

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Nurse)
*VENUE: Low MR unit
*DATE:
*ID: BCN041
*INTERVIEWER: DJW

INT: WELL FIRST OF ALL THANK YOU FOR AGREEING TO BE INTERVIEWED. OBVIOUSLY I KNOW YOU'RE BUSY, IT'S NICE OF YOU TO GIVE YOUR TIME UP LIKE THIS. I'D LIKE TO START OFF WITH QUESTION ONE WHICH IS ...

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

Nurse: I started work October 2001.

INT: AND THAT'S AS A BREAST CARE NURSE?

Nurse: I actually worked in Nottingham as an assistant breast care nurse ...

INT: OH RIGHT.

Nurse: ... from, I'm trying to work out, 1997, that was a 12-month contract.

INT: RIGHT OK, AND THEN YOU'VE BEEN HERE?

Nurse: And I've worked, kind of, as a role in the breast care nurse, the Leicester Royal Infirmary, it was kind of, came under the title of Body Image Support Nurse, but that's before everything came under one house here. I did some, my client groups were breast cancer patients, head and neck cancer patients and, you know, to do with altered body image and support really.

INT: YEAH, OF COURSE.

Nurse: I've kind of had a hand in, you know, in that kind of field for quite some time really.

INT: OK. AND JUST THINKING ABOUT THE SORT OF DAY TO DAY RUNNING OF THE SERVICE, YOUR LIKES AND DISLIKES, THE UNIT PHILOSOPHY, ETC, ETC, ALL THE THINGS TO DO WITH THE SERVICE HERE ...

*Q2. TELL ME WHAT IT'S LIKE TO WORK AS A SPECIALIST NURSE IN THIS BREAST SERVICE?

Nurse: Erm, of all the experiences that I've had, that I've just mentioned, I really enjoy working here and, although it's only two days a week, you know, it's very full-on days, very busy, and I just feel motivated, I feel stimulated, you know, quite keen to work here really, and the team I work with is, you know, a very good team, we communicate well with each other and, you know, and it's a nice atmosphere to work within really.

INT: OH THAT'S GOOD, THAT'S GOOD NEWS. IS THERE ANYTHING ABOUT THE SERVICE THAT YOU THINK PARTICULARLY MAKES YOUR JOB EASY HERE?

Nurse: Is it, a lot of it is the teamwork and that's not just my colleague breast care nurses, it's right through to the consultants, the clinic staff, you know, the NAs, the clinic staff, you know, we all work together and we all know, we all respect each other's roles and we all, you know, we don't take that away from each other, we, you know, we utilise that.

INT: AND IS THERE, ON THE OTHER SIDE OF THE COIN, IS THERE ANYTHING ABOUT THE SERVICE HERE THAT CONSTRAINS YOU IN ANY SORT OF WAY THAT ...?

Nurse: Strain me?

INT: CONSTRAINS YOU?

Nurse: Constrains me ... I don't actually feel constrained in any way really. I mean, you know, you feel like, you know, you're able to get on with your work and do that effectively without too many constraints really and, you know ... so no, not really.

INT: AND HOW DO YOU FIND WORKING HERE COMPARED TO OTHER PLACES YOU'VE WORKED AS A BREAST CARE NURSE?

Nurse: I feel ...

INT: OR SPECIALIST NURSE, I SHOULD SAY.

Nurse: Yeah, erm, I feel that, you know, I'm more suited to working in here, this environment here, really, just because of the points I've mentioned before: the teamwork, the communication - I think that's a big thing really, that we're all able to approach each other, you know, if you've got a problem or you've got an issue, you're able to discuss it and deal with it, you don't feel intimidated by other members of staff at all really.

INT: OH GOOD.

*Q3. DO YOU FEEL THAT PROFESSIONALS HAVE DIFFERENT STYLES OR WAY OF WORKING, AND IF SO, WHAT HAVE YOU OBSERVED THE WAYS OF WORKING HERE, AND STYLES YOU'VE OBSERVED?

Nurse: Is that within the breast care nursing team or just as a whole?

INT: AS A WHOLE, YEAH, SO CONSULTANTS AND NURSES.

Nurse: Yeah, I mean, there are different styles, you know, obviously. The nurses tend to be very similar in that sense, that we, you know, we have similar styles in how we approach things. I mean obviously our personality comes through, you know, you're not, you might be a bit more assertive than others and vice versa, but we are, you know ... Erm, consultants I suppose, there is a difference sometimes in the consultants and I suppose that comes just down to the fact the way they work really, I mean, some consultants when you [???] diagnose, can perhaps seem a bit, you know, blunt with the diagnosis, whereas others tend to, you know, might be a bit more softer in their approach and, you know, it works both ways, depends on the individual really.

INT: MM, YEAH, THAT'S RIGHT. IT DEPENDS ON WHAT THE PATIENTS WANTS IN TERMS OF INFORMATION ...

Nurse: Yeah.

INT: SOME LIKE THE SORT OF ...

Nurse: That's right.

INT: ... YOU KNOW, THE SORT OF DIRECT SORT OF APPROACH AND SORT OF JUST TELL IT LIKE IT IS AND ...

Nurse: Because some patients really appreciate that and they'll say, 'I really appreciated the way, although it seemed that was direct and I know,' and some others might perhaps be off-putting by, you know, that, so you can't always ...

INT: NO, IT'S A BIT DIFFICULT, IT'S SO VARIABLE, ISN'T IT, AT TIMES?

Nurse: Yeah.

INT: ERM, I WANT TO MOVE ON TO BEFORE A CONSULTATION NOW WHERE A DIAGNOSIS IS TO BE GIVEN, AND I'D LIKE US TO, FROM THIS POINT IN THE INTERVIEW, I'D LIKE US TO FOCUS ONLY ON NEWLY DIAGNOSED BREAST CANCER PATIENTS.

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

Nurse: Erm, it's normally on a Monday. Obviously I don't, I've not attended those because that isn't my working day, it's a Monday.

INT: RIGHT, OK. SO I CAN'T ASK YOU NUMBER FIVE THEN, CAN I?

Nurse: No, I can't attend that because I'm not here.

*Q5. HOW DO YOU USUALLY FEEL AFTER AN MDT MEETING? [not asked]

INT: WE'LL GO ON STRAIGHT TO NUMBER SIX THEN, WHICH IS ...

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

Nurse: Right. Probably, give them, speak to them and introduce myself as a breast care nurse, give a contact card and say 'If you have any questions now until perhaps you return next week or, you know, feel free to phone us, to discuss any issues from today.' If I suspect that, you know, the team suspects that this is highly likely to be going to be a cancer and the patient's unaware of that just yet, erm, until the investigations confirm that, then I might just try and introduce and say, you know, 'If you want to bring a friend with you ...' you know, because some ladies come on their own, and I think that can be quite hard, as just trying to look ahead really and just try and, you know, make it an easier time if you can for the patient.

INT: RIGHT, OK.

*Q7. WHAT WAY, IF ANY, DO YOU THINK PATIENTS HAVE PREPARED THEMSELVES FOR THE NEWS THEY'VE GOT A BREAST CANCER?

Nurse: In what way are they prepared?

INT: YEAH. NOT FROM THE PROFESSIONALS BUT FROM THEMSELVES, IF YOU LIKE, YEAH.

Nurse: Yeah, how they come in, er, I think some patients do have a suspicion. They come to this clinic and the nature of what we do her, you know, it does create some anxiety for patients. It's the unknown. And I think through the investigations they can come to their own conclusion that this might, you know, turn out to be a cancer, and so they can actually, you know, voice their suspicions themselves really. And also if they're going through certain

investigations it becomes more real that this could be a possibility and that's, I suppose, preparing for the, for the diagnosis really.

*Q8. AND PRIOR TO A CONSULTATION WHERE YOU KNOW THAT A PATIENT WILL BE GIVEN A DIAGNOSIS OF BREAST CANCER, DO YOU HAVE ANY EXPECTATIONS ABOUT HOW THAT CONSULTATION' GOING TO GO, AND WHAT WOULD IT BE BASED ON IF YOU DID?

Nurse: Erm ... I think it helps having met the patient before really. Erm, there are some occasions where, obviously with the clinics are extremely busy and you're needed to go and see a lady who's perhaps been diagnosed and you haven't met them before, that sometimes is difficult in the sense that you haven't met them and gained kind of an overall view of how they might react really, so you don't know what you're going in to and what their reaction is. So it does help to have, having met the patient really, and then you can get an idea of how perhaps they're going to react and what support you need to be able to give them, or their partner as well.

