAT A PATIENT HAD A BREAST CANCER, IS THERE ANYTHING ELSE YOU, OR ANYONE ELSE IN THE TEAM WOULD DO, OR SAY TO THEM, AT THAT STAGE?

Nurse: Well, I think, you know, if they've been given a provisional diagnosis then I think a lot of it is in how it's given, you know, and, erm, us giving them as much information to take away as possible, and support, you know, that they know that they are supported, that they're able, that they're given a contact card, that they know that they can, you know, contact us at any time, you know, we tell them when we're available and that they can ring and to, you know, erm, and as I say information, tell them as much as you can because it might be that, erm, it might not be that you've got a diagnosis at that point because it might be that they're having to come back, so ... are you talking about somebody that's been diagnosed or ...

INT: NO, SOMEBODY WHO, IN PARTICULAR, WHO'S KIND OF HAD TESTS WAITING FOR RESULTS AND THEY'VE GOT TO COME BACK THE FOLLOWING WEEK.

Nurse: Yeah, so you just have to give them as much inform-, you just have to be as honest as you can be, I think, you know, and you have to give them as much support as you can, give them as much information as you can so that they can take it away. But I think support is the most important thing, that they know that there's somebody there that, you know, the breast care nurses, that they know that there's somebody there that they can get in touch with and talk to whenever they want to. And go through things, because it might be that they just haven't taken anything on board and that if they want to come back and speak to us they can, you know, if they want to come back, you know, physically come back and speak to us they can do. Or if they want to ring us, you know, that they're given a contact card. And, you know, make sure that before they go that they know, that they understand what they've been told, because sometimes they don't, you know, the doctor can go through everything and then when you take them away they haven't got a grasp on what's been said so it's, you know, that you make sure that, you know, that they do understand what's been said. And you give them, sometimes they're on their own and sometimes it's like, we like to give them the opportunity to say, 'Do you want to ring somebody and get them to come along?' so they've got another pair of ears to hear what's being said. Because again, you know, even if you do go through it, they might go away and still not have got a grasp on it. So, as I say, it's important that they know that they can get back in touch with us.

*Q7. IN WHAT WAY DO YOU THINK PATIENTS, IN ANY WAY, ARE PREPARED THEMSELVES FOR THE NEWS THAT THEY HAVE BREAST CANCER?

Nurse: I think, erm, from the previous visit, I think the support, knowing that they've got the support, erm, and information, they've been given as much information as, erm, they can, I think, erm, sometimes it can, you know like the GP, you know if they've come to the symptomatic clinic and they've got a lump I think sometimes the GP can have indicated that they might - not all GPs but very occasionally you get some GPs who, you know, do, you know, some patient'll come along and say, 'Oh the GP did say he thinks it, you know, he was a bit unsure that it might be something a little bit suspicious,' so they might have like planted the seed there. Sometimes they feel like they know themselves if they come along to the clinic, you know like you get some ladies that come along and say 'I know, I know I've got breast cancer, because I've got a lump I know,' and you know you try to sort of like reassure them and say, 'Well, until we do the tests, you know, let's take it one step at time, 'til we've done the tests and we've got the results we won't know,' you know, 'Let's just take it slowly.' And you can't convince them otherwise. So ...

INT: DO YOU THINK THAT'S A KIND OF COPING MECHANISM?

Nurse: Yeah.

INT: DO YOU THINK THEY KIND OF 'WELL IF I KNOW, IF I SAY I'VE GOT BREAST CANCER NOW' [???

Nurse: Definitely, so I think those that, you know, in a way that's them preparing themselves, that's when they're prepared I suppose, and I think anybody who's, I think any woman would feel like that if they've got a breast lump. Not necessarily that they'd got cancer, but I think they'd come thinking, 'Well it might be or might not be,' so if they're, you know, in your mind you do prepare yourself for something anyway, you know, whether it's going to be, you know, whether it's, you know, breast cyst or, you know, particularly if they've got a lump.

*Q8. PRIOR TO A CONSULTATION WHERE YOU KNOW THAT A PATIENT WILL BE GIVEN A DIAGNOSIS OF BREAST CANCER, DO YOU HAVE ANY EXPECTATIONS ABOUT WHAT THAT CONSULTATION'S GONNA BE LIKE AND WHAT ARE THEY BASED ON?

Nurse: Yeah, erm, I was thinking about this one because ... yes you do because (1) I think, going back to sort of like the MDT and you might have the, you might have, you know their results. If you've met the lady previously, I think that sometimes, and I was thinking back to a young lady that I'd met just before Christmas and, erm, and she was coming back on Christmas Eve for results that were absolutely horrendous and she was only young. And I can remember, you know, up to sort of like two or three days before, I felt quite anxious about that because I was anxious about how she was going to react, because I thinking, you know, all the things like she's only young, you know, she's this, she's that, she lives on her own, how's she going to cope? And, you know, all those kind of things, and actually when it came to the actual consultation she was, she came with her brother, and she was totally prepared, she had lots of questions to ask and she was absolutely brilliant and she, and it was, went totally the opposite way to the way I thought, she reacted completely different. And I think, you know, the fact that, erm, as I say, that you've met them previously, that you know some of their personal details, so sometimes you have in your own mind how you think that person may react. And they can just surprise you and be absolutely fan-, because they've got the coping mechanisms in place. And another example was that I had another young lady a few weeks ago and she was absolutely fine and she came with her Mum and her Mum absolutely crumbled, and she was struggling to cope with her Mum, you know, and I was there, and that was difficult because her and I were trying to cope with the Mum that was like really upset and was crying and very, really, really emotional. So that was quite difficult because you just can't, you know, and in that respect, and when I went in to see her with the consultant, this particular girl, I knew that she was going to cope quite well from the way she'd been the week before and as I say, and she did but it was like her Mum that was there was that was like, you know, really difficult. And I think you know, if they've been, you know, you can be unsure of how they're going to be before you go in because if they've been really anxious or tearful the week before and you know that they're coming back for horrible results, then you don't know, you kind of like think, 'Oh goodness, what's ...?' you know, 'How are they going to be? How are they going to cope?' so you know I think you do sometimes go in with preconceived ideas of what it's going to be like. And that can have an effect on how, you know, you, I think you feel, because I think you do, you can go in feeling a little bit anxious yourself as to how they're going to be.

INT: AND WHAT ABOUT, YOU KNOW, OBVIOUSLY THERE'S DIFFERENT CONSULTANT RUNNING DIFFERENT CLINICS AS WELL, DOES THAT HAVE AN IMPACT AT ALL ABOUT HOW YOU MIGHT EXPECT A CONSULTATION TO GO? SAY 'OH WELL IT'S MR Y THIS AFTERNOON' OR 'MISS X OR SOMETHING,' YOU KNOW THEY'VE GOT THEIR CERTAIN WAY OF WORKING ...

Nurse: Well I only work, I mean it's quite, it's quite different in this unit and Marlene probably told you yesterday that we don't all work, we all work with our own consultant, and I've only just recently started working with one of the consultants on a Friday and, erm, in the symptomatic clinic ...

INT: HOW HAVE YOU FOUND THAT THEN FROM WHAT YOU'VE BEEN USED TO?

Nurse: Erm, I've recently, well, because I'm actually there when the consultant's, you know, doing the, you know, talking to the patients and giving them their results, erm and, you know, part of the decision making process now, you know, with the patients, I've quite enjoyed that because before I've just been with the registrars, so they may be, the patients may be getting their results, the provisional results from the registrar, but I've not been there when they come back to discuss with the consultant about their treatment options. So from that point of view I feel like I'm going through the whole process with them now, you know, which is quite good because I might see them the week before with the regi-, you know, I might have seen them the week before, either the screening clinic or at previous symptomatic clinics, so it's quite nice to be able to see them when they come back to see the consultant and be part of that. And that's only just, that's only happened for me within the last few weeks. So I don't know how ... I think knowing some of the personalities of some of the consultants, I think that, you know, when you, erm, you know from handover, when we have handover and colleagues tell you about the patients, you sometimes think, well you wonder how, you know, there can be personality clashes with some of the consultants, but as I say, because I'm only in with one particular consultant I don't really ...

INT: YOU CAN'T SORT OF COMPARE DIRECTLY AT THE MOMENT.

Nurse: No, no. No, because, you know, we all seem to, like Jane works with one particular consultant; Sue works with another: Marlene works with another and I work with ... so it's, you know, we all tend to sort of like keep to one consultant.

INT: OK. ERM, WE'LL MOVE ON NOW.

[Interruption in recording]

*Q9. HOW WOULD YOU DESCRIBE YOUR FEELINGS BEFORE SUCH A CONSULTATION? [Not asked?]

INT: SO I'D LIKE TO TALK ABOUT WHAT HAPPENS DURING A CONSULTATION WITH A NEWLY-DIAGNOSED PATIENT.

*Q10. CAN YOU JUST TALK ME THROUGH WHAT HAPPENS IN A CONSULTATION WHERE DIAGNOSIS AND TREATMENT OPTIONS ARE BEING DISCUSSED WITH A PATIENT WITH BREAST CANCER. SO IMAGINE THE PATIENT'S JUST COME IN, THEY'RE THERE IN THE CONSULTATION, JUST SORT OF SKETCH THROUGH WHAT HAPPENS IN THE CONSULTATION.

