

\*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Nurse)

\*VENUE: Low MR unit

\*DATE:

\*ID: BCN038

\*INTERVIEWER: DJW

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

Nurse: The unit? I've worked here for, it'll be six years in April, prior to that I was here up on the ward, which was a female general surgical ward which encompassed breast ladies and towards the end of my time on that ward, before I got this job, I was looking after ladies who were having breast surgery, and then I applied for this job and left the ward and came in this post. It's six years in April.

INT: OH RIGHT, OK. SO IT'S A SIMILAR SORT OF STORY TO THE LADY I'VE INTERVIEWED EARLIER TODAY.

Nurse: Yes, that's right, yes, yes.

INT: YES, OK. HOW DO YOU FIND WORKING IN HERE INSTEAD OF WORKING IN THE WARD THEN?

Nurse: It's very, very different, entirely different, because you're not working shifts for a start, you're not in uniform, you've got a completely different identity and certainly people can treat you differently. I really enjoy the job, erm, I get a lot out of it. It's very diverse because we do lots of things and you're not just dealing with diagnosing the breast care because we run lymphoedema clinics, we run seroma clinics, we fit prostheses, so we do a whole range of roles really, which is really nice. But it is, it's very, very different, very different indeed. And of course on the ward all you see are women who are having their surgery or have had their surgery: you have very little knowledge of what went on before and what went on afterwards, whereas this role you will actually see them even before they are diagnosed, when they're going through the process of investigation. And then you see them at time of diagnosis: you also go and visit them on the ward, and also you see them after, following their surgery. And you also see them when they come back for their follow-up appointments, if they come to the seroma clinic, we also see them on oncology clinics as well. So there's quite a wide, erm, contact with them really, which is nice, because you get more of an overview, much wider picture.

INT: YEAH, FULLER PICTURE. OH, THAT'S NICE. SO I MEAN THINKING ABOUT THINGS LIKE UNIT PHILOSOPHY AND THE DAY TO DAY RUNNING OF THE SERVICE, YOUR LIKES, YOUR DISLIKES ...

\*Q2. WHAT IS IT LIKE TO WORK AS A SPECIALIST NURSE IN THIS BREAST SERVICE?

Nurse: It's actually, for me personally, erm, I actually enjoy the job. I don't think I would have stuck it out for six years if I hadn't. Like I've just mentioned, you know, it's very diverse, it is different, it's nice that it's Monday to Friday, you've got a variety of team of staff that you work with, and also within the breast care nursing team it's a lovely team, I'm sure you may well have picked that up already when you've been ...

INT: YEAH, YEAH, I'VE BEEN MADE VERY WELCOME, THANK YOU VERY MUCH.

Nurse: And it's a lovely, lovely team, and it's nice to work with a variety of personalities, shall we say. Sometimes it can be stressful, not because 'Gosh, I'm just about to go and see this lady, you know, I've got to be there when

she's diagnosed,' I don't get stressed about that, it's really time constraints. Time constraints are a big issue and, because it's such a big unit, and because we have such big clinics, your time is, is definitely limited on how much you can spend with patients. And sometimes I am very aware that when I'm in talking with a patient and discussing things, that there's somebody else waiting to be seen and I know that certain consultants wait for you because they know you, they want you to be there when you're discussing things with patients. So sometimes it can be stressful in that sort of respect. Erm, but it's a really, really nice job and it's, it's nice to see the whole picture. When you see the patients when they're diagnosed, and you see they're very upset, very distressed, and then you see them after all the treatment's done and they've got back on with their lives, and they look so much different when they come back and they've got back on with their working lives or whatever, and it's nice to see them come out the other side really.

INT: YEAH, OH THAT'S GOOD. THINKING ABOUT THE SORT OF STRUCTURE OF THE SERVICE FROM LIKE A THUMBNAIL SKETCH IF YOU LIKE OF HOW THE PATIENTS COMING IN, THERE'S TWO ROUTES FOR THEM, THERE'S THE SCREENING AND THE SYMPTOMATIC, THINKING ABOUT HOW THEY COME IN AND THE SORT OF, LIKE, CAN YOU GIVE ME LIKE A THUMBNAIL SKETCH OF LIKE THEIR, JUST THEIR PATHWAY THROUGH THE CLINIC FROM WHEN THEY'RE SORT OF, THE TWO ROUTES?

Nurse: Yes.

INT: JUST THE BASICS, JUST GIVE ME AN OVERVIEW OF THAT.

Nurse: Well, would you like me start on screening on first?

INT: YEAH, OK.

Nurse: Women who have had their mammograms done on the National Breast Screening Programme, obviously they come here for their mammogram or they go on the mobile, and they have their mammogram assuming that everything's OK, and then suddenly they will receive this letter to come back for what we call the second stage of screening, and in that letter it does say, 'You can actually contact a breast care nurse if you wish to discuss anything, any further details,' and we do actually receive quite a few phone calls prior to them coming here for their second stage of screening, and you can actually sense the anxiety on the phone with these ladies because you've got to be aware that as far as they're concerned they're fine, they haven't presented with a lump, they haven't been to their GP with a problem, and they often naturally assume they have a breast cancer because we're inviting them back. And it's just going through with them what is likely to happen when they come back and just to try and advise them that, just because we're calling you back, it doesn't automatically mean you've got a breast cancer, it just means that something looks different and we need to bring you back and have another look at you. So we do get quite a few phone calls. And when they do come here to their appointment, these women are different to symptomatic women - these women are very, very different, and they do appear to me by far much more stressful because there's nothing wrong with them, you know, they've not complained of a problem in their breast. And so often they need a lot, a lot more dealing with really in the sense that you've got to try and calm them down before they even come to the clinic sometimes, you know, on the phone. So when they do come they go through the initial tests, the vast majority of them thankfully for fine and we can wave goodbye to them and send them on their way, and often there's a few tears of relief, as you can imagine.

INT: YEAH, I CAN IMAGINE, YEAH.

Nurse: Erm ... that's the screening pathway really, and then once they're diagnosed they then are, they go to a consultant surgeon to discuss treatment plans ...

INT: THAT'S WHEN THE PATHWAY, TWO PATHWAYS SORT OF DIVERGE AT THAT POINT?

Nurse: Correct, yeah. The symptomatic clinic is women and men who obviously have found a problem and they go to their GP and they're referred here to a consultant surgeon to go through the process of a one-stop clinic, mammograms, ultrasounds, FNAs, whatever. Erm, and then obviously diagnosis is made and that's where treatment options are discussed with them.

INT: AND THEN WHAT IS THE ROUGH SORT OF PATHWAY AFTER THAT THEN?