INT: YEAH. DO YOU FIND AT ALL THAT, YOU KNOW, THAT IF A PATIENT'S GOING INTO A CONSULTATION WITH A CONSULTANT THAT THEY MIGHT NOT HAVE SEEN BEFORE BUT YOU HAVE, DO YOU FIND THE CONSULTANT WILL LIAISE WITH YOU FIRST IN ANY WAY TO FIND OUT A BIT MORE ABOUT THE PATIENT OR, YOU KNOW, WHAT YOU'VE EXPERIENCED WITH THEM?

Nurse: Yeah, most are very good like that. I mean I sometimes, if they don't approach me, that's where we're very good at communicating here and we work as a team, because if I've got a lady and I perhaps have got some concerns about how she may react and I've got an, you know, an understand about how she might react, then I might liaise with the consultant about that and just say, 'She seems very anxious, she seems, you know, she's come alone,' you know, just to give her a bit of a picture of how this patient's going to be as well before she actually gives the news.

*Q9. AND WHEN YOU KNOW YOU'RE GOING TO GO INTO A CONSULTATION WHERE A PATIENT'S GOING TO BE RECEIVING BAD NEWS, CAN YOU, HOW WOULD YOU DESCRIBE YOUR FEELINGS BEFORE SUCH A CONSULTATION?

Nurse: My feelings?

INT: MM.

Nurse: Erm ... I just, basically I feel quite composed and quite focused on what I need to do. I know what my role is and the type of things I need to have, you know, I kind of prepare myself with literature that I'll probably need so that I don't have to keep going in and out of the room. So I try and get everything together that I'll possibly need, erm, but, you know, I mean I feel quite composed and quite focused on what I need to do really. I don't feel threatened or phased by, you know, and even if I haven't met the patient, you know, it's part of your role and why you're in the specialist role is to deal with that.

INT: YEAH OF COURSE. ARE YOU TYPICALLY IN A CONSULTATION WHEN DIAGNOSIS IS BROKEN, [???

Nurse: Yeah.

INT: THE REASON I ASKED THAT WAS ...

*Q10. COULD YOU NOW TALK ME THROUGH WHAT HAPPENS IN A CONSULTATION, JUST GENERALLY WHERE DIAGNOSIS AND TREATMENT OPTIONS ARE BEING DISCUSSED WITH A PATIENT WITH BREAST CANCER.

Nurse: Right, is that where the patient's just ... come in and sit down.

INT: YEAH, WHEN THE PATIENT'S JUST COME IN, YEAH.

Nurse: Right. The consultant tends to start off really and she'll discuss, you know, with the patient the findings of any investigations and kind of come to the point where then she says, you know, 'We have found a cancer, a breast cancer,' and she'll go through, talk through that and if there's any immediate reaction from the patient, say she becomes upset, you know, we deal with that there and then before we proceed again, give her some time to, you know, take that news in, or if there's any questions straight away from that we'll answer those. And then she, the consultant will probably talk about the options available really, and then she'll perhaps gesture, 'This is Jane ...' and introduce me, if I haven't met them before, she'll introduce me as the breast care nurse and, 'If you want to go off with Jane and have a talk about what I've just said, read some literature,' and then I do that bit and then we come back in to see the consultant again to re-discuss things. So it tends to be what happens, and then obviously if there's dates can be had for surgery or, you know, things like that are discussed. But it depends on the individual really and what they want to hear, and what, how much information and how they've reacted really.

INT: SO APART FROM YOURSELF AND THE CONSULTANT AND THE PATIENT, WHO ELSE IS TYPICALLY IN THE ROOM?

Nurse: It varies sometimes with the consultants, erm, sometimes we have a clinic nurse, who's the registered nurse, that's with one of the consultants. There'll be the consultant, myself, and then the registered nurse in there who's doing all the liaising with the files and, erm, but other consultants there might just be himself and myself. So, it can vary a little bit between each consultant. As I said, they have different ...

INT: MM, AND THE RELATIVES THEY BRING ALONG WITH THEM, YEAH?

Nurse: And the relatives, yeah, yeah.

INT: LET ME SEE, WHEN, YOU OBVIOUSLY GO IN WITH A COUPLE ... DO YOU WORK WITH MORE THAN ONE CONSULTANT DURING A CLINIC, YOU ...

Nurse: Well there's the consultant and then, erm, you know, he has his registrars and specialists as well working, and sometimes they may, you know ...

INT: MM, BUT ON DIFFERENT DAYS YOU'LL WORK WITH DIFFERENT CONSULTANTS, AM I RIGHT IN THINKING THAT?

Nurse: Yeah, yeah.

INT: YEAH, YEAH.

Nurse: Although I work two days, there's two consultants that I can work with.

INT: RIGHT, OK. SO THINKING ABOUT BOTH CONSULTANTS NOW THAT YOU WORK WITH, DO THEY TEND TO USE WHEN TALKING ABOUT DIAGNOSIS AND TREATMENT AND THINGS, DO THEY USE THINGS LIKE WHAT WE CALL TOOLS OR AIDS, LIKE X-RAYS OR MAMMOGRAMS, DIAGRAMS, DO THEY DRAW ANYTHING LIKE THAT? DO YOU EVER SEE THOSE BEING USED AT ALL?

Nurse: Yes. Not all the time with each patient, it's not like a routine thing that they do with each individual, but sometimes if they find that the patient's having difficulty in understanding, that sometimes that showing them the mammogram on the x-ray can be quite helpful. Sometimes, you know, that happens. Or when discussing the types of surgery, some of them will write, do a little diagram just to, you know, about wide local excision, that this happens, we take the lump and a clear margin, and they kind of clear that on a little diagram sometimes just to, to try and help, you know, them understand the different types of surgery. So, yes, you know, they do but it does vary.

*Q11. AND CAN YOU TELL ME ABOUT ANY ADDITIONAL TIME YOU USUALLY SPEND WITH A PATIENT AFTER THE PART OF THE CONSULTATION WHERE THE DOCTOR, THE CONSULTANT'S BEEN PRESENT?

Nurse: Is that in the whole process and seeing the patient from the start ...

INT: YEAH, I MEAN, INITIALLY, STRAIGHT AFTER YOU'LL PROBABLY TAKE THE PATIENT WAY BY THEMSELVES, YES, SO IF YIOU CAN TELL ME ABOUT THAT FIRST AND ...

Nurse: Yeah. Well, what happens is, after diagnosis, then, so the breast care nurse is present and then we give the patient the opportunity to go into a quieter room environment just go through what the consultant has said and just, you know, give them some support in terms of literature and see how, you know, we always give them the opportunity - some don't always want that so we always ask first if they, if we, you know, if they prefer that. And then, so we always talk about what's been said and deal with that then really.

INT: AND WHEN YOU SORT OF, WHEN YOU'RE ACTUALLY IN THERE WITH THE PATIENT AT THAT PARTICULAR TIME, DO YOU HAVE A SORT OF, KIND OF SAY, A PREFERRED APPROACH TO SORT OF START OFF A SORT OF SESSION WITH, YOU KNOW, YOU WANT TO TRY AND START WITH?

Nurse: Yeah, I mean, it's not, I don't have a set spiel that I come out, you know, but I think in this role it helps to have some kind of different spiel scenarios that you can, you know, adapt depending on the individual really. So, you know, so, yes, you make the first, get the patient and all the relatives to sit down, or I'll sometimes offer them a cup of tea or a drink, just to, you know, to start off with. And then just, you know, sit down and just ask them how they feel and things like, 'Have you understood what's been said?' and try and get them to tell me perhaps what they heard, so that gives me some help as to what they actually understand, and I can use that as a basis really just to ... see what they actually understand and what they don't. And if there's a problem I feel that they don't really understand what's been said, I can liaise with the consultant and say, 'I really feel, you know, you might need to speak to them again really' ...

INT: RIGHT, YEAH.

Nurse: ... or give them that opportunity. So ...

INT: AND DO YOU HAVE ANY OTHER CONTACT WITH THE PATIENT AFTER THAT, UP UNTIL THE POINT WHERE THEY HAVE SURGERY?

Nurse: Yeah, I mean, obviously, we'll give them a contact card and we encourage them to contact us and I tend to explain, because they always see us being really busy, 'Oh, I don't want to ring because you're really busy,' and we try to, you know, overcome that by saying, 'We are busy, yes, but, you know, we have time and if you were to contact us, you know, if we're busy, then we'll come,

we'll ring you back within that day to speak to you. But, you know, you're more than welcome to come in and have a chat with us or just telephone us if you've got any queries or questions about what's been said to today or any concerns about your surgery or ...' try and encourage that really. But we don't actually go to the patient's home or anything, you know. We try and encourage them to come to us really, or contact us. We don't telephone them after that point, unless we really feel it's necessary just to check up, see how they are.