Nurse: I think one of the first things is, you know, like that you need to establish what, why, you know, ask the patient what they've been told previously because it might be that it's not the consultant, because depending on if it's a symptomatic clinic and it's a one-stop clinic, then yes, they will have seen the consultant, but if it's a screening clinic they may have seen one of the other doctors prior to, you know, seeing the consultant, so it's important that, you know, like they establish what the patient understands and what they know of why they're there, erm, and then they go on to discuss the results, you know, like of the biopsies of FNAs, whatever they've had, explain to them about that and, you know, what it's shown, that it is a breast cancer, and then they go on to

discuss, you know, like, then they usually sort of like talk about, erm, past medical history problems, individual circumstances, you know, if there's anything going on with the patient personally, they'll talk about that. And then they go on to talk about treatment options and surgical options. Then they go on, usually then there's some kind of general discussion between the patient and the consultant. They then might go on to have, you know, they'll tell them that they need to have staging tests done. At that point that's usually the point when we take them off and have a chat with them, so we'll go through everything that's been said to them, make sure that they under-, what they understand, do through all the, you know, give them the written information, any support booklets that they might want, erm, whether they, you know, that's if they want to stay and go through things - if they don't then they're given the opportunity to come back at some point and go through with us again. And then they go off to have their staging tests done. And then they, you know, they might come back the following week to have their consent forms done, sometimes they're consented on the same day if they're happy to go ahead and consent for the surgery.

INT: SO IS IT ALWAYS THE CONSULTANT THAT SORT OF TELLS THEM THE DIAGNOSIS, THE NEWS?

Nurse: No, no, sometimes it's the Registrars that do it.

INT: OH, AYE, OK, YEAH.

Nurse: So it might be, depending on the clinics, sometimes it's, erm, the registrar and then they'll come back the following week and see the consultant to go through the, you know, the surgical options. The registrars might, might tentatively, you know, discuss with them about surgery, but then, you know, and tell them the surgical options, erm, there are some, some specialists, you know, associate specialists down here who sometimes, erm, do discuss, you know, when they've got the results, discuss surgical options, but that's interesting because I had a conversation with one of the consultants the other day who felt that, erm, if, you know, if one of the associates is not a surgeon themselves, erm, you know, shouldn't be discussing surgical options with somebody. So you might argue that then should they really be giving them their results because you can't really give somebody their results and then not discuss what the possible options would be.

INT: [???

Nurse: So that, you know, and that's only happened in the, that's only been talked about in this last week. So, but I think that that's something that the consultant's going to take up, you know, with the associate specialist, you know, and see how that goes on.

INT: SO WHO'S NORMALLY IN THE ROOM WHEN A DIAGNOSIS IS GIVEN? THERE'LL BE OBVIOUSLY THE CONSULTANT, THERE'LL BE ...

Nurse: The consultant, occasionally there are medical students there, erm, myself

INT: OR A RESEARCHER, I'VE BEEN IN BEFORE, YOU KNOW WHEN I WAS DOING PREP FOR THIS WORK.

Nurse: Yeah, yeah.

INT: [BREAK IN SPLIT TAPE - SOMETHING MISSING?]

Nurse: It is, isn't it? It's a real eye-opener. And then there'll be a breast care nurse and the patient and any relative that's with the, anybody that's with the patient.

INT: AND AMONG THE CONSULTANTS THAT YOU'VE OBSERVED, DO YOU THINK THEY HAVE A SORT OF PREFERRED SORT OF APPROACH TO SORT OF DIAGNOSIS? DO THEY HAVE A SPIEL AS THEY LIKE TO CALL IT, YOU KNOW, WHEN THE PATIENT COMES IN OR ...?

Nurse: Yes, yeah, they do. Yeah, most, you know, sort of like, well I've only observed one of the consultants and, yes, they do have their own spiel, which is quite interesting, the way some of them say things.

INT: CAN YOU SORT OF JUST BRIEFLY DESCRIBE IT?

Nurse: Yeah, I mean, there's, one of the particular consultant he'll tend, erm, tends to say, you know, 'You've got a little cancer,' you know, which is quite sort of like, it's just the way, whether it's the way he just copies with, you know, saying, but, you know, he'll tend to say, 'Oh you've got a little cancer and this is ...' you know, and then go on to discuss what treatment options would be available, you know. But, erm, and this particular consultant likes to, will examine the ladies in the examination room and then will let them get dressed and fetch them through to the consultation room then. And always brings his chair out from under the desk, you know, like so, and sits sort of like to one, not directly in front of the lady but to one side but not so that the desk is like ...

INT: LIKE A BARRIER BETWEEN THEM.

Nurse: Yeah. Which is quite nice, but doesn't like sit fa-, you know, face on, so it's not quite to intimidating. But you can see the ladies' reactions when they, because, when they're coming back for their results, particularly if they've been the week before, and they're examined and then they come into the consult-, and you know, you just know that they know that there's something because you can see it on their faces. Or they'll come through and sit down and then the consultant moves the chair and some of them will say, 'Oh, you're going to give me bad news, aren't you?' and they kind of like know before he's even said anything.

INT: YEAH, YEAH, IT'S, WELL I MEAN, WHAT IS IT, IS IT 65 OR 70 PER CENT OF COMMUNUCATION'S BODY LANGUAGE ANYWAY.

Nurse: Yeah, yeah.

INT: THE THINGS THAT WE ACTUALLY DO, SO, ERM, YOU DO PICK UP [???

Nurse: Of course you do, yeah.

INT: I MEAN I SUPPOSE THAT, I WAS JUST GOING TO SAY, YOU'VE BEEN TO THE CONSULTATION WITH THEM, WE'VE TALKED ABOUT SORT OF THINGS LIKE PEOPLE IN THE ROOM AND WHAT-HAVE-YOU, ERM, YOU THEN OBVIOUSLY WALK WITH THE PATIENT TO A SEPARATE, QUET ROOM?

Nurse: Yes, yeah.

INT: YEAH, SO TELL ME A LITTLE BIT ABOUT THAT.

Nurse: Well, erm, what I usually do is establish that they understand what the consultant's said to them, what their understanding is, establish that they do understand that they've told that they've got a breast cancer, and you know by asking them what they understand, because it's surprising because some ladies'll

say, 'Is it benign or is it malignant?' because they don't, and so then you have to go on and explain the difference between benign and malignant, because sometimes they haven't, they've taken on board what the consultant's said, but then quite a lot of people, as I say, don't know the difference between benign and malignant, you know, so they just, you know, you have to established that they understand that, yes, they have got a breast cancer. And then I go on to discuss, I ask them then if there's any questions that immediately pop out of their, you know, their head, you know, do they want to ask. And then we're, you know, because sometimes ... and then, but at that point you then find that sometimes they go like ten steps ahead, you know, immediately because they usually then, one of the questions that quite often is asked is, 'Do I need to have chemo?' that's one of the things that I find the ladies tend to ask, 'Do I need to have chemo?' you know, so, you know, I answer it and then I say, 'But I'll take you back now, because we've gone like way down the road, so I'll take you back ...' And we talk about what the consultant's talked to them about, make sure that they understand, and then I give them the written information, go through all the written information, discuss with them about coming, the surgical treatment that they would be having, their in-stay, erm, all the practical issues with regards that, they'd have their drains, how long they'll be in, what happens when they go home, you know, coming back for their results, and then talk about, you know, whether they might, you know, if they need to have further treatment and I briefly talk about that, I don't go into it in depth, and I try not to let them draw me into, because I think, you know, like, because what I tend to say that, you know, 'That will be discussed...', you know, 'When you come back for your results we'll go through that in more detail at that point,' so, you know, I just briefly talk about that. I make sure that they've got appropriate information if they need it, like some people want booklets about talking to children, some people want booklets, you know, about all sorts of things. Make sure that they've got support group information if they want it, you know, so that they can get in touch with other people if they want more information. Make sure that they've got a contact card, that they know how to get in touch with us, and, you know, then we go on to discuss about that the need to have staging tests done, why they need to have their staging tests done. And then, erm, I'm not involved with this particular consultant, but there's one consultant who goes through the treatment options with the ladies and then sends them away with the consent form and whoever the breast care nurse then, and sometimes I, although I don't, I'm not actually in with that particular consultant, it's one of my colleagues that is, sometime I'm actually asked to go and go through a consent form with somebody, which is quite difficult when I've not actually been in on the decision, you know, when I've not actually been there ...

INT: WHILE THEY'VE MADE A DECISION AND BEEN TALKED TO AND ALL THE REST OF IT, YEAH.

Nurse: Yeah, so then I have to go, you know, and, you know, I'll, sometimes I've been asked, 'Can you go with this lady while she goes, and go through her consent form with her?' so then I have to go in but it's like going in blind really. And before I'll do that I will make sure that, you know, that they understand, they tell me what they've told, make sure that they understand. But it's difficult because you're only guided by what they're saying to you.

INT: YEAH, OF COURSE.

Nurse: And when you've not been there and heard what the consultant said to them. And they might ask me things that, if ...

INT: [???] INTERPRET UNDERSTAND SO MUCH OBVIOUSLY, YES, YEAH.

Nurse: Yeah, yeah. I mean and I have said that I don't particularly like doing that because it's, you know, but sometimes it's unavoidable because it depends on, you know, that particular consultant's work, you know, clinic that day and how busy the breast care nurse is that's with that consultant. So sometimes, you know, it does happen. But I don't particularly like, as I say, because it's, you know, you feel that, you know, quite often I have to say to the lady, 'You need to go back and ask the consultant that when you go back in,' because I wasn't there, you know, to be able to hear what the, because they'll say, 'Oh, the consultant said 'What does ...' you know, said this ...' and because I wasn't actually there to be able to hear what they'd said I can't always comment, you know, and give them an answer so that's, that can be quite difficult really...

INT: YEAH, I BET IT CAN.

Nurse: ... you know, from that point of view.