Nurse: The rough pathway after that is, it depends on the consultants: once a diagnosis is made some consultants will bring them back the following week following discussion of treatments and they have their blood test and chest x-ray and a tracing of the heart and they're brought back next week, so they're given the written information so they can go away home and think about it and read the information and then they come back. And I think that's a good way of doing it because at the time of diagnosis they can't always think straight and they don't take on board everything that's said to them, and I think they need that week to sort of get their head round everything really. And you often find that when women do come back the following week they are very much more focused, they've obviously had time to think about things, talk to people, get on the website, get information off wherever they want to get the information from, and knowing that their blood tests and chest x-ray and ECG are OK, then obviously we can plan surgery. Obviously that's if a decision has been made of what operation they have decided on. Some of the consultants don't do that: they see them at the time of diagnosis, do their blood tests again, chest x-ray, ECG, we give them the written information and we sit down and talk to them, and then some are not seen again by the consultant, back in the outpatients, back here, unless we feel that they need to come back. And they're actually quite flexible, they'll say, 'That's fine,' you know, 'Put them on the clinic and we'll see them again.' Or if there is a decision, ie mastectomy, wide local, and they haven't really given it some thought and there are some, shall we say, unanswered questions in the fact that it's a difficult situation, and so therefore they may well bring them back the following week. Erm, but personally I prefer them to come back the following week because you know that the blood tests are OK, you know that the chest x-ray and ECG's OK, because often if they don't come back the following week and on the rare occasion that there is a problem, then you have to pick up the pieces again really and start from scratch. And that has happened a couple of times and it's caused us quite a few problems really. Erm ... but I do like the way that we bring them back the following week and it gives them then that time to think about things really.

INT: YEAH, AND THEN AFTER THAT THAT'LL BE, THE NEXT TIME YOU SEE THEM IS, WOULD YOU SEE THEM PRE-OPERATIVELY?

Nurse: Only if they wish to come back and talk to us or if they wish to phone. We don't routinely bring them back unless, as I say, we want to see them personally or they want to see us, but we do go and see them up on the ward when they come in, when they are admitted we then go up and see them on the ward and we generally like to see them on a regular basis on the ward, we don't just see once, we aim to see them prior to surgery just to go through 'Is there anything else you want to go through before surgery? Anything you don't understand?' just go through everything really again; and we see them following surgery. Again it's just keeping contact with them and making sure that they're OK, and obviously you're looking out for problems that may occur, in particular psychological morbidity, you know, depression, anxiety, and obviously giving

them advice and support and women have a variety of issues that they want to talk to you about, a lot of them may say 'I want you to talk to me about chemotherapy,' some'll say, 'I don't want to know anything but when can I drive?' So we're there for advice and support really, and to monitor them. Following surgery they come back here to the breast care unit for the results of surgery and again we see them, again for following them through, erm, and then we have an idea of the results, what further treatment they require, chemotherapy, radiotherapy, whatever. And again we can give them written information about that if they wish to take it home with them. And if they've got a seroma we can drain that off while they're here, erm, or any little issues, you know, my little soft prosthesis isn't quite right, or ... you know, anything like that, we're there. And when they come back for their first oncology appointment we again sit in there so again it's continuation, by which time you get to know your patients, you know, you've got to know their personality. And it's always useful for the consultants as well because, for example, the oncologist would not have met this person before and it's nice for us to go in and say, 'Well actually I know this lady .. her husband died three weeks ago ...' or something like that, or just something that tells the oncologist a little bit about the lady.

INT: TO MAKE IT PERSONAL, YEAH.

Nurse: Yeah. And they like that and I think that's useful for that information really for them, because it could have a difference on what treatment is offered to them. Erm ... so yeah, yeah, and then we, we don't tend to see them then because they go off and have treatment, whether it's chemotherapy, radiotherapy, so we do miss them unless they come to a seroma clinic in the meantime, and then we'll pick them up again in the seroma clinic. And then we don't often see them again until they come back for their outpatients appointment, fellow-up, which is six months later. Some we may pick up in the prosthetic clinic, you know, when they're having their prosthesis fitted following surgery. But they will always contact us, you know, whether it's six weeks down the line, whether it's six months, two years. I had a phone call from a lady this morning, 'I'm Mrs So-and-So, I had my surgery two years ago, can I just talk to you about ...' you know, so they always know that they can contact us. And they do, which I think's a good thing.

INT: MMM, YEAH, THAT SOUNDS GREAT. GIVEN WHAT WE'VE TALKED ABOUT, IS THERE ANYTHING HERE WITH THE TEAM AND THE SYSTEM AND STUFF LIKE THAT THAT YOU THINK REALLY HELPS YOU SORT OF DO YOUR JOB AS A BREAST CARE NURSE?

Nurse: I think it's having support with the consultant, with some of the consultants really, knowing, they recognise our role is really important and we are a pivotal role really. And we're a bit of everybody, you know, if there's anything, they always come to us, whether it's consultants, junior doctors, screening, surgical staff, they always come to us. If there's a problem, speak to a breast care nurse, because they know that we can deal with things. Which is nice in a way, but it means that we're taking on board more things, which again, it's all time constraints. If I could say could I have something, it would be more time please really. I think it is, going back to what I've just mentioned about the consultants, they recognise our role and they are very, very good and they will listen to what we see, and they, we're able to go in and share our opinions and our knowledge with them. If there's something we don't agree with or something we're not happy with, we can say, 'Ooh, well what about this?' or 'I'm not quite happy about that,' or ... and, you know, which is a nice culture to work in. I don't know if that's what you want actually, Dave, do you want anything more than that?

INT: NO, IT'S WHAT YOU FEEL THAT YOU THINK IS THE THING THAT REALLY HELPS YOU TO DO YOUR JOB, YOU KNOW, WHICH YOU THINK FACILITIATES THE JOB IF YOU LIKE. I MEAN

THE OTHER SORT OF SIDE TO THAT IS, LIKE, IS THERE ANYTHING HERE ABOUT THE SYSTEM, THE WAY THE TEAM WORKS OR ANYTHING THAT YOU THINK PERHAPS HINDERS YOUR JOB? YOU'VE MENTIONED TIME, THE TIME CONSTRAINTS, ANY OTHER CONSTRAINTS YOU THINK YOU COULD THINK OF?

Nurse: I think it's, what doesn't help is the amount of patients we have on a clinic - that is a real big issue.

INT: BECAUSE IT'S A BIG UNIT.

Nurse: It's a big, big unit and when you think a lot of patients that come here are normal, you know, their deemed benign or normal, there is absolutely nothing to worry about really. And I think you can become so overwhelmed with the amount of patients that you see in a day, erm, for example you start your clinic at 9 o'clock in the morning and sometimes the clinic's still going on in the afternoon and you've got another clinic in the afternoon to go to, so you're literally going from one clinic to another. And sometimes you do need that time just to get your head round everything, sit down, you know, chill out for an hour if that was possible, but unfortunately with the best will in the world we don't, and a lot of it is due to the volume of patients that we have coming through the clinic. And it's the time that you're allowed to give. And it's just an enormous pressure on the service, because you have targets to meet and once upon a time you could have probably 15 on a clinic, which is a nice number for a couple of doctors or maybe even one doctor, although that's pushing it, 15, but with the targets that you've got to meet, they're putting more and more patients onto the clinics because you've got to see them within so many weeks. Erm, and you've got to meet your targets, and it just causes enormous pressure on everybody to see patients. And it does have a knock-on effect because everybody gets worn out, everybody gets stressed, gets tired, lethargic, and, you know, people generally get run down and fed up, you know, in that sort of situation. Erm, so if we could have less patients and a bit more time that would be very nice, please. [chuckles]

INT: WELL I'M AFRAID I CAN'T ORGANISE THAT FOR YOU.

\*Q3. DO YOU FEEL THAT PROFESSIONALS HAVE DIFFERENT SORT OF STYLES OR WAYS OF WORKING, DIFFERENT APPROACHES, SORT OF THING, AND IF SO, WHAT SORT APPROACHES AND STYLES HAVE YOU OBSERVED HERE?