INT: YES. AND WHEN YOU'RE SORT OF TALKING TO PATIENTS ABOUT PARTICULAR TREATMENTS OPTIONS AND THINGS, DO YOU GET AWARE OF ANY INFLUENCES COMING THROUGH ABOUT HOW THEY'RE GONNA, MIGHT MAKE THEIR TREATMENT DECISION ...INFLUENCES FROM EITHER EXTERNALLY OR INTERNALLY ?

Nurse: Yeah. Erm, as I say, you get a variety of different ladies and what, erm, sometimes they're very keen not to have the breast removed because of body image issues and we can tell that's quite apparent sometimes, the way they're talking. And some ladies are really kind of quite passive, you know, 'Whatever ...' you know, 'Whatever you, you know, feel is best ...' you know, so you can get a little of a feel about how they might react really.

INT: MM, YEAH. AND I MEAN OBVOIUSLY YOU'VE GOT A, WHEN WE WERE TALKING EARLIER ON YOU MENTIONED THAT YOU'VE DONE A LOT OF BODY IMAGE WORK YOURSELF, HOW DOES THAT TRAINING SORT OF PREPARE YOU FOR, YOU KNOW, SOME OF THE ISSUES YOU'VE JUST BEEN MENTIONING HERE, WITH LADIES WHO HAVE THAT KIND OF FOUCS ?

Nurse: It's made me aware that it's a big issue for some ladies, and it's not an issue, oh, you know, they're a bit concerned about their body image, and then you leave that and you go on - that is quite important, that can be the ultimate thing for some ladies. It's extremely important and we need to address those issues and I'm quite keen just to, you know, find out what their feelings are about the types of surgery and, you know, because it, from my experience in my body image role, it doesn't affect just the patients but how they feel about their partners as well, and the sexuality side ...

INT: YEAH, OF COURSE.

Nurse: ... there's lot of different issues. I think, you know, if you, at that point it's quite important just to, if you find any, they express any concerns, to address them and just see what we can do for them really.

INT: AND DO YOU YOURSELF USE ANYTHING, YOU KNOW, WHEN YOU'RE CONSULTING WITH THE PATIENT HERE AFTER SEEING THE DOCTOR, DO YOU USE ANYTHING LIKE MAMMOGRAMS, X-RAYS, DIAGRAMS, ANYTHING LIKE THAT? ANY KIND OF TOOLS OR VISUAL AIDS?

Nurse: No, no, no. I mean if the consultant's drawn a diagram sometimes just to explain the wide local excision option, and, as I say, if the patient's expressed that they're just a bit concerned, can they can go through that again, because, 'I'm not quite, I don't quite understand that,' I might say, you know, 'This is what he's trying to do, he's trying to show you that, you know, they're going to take the lump ...' I kind of gesture with my hand, you know, 'Going to try and take a larger margin of healthy tissue around it,' and just kind of repeat what he's said, just to reinforce, you know, just to give that more information, but I don't actually show them. Unless they request anything, if they want to see a picture or they ask how long their scar's going to be, you know, you can give them some kind of indication. But obviously it's not ... not a true indication, it's just a ...

INT: YEAH, JUST LIKE A SORT OF AIDE MEMOIRE, SORT OF THING?

Nurse: Yeah. Because I think sometimes, through experience, some patients, like with mastectomy, they get this vision in their mind that it's going to be, they're going to be left with like a raw area really, and I've had patients say that to me after surgery. So, you know, I sometimes feel it's quite helpful just to check out what their understanding is ...

INT: ABSOLUTELY, YEAH.

Nurse: ... and how they they're going to be following surgery, 'cos you're trying to reduce anxiety and if you can help then, you sort of try ...

INT: I MEAN OBVIOUSLY, I MEAN, I SEEM TO REMEMBER A SORT OF MASTECTOMY YEARS AGO WAS QUITE A RADICAL SURGERY, WASN'T IT? I MEAN [???] SORT OF THING. AND I CAN UNDERSTAND WHY PEOPLE FEEL LIKE IT'S, YOU KNOW, QUITE A ...

Nurse: Even now, you know, there's still patients that might say, express 'Oh, I thought it was going to be ...' because to them, the lay person, it's, 'They're going to remove my breast,' so they don't understand the technical side of surgery. So, you know, those fears are quite real for some ladies.

INT: OH I CAN IMAGINE, YEAH. AND WHEN YOU SORT OF ... OH SORRY, I WANT TO MOVE ON JUST A LITTLE BIT TO, YOU DON'T DO HOME VISITS, RIGHT? DO YOU TEND TO SEE THE PATIENT AT ANY OTHER TIME BEFORE THEY COME INTO CLINIC TO HAVE THEIR OPERATION?

Nurse: Sometimes on point of diagnosis, sometimes they have the staging tests for coming into theatre, so they're not actually, and we give them literature that's appropriate for the type of surgery that they're having, to take home and read. I think that's helpful because then they come back the following week and sometimes they have some real rational questions that are quite relevant to ask then, because they've had time to think about it and ask the relevant questions, they challenge any decisions or options that we've offered them, to gain more information really. So we might, we'll probably see them again a week later in clinic, just to see their staging tests are fine and go through the surgery options again. And that's, sort of, they're consented then within clinic, we consent most patients within clinic.

INT: RIGHT, OK.

Nurse: So we usually give them that that week just to go over the literature and about what we've said and come back. And after that we tend to see them perhaps on the ward then. Some ladies go to pre-assessment clinic, it depends on the consultant, but we don't tend to attend those unless we're called for really.

INT: RIGHT, OK. AND DURING ALL THESE, THIS TIME, YOU'RE NOW BUILDING UP QUITE A RAPPORT WITH THE PATIENT I SHOULD IMAGINE, WHAT ARE YOUR FEELINGS ABOUT DISCUSSING THESE SORT OF ISSUES REGARDING SURGERY AND TREATMENT AND THINGS?

Nurse: Erm, most of the times we're quite comfortable because, you know, our role is to listen to the consultant and the terminology he's used and how he's pitched it and try and, you know, because you don't want to actually influence their decision really, but in a way you want to support the decision that they're going to make so, so you tend to reinforce what the consultant's said and use similar terminology, and just check out whether they've understood. Sometimes it's difficult because, you know, type of terminology they sometimes use, the patient, you can see that they've not really understood what that's actually meant, like a tumour, a malignancy - sometimes they don't understand, unless you actually say the word 'cancer' it doesn't actually register. And if I check that out and I, you know, by talking to the patient I feel that they've not really fully understood that, you know, they have a breast cancer by the way they're talking, then I'll perhaps get the consultant just to, you know, have

another word with the patient, you know, just to make sure that they fully understand what's happening.

INT: THINKING ABOUT ALL THE PATIENTS WITH BREAST CANCER THAT YOU SEE, HOW LONG DO YOU THINK IT TAKES A PATIENT TO DECIDE WHAT TREATMENT THEY'RE GONNA GO FOR, FROM THE POINT WHEN THEY'VE HEARD THEY'VE GOT CANCER TO THE POINT WHEN THEY ACTUALLY SORT OF HAVE THEIR OPERATION, WHEN DO YOU THINK IT, HOW LONG DOES IT TAKE THEM USUALLY TO MAKE THAT SORT OF DECISION?

Nurse: Again that varies, because some patients are very, quite assertive, and they know that, you know, they've been diagnosed and although they're quite, extremely upset by their reaction, they're quite keen to, now that they know it's a breast cancer, to press on and get on with surgery. And so some are quite keen sometimes to sign the consent there and then, you know, of what they want. And that's even before the breast care nurse has actually had chance to speak to them following their diagnosis by the consultant. So some are quite keen. Others are bewildered and need a bit more time, but, you know, we do take each patient ...

INT: YEAH, INDIVIDUALLY.

Nurse: ... individually, to chat to them afterwards. And some are still keen and they, you know, even, like we say, we bring patients back after a week, they're still keen on the decision that they've made. So it does vary. Some come back to clinic a week later and they're still struggling with the options, and so on those circumstances, you know, we try and give them a bit more time because it's important that they feel they've made the decision really.

INT: I'D LIKE TO MOVE ON A LITTLE BIT TO, ABOUT PATIENTS' INFORMATION NEEDS.

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

Nurse: Erm, a lot is from experience, having perhaps cared for someone in their own family, or they've got some links with family, neighbours or, 'I know a friend who's had a mastectomy and, you know, she's told me this ..' and so there's quite a few patients come with some knowledge about, you know, their expectations. They know that, a lot more are aware of the mastectomy option as opposed to the wide local excision option, they tend to know that a bit more. They know things about the drug Tamoxafen, they can say, 'Oh, I've heard about Tamoxafen,' and whether that's relevant or not they sometimes bring that up. Erm, things about lymphoedema that, you know, they sometimes talk about, you know, lymphoedema and the problems that some of their friends have had with that, and, 'Is that gonna be relevant to me?' So they have some understanding, some, before they come, I think, because of the media and, you know ...