INT: DURING CONSULTATIONS DO YOU, ERM, DO ANY CONSULTANTS OR YOURSELF USE THINGS LIKE ANY TOOLS, LIKE X-RAYS, MAMMOGRAMS, DIAGRAMS, PICTURES, ANYTHING LIKE THAT?

Nurse: Oh, yeah, yeah. Erm, they'll, quite often they'll, not always, they don't do it with everybody, but quite often they will show them their mammograms. Not so much the ultrasounds but they'll show them mammograms because, you know, particularly in a screening clinic, erm, when they do, erm, the consultant that I work with always draws a picture of like the surg-, you know, sort of like in relationship to the area that is going to be removed, or if it's the, you know, if it's a wide local then he'll show them the area that is going to be removed in relation to, like, the axilla and shows them on a diagram how the scar would be, where it would be. And if it's a mastectomy he always draws a picture of like where the incisions will be on the breast and he does that for everybody. So, always draws his diagrams.

INT: AND DO THEY GET WRITTEN INFORMATION AS WELL FROM YOURSELF?

Nurse: Oh yeah, yeah, they get ... and they'll get both, you know, like if they've, obviously, if they're offered both options of surgery then they're given both lots of information and we go through both lots of information with them.

INT: AND WHEN YOU'RE IN THE CONSULTATION, JUST TRYING TO THINK IN GENERAL NOW, ACTUALLY IN THE CONSULTATION WITH THE CONSULTANT, WHO TENDS TO ASK MOST QUESTIONS, WHO TENDS TO DO MOST OF THE TALKING? IS IT THE PATIENT/DOCTOR, WHO IS IT?

Nurse: Erm ... it varies, I think it varies on how the patients take the results, and I think, you know, and I think it depends on, you know, because if they're absolutely stunned, you know, some patients are absolutely stunned, and they just sit there and they just nod and say 'Yes,' and, you know, at that point sometimes I'll say, 'Do you ... are you, you know, are you understanding what the consultant's saying to you?' because sometimes you can see, you know, that they're not taking anything on board, and sometimes you have to say, 'We need to ...' you know, and sometimes the patients'll be so upset that you have to say, 'I'm going to take you away ...' you know, like, for, you know, like, 'Do you want to, you know, go away and we'll sit in a quiet room for 10 minutes ..' or however long it takes, and take them back. Because sometimes it's, some people can't take it on board straight away, you know, because they're so upset, you know, so sometimes you have to stop the consultation and say, you know, like, 'We need to go away and just, you know, sit and be quiet for, you know ...' or it might be that you need, if they're on own, you need to, you know, and they're really upset, that you need to be able to give them the opportunity to

say, you know, do they want to ring somebody to come in and be with them, you know, because they can't take in, you know, take all the information on board.

*Q11. I'D LIKE TO MOVE ON NOW A LITTLE BIT AND TELL ME ABOUT ANY ADDITIIONAL TIME YOU USUALLY HAVE WITH A PATIENT AFTER THE PART OF THE CONSULTATION WHERE THE DOCTOR IS PRESENT? WE'VE OBVIOUSLY TALKED ABOUT, YOU KNOW, YOUR TIME WITH THEM IN THE QUIET ROOM AND THAT, YOU DON'T DO HOME VISITS ...

Nurse: No.

INT: WHAT ARE, HAVE YOU GOT ... THERE'S A LIST THERE, CAN YOU TELL ME ABOUT ANY OF THOSE PLEASE OR ALL OF THEM IF YOU CAN?

Nurse: Well I mean the outpatients immediately post-doctor we've talked about. We do, erm, sometimes telephone, call them at home because we might, they might have ...

INT: YOU CALL THEM AT HOME?

Nurse: Yeah, because it might be that they've asked, you know, like, that they've gone, that they've asked something and it might be that at that point in time you can't get back to the consultant, you know, because it might be something that you don't know that you need to, you know ...

INT: GO AND CLARIFY SOMETHING.

Nurse: ... and you might need to say, 'Well, I need to clarify that with the consultant,' so you may ring them at home. But I mean we don't tend to ring to see how they've coped with their results, you know, we tend to, unless, you know, it's somebody that's, you know, very occasionally you might ring them and see how they're getting on. But, erm, we don't usually see them in pre-assessment clinic but, having said that, if, you know, somebody was in pre-assessment clinic and, you know, my colleague that works over there, Sue, if she rang over and said, you know, 'I've got somebody here and she's not sure about what's been said and she's, you know, really upset ...' and it's somebody that I've seen or I know, or, you know, I might, or one of my co-, or it's, one of my colleague's has seen them, it might be that we'd go, you know, we'd go over there and see that lady and make sure that they do understand, you know, what's been said or we might say, you know, they can come over here and we can have a chat and go through things with them, that's not a problem. We do see them on the ward pre-operatively because we go up on the day of admission, you know, and see them, and then we see them daily on the ward. Erm, and then it says 'Is there any other time that you might see them?' and sometimes we offer that, you know, if they've been given their results and they want to just go away and we give them the written information and they don't want to stay at that point because they can't cope with it and they just want to run away and go home and get to grips with it, then we make sure that we give them the opportunity to come back. And that's, as well, that's another time that I might ring them and say, 'Well, instead of you ringing me and letting me know, do you want me to ring you?' you know, and I'll leave it and ring them either later that day or ring them the following day and say, 'When do you want to come back and see me?' you know, so that's another time that, you know, and sometimes they'll ring, you know, as I say, they'll ring up, and sometimes you might see somebody three or four times before, you know, they come for surgery because they might ring in to say, 'Can I come ... you know ... and see you?' and you might talk to them on the phone and then you might think, 'Well I'm not ...' you know, this isn't, you know, we're not getting anywhere here really, you probably need to sit down one to one and speak to them, you know, face to face. So you invite them to come along to the breast care centre and they'll come back and we'll go and sit and have a chat and go through things again.

INT: MM, YEAH. SO WHAT SORT OF THINGS MIGHT YOU DISCUSS AT THESE STAGES?

Nurse: Sometimes they might just want to go through the results again, they might want to go through their treatment options again, you know, if they're unsure about what, you know, if they've been given, you know, both options, wide local excision as opposed to mastectomy, why have they been, you know, why have they been given both options, you know, and you go through, you know, the both options. They might want to talk about, particularly if they're thinking about mastectomy, they might, they tend to go away and then they'll want to speak to you about reconstruction or they'll want to speak to you about prosthesis, and you might, you know, at that point sometimes have brought ladies back and said to them, you know, if they've said, 'Well I'm really thinking about, you know, having a mastectomy,' and you know I've brought ladies back and said, 'Well, do you want to come back and look at the prosthesis?' you know and we take, fetch them back and they go in the fitting room and we show them the prosthesis and, you know, the permanent prosthesis and the temporary prosthesis and, you know, and give them, you know, written information about that. So, and that, you know, sometimes helps them cope.

INT: YEAH, MM. AT ANY OF THOSE POINTS ARE YOU AWARE OF ANY KIND OF SORT OF EXTERNAL INFLUENCES ON THE DECISION MAKING THAT COMES INTO THINGS?

Nurse: Yeah.

INT: LIKE BEYOND THE UNIT OBVIOUSLY.

Nurse: Yeah, because they go away and they talk to their family and they talk to friends and they know, and all, I mean I tend to say to the la-, I tend to say, because they'll come back and they'll say, 'Oh I know such and such a body has had a mastectomy,' or 'Somebody's told me, somebody's that had a mastectomy ...' or 'Somebody's had chemotherapy...' or ...you know, maybe a family member's had breast cancer so, you know, and I always, they tend to say to you, I mean as soon as they go out and tell people that they've got breast cancer, then people come out of the woodwork and tell them all sorts of things, you know, that they know people, and I tend to say to them, that I think sometimes you have to choose and be careful who you tell because there's always people out there that, you know, and we all know somebody that the minute you say something, who'll tell you all the bad things, you know, and I think, you know, they have to have a bit of self-preservation really to protect themselves against that, you know, because there are people out there that don't mean to be but always tend to tell people, as I say, the negative things, you know, and it can be quite mean really sometimes because they'll say things to people that, you know, they don't think about, you know. So, yeah, they do get a lot of information from lots of people around them. And, you know, partners, you know, when the ladies come along partners sometimes have a lot of, you know, influence on how, you know, what decision they might make with regard to surgery. And I think they find it difficult, I think a lot of ladies find it difficult because they tend to sometimes say, particularly if they're thinking about mastectomy, because, obviously because they're looking, they're thinking about their body image and their sexuality and their femininity, and the partners, and you quite often hear the partner say, 'Well it doesn't bother me, you know, as long as I've got you it doesn't bother me.' And I think the ladies find that quite, you know, a lot of ladies find that quite difficult because, you know, it's, you know, they think, I think they, I was talking to a lady recently and she said, 'I know what my husband's saying but ...' she said, '... but, you know,' and she said, 'And I hear what he's saying and I understand it, but ...' she said, 'neither of us know what the impact will be after surgery.'

INT: WHEN YOU ACTUALLY HAVE TO FACE IT.

Nurse: Yeah, and she was talking about, you know, and she, and then we, you know, we talked about, you know, physical, you know, physical relationships, sexual relationships, because she was really concerned about that, but she understood what her husband was saying and I think most of us would understand that, you know, and it's ...

INT: AND IT'S PROBABLY ALSO THE FACT THAT SORT OF, I MEAN HE MIGHT NOT BE BOTHEED OR HE MIGHT FEEL THAT, YOU KNOW, YES I CAN COPE WITH THAT BECAUSE I UNDERSTAND IT'S HAPPENED, BUT IT'S SORT OF LIKE HOW SHE WANTS TO PRESENT HERSELF TO HIM AS WELL, YOU KNOW, SHE MIGHT WANT TO THINK, WELL, YOU KNOW, I WON'T FEEL HAPPY ABOUT THE WAY I'M GOING TO LOOK TO YOU, YOU KNOW.