Nurse: Right, they all have their own ways of doing things, erm, certainly one consultant in particular likes everything just so, likes everything done properly, straight to the book, everything has to be done as it should be done, no cutting corners, you know, labels on the top of the notes, you know, to make sure, dates on, everything has to be done correctly. They have a certain style in the sense that you know that there is a routine that is done within the clinic and you know what you should and shouldn't do in that particular clinic. Patients themselves, erm, once they sit in clinic and they're given a diagnosis, you know what is going to be said, you can almost paraphrase what is being said, you can do it word for word what is going to be said to that patient. Erm, and obviously even where the patient is within the clinic environment, you know, some have them in the clinic rooms, in the examination rooms, some actually have them in the consultation room themselves. And so, again, it just depends on the consultant. Some doctors are a little bit, not laissez faire, I think that's a bit, makes it sounds as if they're a bit haphazard really, it's not quite true, you know basically what they're going to do and you work round that. Because I've worked with all of the doctors so you get to know their styles and their ways of working. But you do know how that particular consultant likes to work and you know exactly what they're gonna say and what they're going to do and

what's going to happen next. So you're prepared and you know and you get yourself ready for that particular consultant.

INT: MOVING ONTO BEFORE CONSULTATION WHERE A DIAGNOSIS IS TO BE GIVEN, AND FROM THIS POINT OF VIEW, 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 GONNA RECEIVE THE DIAGNOSIS OF BREAST CANCER?

Nurse: The MDT meeting is every Monday lunchtime. In relation to the clinic where patients are given a diagnosis, it is before, often it can be done before the patients are diagnosed because they, say a lady came to a clinic today, for example, had an FNA and it was equivocal or it was suspicious, then they have a core biopsy. Obviously the patient may not be aware of their diagnosis today: it might be that, yes, it's suspicious but they haven't confirmed diagnosis. And then on Monday it'll be discussed in the MDT meeting and it's then we can actually confirm from the core biopsy that it's a cancer or whatever. And then the patient will come back on the Wednesday, for example, where diagnosis is actually given to the patients. Sometimes patients are aware before the MDT meeting of their diagnosis, like today, for example, an FNA's done, it's confirmed a malignancy, or even they've had a core biopsy, a core and drag, the drag can often give us a diagnosis, and again they're discussed the following Monday and the patient may have already been told on the Wednesday that they've got a breast cancer. The following Monday, the MDT, it's discussed or confirmed that they've got a malignancy and they'll come back on Wednesday to discuss treatment.

INT: HERE'S A QUESTION FOR YOU ...

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

Nurse: Sometimes you feel as if you know something that other people don't know, and especially when they're discussing the results on, you know, from patients who've had their surgery, and you, with the best will in the world, you're willing for the patient to all have good news, and sometimes when you know that they've got a big tumour, got lots of nodes involved, you know the outlook is not good, sometimes you think, 'Oh dear ...' you know, and you've got that knowledge but the patient doesn't know that yet. And sometimes you wish you didn't know that knowledge because you may still have to go and see that patient before they come back to clinic, because they may still be in on the ward. And if it's really good news you're bursting, you want to tell them, you want to say, 'This is really good news,' but you can't, erm, and so you have to be quite, very careful indeed what you say because obviously you may just inadvertently say something to the patient. Or often they'll say, 'Oh do you know anything?'

INT: I WAS GOING TO ASK YOU THAT ACTUALLY.

Nurse: I've had that a couple of times, they say, 'Do you know anything?' and as much as I, to be fair, there are the odd time I do know something, but I can't say, 'Yes, I know something,' because they'll want to know what it is and I can't tell them that, and that sits uncomfortably with me because it means lying, although it's a little white lie, and I'm not the sort to lie, you know, you feel you don't want to give that information, you've been economical with the truth as it were. So I don't enjoy that at all. Erm, that's really all I feel about it. From our own personal viewpoint, breast care nurse's point of view, we just sit in the back and we don't take part in the MDT.

INT: JUST SORT OF MAKE NOTES.

Nurse: Nobody, yeah, we just make notes of the patients' histology, but we don't get involved, we're never asked our opinion, we are, we just sit in the back, which is not how an MDT should run really, everybody should be involved. But it's a historical thing, it's something that's always been done, or should I say not been done, erm, and we just sit there. There's the odd time I've chipped in and said something when I felt it was relevant, but nobody'll turn round say, 'Oh what do you think?' or 'How do you think the woman will take this?' or ... nothing, nothing.

INT: YEAH, IT IS A BIT UNUSUAL. I MEAN I'VE BEEN AT MDTs WHERE BOTH STYLES HAVE BEEN, YOU KNOW, EVIDENT REALLY, NOT JUST IN, NOT ONLY IN BREAST BUT IN LUNC AND COLORECTAL, WHEN I DID THOSE STUDIES, AND IT'S DIFFERENT REALLY. I MEAN THERE WAS ONE WHERE I REMEMBER I WENT IN AND THEY WERE ALL SITTING FACING THE FRONT AND IT WAS LIKE A CLASSROOM; AND THEN THERE WAS ANOTHER ONE WHERE THEY WERE ALL SITTING ROUND THIS TABLE AND THEY HAD A NICE SORT OF BREAKFAST OUT AND STUFF LIKE THAT AND, YOU KNOW, THE CLINICIAN WAS SORT OF, [???] 'WELL LET'S JUST QEURY THE BREAST CARE NURSES AND SEE WHAT THEY SAY,' AND YOU KNOW, IT WAS ALMOST LIKE A, I DON'T KNOW, I WAS GOING TO SAY IT WAS LIKE A NIGHT OUT, BUT [???] IT WAS LIKE A MEAL TYPE OF, YOU KNOW, WHEN YOU'RE ALL SITTING AND HAVING A MEAL AND DISCUSSING THING, I GUESS, THAT KIND OF ATMOSPHERE. BUT I MEAN, HOW DO YOU SORT OF FEEL ABOUT THAT THEN?

Nurse: I feel, I feel it would be nice for us to have our say because we know the patients better than anybody within that room and it is like being in a classroom - you're the naughty schoolgirls that sit at the back [chuckles] you know, and all the ...

INT: [???]

Nurse: ... you do, it's like being in a classroom, you, everybody's sat and facing the front and the pathologist is sat in the middle going through the slides. Radiologist on one side, there's consultant surgeons are probably sat the other side, and it's very much a them and us. And it's not, it's not a very friendly lovey-dovey sort of meeting at all. It's very quick, it's very 'Right, come on, let's get on with it,' it's very much a conveyor belt, and it's purely because the numbers that we have to discuss, we haven't got the time to go through each patient as it properly should be done really in an MDT meeting. And I think that's probably one way, one reason, perhaps, why they don't involve us because they know that 'Well, we haven't got time to discuss this ...' you know. 'Let's just get on with it, let's just see what the results are and does she need chemotherapy, radiotherapy, further surgery ...' and that's it. It's all a bit cold, erm, with the best will in the world you can only do what you can do with the time that you've got.