INT: YEAH, IT'S VERY HIGH PROFILE.

Nurse: [???] yeah. So they've read things and, whether that's relevant or not, but they've read it and they have some awareness.

INT: AND DO YOU THINK THAT A PATIENT'S LEVEL OF UNDERSTANDING AND KNOWLEDGE ABOUT CANCER AND ITS TREATMENT OPTIONS, IF THEY KNOW A LOT OR A LITTLE, DO YOU THINK THAT LEVEL OF UNDERSTANDING OF THAT, DOES IT MAKE IT, FOR AN EASIER OR HARDER CONSULTATION PROCESS, DO YOU THINK?

Nurse: Again, that's, again, down to the individual. You can have some patients that, as I've spoken, have an awareness, they have a friend, and I don't particularly, you know, find that difficult because, you know, they're just

talking about their experiences and I think that might help them at the time because they know someone that's been through it. There are some patients that are very, erm, keen to access lots of information before they come, erm, like looking on the internet and doing a lot of research sometimes before they come. Erm, so it's sometimes difficult to bring them back to the beginning really, because sometimes they can go off on a tangent about different treatments and things and you, it's important to acknowledge those because obviously they've got an interest in that, but to bring them back to why we're here, you know, at point of diagnosis, and what's going to be happening for them as an individual. But, you know, always to say that, you know, 'We can talk about those issues, you know, if you want to,' but, you know, try and ... they have a lot, you know, some come with lists of questions and files and, you know, internet papers and ... so ..

INT: WHEN YOU GET, I MEAN, DO YOU GET ANY PROBLEMS WHO ARE MISINFORMED, THEY'VE, YOU KNOW, PICKED UP INFORMATION WITH IS PERGHAPS WRONG OR OUT OF DATE OR ANYTING LIKE THAT? DO YOU THINK THAT'S A BIG PLACE TO [???

Nurse: Yeah. I think you do get an element of patients that come with, because there's a lot of media and a lo of publicity about, oh, you know, you can't dye your hair because that's, you know, there's like articles in the Daily Mail is one of them, and there's lots of published articles saying, you know, 'Hair dye has been linked to breast ...' you know, or 'This has been linked to breast cancer,' and for the lay person reading that they only see it as true.

INT: YEAH, OF COURSE, IT'S IN BLACK AND WHITE.

Nurse: Yeah, so we kind of say, you know, 'There's lots of publicity out there but we don't know who's conducted the study; we don't know whether it's, you know ... but if you've got a problem or an issue, a burning issue you want to raise with us, come back to us and we can sit down and discuss that with you.' So ...

INT: MM. THERE WAS ONE IN THE PAPER THE OTHER DAY, I WAS READING ON THE TRAIN, A DRUG CALLED S.F.R. SOMETHING 136, OR SOMETHING LIKE THAT, AND IT WAS JUST, I MEAN READING THE ARTICLE IT LOOKED LIKE A MIRACLE CURE, YOUKNOW, SORT OF THING, I WAS SORT OF LOOKING AT IT, AND I THOUGHT, 'THAT JUST CAN'T BE TRUE, I'VE NEVER HARD OF THAT.'

Nurse: No. And it's when high profile personalities, like the Karen Keating, you know, it's, there's a lot of publicity because she's a high profile personality, there's lots in the paper and suddenly there's lots of other issues, you know, topical issues about breast cancer and statistics and, you know, it's, and people that read papers are obviously going to read those because it might be relevant to them.

INT: YEAH, OF COURSE.

Nurse: So that can be a difficulty sometimes for the team really.

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

Nurse: Right. On the diagnosis, generally people want to know sometimes what size it is, you know, and whether it's treatable, and what treatments can be offered, you know, and when's the date for surgery, you know, this type of information they need. And what's the ward I'll be going on and what's it called and, you know, there's lots of information like that that they feel they need.

Erm, especially the leaflets that we have, written information leaflets on the surgical options like mastectomy and the wide local, they kind of welcome those because they can sit down and read through them and find out a bit of information really. But they like to, you know, a lot of patients tend to want to know that it's treatable, erm, you know, and that there is options available, you know, and what options are they. And sometimes even ahead of that they want to know what treatments are there after surgery as well, 'I've heard about chemo ...' or heard about radiotherapy, 'Will that be relevant to me?' and it's just, I think collectively they're just trying to get as much information in one short time as they can, just to try and get to grips with it really, and try and get some understanding.

INT: AND WHEN YOU'RE TALKING ABOUT THINGS LIKE DIAGNOSIS, ERM, DO YOU THINK THERE'S ANY INFORMATION THAT IS NOT, THAT IS GENERALLY NOT VERY WELL UNDERSTOOD BY PATIENTS? JUST TALKING ABOUT DIAGNOSIS, ANYTHING THEY DON'T TAKE IN VERY WELL, JUST IN GENERAL?

Nurse: [???] Erm, no, I think it's, if you don't follow on after the consultation at diagnosis and take the patient away to a room like we're in now and spend some time with them to go through things, then, yes, I think they might have difficulty understanding what it all means, and I think that's important for the role of the breast care nurses, because she's then got that, taken that time aside to sit down with that patient and go through, answer any of their questions, and if she can't then bring the consultant back, you know, and spend that time just with the patient, going through, and giving the literature and, you know, we go through the booklet with the patient as well, you know, because there might be the odd thing that might not be relevant, so I might say, 'That's not relevant for you,' and I'll cross that out rather than just give them a leaflet for them to go home ...

INT: YEAH, [???]

Nurse: You know, we have a few different leaflets that we have and I feel it's really important to go through that with the individual when you're handling it, not just hand it, because you don't know what their understanding of it is, so ...

INT: YEAH, EXACTLY. A LOT, I MEAN A LOT OF THIS KIND OF RESEARCH WE'RE DOING HERE, A LOT OF THE STUDIES, DIDN'T SORT OF REALLY INCORPORATE RESEARCH WITH THE SPECIALIST NURSES SORT OF THING, WHICH IS, I MEAN, MORE RECENTLY, YES, IT HAS BECOME MORE RESEARCHED, BUT THIS IS WHY WE WANT TO INCLUDE THE VIEWS OF EVERYONE IN THE UNIT THAT WORKS WITH THEM BECAUSE, YOU KNOW, AT EVERY STAGE OF THE PROCESS THAT PERSON'S GRADUALLY PICKING UP MORE INFORMATION AND ...

Nurse: Yeah, because sometimes they'll say, 'I don't quite ...' you know, I'll say, 'Have you understood what's been said to you' you know, and they'll say, 'Well, no, not really, I just, I don't really know what he's just, what he's just said to me really. I know I've got cancer but I'm, you know, it's all up here at the moment. So ...' you know, that's why important that the patients don't just go home after their consultation, that they've had time to sit down with a breast care nurse, and then we can highlight any areas where they need more information and perhaps help them with that.

INT: MM, YEAH.

*Q14. WHAT DO YOU THINK ARE THE MOST IMPORTANT PIECES OF INFORMATION PATIENTS NEED OR PERHAPS WANT TO KNOW ABOUT TREATMENT AND WHEN ARE THEY RAISED?

Nurse: Erm, sometimes like the length of treatments as well, how long am I going to be in hospital or when am I going to be in hospital, and how long am I likely to be in for, and am I going to do this after I've been in hospital, and when will I get the results of everything and, you, know, those are kind of the key things really. Just so they've got some idea in their head that certain things will happen at a certain time.

INT: RIGHT, OK.

Nurse: Erm, so yeah, I think that's ... that question.

INT: AND IS THERE ANYTHING ABOUT TREATMENT OPTIONS, WHEN YOU'RE TALKING ABOUT TREATMENT OPTIONS, AGAIN IS THERE ANY INFORMATION YOU THINK THAT GENERALLY IS NOT UNDERSTOOD VERY WELL?

Nurse: Erm, sometimes, erm, Tamoxafen is sometimes not understood very well because some ladies feel, you know, they've read that, or they've got a friend that's on Tam-, 'Well, my friend's on Tamoxafen, why am I not on Tamoxafen?' you know, so that's not, I'd say that's not always generally understood very well by patients because a lot, some ladies perhaps feel that they're not, they don't really understand why they're on the tablets sometimes. Or, if they're not on the tablet, well, 'This lady's had the same surgery as me but she's got the tablet and I haven't,' you know, it's just ... so I'd say perhaps that's one of the things that's not generally understood really.

INT: OK. JUST MOVE ON A LITTLE BIT, OR WE'LL BE HERE TILL LUNCHTIME. WHAT A PATIENT IS OFFERED, ERM, CAN YOU TELL ME [???] ...

*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: The factors that influence that decision?

INT: YEAH, MM.