Nurse: Yeah, yeah. And I think that's, I think that's a partner's coping mechanism as well to say, you know, like, 'Well it doesn't bother me as long as I've got you,' but then they don't, I don't think they take on the full impact, I don't think partners take on the full impact of how, you know, it's going to affect them after surgery, you know. Some do but a lot of men don't, it's surprising how many partners do say, you do hear them say, you know, as I said, you know, 'It doesn't bother me as long as I've got you.'

INT: MM, YEAH. I THINK ONE OF THE THINGS THAT I HEARD WHEN I FIRST CAME TO SHEFFIELD WAS I HAD TO FINISH OFF A STUDY THAT WAS LOOKING AT WHY WOMEN WITH BREAST CANCER DON'T JOIN CLINICAL TRIALS AND AS PART OF THAT WE USED TO LEAVE A QUESTIONNAIRE WITH THEM WHICH I THINK IT WAS THE EORTC QLQ30, I THINK IT WAS, QUALITY OF LIFE QUESTIONNAIRE, AND THERE WAS A COUPLE OF, WELL MORE THAN A FEW, A GOOD FEW MEN ACTUALLY SAID TO US, YOU KNOW WE WENT BACK TO DO [???] INTERVIEWS WITH THESE PEOPLE, SAID THAT THEY'D ACTUALLY HELPED THEIR PARTNER COMPLETE THE QUESTIONNAIRE AND THEY SAID THEY HAD HAD NO IDEA WHAT THIS PERSON WAS GOING THROUGH UNTIL THEY ACTUALLY STARTED READING THE QUESTIONS AND SEEING HOW THEY WERE BEING FILLED IN. YOU KNOW, AND THEY REALISED JUST HOW COMPLEX IT WAS. I THINK SOMETIEMS YOU TEND TO SEE THE PERSON AS A WHOLE AND YOU TEND TO SORT OF SEE THEM AS A BODY AND A PERSON AND SOMEONE YOU KNOW, AND NOT ACTUALLY SEE INSIDE THEIR MIND, WHICH IS VERY DIFFICULT, IT'S VERY DIFFICULT.

Nurse: Yeah, I don't think the partners see, don't think, they don't think about the emotional implications it's going to have on, you know, on that, you know, on their partner, you know, how it's going, you know, how they're going to feel with only one breast, you know. And I just don't think, because they just think, 'Well I'm just ...' you know, '... I just want my wife to be here,' you know, 'I want my partner to be here,' and they don't think about, you know, what their part-, you know, that side of it, you know, and they see them and they see that they're upset when they get their results and, you know, the majority of partners are very supportive, but then, but they're only focused on that point in time, I don't think they think beyond that, you know, and you know that the ladies are thinking - even at that point they're thinking beyond that.

INT: I'M AWARE WE'VE GONE OVER AN HOUR NOW ... COULD WE JUST MOVE ON TO PATIENTS' INFORMATION NEEDS PLEASE.

*Q12. IN YOUR EXPERIENCE, WHAT DO PATIENTS TEND TO KNOW ABOUT BREAST CANCER AND ITS TREATMENT OPTIONS BEFORE THEY SEE YOU?

Nurse: Erm, I think some know, I put some very little, some know nothing, because I had a lady the other day that said, you know, 'I don't read anything, I don't read anything about health, I know nothing. I don't, you know, listen about things like that,' so, you know, she had no idea about anything. And a very intelligent lady didn't, you know, but she just said, 'I just don't get involved in that,' you know, in women's health issues. And then you get some people that, like we said before, that know, that come along and say, 'Oh, yeah,

I know somebody that had breast cancer and they told me this, this and this,' or they come, you know, like, and they've, they've read up even before they've had, you know, like, you know, before they've had a diagnosis, so you get some people coming along, as I've said, that say, 'Oh I know, I'm sure I've got breast cancer,' so they'll have read up all about and think, you know, and know everything about it. Or, and you get the people that come along with big folders full of information, you know, ready to ask lots and lots of questions. So you can go from one extreme to the other: some know nothing and some, you know, tend to think that they know everything about it.

INT: DO YOU THINK THAT SORT OF RANGE OF INFORMATION THEN FROM LIKE VIRTUALLY NOTHING TO THE BIG FOLDERS YOU'RE TALKING ABOUT, DO YOU THINK IT MAKES FOR AN EASIER OR A HARDER CONSULTATION PROCESS IF THEY'VE GOT LOTS OR NO INFORMATION OR ...?

Nurse: It makes it hard-, I think those that know nothing can be hard because you need to, you know, establish, you know, when they say they don't know anything you need to establish what they don't, you know, sort of like ...

INT: WHAT THEY EXACTLY DON'T KNOW.

Nurse: Yeah. And I think that's easier to cope with. Those that come with like the big folders is really worrying because you're kind of like, and we all cringe, we all say that we cringe when we see somebody come in with a big folder because, you know, it's nice to know that they've been interested and that that they're informed, but then you worry about, it can feel intimidating as well, you know, because you do get the people, we had somebody recently that came with a big folder and two tape recorders to tape the consultation. So that can be really intimidating.

INT: WHAT ARE YOU TRYING TO SAY ...? [CHUCKLES] I ONLY BROUGHT TWO MICROPHONES.

Nurse: It can be intimidating and it's intimidating, you know, and my colleague that was involved in that with the consultant said they found it really intimidating, and you worry about where, as I say, where they've got the information from, you know ...

INT: YEAH, THAT'S THE THING, ISN'T IT?

Nurse: ... and some of it's not relevant, some of it's old information, and you have to start, and that in itself really is harder than establishing somebody, you know, how much informa-, how little some people's information is, because sometimes you've got to start unravelling all the information that they people have like taken on board, you know, when they've heard lots ...

INT: SO IT'S LIKE MIS-INFORMATION THEY'VE TOOK ON?

Nurse: Yeah, yeah. And, you know, like, and they have a lot more questions and the consultation can be a lot harder because they've completely sometimes missed the point, we've gone, and they're looking at things that are way ahead instead of looking at, you know, sorting, tackling what's on initially, you know, and they can have, you know, a list full of questions which isn't relevant really to what's going on with them at that point, and you can't sometimes fetch people away from that, you know, so that can be difficult.

*Q13. WHAT DO YOU THINK ARE THE MOST IMPORTANT PIECES OF INFORMATION PATIENTS NEED OR WANT TO KNOW ABOUT THEIR DIAGNOSIS AND WHEN DO THEY GENERALLY BRING THEM UP?

Nurse: Well they, erm, usually when they're given, you know, they usually ask when they're given their results, and I think one of the things that the ladies tend to ask is what, they'll say, 'What type of cancer is it?' and, you know, and the majority of the time we have to say, 'We don't know the full picture until, you know, we've actually excised it and removed it.' They usually want to know how big is it, are there any glands involved, and one of the other things that they tend to say is, 'How long has it been there?' you know. So they're the things that they tend to want to ask at diagnosis.

*Q14. AND SIMILARLY WHAT DO YOU THINK ARE THE MOST IMPORTANT PIECES OF INFORMATION PEOPLE NEED OR WANT WHEN IT COMES TO TREATMENT OPTIONS AND WHEN ARE THEY GENERALLY RAISED?

Nurse: Erm, treatment options, they usually want to know what type of treatment, obviously, whether it's, you know, what the treatment's gonna involve, whether they're going to have, you know, what type of surgery, whether they're gonna have chemotherapy, radiotherapy, erm, if, you know, one of the questions that they usually ask when they know that they're going to have surgery and, you know, is, as I say, one of the things that is 'Oh, am I gonna have chemotherapy, am I gonna lose my hair?' and that's even before they've even had the surgery. And then they ask, tend to ask about, those that are having, that choose to have mastectomy tend to ask about reconstruction, they ask about prosthesis, erm, and, you know, then the practical issues, 'How long am I gonna be in hospital?' One of the things that some ladies ask is, 'Will I be cured?' you know, 'Once they've had this surgery is that it? Will I be fine?' you know.

INT: I'LL MOVE ON NOW TO WHAT A PATIENT IS OFFERED.

*Q15. WITHIN THE CONTEXT OF YOUR UNIT'S GUIDELINES AND PUBLISHED RESEARCH, PLEASE DESCRIBE THE FACTORS THAT WOULD LEAD YOUR TEAM TO OFFER A PATIENT...

*a. IN THE FIRST INSTANCE, ONLY BREAST CONSERVATION SURGERY?

Nurse: Erm, well obviously it depends on, they'd look at the size of the tumour, where it is in relation to the breast, and they'd look at the histology to see whether, you know, sort of like whether there's, erm, you know, the margins on the tumour are fairly, ... erm, I'm trying to think of the ward, this is where my lack of knowledge is now ...

INT: DON'T WORRY ABOUT IT.

Nurse: ... well one of the consultants said to one lady last week, he said, 'Some of them are, you know, have got really defined edges and some have got fuzzy edges,' diffuse, that's what he said. So I mean that depends sometimes because they can say that if it's got diffuse edges then that might mean that they can't necessarily get a clear margin. So, erm, they look at, as I say, the size of it, the relationship to where it is in the breast for a wide local, and the size in relation to the lady's breast. If they know it's a well-defined lump and they can just remove it as a lumpectomy then that's a choice that they would make.