INT: BUT I THINK ALSO IN SOME MDTs I'VE CERTAINLY PICKED UP ON WHEN I'VE BEEN THERE IS THAT IT'S NOT JUST ABOUT, YOU KNOW, THE PATIENT, THE WAY THEY'RE GONNA TAKE THEIR DIAGNOSIS OR ANYTHING LIKE THAT, IT'S OFTEN THEIR SOCIAL ISSUES AND THEIR FAMILY ISSUES AND STUFF, SO THAT I THOUGHT THAT THE BREAST CARE NURSES COULD ACTUALLY SORT OF CHIP IN WITH THINGS AND SORT OF SAY, 'WELL, YEAH, IT'S ALL VERY WELL AND GOOD SAYING THEY'VE GOT THIS TUMOUR AND THIS KIND OF TREATMENT AND THIS KIND OF TREATMENT, AND WHATEVER,' IT'S LIKE 'WELL DO YOU REALISE THAT, LIKE, SO-AND-SO'S DAD'S JUST DIED' OR THAT LIKE THEY'VE GOT A VERY STRONG RELIGIOUS OR CULTURAL SORT OF ... ESPECIALLY HERE, YOU KNOW.

Nurse: Yeah, absolutely.

INT: SO THERE'S THAT KIND OF THING THAT I'VE NOTICED THEY TEND TO COME OUT WITH.

Nurse: Yeah, yeah, no, it's very much straight to the facts of the histology and that's it. Obviously they chip in a few things if there is something, erm, for

example we've had one lady with learning difficulties, how are we going to tackle this one because you've got issues of consent for example. And she's got a massive, massive tumour, and this woman is like a double G, she's huge, and ideally this lady needs a mastectomy but no way could this lady have a mastectomy, she's got a whacking great big node. So, you know, in them sort of situations they are discussed, you know, 'What are we going to do with this patient?' erm, but with results it's, 'Right, OK, she's a grade three, node negative, right chemotherapy, radiotherapy ... yeah, yeah, right, next one.' And that's literally how it is really, to be honest. Erm, occasionally, if there are a few things that are not quite right then they just sit and talk about it a little while, a little bit longer, but generally it's, 'Right, let's move on to the next one,' and that's it really.

\*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 TO, OR DO OR SAY TO THEM, AT THAT STAGE? WE'VE KIND OF TOUCHED UPON THIS ALREADY ...

Nurse: Yeah, they are, they are warned really, or they are advised that we are suspicious that this could well turn out to be a breast cancer: most of them do that. I have to say there's the odd one or two - not the permanent doctors but sometimes some of the registrars that don't always say it, they'll probably sit on the fence 'Oh well we need to find out what it is,' erm, especially if it looks like a barn door cancer, and I often say to them, 'Look, I think you need to sow the seed really, and tell them.'

INT: IS IT ALWAYS THE CONSULTANT OR THE SPR THAT DOES THAT THOUGH, [??]? ?

Nurse: Yeah, it's usually the consultants or the clinical, even, the clinical assistants will also mention it to them as well. Erm, and obviously if the patient asks, you know, we tell them, you know, but often we've told them before. If, there's been the odd couple of occasions where it's not been mentioned and it's a barn door cancer and I've spent a few minutes - just a few minutes - with the patient afterwards when the doctor's gone back into the other room, and I've just given them a contact card and just had a little word with them. And I've sort of hinted then, you know, 'We need to find out what it is,' and often they will say, 'Well do you think it is cancer?' 'Well, it potentially could be.' So I don't have worries telling them that, erm, and I know that that is good practice really because I know that the consultants would tell them that anyway, and the registrar might not be aware, because sometimes I don't think they're in a position to give, break bad news, and I think sometimes it can sit uncomfortable with them because they don't know how to deal, or they've not had regular ...

INT: EXPERIENCE OF DOING IT.

Nurse: ... of doing it, yeah, quite.

INT: YEAH, THAT'S MY SORT OF OPINION AS WELL ACTUALLY.

\*Q7. WHAT WAY, IF ANY, DO YOU THINK PATIENTS ARE THEMSELVES PREPARED FOR THE NEWS THAT THEY HAVE BREAST CANCER? I MEAN YOU'VE GOT TWO GROUPS OF PEOPLE: YOU'VE GOT YOUR SCREENING PATIENTS WHICH ARE DIFFERENT TO YOUR SYMPTOMATIC PATIENTS ...

Nurse: Yeah, absolutely. Well, often patients come with pre-conceived ideas anyway because a lot will also depend what the GP has said to them. With the symptomatic ladies, it depends what the GP says to them, because often they already know when they come because their GP said, 'Look, you know this is cancer, don't you?' because often it's quite obvious that it's a cancer. Or for example what happened on Friday, we had a young girl come to clinic, she came on

her own because her GP said, 'Oh, I don't think it's anything to worry about,' she's got a big cancer. And so she came on her own with the knowledge that, 'Oh, it's probably nothing to worry about,' and hey presto, she's got a breast cancer and she was absolutely devastated. Erm, I think ladies with a lump often assume it is a cancer unless those who've had cysts before, they sort of get into a false sense of security, 'Oh it's probably just another cyst, I've had them before,' and often, when it's not a cyst, they obviously are quite surprised, you know.

INT: YEAH I THINK, I DON'T KNOW IF I SAID YESTERDAY, I HAD A LADY AT THE DISCUSSION GROUP, ONE OF THE [??] EXACTLY, SITTING RIGHT NEXT TO ME, THAT WAS HER STORY EXACTLY.

Nurse: Yeah, yeah. Erm, but it very much depends, especially if they've had a family member recently or got a friend who's died or going through the process, which coincidentally we have so many women, because it's such a common disease, we have so many women coming to the clinic who have said, 'My sister's had breast cancer,' or 'My friend's just died,' erm, you know, so obviously this is still in their mind that, well, potentially this could be a breast cancer. So women are very aware. And also because the media, breast cancer is so high profile, they assume that every lump and bump is a breast cancer. So you find more often than not they assume it's a breast cancer. The odd one you get a surprise who has no idea it's a breast cancer, and are completely gobsmacked when we tell them it's a breast cancer.

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

Nurse: Yeah, I know exactly what's going to happen, I know, we've just mentioned this before ...

INT: YEAH, YOU MENTIONED IT, YEAH.

Nurse: Yeah, I know exactly what's gonna happen, erm, so I know what to get ready. I get all my paperwork ready, I get my contact car, I've got the patient's notes, I know exactly what I need to do and I know exactly how the consultation's gonna go.

INT: IN TERMS OF THE CONSULTANT SIDE OF THINGS?

Nurse: What's gonna say, on the consultant side of things what's gonna be said, yeah, yeah.

INT: WHAT ABOUT THE PATIENT SIDE OF THINGS?

Nurse: The patient side of things, that's, sometimes you do have an idea what's gonna happen because ideally what we tend to do is see the patient prior to them being diagnosed, for example when they're going off having their mammogram, ultrasound, once they've been examined by the doctor and of course, if you have an FNA, then obviously we're getting involved in that, and I think that's really because while you're there with the doctor and they examine them and they're doing needle test, you're there and you can say, 'Has anybody come with you today?' so you've got an idea are they on their one, have they got somebody with them, and you get a little bit of a feeling of how they are. Are they very, very anxious, you know; are they a bit sort of blaze or, you just get a general feeling of how they are. So when you go in for the second time to confirm diagnosis, to tell them that they've got a breast cancer, you've generally got an idea of how they're going to react, and often, 99 per cent of the time I'm pretty right really. And I can remember only recently there was a lady and a

gentleman, it was her husband, and they were in there, and I said to the consultant, I said, 'She's not going to be a problem but her husband is.' And he said, 'What made you say that?' and I said, 'You just watch.' And sure enough the husband just absolutely fell apart and I just had this feeling, I just knew that he was gonna fall apart. She was fine, she was fine, but he just completely fell apart. So ... but you get to know about that prior to them being diagnosed, when they're going through their staging, you know, through their ...