Nurse: I mean obviously that's the consultant's, he's got the, you know, that's his area, his field of specialty, so he'll look at the mammograms, clinically his assessment of where the breast cancer is, obviously all the other, the tests, just see, erm, and he'll come to some kind of conclusion as to which treatment option is the best, whether we offer options or whether we just offer one option. And he tends to explain to the patient that, you know, that we could actually remove this lump without removing the whole of the breast, and then he'd explain his reasons why. Erm, but some ladies might, you know, he'll ask them how they feel about that and some ladies, you know, are quite, the majority are quite comfortable with that decision that they're not going to lose their breast and that they can still retain some of their breast, but some perhaps, you know, fear of it coming back, might want to discuss the option of mastectomy and, you know, so that it is still, you know, an option. It's not just you can have wide local excision, you know, I think generally as a whole they can, they are given that option to have alternative surgery if they feel strongly about that. Erm, but again it's the fact that, it's whereabouts in the breast it is, you know, that plays quite a high factor in determining what type of treatment options you offer. But if a consultant can offer the less surgery by removing the breast, the lump without removing the whole of the breast, he will give that as an option. But generally will offer, if he, a mastectomy if he feel, you know, he'll mention that there is this option too, but generally as a whole they may go for the lesser surgery.

INT: YEAH, MM.

*b. ONLY A MASTECTOMY [not asked]

*c. A CHOICE BETWEEN MASTECTOMY & BREAST CONSERVATION SURGERY [not asked]

*d. OTHER TREATMENTS [not asked]

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

*Q16. DO YOU THINK PATIENTS ARE GETTING THE DEGREE OF CHOICE THEY WANT WHEN IT COMES TO SURGICAL OPTIONS?

Nurse: Yeah, I would say they are, yeah. Erm, there's a few that perhaps, that don't, that feel, you know, if say a mastectomy is the only option because of where the lump is and the nature it is, of it is, in the breast, then sometimes mastectomy can be the only option, depending on the size and, erm, and so that can be quite disappointing sometimes for the lady, and basically that, you know, you have explain the reasons for that and go into the reasons for that really. Erm, I think generally most patients are given a choice ... yeah, I would say most, I would, I've never really felt that some patients haven't really been given the choice really, you know, I mean, obviously, you take into account all the imaging and things, just to make sure that the diagnosis and the treatment is the right one for that individual really.

INT: MM. WHERE PATIENTS ARE GIVEN A CHOICE, I MEAN, DO YOU EVER FIND THAT THEY ARE SURPRISED IN ANY WAY THAT THEY'RE BEING ASKED TO MAKE A CHOICE OR SOMETHING?

Nurse: Yeah, yeah. I thin that's quite difficult for some ladies: some ladies welcome that choice because, you know, if you've got the different options to choose from and, you know, but I'd say a lot of the ladies do find that quite a difficult choice because we are the professionals, they see us as the professionals and you often get, 'Well, you're the professionals, I'll go with what you say,' you tend to get that feedback quite a lot from some ladies. I think if we could, some ladies will actually express, 'If you could just tell me what I need to do, then I'll go with that,' so it's, they've found the actual deciding which option to take one of the difficult things to have to do really, because they don't have a lot of information and, you know, they've just come to clinic and being diagnosed and it's just turned their world upside down, and to make a decision like that can be quite difficult, I would imagine, I mean, I've not been there myself but ...

INT: RIGHT. THE NEXT QUESTION, IT SAYS CARD HERE, BUT YOU'VE GOT THE OPTIONS IN THAT THING ...

*Q17. SO THINKING ABOUT YOUR EXPERIENCE WITH THE PATIENTS YOU SEE, CAN YOU PLEASE LOOK AT THE RESPONSES BELOW AND TELL ME, DURING CONSULTATIONS, WHO GENERALLY MAKES THE FINAL DECISION ABOUT WHAT SURGICAL TREATMENT TO HAVE? CAN YOU CHOOSE FROM THOSE FIVE?

Nurse: I've chosen the first one but I've added some to it.

INT: OK, SO ... IF YOU CAN TELL ME, JUST READ OUT THE FIRST ONE, IT'S ...

Nurse: 'The patient tends to make the final decision regarding the treatment they will have ...

INT: YEAH, AND THEN YOU SAID ...

Nurse: '\... after carefully considering all options with the consultant and the breast care nurse, through questions and written literature.'

INT: OK, RIGHT. I'D LIKE TO MOVE ON NOW TO COMMUNICATING WITH PATIENTS WHO HAVE BREAST CANCER. IN PARTICULAR I'D LIKE JUST NOW TO FOCUS ON PATIENTS IN WHOM, FOR CLINICAL REASONS, MASTECTOMY IS NOT THE ONLY OPTION. OK? RESEARCH HAS IDENTIFIED THAT PATIENTS WITH BREAST CANCER TEND TO FALL INTO ONE OF THREE DECISION MAKING STYLES, THESE ARE THE ACTIVE, COLLABORATIVE AND PASSIVE DECISION MAKERS THAT WE SPOKE ABOUT EARLIER. IN THIS FINAL SECTION OF THE INTERVIEW, I'D LIKE TO ASK A FEW QUESTIONS ABOUT HOW YOU FIND COMMUNICATING WITH THESE TYPES OF PATIENT, EVEN IF PERHAPS YOU DON'T THINK OF THEM IN TERMS OF ACTIVE, PASSIVE AND COLLABORATIVE. I'D LIKE TO START WITH SITUATIONS WITH ACTIVE DECISION MAKERS AND FOR THE PURPOSE OF THE STUDY WE DEFINE ACTIVE DECISION MAKERS AS PATIENTS WHO TEND TO MAKE THEIR OWN FINAL TREATMENT DECISIONS, EITHER WITH OR WITHOUT SERIOUSLY CONSIDERING THEIR SPECIALISTS' OPINION.

*Q18. FIRST OF ALL, I WOULD LIKE YOU TO THINK ABOUT A SITUATION POSSIBLY YOU'VE HAD WITH A PATIENT OR PATIENTS WHO WERE ACTIVE AND, WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, PLEASE TELL ME ABOUT YOUR EXPERIENCES WITH THEM UP TO THE POINT WHEN A TREATMENT DECISION WAS MADE.

Nurse: Mm, I'm trying to think, I've obviously been off for a little while, but I can think of a lady, it might be a little bit vague because it's her, I've been off for, it's over a year ago, but she came to clinic with quite a large breast lump and obviously the ultimate was that it was a breast cancer, erm, and she used to come to clinic on her own and sometimes with a partner but he never came into the consultation room with her, she didn't want him in. And she was really against a mastectomy, she really didn't want a mastectomy, but remembering back to her clinical findings, I think that was the only option she had. Is that ... because you, is this, the person's supposed to have the option, is that what ...

INT: ERM, YES, THEY'RE SUPPOSED TO HAVE A CHOICE.

Nurse: Yeah, all right, no she didn't have a choice then actually.

INT: RIGHT, OK. WELL TELL ME ABOUT HER ANYWAY, I MEAN, IF THAT'S THE ONLY PERSON YOU CAN REMEMBER.

Nurse: Yeah, she didn't actually have a choice, the mastectomy, because of the size and the location of where the breast was, she didn't have an option. I think she would have preferred the option, and she had some difficulty with that. And so it was agreed, she was agreed, because of the size, she had some pre-operative chemotherapy to reduce the lump size and I think the outcome was that, I think she did push to have a wide local excision, that's why I'm thinking of this lady. But it took a long time, she did DNA a few times and didn't come back to clinic and, but eventually, you know, we, I remember sitting her down with the consultant and really talked through the options and I think she was quite adamant that she didn't want the mastectomy. But we'd shrunk the tumour down with the chemotherapy pre-operatively and I suppose, you know, it wasn't the best option that perhaps was going to be for her, but she was adamant that that was the option that she wanted. And I think we did do a wide local excision and I think the outcome was that we didn't, you know, we didn't

have to re-do any further surgery. So ... I can't remember, it's a bit vague, I can't ... [chuckles]

INT: YES, THAT'S FINE, THANK YOU. HOW ... AS WELL AS YOU REMEMBER, HOW DID THE PATIENT GET ON WITH THE CONSULTANT?

Nurse: It was a bit, erm, the patient found the consultant perhaps a bit, her manner a bit abrupt and a bit, you know, to the point. And so she, I don't, I'm not sure if she actually ... she always, she felt that she needed to perhaps just go through things after she'd been in there and sometimes we'd make a point of seeing her before she went in just to check out how she was feeling that day, and that, just to give her some support really. Erm, but yeah, I suppose, you know, you do have patients that are a bit more difficult to deal with this, and she was one because she was very active, she knew what she wanted and really quite forceful in what she wanted.

INT: AND YOURSELF, HOW DID YOU GET ON WITH HER? DID YOU DEAL WITH HER EVERY TIME THAT SHE CAME OR DID IT VARY?