*b. AND WHAT SORT OF FACTORS WOULD LEAD THE TEAM TO OFFER A PATIENT ONLY A MASTECTOMY?

Nurse: Erm, well, depending on size, whether it's unifocal or whether it's, probably if it was multifocal. If it was in two separate quadrants of the breast or it was, you know, if you'd got something that was scattered, you know, scattered across the whole of the breast, or if it was quite a large central area of the breast might indicate that they'd do a mastectomy. Erm ... I've lost the plot now as to what else I can think of.

INT: THAT'S OK, DON'T WORRY.

*c. AND WHAT SORT OF FACTORS WOULD LEAD THE TEAM TO OFFER A PATIENT A CHOICE BETWEEN THE TWO TREATMENTS, MASTECTOMY AND BREAST CONSERVATION?

Nurse: Erm ... I think it, erm, it would depend on, I think a lot would depend on what the patient wants, you know, because there might be, and, erm, other fact-, you know, other factors, it might be that they've got somebody in the family, that's got a family history, erm, and, you know, family history of breast cancer, and it might be that they're really anxious that if they just had a wide local and they were told that, if they didn't get a clear margin they might need to have further surgery, so that lady might particularly want to go on to have a mastectomy. Erm ... I don't know, I can't think.

INT: RIGHT, OK.

*d. OTHER TREATMENTS [Not asked]

INT: THE LITERATURE SUGGESTS THAT PATIENTS VARY IN THE DEGREE OF INVOLVEMENT WHEN MAKING DECISIONS ABOUT WHAT SURGERY TO HAVE: SOME PATIENTS WANT FULL CONTROL OF THE DECISION MAKING PROCESS; SOME PREFER TO SHARE CONTROL; OTHERS PREFER TO LEAVE IT TO PROFESSIONALS TO TAKE THAT CONTROL.

*Q16. DO YOU THINK PATIENTS ARE GETTING THE DEGREE OF CHOICE THEY WANT?

Nurse: Yeah, yeah, I think they do. I think, you know, erm, I think they're given, you know, from what I've seen in the consultations, I think they're given, you know, all the facts and, you know, they look at, you know, the cir-, you know, the circumstances around it and, you know, they are given a choice, you know.

*Q17. AND THINKING ABOUT YOUR EXPERIENCES WITH THE PATIENTS YOU SEE LOOK AT THE RESPONSES BELOW AND TELL ME, DURING CONSULTATIONS, WHO GENERALLY MAKES THE FINAL DECISION ABOUT WHAT SURGICAL TREATMENT TO HAVE?

Nurse: Well I put that the patients tend to make the final decision regarding the treatment, but I've put as well ...

INT: IS THAT NUMBER ONE, YEAH?

Nurse: Yeah, yeah, but I've put, sort of adding to that, you know, 'after seriously considering the surgeon's opinion' because I think, you know, they can't make a choice without being given all the facts.

INT: SORRY, IS THAT 'AFTER SERIOUSLY CONSIDERING THE SURGEON'S OPINION'.

Nurse: Yeah, but they do make the final decision.

INT: OK. I'D LIKE TO MOVE ON TO NOW COMMUNICATING WITH PATIENTS WHO HAVE BREAST CANCER. AT THIS POINT I'D LIKE US TO FOCUS ON PATIENTS IN WHOM, FOR CLINICAL REASON, MASTECTOMY IS NOT THE ONLY OPTION. RESEARCH HAS IDENTIFIED THAT PATIENTS WITH BREAST CANCER TEND TO FALL IN ONE OF THREE DIFFERENT DECISION MAKING STYLES OR GROUPS, IF YOU LIKE: THESE ARE ACTIVE, COLLABORATIVE AND PASSIVE DECISION MAKERS. IN THIS FINAL SECTION OF THE INTERVIEW I WOULD LIKE TO ASK YOU A FEW QUESTIONS ABOUT HOW YOU FIND COMMUNICATING WITH EACH OF THESE TYPES OF PATIENT DURING THE CONSULTATION PROCESS THAT LEADS TO A FINAL TREATMENT DECISION. I WOULD LIKE TO START WITH THE SITUATION WITH ACTIVE DECISION MAKERS AND WE'VE GOT A DEFINITION THERE WHICH IS PATIENTS WHO TEND TO MAKE THEIR OWN FINAL TREATMENT DECISIONS EITHER WITH OR WITHOUT SERIOUSLY CONSIDERING THE SPECIALIST'S OPINION.

*Q18. I WOULD LIKE YOU TO FIRST THINK ABOUT A SITUATION YOU HAVE HAD WITH AN ACTIVE DECISION MAKER, AND I KNOW YOU MAYBE DON'T THINK ABOUT IT, BUT TRY TO THINK ABOUT IT IN THAT CONTEXT THAT WE'VE DESCRIBED. WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, PLEASE TELL ME ABOUT YOUR EXPERIENCE WITH THEM UP TO THE POINT WHEN A TREATMENT DECISION WAS MADE. COULD YOU THINK OF SOMEBODY YOU THOUGHT WAS ...

Nurse: Yeah, I did yeah.

INT: COULD YOU TELL ME A BIT ABOUT THAT?

Nurse: Yeah, erm, it's OK for me to, obviously I won't disclose the patient but it's all right for me to tell you about their ...

INT: YEAH, ALMOST LIKE IT WAS LIKE AN MDT OR SOMETHING BUT JUST DON'T MENTION THEIR NAME.

Nurse: Yeah, yeah. Erm, well this was a lady who came to clinic and she was a 59-year-old lady who'd previously had a mastectomy 28 years ago when she was 31. The information that she had was quite limited, she'd had it from another hospital, and her husband was with her, and even from the point of view, you know, we asked why she, you know, obviously she was diagnosed with breast cancer, but she wasn't given, she'd had like 30 years, it was 28 years ago but she said 30 years ago, they didn't tell you sort of like what grade it was, what this that or the other, they just told you that you'd got breast cancer and that they needed to do a mastectomy. And she'd gone on to have chemotherapy and radiotherapy. And she said, and her, her words were that she didn't ask lots of questions neither, she said she was only 31, she'd got two children, one was two and one was four at the time, and she just wanted to get on with it and get on with her life, and she put it behind her. Erm, and she came, so that she'd had a mastectomy on the right, and she came with a lump in her left breast. And she was asked, and she felt quite upset I think because the doctor that saw her said to her, 'Do you regularly examine yourself?' and she said, 'No, not really,' and she said, you know, and I think she, and she, and I think she felt upset that she felt as if she was being, erm, accused of not examining herself really because, you know, but then ...

INT: AND BEING IRRESPONSIBLE ABOUT IT?

Nurse: Yes, yeah, because she'd had previous surgery.

INT: WHEN YOU SAY THE DOCTOR, IS THAT THE CONSULTANT OR THE GP?

Nurse: No, it wasn't the consultant, it was one of the other doctors in the clinic, one of the clinical specialists.

INT: OK.

Nurse: Erm, and I think because she'd had previous surgery I think she felt that, you know, erm, the patient felt as if, you know, she'd neglected herself basically by not examining herself. And I think the doctor realised that because then she went on to say to her, 'But you did have a mammogram two years ago and that was absolutely fine,' so you know, because the lady herself said, 'Well I didn't examine myself because I didn't

[BREAK IN SPLIT TAPE - SOMETHING MISSING?]

didn't want to examine myself any more,' she said, 'I just put it behind me.' So and I think the doctor ...

INT: DO YOU THINK PERHAPS SHE WAS FRIGHTENED OR SOMETHING OF WHAT SHE WAS GOING TO FIND?

Nurse: Yeah, yeah. And I think the doctor had realised that she, you know, you could, because you could see that she looked upset because she'd asked her, 'Do you regularly examine yourself?' And the doctor said to her, 'Well you know, it would, you know, if you had have noticed anything, this has only happened in the last two years anyway,' because I think the lady was then questioning 'Should I, should I have examined myself, you know, would I have come sooner?' and no, she probably wouldn't have done because, you know, her previous mammograms of two years were absolutely fine. She then was told, she was given her histology and she was told that she'd got this quite large lump, 46mm, and she was a small-breasted lady and she was, erm, she didn't see the consultant, the doctor that saw her was, had been and discussed the case with the consultant, and the consultant had advised treatment options to be discussed with the patient. So the doctor came back and they discussed neo-adjuvant chemotherapy to, you know, reduce the size of the lump and then go on to do a wide local excision, and the other option was to go ahead straight, you know, was to go straight for a mastectomy. And she, the lady asked if she went for a mastectomy would she need to have chemotherapy afterwards, and the answer was that we wouldn't know because she was concerned 'cos she'd had chemotherapy before and she didn't, you know, she wasn't keen about the chemotherapy, and she wasn't keen about having neo-adjuvant chemotherapy because, given the fact that she'd had it before, erm, and when she, when we discussed, when the doctor discussed with her about having a mastectomy and not being certain whether she might have to have chemotherapy, but it may, it's highly unlikely, erm, she immediately, you know, said, 'No,' she said, 'No, that's ...' she said, 'I've made my mind up.' And she just said, 'I've made my mind up, I want a mastectomy, given the fact,' she said, 'that I've had a mastectomy in the past,' she said, 'I want a mastectomy.' And she turned to her husband and she said, 'Do you agree with that?' and he said, 'Whatever ..' you know, 'it's your decision, you ...' you know, but he said, 'If that's what you want,' he said, 'I think you're making the right decision.' And she said, 'Because, if I have a mastectomy,' she said, 'I can have reconstruction and I can have reconstruction on the other side,' so they talked, the doctor talked with her about reconstruction, because she said nobody had offered her reconstruction from the previous surgery, no-one had ever mentioned it to her or spoke to her about it, but I mean she hadn't had, bear in mind ...