\*Q9. YEAH. SO I MEAN TALKING ABOUT CONSULTANT SIDE OF THINGS AND THE PATIENT SIDE OF THINGS, FROM YOUR SIDE OF THINGS WHEN YOU'RE GOING INTO THIS TYPE OF CONSULTATION, WHAT ARE YOUR FEELINGS TOWARDS THE CONSULTATION?

Nurse: I like to be organised. I don't get stressed, I'm not stressful, I don't get the butterflies thinking 'Oh goodness me, how ...' you know. I'm not that at all, don't, just don't go there, you know, I just don't feel that at all. Erm, I just like to make sure that I've got everything organised: have we got the blood forms ready, you know, have I got the written information, and I like to say, 'Right, what we doing?' You know, and you say, 'Right, is she having a wide local, is she a mastectomy or, you know, what do you think?' And often we can look at the mammograms together and say, 'Ooh yes, yes, there's quite a lot involved in that,' you know. You know, so we know from the start what's going to happen and then you go in and see the patient.

INT: I'D LIKE TO MOVE ON TO DURING A CONSULTATION NOW

\*Q10. CAN YOU JUST PLEASE TALK ME THROUGH WHAT HAPPENS IN A CONSULTATION WHERE DIAGNOSIS AND TREATMENT OPTIONS ARE BEING DISCUSSED WITH A PATIENT WITH BREAST CANCER. SO IMAGINE THAT THEY'VE CUT KIND OF WALKED IN TO THE DOOR NOW, INTO THE CONSULTANT'S OFFICE. SO WHAT KIND OF HAPPENS AFTER THAT THEN?

Nurse: Right, erm, sometimes the consultants will go through briefly why they were here, you know, 'You came with a lump, you've had a mammogram, you've had an ultrasound, the needle test has confirmed that you've got a breast cancer' and then treatment options are discussed with them. And usually he kicks off by saying, 'Usually we treat this first of all with surgery' and sometimes, depending on the consultant, will depend on what they actually say to them and how they say it. Some consultants will say, 'The needle test has drawn off a few little abnormal cells ... so you have got a little cancer in your breast.' Some other consultants will say, 'The needle test has shown you have a breast cancer.' ... quite blunt, quite straight to the point. And then they sit down and talk to them again about treatments. They're not often shown the mammograms, sometimes they're asked, you know, would you like to see them, or a patient will say, 'Can I have a look at my mammogram?' but they're not routinely shown the mammograms and say, 'Look this is your cancer here,' you know, let them look at them. But the consultant will talk to them about treatments and then some will mention the word chemotherapy, some won't - it depends on the patient. If they're young, one of the consultants will say, 'Because you are young you are likely to have chemotherapy,' some of them won't even mention chemotherapy.

INT: MM, DO YOU FIND THE CHEMOTHERAPY, WHAT KIND OF REACTION DO PATIENTS HAVE TO THAT?

Nurse: Some of them are absolutely gobsmacked really because, not only are you telling they've got a diagnosis of a breast cancer, and suddenly you're throwing the word chemotherapy in and it's 'Hey, you know ...' it's all too much, you know. The thought of having surgery and chemotherapy, you know, especially if they need a mastectomy, it's all too much. So I think a lot of it depends on the patient because sometimes they want to know everything and sometimes they don't want to know anything. And I think you have to be very careful and judge your patient as to what information they can take at that time. Certainly they need

to know they've got a breast cancer and then obviously discuss about how we're gonna treat it, because often that's what they need to know, how we're gonna treat it. Again, depending on the consultant we'll discuss about the surgical options - mastectomy, wide local excision, etc. Erm, and then following consultation we then take them off into a counselling room. That's if they wish to, again you're guided by your patient. If they're so stressed out it's no good taking them into a cupboard, you know, you might just take them in there just to get a breathe for a minute, but it's no good discussing anything with them because all they want to do is go home. And often if they're really upset and distressed, I'll give them a contact card and you make an appointment to come back and see us, because you just, it's just useless sort of discussing things with them. So I'll make arrangements to see them in a few days' time, and then we can sit down and go through things again with them. Some patients, a lot of them are quite to go into the counselling room and discuss things with you, and we go through again the treatment options that are available and everything at that point and then they generally go home. And then, like I said before, some will come back the following week, some won't.

INT: SO SORT OF IS IT ALWAYS A CONSULTANT THAT TENDS TO GIVE THE NEWS ABOUT THE ACTUAL DIAGNOSIS?

Nurse: Not always, sometimes it's the clinical assistants that give it.

INT: YEAH, RIGHT, OK.

Nurse: Erm, like for example on Friday, erm, the clinical assistant gave the young girl the diagnosis of the breast cancer, and she was too distressed, I couldn't do anything with her, you know. So we sent her home and came back yesterday, so ...

INT: AND WILL THE CLINICAL ASSISTANTS DISCUSS TREATMENT OPTIONS AS WELL?

Nurse: In a vague sort of way, erm, in the sense that, because they're not surgeons, they can't make that decision. Sometimes you can get an idea, well, yes, you know, if you've got a tiny little tumour on the outer side of the breast, then yes you can say, 'Well I'm pretty sure this is quite suitable for a wide local excision but you'll see the surgeon next time and they'll go through everything with you again.' Erm, some clinical assistants are much better than others at dealing with it and it depends, it depends who you actually see to be honest.

INT: WHEN YOU SAY BETTER AT TALKING ABOUT TREATMENT OPTIONS OR THE DIAGNOSIS AS WELL?

Nurse: Yeah, a bit of both really.

INT: BIT OF BOTH.

Nurse: Some are really good at it and they'll sit down, they're brilliant; others are not so, not so good really.

INT: AND SO WHEN A PATIENT'S IN THE CONSULTANT'S ROOM, WHO'S TYPICALLY IN THE ROOM WITH YOU? THERE'LL OBVIOUSLY BE YOURSELF, THE CONSULTANT, THE PATIENT ...WHO ELSE?

Nurse: Sometimes there's the outpatients nurse as well, erm, but invariably if they know that a diagnosis is going to be made they step outside, so there's often the patient and a relative or a friend there, we obviously encourage, you know, somebody to come with them. Yeah, and there's myself and the doctor.

INT: AND WHAT ABOUT THINGS LIKE, ERM, YOU MENTIONED MAMMOGRAMS, WHAT ABOUT ANY OTHER TOOLS USED SUCH AS WRITTEN INFORMATION, DIAGRAMS, PICTURES, ANYTHING LIKE THAT?

Nurse: Yeah. The written information that we give them is our own written information that was devised here, and we do have written information on mastectomy, we have written information on wide local excision, they have our contact card, they also have information about the local support group, they have a cancer booklet. For the young women I offer them, especially those with children, there is a booklet that I can offer them which is how to tell children who's mother's got breast cancer, which is really useful. And any other information that they feel that they need at the time of diagnosis. I don't give them information about chemotherapy and radiotherapy at the time of diagnosis because we don't know a lot of the time if they need that, erm, and I think that's just too much information at that time. I'm guided by the patient, what they, you know, what they want, because some women won't even accept a mastectomy leaflet, you know, they say, 'No, don't want that,' and that's fine, like it's entirely up to them. But you feel you need to give them the information because of litigation purposes, because ...