Nurse: No, sometimes it does vary, that's, you know, but I did see her on a few occasions and especially when she was in the ward and, you know, I didn't feel that we had any difficulties, you know, just spent, I, perhaps, you know, give her a little bit of time just to express how she feels and, you know, her reasons for wanting to make the decision that she did, you know, and that she was comfortable with that decision.

INT: WHEN YOU WERE TALKING ABOUT THE ACTUAL DECISION THAT SHE ... WAS THERE ANY INFLUENCES THAT WERE APPARENT? DID YOU PICK UP ON ANYTHING THAT, WHY THIS DECISION WAS BEING MADE IN SUCH A WAY?

Nurse: Her decision?

INT: YEAH, HER DECISION.

Nurse: I felt body image was very important to her, she was a well-dressed individual and took pride in her hair and things, and I suspect from talking to her, a few things came out in conversation, I'm not sure about her relationship with her partner and how his feelings towards, because, you know, he never used to come in and she used to deal with that side of things on her own.

ING: RIGHT, YEAH.

Nurse: And so I think, deep down I think there was, you know, a body image issue really. But ... I think, you know, she seemed OK after she'd the type of surgery that she wanted, and then it turned out OK.

INT: YEAH, I WAS GOING TO SAY, YEAH, I WAS GOING TO SAY HOW SATISFIED WITH THE EXPERIENCE DO YOU THINK SHE WAS?

Nurse: Yeah, yeah. But I mean at the time she was, I suppose at the point of diagnosis it was, at the time it would have been, it wouldn't have been feasible to actually have done like the wide local excision really without giving her some chemotherapy beforehand. I think that helped a lot, just to, you know, ...

INT: AND LOOKING BACK NOW, HOW SATISFIED DO YOU THINK YOU WERE WITH THE EXPERIENCE WITH THAT PATIENT?

Nurse: Erm, I wouldn't say it's been my most satisfying interaction with a patient. I feel, you always feel that you want to be able to help them more but, you know, there's only so much you can do to help them with their, you know,

their reaction and how much intervention they want from you. You know, because obviously we're there to support them but they need, then it's important that they feel that they want that support at the same time. The last thing you want to do is, you know, pressurise patients into sitting down and talking through their fears and concerns if ... they need to feel comfortable to do that really. So each time we'd just give her the option to go into a quiet room and to talk about the consultant, if there's any questions from that she wants to discuss or any concerns, so ... and that each time perhaps be able to, you know, give a little bit more help really.

INT: THINKING ABOUT SORT OF ACTIVE DECISION MAKERS IN GENERAL NOW, AT WHAT POINT DO YOU THINK YOU BECOME AWARE THAT YOU'RE TALKING TO SOMEBODY WHO IS ACTIVE IN SORT OF THE CONTEXT WE'RE TALKING ABOUT NOW?

Nurse: Erm, just the way they, you know, react to the diagnosis really and, you know, even, you know, they can be upset and they can be weepy, you know, they can have moments when, you know, I need to just stop and give them some time but as they've collected themselves together again I think, you know, they seem quite focused that, you know, seem to have taken it on board and then, you know, ...

INT: THESE ARE THE ACTIVE PEOPLE RIGHT?

Nurse: Yeah.

INT: YEAH?

Nurse: They seem quite focused on what they want really. Erm, and sometimes, you know, if they've brought, the questions they ask, you know, they'll be quite [??] and they'll ask lots of questions and relevance to, you know, to keep checking, challenging the consultant, you know, 'Why is that decision?' you know, 'And why have you made that decision?' and just challenging all the time and asking the right questions. Just for them to gain more information really. I think they're just, you know, quite intelligent people that have got information needs and that's their way of gaining the information really. And I think it helps them make the decision.

INT: AND WHEN YOU DO HAVE THAT SORT OF AWARENESS OF YOU'RE TALKING TO THIS PERSON WHO'S QUITE ACTIVE, DOES THAT SORT OF CHANGE OR INFLUENCE YOU IN HOW YOU'RE GOING TO APPROACH THAT PERSON IN SUBSEQUENT MEETINGS AND CONSULTATIONS?

Nurse: Erm, no, I mean obviously I take into account the type of questions that they've asked and I'll, you know, that gives me the impression that they, you know, have information needs and that, you know, they will seek that information themselves quite actively so that they can come to their decision about what surgery they want. But, you know, at that stage I'm quite, you know, it's important for me to, you know, stay focused and, you know, remember and listen during the consultant what has actually been said and what's not been said, you know. I suppose it makes me more aware sometimes just to listen more attentively to what's been said between the consultant and the patient or relative. So that, you know, I don't, you know, keep it focused and, you know, so that I'm not going to say anything that's not been said - not that I would but just try and remember what terminology's been used and what questions have been answered.

INT: I'D LIKE TO MOVE ON NOW TO A SIMILAR SITUATION BUT WITH COLLABORATIVE DECISION MAKERS. FOR THE PURPOSE OF THE STUDY WE DEFINE COLLABORATIVE DECISION MAKERS AS PATIENTS WHO TEND TO SHARE FINAL TREATMENT DECISION RESPONSIBILITIES WITH THEIR SPECIALISTS.

*Q19. SIMILAR TO WHAT WE'VE JUST DONE, IF YOU CAN THINK OF SOMEBODY IN PARTICULAR WHO YOU THOUGHT WAS PARTICULARLY COLLABORATIVE, THAT WOULD BE GREAT. IF YOU CAN'T TRY AND SPEAK ABOUT THEM IN GENERAL, BUT JUST DON'T REVEAL ANY CONFIDENTIAL DETAILS. TELL ME, DO YOU HAVE ANYBODY PARTICULARLY IN MIND OR ...?

Nurse: Erm, yeah, one of the patients presented in clinic, she had a breast lump, turned out to be a breast cancer that could be treated either way really, wide local excision or mastectomy, and the, it wasn't the actual consultant that saw her, he was a specialist, erm, who saw her in the same clinic. He kind of felt that, talking to me beforehand, a mastectomy might be the better option for this lady and I could sense that that's the way he wanted to go with it, erm, and I was ... erm, wondering, you know, what he was going to actually say to the patient, or obviously I thought he was going to go in there and say, you know, mastectomy is the option really, and not really give her an option. But then, you know, he did actually give her the option of wide local excision, but that's a bit later during the conversation which I think maybe he could have handled that a bit better.

INT: RIGHT, YEAH.

Nurse: I think, you know, he kind of went in with the idea that mastectomy would be the better option for this lady, but he knew that perhaps, you know, we could actually treat it with a wide local excision, it just might mean that the cosmetic side of thing might not be ...

INT: AS GOOD.

Nurse: ... as good or, you know. So he introduced that a bit later and so, you know, after speaking with her and we just left her with her husband with her for a little while just to have some time together, you know, just made sure I'd clarified with him that, yes, this lady can have the option, you know, 'Is it mastectomy that you want her to have? You've just mentioned wide local excision, you know, therefore you've given, you have given her the option,' and [???] 'Yes,' ... 'So therefore I can give her both written literature on both options.'

INT: YEAH, YEAH OF COURSE.

Nurse: And then speaking to her afterwards, just to go through those, the different options and check out her feelings towards the body image side of the surgery because the wide local excision would have left, because it was near the nipple, it would have left, she would actually have the nipple removed actually, so it would have been difficult to fit a prosthesis afterwards and there could have been some difficulty. So just, you know, we mentioned that and talked about that and how she felt about that, with the different options. She kept saying sometimes, 'Well, I can sense that he prefers me to have the mastectomy,' you know, and it's 'Well, you've been given the option, you can have both, you know, and we can talk through it, I can get him to come back in and re-explain it.' So I do find some particular doctors perhaps, you know, not, I think sometimes it's good to be direct and blunt and just say how things are, 'You have two options,' rather than sometimes go round the houses a little bit, because I think it confuses the patient.

INT: RIGHT, YEAH, YEAH. SO WHAT DID THIS PATIENT HAVE IN THE END?

Nurse: She's coming back today.

INT: OH RIGHT, OK.

Nurse: Yeah, she's been given the literature and we've had a chat with her and she's going to go home and think about the different options and all the factors, the pros and cons of both options, you know, she can, I've encouraged her to perhaps write a list of questions ...

INT: YEAH, ABSOLUTELY.

Nurse: ... that might be appropriate (a) for mastectomy (b) for the wide local, you know, because I think that time's important for her to perhaps sit down with her husband and go through that. Erm ...

INT: DO YOU HAVE ANY KIND OF SORT OF GUT FEELING ABOUT WHAT SHE'LL GO FOR? DID YOU PICK UP ANYTHING IN THE CONSULTATION THAT SHE MIGHT SWING ONE WAY OR THE OTHER? I MEAN I KNOW IT'S JUST PURELY HYPOTHETICAL BUT ...