INT: TWENTY YEARS WAS THAT?

Nurse:... that, it's 28 years ago.

INT: WAS THAT POSSIBLE TO HAVE RECON-, I'VE NO IDEA?

Nurse: I've no idea, but I mean, she was only followed up for seven years after that so she'd actually not been seen by anybody for 21 years. So, a long time, you know, not, you know, not to see anybody. So she immediately decided that, you know, and, you know, 'That's it, I'm having a mastectomy,' and when I spoke about, erm, I spoke to her afterwards, she was, you know, 'No, I've made' you know, 'cos we talked about, went back over the treatment options with her and she was, 'No, I definitely want the mastectomy. I've previously had a mastectomy and ...' you know, but she was quite logical about the way she thought about it, you know, and I think she made the right, you know, I think she did make the right decision for herself.

INT: SO HOW DID YOU GET ON WITH THE PATIENT?

Nurse: Really well, you know, she was a really nice lady and she was, you know, because, although she was, erm, limited in what she knew about her previous

surgery, you know, she was, erm, quite logical about how she thought about things because she knew how she'd, because on of the things was that she was saying, 'If, well if I have neo-adjuvant chemo,' I mean obviously given the fact that she'd gone through chemo before and she knew that she'd have to go through chemo again, and that she'd have, you know, a wide local excision and that there may be, you know, the risk that she might need to have further surgery if there weren't clear margins, you know, I think that she, you know, I personally think she made the right decision for herself, you know, because, you know, because her, and she said, you know, like, 'Well, if I have a mastectomy I can have, you know, reconstruction, you know, on both sides and, you know, so ...'

INT: WAS THERE ANY OTHER INFLUENCES APPARENT FROM OUTSIDE OR [???] ?

Nurse: No, because I mean this is a lady that actually came to clinic and was like, you know, diagno-, you know, diagnosed on, you know, on the day that she came.

INT: THE ONE STOP.

Nurse: The one stop clinic. So I think the only, the other influence was the fact that she'd had surgery 8 years ago. So, you know, and the other treatments that she'd had, and that was her biggest influence, because her husband was very supportive but he was, you know, like much, you know, 'Well, the decision is yours,' you know, but, you know, he was in agreement, but I mean, as I say, I think her overall influence was the fact that she'd had previous surgery.

INT: LOOKING BACK, HOW SATISFIED DO YOU THINK YOU WERE WITH THAT EXPERINCE WITH THAT PATIENT?

Nurse: I thought it went, I was OK with that, I mean, you know, I don't ever say, you know, if they, you know, I would never have said, 'Oh I feel you're ...' you know I don't think I'd ever say to somebody, 'I think you've made the right decision,' and I went away and I did to speak to colleagues afterwards and they all said that they felt that, you know, like, that she was, you know, making the right decision for herself. And I, you know, I did ask the lady did she feel that, you know, I always say, 'Do you feel that,' you know, 'that's the right decision for you?' and she was quite, 'Yes, I know it's the right decision for me.'

INT: AND SO DO YOU THINK SHE FELT SATISFIED WITH THE OUTCOME AS WELL THEN?

Nurse: Yes, yeah ...

INT: ... WITH THE EXPERIENCE.

Nurse: ... And she asked lot of questions about reconstruction and so I think she was quite focused on what she wanted you know.

INT: THINKING ABOUT ACTIVE DECISION MAKERS IN GENERAL, I MEAN SORT OF HOW SOON DO YOU THINK YOU KNOW YOU'RE DEALING WITH SOMEONE WHO'S QUITE ACTIVE, I MEAN I KNOW YOU PROBABLY DON'T THINK OF IT IN TERMS OF ACTIVE DECISION MAKERS, BUT SOMEBODY YOU NOW, USING THIS DEFINITION AND WHAT YOU'VE TOLD ME, THINK, YOU KNOW, THAT, HOW SOON DO YOU THINK YOU KNOW ABOUT ...?

Nurse: I think people that are quite, that are well-informed, you know, erm, as I say, you don't kind of like think of it but I think those that are well-informed, erm, and are able, and cope with, you know, when they're given their results and are able to think quite clearly, you know, and those that ask lots of questions, you know, and you know that they understand, I think they're the

ones that do make, you know, quite, you know, do make quite clear decisions of what they want.

INT: AND WHEN YOU REALISE YOU'RE DEALING WITH THAT KIND OF PERSON, HOW DOES THAT SORT OF SHAPE YOUR APPROACH TOWARDS THAT PERSON, YOU KNOW, HOW YOU'RE GOING TO DEAL WITH THEM LATER ON AND WHAT-HAVE-YOU? IS THERE SOMETHING YOU MIGHT SAY, 'WELL, THIS PERSON'S A ... YOU KNOW, QUITE BLAH, I WANT TO DO, I'M GONNA DO THIS' ... OR 'I NEED ...,' OR YOU'RE THINKING THIS OR WHATEVER?

Nurse: I think, you know, I think it makes our job easier because you know that you've got somebody, but then you do, you know, because you're kind, they're the people that ask, you know, that do tend to ask the questions and, erm, I mean, and the people that tend to cope that, you know, that do cope quite well. But then you do go away sometimes thinking, you know, even though you think, 'Oh yeah, they're really the type of people that say "Right, come on, yes, let's get on with it, I just want to get on with it"' and then you're never quite sure whether they're the ones that afterwards are going to sort of like crumple in a heap in the corner, you know, so you're always, you know, it's always at the back of your mind that, you know, although they are quite active about making their decisions and they are coping quite well, that there is probably going to be a time when they're not going to be, you know, and you just have to be, make sure that, make them aware that you are always there for them, because you don't want them to, you don't want them to feel that, because you know they've made the decision and they are, you know, quite active as we say, that, you know, that they don't have to feel that they're on their own about making that decision and that there are other people there that can support them, you know, you don't want them to, you know, go away, 'Oh, they've just asked me to make this decision and left me to it,' kind of thing.

INT: SO OVERALL HOW ARE YOUR FEELINGS ABOUT THAT PARTICULAR EXPERIENCE?

Nurse: I, you know, I feel all right about it because I think, you know, like, they're, you know, as long as I, as long as I've established that I know that, you know, the patient's, you know, comfortable with the decision that they've made, you know, and that they know that I can, you know, that they can approach me or one of my colleagues if they need to go over other things or if they need to speak, come back and speak to the consultant, because it might be that, you know, they will be, appear to be active and make a decision, and it might be that they might go away and want to, you know, think about it and, you know, realise that they've made the wrong decision, and that they are able to come back and say, you know, prior to surgery, that they can come back and say, you know, 'No, I'm sorry, I've changed my mind,' you know.

*Q19. I'D LIKE TO LIKE TO MOVE ON TO THINK ABOUT COMMUNICATION WITH COLLABORATIVE DECISION MAKERS, PATIENTS WHO TEND TO SHARE FINAL TREATMENT DECISION RESPONSIBILITIES WITH THEIR SPECIALIST OR SPECIALISTS. I'D LIKE YOU TO THINK AGAIN ABOUT A PATIENT WHO'S COLLABORATIVE AND, VERY SIMILAR TO WHAT WE'VE JUST DONE, WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, TELL ME ABOUT YOUR EXPERIENCE WITH THEM UP TO THE POINT WHEN A TREATMENT DECISION WAS MADE.

Nurse: Right. Erm, this was a 52-year-old lady that came to the screening clinic and I'd met her the week before, erm, and she saw one of the clinical associates and she was told, erm, that ... no sorry, I didn't, because I didn't meet her but one of my colleagues met her, I met her when she came back to see the consultant ... that she was told the previous week that something had been seen on the mammograms that was not obviously suspicious - I'm not quite sure when you say, you know, when I read that, you know, how can you say to somebody, 'It's not obviously suspi- ...' you know ...

INT: YEAH, IT'S A STRING THING.

Nurse: It's quite a strange, when I read, erm, so it's difficult to know what she took away from that, and she came back for the core results the week after and was told that she'd got a cancer. She'd previously had double bypass surgery five years ago, was otherwise fit and well, erm, and the consultant discussed both surgical options with her, wide local excision and mastectomy, erm, but this lady had, erm, quite a large lump in a small breast, but, erm ...

[BREAK IN SPLIT TAPE - SOMETHING MISSING?]

Nurse: ... the consultant did say to her that, although it was a quite large lump, he talked about lots of, all the other factors, and said to her that, 'cos she asked lots of questions and she asked about, you know, one of the questions that she asked was 'Does that mean that the whole breast is affected?' and he said no, and he went on to explain to her about it's a large lump and it's in one area of the breast but you have, you know, in relationship to the size of her breast, erm, and he then talked about considering other factors such as looking at the histology because on the histology it had got diffuse edges so he was explaining to her that, obviously, when he was doing the surgery, that it's more difficult to establish a clear margin when it's got diffuse edges, and he'd be uncertain of whether he could definitely get a clear margin, and with a wide local excision that she would, that she could possibly lose a large part of her breast and possibly the nipple. But, however, he said to her, you know, 'But there is, you know, we can still do, you know, just remove the lump if that's what you want,' he said, 'or the option is to remove the whole breast.' And, as I say, all the way along she kept stopping him and asking him questions and, you know, and he was answering the questions. And her daughter was there as well and she said, you know, her daughter said to her Mum, 'Do you mind if I ask some questions?' so she was, you know, asking questions as well, and at the end of the consultation she said, she was given both types of written information for wide local excision and mastectomy, but said that, you know, that she would probably, erm, choose to have a mastectomy. And she went away and we talked about it and she came back the following week and spoke to the consultant again and decided that she would go ahead and have the mastectomy. But she, to me, was a person that was quite sure of what she wanted but, you know, and asked lots of questions, and it was very much a two-way thing between her and the consultant. And I think, and I thought it was a really good consultation from the consultant's point of view because he talked about, he didn't just say to her, 'Well you've got a large lump in your breast, yeah we could probably removed it, but it'd be more suitable to do a mastectomy,' and although it was erring on the side of, like, well, you know, you could have almost said 'Oh well he is a bit more biased towards a mastectomy,' but I think it was all the influencing factors around that were more influential than anything else. But he actually gave her all that information, but did still say to her that 'If you want to have ...' you know, 'if you want me to just remove the lump, I'm quite happy to do that.' You know, and I thought that was, you know, I, that's one of the best consultations I've been in, I think, because I thought, you know, he gave ...