INT: AND ALSO THE FACT IS THEY MIGHT CHANGE THEIR MIND AS WELL.

Nurse: Absolutely, you know, there is that need that you have to give them information because, you know, down the line they may well say, 'Well you never told me that,' and it's all about informed consent, you're giving them the information. But, you know, at the end of the day it's their choice.

INT: YEAH, I THINK, I THINK INFORMED CONSENT, CERTAINLY YOU'VE HIT THE NAIL ON THE HEAD THERE, IS ONE OF THE BIGGEST ISSUE I FIND, I MEAN NOT JUST FROM LIKE THE ACADEMIC THEORETICAL POINT OF VIEW, AND THERE'S A MASSIVE DEBATE THERE, BUT IT GOES RIGHT DOWN THE LINE TO THE FRONT LINES, YOU KNOW, YOU GUYS OR WHATEVER, YOU KNOW, ACTUALLY GETTING IT FROM THE PATIENTS THEMSELVES AND WHEN TO GIVE THEM IT AND WHEN TO ... ALL THIS KIND OF THING, IT'S A HUGE ISSUE. I MEAN I WENT TO A MEETING ABOUT NEW EU DIRECTIVES FOR CLINICAL TRIALS COMING OUT, I MEAN THAT'S JUST GONNA BE A NIGHTMARE TO INTRODUCE, BUT, YOU KNOW MOST OF THE, THE BIGGEST PART OF THE DISCUSSION WAS NURSES AND OTHER PEOPLE IN THE CLINICS WANTING TO KNOW ABOUT HOW IT'S GOING TO AFFECT THEM FOR INFORMED CONSENT. [???

Nurse: Yeah, sure.

INT: JUST OUT OF INTEREST, COMPLETELY ASIDE FROM THIS ACTUAL PROJECT, WOULD YOU EVER DISCUSS CLINICAL TRIALS WITH PATIENTS OR ANYTHING ELSE?

Nurse: Erm ...

INT: I KNOW YOU'RE RECRUING ON MY STUDY BUT I MEAN ... CLINICAL TRIALS THEMSELVES.

Nurse: Yes, only on oncology because we did have the [???] trial which was relevant to our breast cancer patients and that is with the [???] drug and obviously all the trials with [???] and things. And at the time of giving them their results and we know that they were going to embark on chemotherapy, we actually said to them at that point 'There are some trials going on at the moment, you may or may not be eligible for those trials, so just be aware that the oncologist may discuss trials with you,' and it was just left at that really. But, to be honest, we haven't got any trials going on here at the moment because the, erm, the [???] trial is now closed. But we have been involved in trials, we've been involved with a Tamoxafen trial, ATOM [?] and that's discussed with patients who are just about to stop Tamoxafen after five years, and obviously we go through that, but we do actually have a research nurse who

does that job [???] , so she does all that and she sometimes is aware of patients who are eligible for certain trials, but they're often chemotherapy trials in women who have got metastatic disease, which we don't generally get involved in because they're all basically Leicester Royal, you see.

INT: YEAH, THE ONCOLOGY SECTION.

Nurse: Yeah.

INT: I JUST COMPLETE [???] I DID SOMETHING IN THIS CLINICAL TRIAL [???] ER, YEAH, SO, RIGHT WHAT ABOUT THE CONSULTANTS, DO THEY ACTUALLY USE ANY OTHER TOOLS APART FROM, YOU MENTIONED MAMMOGRAMS, DO THEY ACTUALLY USE ANY DIAGRAMS, DRAWINGS, ANYTHING LIKE THAT?

Nurse: Sometimes they do, it's just a crude drawing. One of the consultants in particular, when he's describing ductal carcinoma in situ, he will just get a little scrappy piece of paper and just draw it and say, 'Right, this is the duct of the breast ..' and he sort of draws little overgrown cells and he explains DCIS to them. But actual picture as such, no we don't, we don't. Having said that one of the consultants has brought some of their own written information and it has just got some small little diagrams within that written information, and that's their own written information which they've, it's copyrighted and it's something that they've had for quite a time, it's not something they've just written while they've been here, it's something that they've brought with them. And as I say it's got little pictures and diagrams on, showing how they cut for a mastectomy and what they do and they can cut underneath the armpit and things. So, it's only just a crude little diagram, that's all really.

INT: SO THINK ABOUT THE CONSULTATION AND YOUR TIME WITH THE PATIENT IMMEDIATELY AFTER THEY'VE BEEN TO SEE THE DOCTOR SO WHAT ARE YOUR FEELINGS ABOUT WHEN YOU'RE DISCUSSING THESE ISSUES AND THAT?

Nurse: I think you feel that you need to inform the patient and that they need to know the information and, again, you feel that you've got to spend some time with them, and you have to give them the written information, because you know if they're coming back the next week, you know that they've got to have the written information so that they've got time to think about things. Erm, so I do feel 'I must get this lady into the counselling room because I need to talk to her,' you know, even if it's just to give her a contact card and just to make sure she's OK before she goes home, rather than just walking out of the clinic and going, 'cos you know that as soon as they across the car park I always have this worry that they're just gonna fall apart, you know, and nothing's been said to them from our point of view. So there's, I personally feel I've got to get them into a cupboard, I want to just get them into a nice, cosy atmosphere like this room for example and just give them a few minutes, just to gather their thoughts just for a second or two, and then I can give them the written information and offer them if they want to discuss anything with me on what's happened. But I don't feel, I don't feel stressed other than I'm just aware, 'Well I've only got 10 minutes to see this lady because I know I've got another lady waiting to see me in a few minutes,' or 'She's the last lady on clinic so it doesn't matter, I can spend as much time as I can with her,' you know. So, but I don't feel, I don't feel stressed or uneasy at all in that respect, I don't feel anxious, I just feel the need that I need to get her, get them into the counselling room and just ... just have a little, a few words with her really.

\*Q11. CAN TELL ME ABOUT ANY ADDITIIONAL TIME YOU HAVE WITH A PATIENT AFTER THAT PART OF THE CONSULTATION WHEN THE DOCTOR'S BEEN PRESENT, YOU KNOW, ONCE THEY'VE GONE HOME, THEN THEY COME BACK?

Nurse: Yeah. Erm, sometimes they will come back within a week, just to come back and talk to us, but that is a, you know, an arrangement we make at the time when they're diagnosed. They will phone us if they wish to, and invariably they do. If they come back the following week, then obviously we will see them again the following week when they come back to clinic: those that don't come back to clinic, who are just coming straight in, unless they phone or unless we make an arrangement to see them, we won't see them until they come on to the ward for their surgery.

INT: WHAT SORT OF THINGS WOULD YOU DISCUSS AT THESE TIMES WITH THESE PATIENTS?

Nurse: Are you talking about after the diagnosis and we take them into the counselling room or at these other times?

INT: AT THESE OTHER TIMES.

Nurse: Other times: Well it depends what was discussed after the time of diagnosis, for example if they just wanted a contact card and some written information to go home, that's fine, but when they come back we generally go through surgery again, the surgical options and surgery itself, what they're roughly gonna be like when they're in hospital, what ... and really the pathway, what happens from when they come in and when they come back for their results. It's just going through general information. And everybody's different, because some women want to know, 'Well when can I get back to work?' Some'll say, you know, 'When can I drive?' - that is such a common question, 'When can I drive?' Erm, some'll say, 'When will I start my chemotherapy?' 'When do I start radiotherapy?' 'When can I go on holiday?' Everybody comes with their own, with their own ideas, they come with their own questions that they want to discuss with us. Some people say, 'Can you talk to my husband 'cos he's not coping?' or 'Can you see my kids?' I had a lady come to clinic, she'd got three small kids and she brought one of them with her, 'Can you talk to my daughter, she's not coping at the moment?' So I ended up having to chat to her. So everybody is so different. Erm ...