Nurse: I think she would, listening to what the doctor was saying in terms of that he emphasised and talked more about the mastectomy side, and just kind of briefly touched on the wide local excision side and then gave a little bit of insight and talked about, you know, the problems with the cosmetic result following that, but he emphasised more on the mastectomy side. Erm, but I tried to talk and get her to talk about both options really and her feelings of what she understood about both options, so that then she can go away, you know, and look at that and come back today and hopefully reach a decision, and I think, I think body image would be an important thing for her and I think, given the option without, if it was a clear option - mastectomy versus wide ... - I think she probably would choose a wide local, but because of the problems with the cosmetic appearance afterwards maybe she might, I don't know, I'm a bit, you know, undecided about what she might choose really.

INT: HOW DID YOU FEEL THAT THE PATIENT GOT ON WITH THE ACTUAL DOCTOR THEMSELVES, THE CONSULTANT?

Nurse: I think she got on, you know, she was listening and understanding, I mean she was asking quite a lot of questions that were appropriate, asking for more information, but also at the same time, you know, she was, 'Well if you feel that's the best option to go for ...' you know, so she was kind of, you know, asking more questions to get more information so she could make an active decision, but at the same time, you know, she perhaps doesn't know what option to go for. It's very difficult for her so she's kind of looking for guidance as well from him. So ...

INT: AND YOURSELF, HOW DID YOU GET ON WITH HER?

Nurse: Erm, well OK. Her husband was with her and her husband was very, very quiet. I think, you know, he was just in shock of what's been discussed really and I don't think he was holding it together very well at all, but she was totally the opposite, she was 'Right, OK, yes, right,' you know. 'Let's go home and think about it,' and you got this impression that she just wanted to get up and go. Some ladies do, you know, when you've been diagnosed.

INT: OH YES, I MEAN, AS SOON AS THEY'VE HEARD THEY WANT TO GO HOME.

Nurse: Yeah, but I sensed that he had needs and needed to talk through it and it's, when you've got a couple like that of different emotions it's, it can be difficult to meet the needs of each patient.

INT: MM, BECAUSE PRIMARILY YOU'RE THERE FOR THE PATIENT, AREN'T YOU, THAT'S THE THING?

Nurse: Yeah, that's it. And so, whilst we were talking together, it's, you know, very centred on, you know, bringing him into conversation and trying to say, 'Are you OK?' and ...

INT: BUT GENERALLY THERE ISN'T VERY MUCH FOR THE SPOUSES, IS THERE, YOU KNOW, IN THESE INSTANCES? I MEAN I'VE HAD A FEW PATIENTS THAT'LL SAY, ERM, JUST ONE THE OTHER DAY I WAS SPEAKING TO SAID, YOU KNOW, 'I FELT ACTUALLY SORRY FOR MY HUSBAND BECAUSE THERE WAS NOTHING FOR HIM AND HE WAS KIND OF, YOU KNOW, ALMOST LIKE JUST WRINGING HIS HANDS AND WALKING AROUND NOT REALLY KNOWING WHAT TO SAY OR DO.

Nurse: Yeah, because they've not had chance to speak to their wife about how each other feels and, you know, you've got these professionals here and trying to help them, but, and that, sometimes I give them time to, you know, five or ten minutes time to be together alone sometimes if I felt that's important, which I did for this couple.

INT: YEAH, I REMEMBER WHEN MY DAD WAS DIAGNOSED WITH BOWEL CANCER AND I MEAN I'VE DONE PSYCHOLOGY AS A BACKGROUND, BUT I HADN'T REALLY DONE ANYTHING ON THE PSYCHOLOGY OF CANCER, AND I JUST FELT A BIT SORT OF USELESS REALLY, NOT REALLY KNOWING WHAT TO SAY OR ANYTHING LIKE THAT ABOUT IT, YOU KNOW, SORT OF THING. AND I THOUGHT, WELL, YOU KNOW, EVEN WITH THE SORT OF SKILLS THAT I'VE PICKED UP FROM MY DEGREE AND MY MASTERS AND THIS, AND THESE SKILLS THAT I HAVE JUST WORKING IN THE PSYCHOLOGY AREA, IT WAS STILL DIFFICULT FOR ME JUST TO RELAY UNDERSTAND WHAT HE WAS GOING THROUGH. SO I CAN IMAGINE WHAT IT'S LIKE FOR, YOU KNOW, SOMEBODY, ANY SPOUSE, WHETHER IT'S MALE OR FEMALE, WHATEVER CANCER IT IS, TO KIND OF REALLY UNDERSTAND WHAT SOMEONE'S GOING THROUGH.

Nurse: Yeah, sometimes I say, you know, they interrupt and say sometimes like inappropriate things some-, you know, they'll worry about the things that shouldn't really matter, and they were supposed to be going and seeing their son in Bristol that evening, you know, and they were, they'd troddled a long way to come to clinic, and my concern for him was, 'Are you going to be OK to drive home?' you know, I offered them a taxi or to use the phone to ring for someone to collect them, you know, but he, you know, said he would be OK. While his wife went off to have some blood tests and things, I just came back just to see how he was. I just said, 'Are you ...' you know, 'Are you OK?' you know, and he just said, 'No, not really.' You know, that was his opportunity to perhaps just have a little, you know, have a cry and express his fear about his wife, you know, his fears his wife is going to die, you know. And just, you know, address his concerns, without obviously affecting my own professional relationship with his wife, you know, just to give him some support really because I felt, you know, I felt that, you know, that was good, that I was able, I'd got the opportunity to do that really. But we do, you know, I do give them, offer them information that they can have from Breast Cancer Care, they have support networks and telephone support lines that they can ring, contacts for husbands. I very often sometimes mention that, that 'If you find that you need support yourself, you can come and speak to us obviously.' Obviously there's confidentiality with the wife, you know, but, a professional relationship there, but there's, you know, 'You can talk to me about your fears and concerns,' but, or there's the telephone help lines that you can contact and we'll give him some information on telephone numbers and addresses. So they've got something there if they felt they needed it. Because I do think husbands perhaps they don't have the support, you know, professional support really.

INT: YEAH, YEAH, THEY DON'T. NO, THAT'S ...

Nurse: Because they're the main carer ...

INT: YEAH, USUALLY.

Nurse: ... and it's ... most of the time.

INT: MM, YEAH. AND CARERS, DEPENDING ON HOW ILL THE PERSON IS, OFTEN CAN'T AFFORD TO BE ILL THEMSELVES REALLY, THAT'S THE THING.

Nurse: No, and it's about saying the right thing and upset-, and sometimes, you know, it's why we offer the ladies our contact cards to phone us because they can talk to us freely without, you know, feeling that they're being sensitive to their partner's needs and if they say something they might upset ...

INT: THINKING ABOUT COLLABORATIVE DECISION MAKERS NOW IN GENERAL, AT WHAT POINT DO YOU THINK YOU BECOME AWARE, YOU KNOW THAT'S SOMEONE'S BEING COLLABORATIVE IN THEIR DECISION IN THE CONSULTATION?

Nurse: When, erm, they want to discuss both options and they're asking relevant questions for both options. Erm, but at the same time, you know, checking out that these options, you know, are OK and that, 'Is that OK for me to ...?' you know, 'Is that surgery going to help me?' And 'In what way will it help me?' Erm, you know, kind of being involved in their own care really and planning that care really and the surgery options of ... just the questions they ask really and the fact that they're taking on board what the consultant's saying as well and taking note and listening, and asking the relevant questions. And sometimes, you know, asking their partner if they've got any questions that they want to ask a well.

INT: DOES THAT AWARENESS INFLUENCE OR CHANGE HOW YOU CONSULT WITH THAT PERSON?

Nurse: Again, no, not really. Erm, I mean they're, you know, you just treat them as you would more like any person that's been diagnosed really. How role is to perhaps sit down and just to check out their understanding and what they understand about today's consultation and if they have got any information needs can I help with that. If they're upset and in need of support, you know, deal with that as well, you know, it's not, I don't have set, like we talked about spiels and things, I don't have set spiels for different types of patients. I mean everyone's an individual and, you know, if you've met them beforehand it helps just to check out how they are really as a person and how they might react and just deal with that accordingly [???

INT: I'D LIKE TO MOVE ON A LITTLE BIT NOW TO SITUATIONS WITH PASSIVE DECISION MAKERS AND FOR THIS STUDY WE DEFINE PASSIVE DECISION MAKERS AS PATIENTS WHO TEND TO WANT TO LEAVE FINAL TREATMENT DECISIONS TO THEIR SPECIALISTS, EITHER WITH OR WITHOUT THEIR SPECIALIST SERIOUSLY THEIR OPINIONS.