INT: HOW DID YOU GET ON WITH PATIENT THEMSELVES?

Nurse: Really well, again, you know, like, erm, and we went away and, as I say, her and her daughter asked lots of questions and, erm, you know, she was quite clear on, you know, what she wanted and, you know, I gave her the opportunity to, you know, again to ask lots of questions and to ring me if she wanted to ring me up. And she did actually ring me in the week, erm, and asked me to go through the reasons why he'd said about, erm, you know, wide local as opposed to mastectomy, and we went through that again and I asked her did she want to come in and she said no, she just, there were just a couple of things that she wanted to get clear in her head, and then, as I say, she came back the following week and decided that she'd go for a mastectomy.

INT: AND WERE THERE ANY OTHER INFLUENCES APPARENT?

Nurse: No, I think she just went on, you know, sort of, obviously, I mean, she, her daughter was with her and obviously her daughter was, you know, sort of, like, involved herself, you know, asked her Mum, you know, she asked her Mum, 'Do you mind if I ask questions?' so they'd obviously gone away and talked about it between themselves, but I think the fact that she'd such a good consultation and that she'd been given all the facts and was really clear on what, you know, what the consultant had said to her that, you know, like, that, you know, she was quite sure of what, you know, the surgery option that she wanted. And she was able then, because she didn't ask me which was, she was able then, the follow-, you know, because she didn't ask me at the time and I did offer about, you know, when we talked about both types of surgery, about showing her a prosthesis and things like that, and she said no, you know, I'll just, and we just talked about, erm, you know, the surgical options. And I didn't take it on board that she was saying, 'No, a mastectomy's ...' she just didn't want to discuss that at that time. And when she came back the following week and she'd made her decision I then said, then asked her did she want to, you know, go on and look at prostheses and things like that, and then she had loads of questions about prostheses and reconstruction and things like that.

INT: RIGHT. AND LOOKING BACK NOW DO YOU THINK YOU WERE SATISFIED WITH THAT?

Nurse: Yeah, yeah, I thought, you know, 'cos I think, erm, even from the consultation, 'cos I can, you know, I remember sitting there thinking that, you know, this is, you know, at the time, that this is a really good con-, I did actually think to myself, 'This is a really good consultation,' 'cos he spoke to her about everything and, you know, and all the, you know, both surgical options, and I was really pleased that he'd given her both surgical options even though, you know, it was, erm, as I say, 'cos I think that, you know, it might, somebody else might have just along I think and said, 'Well I think mastectomy's the best option here because it's a large lump and smaller breast and ...' you know, 'we can't guarantee this, so I think ...' you know, which, 'cos I know that some do, you know, and I think that, you know, I was quite pleased that he had given her the choice.

INT: AND WHAT ABOUT HER, DO YOU THINK SHE WAS SATISFIED WITH THE CONSULTATION AND THE OUTCOME IN THE END?

Nurse: Yeah, yeah, because, you know, she was, as I say, she, all the way along if she didn't understand she stopped the consultant and asked, and 'What do you mean by this?' and 'Can you explain this?' and, you know ...

INT: AND WHAT TREATMENT DID SHE END UP HAVING THEN?

Nurse: A mastectomy.

INT: SHE WENT FOR A MASTECTOMY, YEAH. SO, SIMILAR TO, I ASKED THE QUESTION BEFORE ABOUT, YOU KNOW, HOW SOON DO YOU KNOW YOU'RE DEALING WITH A COLLABORATIVE PERSON? MAYBE IT'S NOT TOO EASY [???] THE ACTIVES AND THE PASSIVES STAND OUT I THINK, WHAT ABOUT THE COLLABORATIVES ...

Nurse: Erm ... I think those that, erm, I think that those ques-, you know, that'll ask lots of questions and, you know, are prepared, and those that are prepared, you can see the ones that are prepared to listen, you know, and as I say will stop and ask and, you know, and will ask, you know, and will ask lots of questions, not just from the consultant but from us as well, you know. And you know that, erm, and want to know, you know, those that, erm, and want to know both sides of everything, want to be clear about, you know, and as I say

involved, you know, really keen to know what the consultants say, because some, like, will just sit and say, 'Yes, 'No,' 'Yeah, right,' 'Yeah, yeah,' and I think the ones that are collaborative are the ones that ask lots and lots of questions.

INT: SO OVERALL HOW DO YOU FEEL THAT THE CONSULTANT AND THE EXPERIENCE WITH THAT PATIENT WENT?

Nurse: I think it went really well. I think, you know, that she, you know, that the, you know, the actual lady felt that she'd made the right decision and, you know ...

INT: AND WHAT ABOUT YOUR ROLE IN THAT, HOW DID YOU FEEL ABOUT THAT?

Nurse: Well I felt it went, because as I say, from, you know, from the consultation, I thought it went really well and I thought, you know, as I say, I was pleased at, you know, the way the consultation went in the fact that I sat there and thought, 'Oh this ...' you know, 'if this was me I would feel like I'm being told everything and that I'm getting all the facts,' you know, and that it enabled, you know, I thought that the consultant was quite clear and that it enabled the lady to be able to make, you know, a really good, informed decision.

INT: CAN WE MOVE ON TO PASSIVE DECISION MAKERS, PASSIVE DECISION MAKERS ARE PATIENTS WHO TEND TO WANT TO LEAVE FINAL TREATMENT DECISIONS TO THEIR SPECIALIST EITHER WITH OR WITHOUT THEIR SPECIALIST SERIOUSLY CONSIDERING THEIR OPINION.

*Q20. VERY SIMILAR TO WHAT WE'VE DONE BEFORE, CAN WE JUST TALK ABOUT A PASSIVE PATIENT YOU MIGHT HAVE IN MIND AND AGAIN, WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, PLEASE TELL ME ABOUT YOUR EXPERIENCE WITH THEM UP TO THE POINT WHEN THEY MADE A TREATMENT DECISION.

Nurse: Well, I was, this is quite difficult for me because, erm, I didn't have a lot to do with this lady and trying to think ... I can think about passive people in general but it was difficult to find somebody and I'm not sure this lady was initially passive but, having spoken to colleagues prior to the interview, we were think-, you know, because we were all talking about, you know, sort of like thinking about patients, erm, who were passive, collaborative or active, erm, and I think the outcome ... if I tell you the ... you might, you know, this is what we think that, you know, perhaps all along she was passive really, erm, because in general you tend to think of passive patients as those that say, 'Oh I'll do anything,' you know, 'whatever you say, Doctor,' you know, 'you tell me what you think and I'll go along with it.' And this lady came along and she was told, erm, she came to clinic and was seen by one of the associate specialists and was told initially on a drag result that she'd got breast cancer and was told that she would need to, you know, would need to have surgery; came back and, because she'd only had the result on drag cytology, she came back the following week for the full core result and the core result came back as not definitive, so she had to go on and have another core. She came back the following week to see the consultant and was told that, yes, she'd got a breast cancer and, erm, he discussed the surgical options. Now I wasn't involved in this, but I'm using, this is the only one that I could think of as an example. She was told, erm, that, given both options, and she was told that she could have a wide local excision but because it was quite, because it was central breast, that she would lose her nipple, and also told her that she could have a mastectomy. Erm, she was very anxious and I've met the lady along the way, but as I say I wasn't actually there at the actual consultation ... very anxious, unable to make a decision at that moment as to which surgery, erm, and over a period of, it was a couple of weeks before, because she was going on holiday as well ...

BREAK IN SPLIT TAPE - SOMETHING MISSING?]

Nurse ... she'd got a holiday booked and was going off somewhere exotic for three weeks, so, erm, she spoke to myself and she spoke to various colleague and asked lots of questions, decided that she was going to go off on holiday and come back. She came back off her holiday and decided that she wanted to have a mastectomy because she didn't want to have a wide local excision and lose her nipple, and she decided that, and that her issues were that, her biggest issue about having a wide local excision was losing her nipple. And she said, and she felt like she was going to be deformed anyway because she didn't have ... so she decided that she was going to have a mastectomy. Now I met her after she'd had her surgery and when she was actually on the ward she was quite happy that she'd made, and somebody had documented that she was happy that she'd made the right decision for having a mastectomy. I met her in the oncology clinic a few weeks later and she came back and she'd been given her results and she was told that it was all completely excise and that she may need, no glands were involved, and that she made need to have some radiotherapy. She came along to the oncology clinic and she was told by the oncologist that she there was no need for her to have any radiotherapy, you know, and she was just to continue taking, she was on Tamoxafen so she was to carry on with the endocrine therapy, and that was it. And she said, she asked the consultant oncologist, she said, 'Can I ask you a question?' and he said, 'Yes.' And she said, she asked him the question and she said, 'Did I need to have a mastectomy' she said, 'because of the results of the surgery?' And he said, 'No,' you know, 'You didn't.' And she, when we went outside, and she was OK and she was absolutely fine and we went outside and we went into the quiet room and she sad down and ... I got, somebody called me away at that point so I said, 'Oh, excuse me ...' and as I went back in her husband said, 'You did ask, you asked the question and that was the answer and you have to live with it,' so we sat and had a talk about that. And she was, she wasn't, you know, she wasn't, you know, visibly upset or anything, erm, and she said, 'No, I'm ...' and I said, 'How do you feel about that?' and she said, 'No, I'm fine, you know, I asked the questions, I'm fine,' you know, and she's coming back, she said she'd got, she'd made an appointment to come to the reconstruction clinic. But then when I was, I went away and talked to my colleagues and, because of the fact that she was undecided at the beginning and then she'd asked that question at the end, made us think that perhaps she was passive all along really.