INT: FROM WHEN, AN INTERESTING POINT THAT CAME FROM A COUPLE OF INTERVIEWS WAS THAT WHEN A PATIENT'S BEEN GIVEN A DIAGNOSIS TO THE POINT WHERE THEY MADE THEIR MIND UP, JUST GENERALLY, HOW LONG DO YOU THINK THAT IS? I KNOW IT VARIES FROM PATIENT TO PATIENT, BUT IF YOU CAN TRY AND GENERALLY ABOUT ALL THE PATIENTS, HOW LONG DO YOU THINK IT TAKES THEM TO DECIDE WHICH TREATMENT THEY'RE GONNA HAVE?

Nurse: Usually within that week because often they know that they're coming back the following week anyway, and usually they have made their mind up before they come back. There've been, you know, a few patients that can't make their mind up but often they've made their mind well before they come back the following week.

[Interruption in recording]

INT: I'D LIKE TO TALK A BIT ABOUT PATIENTS' INFORMATION NEEDS NOW.

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

Nurse: Their prior knowledge is, I think I've already mentioned this before, is often their experience with other family members or friends, and obviously the media - the media has a huge influence as well. And on the website often we see patients who come to clinics who have already been on the website and they come with a wad of information, and it's quite comical because they come in with their wad and they're flicking through their website information ... 'It says here that ...' you know, and they come out with a question, and in fact some of

the websites actually encourage the patients to ask the doctor their qualification [chuckles] which is quite interesting actually. So, yes, so they do have a lot of, women generally do have a lot of knowledge prior to coming, albeit incorrect knowledge, I have to say. In particular a lot of older women I generally find, they often find that, 'Well, I've got to this age, I didn't think I could get breast cancer,' you know, and they assume that they're automatically gonna have a mastectomy. Younger women are far, much more clued up really on treatments, far by far, much more clued up.

INT: DO YOU THINK THAT HOW MUCH INFORMATION A PATIENT HAS, OR KNOWLEDGE THEY HAVE ABOUT BREAST CANCER AND ITS TREATMENT, DOES IT MAKE FOR A HARDER CONSULTATION OR AN EASIER CONSULTATION, DO YOU THINK?

Nurse: I think it's a bit of both, to be honest, I can't think I can actually say one way or another because it depends very much on the patients. Sometimes they do have their preconceived ideas: for example truly believe that having a mastectomy is the safest option, and it's going to, by having a mastectomy it's going to live, you know, carry on living for a long, long time. Some women don't realise that just by having the lump removed following by radiotherapy is just as safe as a mastectomy, and they, a lot of people are not aware of that is something I'm very aware that they are not clued up on. And so in our position we have to make that know, because some women will make a decision on having a mastectomy because they think it's safer, and we're saying, 'Well, just hang on a minute, you don't have to have a mastectomy unless you really want one, you know, if you more comfortable having a mastectomy you don't have one.' And they're actually quite surprised, you know, because they think, 'Oh ...' because in the olden days that's what they used to do, they used to remove the breast come what may, even if it was a tumour in a massive breast, they still used to do a mastectomy. And also they would recognise about their arm, they used to get dread lymphoedema, and of course that's thankfully not such a huge problem these days. Sometimes it can be more difficult in the sense that people that have gone on the website often pick on new treatments, for example the [??] node biopsies, well of course we don't do that here. And of course they often ask about immediate reconstruction - again, we don't often do that here, only for pre-cancer conditions. And so it's good and healthy in a sense that they have an understanding, but then again if we, by us going through things with them, hopefully it should make them aware so they can make informed decisions. Does that make sense?

INT: YEAH, DEFINITELY, ENTIRELY.

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

Nurse: At the actual diagnosis itself, I mean certainly when they're diagnosed we can't tell them anything more than 'You've got a breast cancer.' With regard to, you know, much more than that we don't actually really know until it's actually been removed and we know exactly what sort of risk it poses to them. Sometimes you get an idea if we know if they've got [??] something underneath the armpit, but with regard to diagnosis we really can't tell an awful lot to them. Some will say, 'Well, am I gonna die?' you know, that's the first thing people sometimes say, but I have to say that's not one of the common questions that they ask at the time of diagnosis. They often say, 'Well, what're we gonna do?' you know, 'How are we gonna treat it?' Erm ... I think that's important at the time of diagnosis, you know, because they do need to know that really.

INT: WHEN YOU'RE TALKING TO PATIENTS ABOUT DIAGNOSIS OR DISCUSSING WHAT THE DIAGNOSIS HAS BEEN, I SHOULD SAY, IF THERE ANYTHING YOU THINK THAT PATIENTS - IT SOUNDS A STRANGE QUESTION - BUT IS THERE ANYTHING YOU THINK THAT PATIENTS SEEM

TO UNDERSTAND VERY WELL ABOUT THEIR DIAGNOSIS? SOMETHING YOU THINK THEY'VE BEEN TOLD THAT AND, YEAH, THEY UNDERSTAND IT STRAIGH AWAY?

Nurse: They certainly are aware that they've taken on board it's a breast cancer because the doctors here are very good at saying the word cancer. There's one doctor that tends to mention a few abnormal cells and then goes on to say, 'You've got a little cancer ...' so all the doctors here are very good at saying, 'You have got a breast cancer,' they don't wishy-washy, they don't go round the houses, they say it as it is because they need to know. Everybody understands what is breast cancer. I can remember many years ago I was in a consultation and the doctor said to the lady, 'You've got a malignant lump in your breast,' and after she walked out the consultation she said, 'Thank goodness it wasn't a cancer.' So you have to tell them as it is, because everybody understands the word cancer. So they do, they are very, very aware, and I think they all understand. And when I take them into the counselling room my first thing is, 'Do you understand what the doctor's said to you?' 'Yes.' And you say, 'Well what ...?' 'I've got a cancer,' you know, we need to get on and get sorted, you know.

INT: I THINK THE WORST ONE I HEARD WAS A CONSULTANT USED TO DESCRIBE CANCER AS A 'WEE BIT OF MISCHIEF' [CHUCKLES] 'YOU'VE GOT A WEWE BIT OF MISCHIEF GOING.' IT CAME UP AT A CONFERENCE THAT ONE. ON THE OTHER SIDE OF THINGS, IS THERE ANYTHING THAT YOU THINK ABOUT WHEN TALKING ABOUT DIAGNOSIS THAT PATIENTS DON'T UNDERSTAND VERY WELL, THAT THEY SEEM TO MISS THE POINT, IT DOESN'T SINK IN VERY WELL ON THAT?

Nurse: Mm, I think sometimes I don't think they get, I don't think they miss the point when they're talking about surgical options, I think it completely blows them away a little bit about the options of surgery.

INT: THE CHOICE?