*Q20. JUST SIMILAR TO WHAT WE'VE DONE DO YOU THINK YOU KNOW SOMEBODY, OR HAVE SOMEBODY IN MIND WHO WAS PARTICULARLY PASSIVE?

Nurse: Yeah [chuckles] tends to be, it affects, sometimes the elderly ladies, you know, they, you know, they come out with, 'Well you know best, Doctor, you tell me. I'll go with whatever you say,' you know. I find those patients find it the hardest to make the decision sometimes because they don't want to make the decision, you can tell from what they're saying, they just want the doctor to say, 'Right, this is what we're going to do, and you're going to come in on this day and have that surgery,' and when they're then faced with the option of whether they have a mastectomy or a wide local excision, they, 'Well, I don't know, I don't know what to do,' and they, you know, they, sometimes if they've got a partner or husband, 'Well, what do you think?' and it's checking, 'What would you do if it was you?' that tends to be the common feedback that you get sometimes, which obviously I can't answer because I've never been in that

situation, [chuckles] and you wouldn't as a professional. And the husband sometimes it quite passive too, 'Ooh, it's whatever you want love, I'll go with whatever you want,' and so you're not really, sometimes you feel like you're not getting anywhere. So ... it's, I think the written information that we offer does help ladies in that way, they can take something then and sit and read about the different options and, and just encourage the ladies, you know, to write perhaps, write down the pros and cons of each option, you know. 'What would be good in that option for you? What wouldn't be so good? And look at both options and try and come to some decision, yeah, of your accord, because it has to be important that it's your decision and that you're comfortable with that decision.' But sometimes they can be more difficult really in a sense that ...

INT: I WAS JUST GONNA ASK YOU, YEAH, I MEAN, THE THREE TYPES OF DECISION MAKER, WHICH DO YOU FIND ARE THE EASIEST OR THE MOST DIFFICULT TO ACTUALLY CONSULT WITH?

Nurse: Mm. I think the collaborative patients tends to be, a lot of patients tend to be in that kind of category really, you know, I think with all them media, they're aware of what's happening and it's a high profile unit and area, speciality, so there's lot of information out there for them to read and they can challenge decisions and also listen to patients, the consultant as well. So I don't think they're actually the most difficult ones. If you had to say difficult, which I wouldn't say they're difficult really, but say the more challenging of the three, perhaps they can sometimes be I'd say the active patients sometimes because, whether you just feel that there's other issues that are perhaps a bit deeper that need addressing before you make that decision, before they make that decision. And perhaps those patients just need that bit more time, a bit more, longer time to just look at the information and have more consultations here with the clinic, just to come to some decision really.

INT: RIGHT, YEAH.

Nurse: Because there's something that's, you know, making them, you know, they're still determined in what they want, you know. But then the passive patients, you know, it's, they just need a little bit of time and information and, you know, you find you just go over things, the same things, but, you know, especially if some patients that come, you know, they can't read and write and so, you know, they don't about what decision to make and then they've got this literature and you find that you're going through it with them quite a few times, you know. And it's, you know, incorporating to help as well, and any friends and families that might be able to read through the information with them.

INT: A COUPLE OF QUESTIONS TO FINISH OFF WITH, I'M GETTING AWARE OF THE TIME NOW. WE'VE TALKED A LITTLE BIT ABOUT THE INFLUENCES ON PATIENTS' DECISION MAKING ...

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

Nurse: I think media, internet - I think internet is quite a bit thing, you know. Sometimes you have this, the internet patient, it's, but, you know, everybody more or less has access to the internet now and, you know, they do, lots of patients, you know, read up, they want to read up, they want to be, play an active role in their treatment really, planning. They, you know, they do read and they take note of what's been said and they'll challenge questions and I think, you know, the media and that has a lot to do with how patients really, you know, influence their decision really. And also friends and family and personal experiences and that.

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

Nurse: I think, obviously the specialist surgeon because, whether it's an influence but, you know, it's his clinical judgement, you know, what's in the best interests of the patient, you know, in terms of health, that's why we're here, we're here to, you know, try and help the patients, you know, and, erm, his decision whether he offers the lady an option or he doesn't, and where, you know, as a breast care nurse our role is to support ...

INT: THAT DECISION.

Nurse: ... that decision, and if we, you know, are uncomfortable with that then we might challenge or say, you know, 'Are you sure?' you know, 'Is she not eligible for this? Or ...' and, you know, hopefully they'll, they'll come back and make that decision really. I would say they make the final really influence.

INT: AND A LITTLE QUESTION I WANT TO SNEAK IN AT THE END HERE, IT'S NOT ON THE QUESTIONNAIRE.

Nurse: Oh no, that's naughty. [chuckles].

INT: IF YOU HAD THE POWER AND MONEY TO CHANGE ONE THING ABOUT THE SYSTEM HERE, WHAT WOULD IT BE?

Nurse: Power and money ... I'd change the layout of this unit because, which we've actually talked about as a unit because it's all going to change and we're kind of taking that into consideration, because the way the consultation rooms are you've got people coming in and out and the waiting room's there, so as the patients are coming out they're faced with all the people who're waiting for mammography, ultrasound, relatives, sometimes children, and if they've just been diagnosed and they're extremely upset ... [???] this room here, we have to walk down the corridor to come to this room, and I think really perhaps we should have like a flow system, you know ...

INT: MM, A ONE-WAY SYSTEM?

Nurse: Yeah, and I think that might be easier for patients because, you know, I'm sure they find that uncomfortable when they come out and everyone stares at you, you know, they're a bit like a goldfish really in a goldfish bowl.

INT: YEAH, THERE'S A COUPLE OF CLIENTS HAVE HEARD SAY THAT BEFORE, AND I MEAN I KNOW CERTAIN, THE CLINIC WHATEVER, IN THE HOSPITAL WHERE I'M WORKING, YOU KNOW, WELL, THERE'S NOT THAT MANY BREAST CARE NURSES, YEAH, AND SORT OF, YOU KNOW, PATIENTS WHO ARE WAITING AND WAITING AND WAITING AND SEEING OTHER PEOPLE GO BEFORE THEM, THEY KIND OF KNOW, 'WELL I'M WAITING TO SEE THE BREAST CARE NURSE.'

Nurse: Mm, yeah. Well it must be embarrassing because like, 'They're saving me till last,' ...

INT: [???

Nurse: ... and yeah, it's true in a way, because you've got more to do and, you know, you're seeing those patients but ...

INT: IT'S NOT IDEAL.

Nurse: ... you're sending those patients off for more investigations so they are going to be the last ones on the clinic.

INT: THERE'S QUITE A BIT OF RESEARCH BEEN DONE ABOUT SORT OF HOW UNITS, NOT BREAST CARE UNITS, BUT HOSPITALS AND HOSPITAL WARDS HAVE BEEN DESIGNED AND STUFF LIKE THAT, ERM, AND IT'D BE WORTH HAVING A LOOK AT SOME OF THAT BECAUSE THEY'VE DONE DIFFERENT TYPES OF, YOU KNOW, QUALITATIVE AND QUANTITATIVE STUDIES BEEN DONE ABOUT HOW SPACE IS USED AND STUFF LIKE THAT. IT MIGHT BE WORTH HAVING A LOOK.

Nurse: Mm, because it gets so cramped on here, if you come here on a Thursday afternoon it is so busy and they, often people come with a relative so there's only so much seating as well and, you know, it's very busy and people up and down the corridors, you know, er, and it's, can be quite daunting really, I think. And it's quite a narrow corridor. So, erm, and when you're calling patients in, you know, you don't know where they're going to be sat, down at the bottom or at the top and ... and if you need to ask the relative to come in, you know, it's, 'Can you come in?' and it's, you know, they think, 'Oh right,' you know, 'I have to go in, obviously there's something wrong, they're calling me in,' you know. So, yeah, if I had the money, I'd re-build it. [chuckles]

*Q23. RIGHT. FINALLY, IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD TO WHAT WE HAVE BEEN TALKING ABOUT TODAY? IS THERE ANYTHING YOU THINK WE'VE MISSED, ANYTHING YOU THINK THAT'S IMPORTANT THAT HASN'T BEEN MENTIONED YET?

Nurse: No, not really.

INT: MM, IT'S PRETTY COMPREHENSIVE [???] ?

Nurse: Yeah.

INT: WHAT'S THAT THEN? OH IT'S AN HOUR AND 14, WE'VE DONE ALL RIGHT, I THINK THE LONGEST WAS TWO HOURS.

Nurse: Was it? Oh right.

INT: YEAH, I CAN'T TELL YOU WHO THAT WAS BUT ... I'LL BET [???]

Nurse: I do waffle on sometimes but ...

INT: NO, IT'S BEEN VERY GOOD INTERVIEW, I MEAN,