INT: MM, THAT'S HARD TO TELL WITHOUT ACTUALLY KNOWING THE PERSON, BUT ...

Nurse: You know, that, because she, you know ...

INT: WERE THERE ANY EXTERNAL INFLUENCES APPARENT THERE? I KNOW YOU ONLY MET HER AFTERWARDS, SORT OF THING, SO IT'S HARD TO SAY ...

Nurse: Not that I'm aware of, not that I'm aware of.

INT: NO, NONE OF YOUR COLELAGUES MENTIONED ABOUT ANYTHING?

Nurse: No, but because of that question that she made at the oncology clinic, made me think this, this lady, you know, I would, kind of thought that she was probably passive and the fact that she was unable to make a decision at the beginning, which was documented that you know, she was unable to make the decision at the beginning.

INT: YEAH, QUITE POSSIBLY.

Nurse: You know, and you kind of like think when, from that end result, you know, was she, was this lady passive all the, you know, all the way through

really? You know, because even up, even, because to ask that question, she obviously felt that she'd made the wrong dec-, you know ...

INT: OR THAT PERHAPS SHE'S BEEN GUIDED [???] TO MAKE A DECISION.

Nurse: Yeah.

INT: YEAH, I DON'T KNOW REALLY. AND HOW DID YOU GET ON WITH HER, ALL RIGHT?

Nurse: Yeah, I got on with her but, you know, felt quite, I think ...

INT: YEAH, MY NEXT QUESTION WAS HOW DID YOU FEEL ABOUT THE WHOLE THING?

Nurse: Well, I felt quite sad for her really, you know, after she'd gone, because, but it was difficult because I hadn't been involved with her all the way along. I'd met her on, you know, at various stages, but not really to establish any kind of relationship and I'd not been there at the actual consultation to know, you know ... and I do remember meeting her sort of in between and she was going, they're semi-retired and they go, they go on like exotic holidays, long-haul holidays, and they were very much a couple that were, erm, you know, as I say, travelled and wanted and, you know, 'Let's get on with it, let's get on ...' you know, 'put it behind us and get on with our lives.' And I don't know whether that kind of, like, you know, well, you know, 'If I have a mast- ...' I don't know whether it like, 'I might as well have a mastectomy, it's ...' you know, 'cos whether she was told that, you know, whether it was the fact that if she was told, you know, which they are told, if they have a wide local excision 'There's always a risk that you may need to have further surgery,' you know, whether it, because I remember having a conversation and them saying, 'Oh we just want to get on with it and put it behind us,' and whether she thought that, you know, whether that was an influence in fact, because as I say they went off on this holiday for about three weeks to Antigua and then came back. And I know the other big influencing factor with her was that she was absolutely distraught about losing, you know, when she was told that, if she did have a wide local excision, that she would have to lose her nipple anyway. And I know she was absolutely distraught about that. But, you know, not being there and then I thought, well, you know, could they, you know, the consultation could have gone on to the, like, well then we could have discussed about, you know, reconstruction of the nipple, we could have talked about ... there could have been lots of things that could have been discussed at that point ...

INT: ABSOLUTELY, YEAH.

Nurse: ... you know, so you kind of like think, well, perhaps she didn't get the best ... you know, because, you know, she needn't have had - well I think that's probably how she feels, you know. Did she, you know, did she make the right decision? Did she ... did she need to have a mastectomy, you know, because and, you know, obviously ... I don't know.

INT: YEAH, IT'S A BIT OF A STRANGE ONE THAT ONE, ESPECIALLY WITH YOU COMING LATER ON. ERM, I NEED TO WRAP THIS UP ACTUALLY, SO LAST COUPLE OF QUESTIONS ... THE LITERATURE TELLS US THERE ARE A VARIETY OF INFLUENCES ON PATIENTS MAKING DECISIONS ABOUT SURGICAL TREATMENT.

*Q21. THINKING FIRST OF ALL IN A WIDER SENSE, BEYOND THE UNIT, WHO OR WHAT DO YOU THINK HAS THE GREATEST INFLUENCE ON PATIENTS' DECISIONS ABOUT WHICH SURGICAL TREATMENT TO HAVE?

Nurse: I've put family and friends and the media, because I think, you know, like, I think family do put, you know ...

INT: WHEN YOU SAY FAMILY ARE YOU TALKING ABOUT PREVIOUS FAMILY WHO'VE HAD BREAST CANCER OR PRESENT FAMILY, OR BOTH OF THEM?

Nurse: I think, well, erm, I think it can be both because if you've got somebody that's got family history then that has a big part to play. And then, erm, you know, talking about, just your immediate family and how they feel, and I think it, erm, a lot depends on, you know, with the immediate family, it depends on the, you know, if it's an elderly mum and they're offered surgery and they're otherwise fit and well, because it's surprising how many elderly patients come to surgery, erm, and say, who are like in their eighties, fit and well, and the daughter comes and the daughter'll say, 'I don't want you to have surgery, Mum,' you know, 'I don't want you to ...' and that quite often happens, and you think that's probably from a selfish point of view because they're probably frightened, you know, probably don't think, you know, 'Oh well, Mum won't be able to cope with surgery,' you know, and lots of ladies do, you know, because you get ladies that come along, you know, are offered surgery at that age - some choose to just have endocrine therapy, but some ladies are offered surgery as not, you know, endocrine therapy or, you know, either types of surgery. So there are lots of influencing factors, and it's surprising, you know, it does happen and they'll say, 'Oh well I'll just try the tablets,' you know, because the daughter, you know, the daughter's perhaps with them and said, 'Ooh ...' you know. Or you get people that, erm, you get elderly ladies that are brought in from nursing homes with their carers who come along and their carers'll say, and no family members come along, and they've said, their family have said that they don't, that under no circumstances are they to have surgery. Well, you know, at that point it's, you know, it's, we've then turned round and said, well, you know, the family member then needs to come along to the next consultation and be here, you know, when we're discussing with the, you know, their mother and the consultant, you know.

*Q22. AND WITHIN THE UNIT, THE CONTEXT OF THE BREAST TEAM HERE, WHO DO YOU THINK HAS THE, WHO OR WHAT DO HAS THE GREATEST INFLUENCE ON PATIENTS' DECISIONS ABOUT WHICH SURGICAL TREATMENT TO HAVE?

Nurse: Erm, well obviously, I think the surgeon, you know, the actual surgeons themselves have ...

INT: WHY'S THAT?

Nurse: Because they're the ones that are telling them the treatment options and, you know, can influence, I think they can influence the ladies into what decision they make, and I think, you know, and the way it's, you know, sometimes it's put over, you know, that, erm, when they're discussing if there's other factors involved, you know, like as to which treatment option would be available. And I think also as well, and I think, going back to the lady, the passive lady, if all things aren't, you know, put together properly I think that can be, you know, the fact that if, you know, you're not discussing, you know, if they've not discussed about things like nipple reconstruction or nipple tattooing or prosthetic nipples and things like that, that can, you know, have a big part on how the patients are going to, you know, what they're going to choose as in their treatment options. Erm, and I think the breast care nurses have a, you know, an influence. I don't think we ...

INT: IN WHAT WAY DO THEY HAVE AN INFLUENCE?

Nurse: Well I don't we have any ... I think we can, you know, be there to help them through how they, you know, to make their decision, erm, you know, as in go through, erm, discuss it, you know, sort of like making sure that they understand what the consultant said to them and giving them the right

information, but I don't think we actually influence the decision. I think we just are there to support them while they make that decision.

*Q23. YEAH. IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD TO WHAT WE HAVE BEEN TALKING ABOUT TODAY? IS THERE ANYTHING WE'VE MISSED?

Nurse: No ... I just found, I just found it a bit, I think I found the bit about, talking about mastectomy and wide local decision, and I think that's just my lack of knowledge ...

INT: [???

Nurse: You know ...

INT: YOU COULD SAY ANYTHING, I WOULDN'T KNOW [CHUCKLES].

Nurse: And I think, because I've only recently been involved with being in with the consultant in the last few weeks, I think it's a bit difficult for me. But apart from that ...

INT: OH I THINK YOU GAVE A AVERY GFOOD INTERVIEW.

*Q24. THERE IS ONE LITTLE LAST THING I'D TO ASK YOU, IT'S A BIT OF A HYPOTHETICAL QUESTION BUT ... IF YOU HAD THE MONEY AND POWER TO CHANGE ONE THING ABOUT THE SYSTEM HERE, WHAT WOULD IT BE?

Nurse: Expand the team. Expand the breast care nursing team, yeah. Because I think there's lots of things that, you know, we could, erm, you know, set up and I think, like home visits, nurse-led clinics, erm, nurse-led follow-up clinics ... ooh gosh, I can't think, lots of things.

[End of interview]