Nurse: The choice. Because often the decision is in their hands whether they're, and they a bit, 'Ooh, which one ... I don't quite know which one to have,' you know, some are very clear what they want and what they don't want, but thee are some that really don't know what to do and are often guided by the doctor. So, although they're clear on the under-, you know, what they understand by the options that are involved, but I don't think that they can quite understand why have they been given an option? Why hasn't the doctor told me I've got to have one or the other? And that's often quite hard for patients really. I don't think it's quite what you were looking for, but ...

INT: I WAS GOING TO SAY THE SAME ABOUT TREATMENTS OPTIONS BUT YOU ... YEAH. I MEAN, THAT'S COME UP A FEW TIMES ACTUALLY, CHOICE, IT DOES SEEM TO BE SOMETHING THAT PATIENTS REALLY JUST CAN'T UNDERSTAND, 'WELL WHY IS THIS GUY GIVING ME, OR WOMAN'S GIVING ME A CHOICE OF WHAT ... DON'T THEY KNOW?' SORT OF THING.

Nurse: Exactly. If they haven't got, they just don't know, some patients just don't know what to do because, you know, you're talking about a real life-changing situation for most women, you know, what do they have? And they don't know what they feel is best for them. And it is difficult and I often say to patients, 'Would you rather, it had been better if the doctor had said to you have this or the other ... and they've said, 'Well, yes, if you had said to me "Go along and have the mastectomy or have the wide local excision" I could accept that, but it's the fact that the choice has been given to me and I don't know what to choose because I've never been in this situation before, I'm not a doctor.' And I hear that time and time again.

\*Q14. SO WHAT DO YOU THINK ARE THE MOST IMPORTANT PIECES OF INFORMATION PATIENTS NEED OR WANT TO KNOW ABOUT TREATMENT AND WHEN DO THEY TEND TO BE RAISED, WHEN IT'S ON TREATMENT OPTIONS?

Nurse: Treatment at the time of diagnosis, erm, that's all I can say about that really, it's time of diagnosis, treatment options are discussed with them. Again when they come back the following week it's gone through again, you know, 'Have you read the written information?' 'Have you thought of anything?' 'Have you come up with any sort of, you know, conclusion of which one you'd feel more comfortable with?' But, yes, yeah, it's time of diagnosis.

INT: CAN WE MOVE ON NOW TO WHAT A PATIENT IS OFFERED, PLEASE ...

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

\*a. ONLY BREAST CONSERVATION SURGERY?

Nurse: Right. It's usually a small tumour, just one, erm ... if it's reasonably small as compared to the breast, size of the breast; erm, previously not had radiotherapy; previously not had a cancer in that breast. Obviously patient's choice. Sometimes they can offer a wide local excision if it's very close to the nipple but often it means removing the nipple but leaving the rest of the breast, but again some doctors would rather do a mastectomy in that situation rather than just remove the nipple. So a small tumour in comparison to the size of breast, patient's choice, erm ... that's about it really.

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

Nurse: If it's multifocal; they've had breast cancer before in that same breast I'm talking about; radiotherapy, they've already had radiotherapy to the breast previously; again patient's choice; if you've got a large tumour in the breast and obviously in relation to the size of the breast, and often if it's quite central behind the nipple as well.

\*c. AND WHAT FACTORS WOULD LEAD YOUR TEAM TO OFFER A PATIENT A CHOICE BETWEEN THE TWO TREATMENTS?

Nurse: In a sense, if they're wide locable they could be offered a mastectomy, if it's, you know, if the patient would feel more comfortable with that, but where it's marginal whether they would, mastectomy or wide local excision, if it's a reasonably sized lump compared to the size of the breast you could do wide local excision but there'd be quite some distortion to the breast, with the rest of the breast, so again it's entirely up to the patient, because some women couldn't cope with a distorted breast and therefore they'd choose, opt for a mastectomy, whereas some women, no matter what you do, say, 'I want my breast,' so again it's patient choice. But it's really, it's sort of if it's borderline mastectomy / wide local excision, you know, if it's one that could go one way or another but it very much depends on the patient what they feel. And ... it really, like I've just said, if it's wide locable they could, they could be offered a mastectomy because some women would choose to have a mastectomy no matter what we say. You know, I've got a lady at the moment, perfectly wide locable, but she's opted for a mastectomy. Our choice would be a wide local but she's also been offered a mastectomy and she's given very good reasons as to why she wants a mastectomy, and that's her choice. So ...

[\*d. OTHER TREATMENTS - NOT ASKED]

INT: THE LITERATURE SUGGESTS THAT PATIENTS VARY IN THE DEGREE OF INVOLVEMENT THEY WANT MAKING DECISIONS ABOUT WHAT SURGERY TO HAVE: SOME WANT FULL CONTROL, SOME PREFER TO SHARE THE CONTROL, AND SOME PREFER IT IF THE PROFESSIONALS TAKE THAT CONTROL ...

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

Nurse: To a degree, yes, I do, yeah. Yes, I do, yeah.

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

Nurse: It's usually the patient. It's either number one or number two, it's a mixture of the two there really: I couldn't quite choose which one of those two and I'm sitting on the fence there, but if you push me for one, erm, I would say it was the second, the patient tends to make the final decision about which treatment they will have following seriously considering, you know, the opinions ... erm, so I would, if you push me, it would be two. But ultimately the patient usually has the final decision.

INT; OK. I'D LIKE TO TALK NOW ABOUT COMMUNICAITNG WITH PATIENTS WHO HAVE GOT BREAST CANCER, AND I'D LIKE US IN PARTICULAR TO FOCUS ON PATIENTS IN WHOM, FOR CLINICAL REAONS, MASTECTOMY IS NOT THE ONLY OPTION. YEAH? THEY'VE GOT A CHOICE. RESEARCH HAS IDENTIFIED THAT PATIENTS WITH BREAST CANCER TEND TO FALL INTO ONE OF THREE DIFFERENT DECISION MAKING STYLES: THESE ARE ACTIVE DECISION MAKERS, COLLABORATIVE AND PASSIVE. IN THIS FINAL SECTION OF THE INTERVIEW I'D LIKE TO ASK YOU A FEW QUESITONS 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 SITUATIONS WITH ACTIVE DECISION MAKERS, PATIENTS TO TEND TO MAKE THEIR OWN FINAL TREATMENT DECISIONS EITHER WITH OR WITHOUT SERIOUSLY CONSIDERING THEIR SPECIALIST'S OPINION.

\*Q18. FIRSTLY, I WOULD LIKE YOU TO THINK OF A SITUATION YOU HAVE HAD WITH A PATIENT WHO WAS ACTIVE ACCORDING TO THAT DEFINITION AND, WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, PLEASE TELL ME ABOUT YOUR EXPERIENCE WITH THEM UP TO THE POINT WHERE A TREATMENT DECISION WAS MADE.

Nurse: OK.

INT: DO YOU THINK YOU'VE GOT SOMEONE IN MIND?

Nurse: Yeah, I've written names down here. Two in particular.

INT: YOU DON'T HAVE TO ACTUALLY GIVE ME THE NAMES, THAT'S FINE, BUT ...

Nurse: No, sure. Erm, one lady in particular, and I'll talk about the first lady, interestingly there are both different consultants. The first lady had neo-adjuvant chemotherapy, she had a large tumour, small breast, and she went of and had chemotherapy. She came back, she had a wonderful response from the chemotherapy and it had actually shrunk down quite well really to the degree that it was wide locable, but, because the original presentation, and because it was neo-adjuvant chemotherapy, there's always the worry of what else is going on with the rest of the breast. And in this sort of situation where somebody has originally presented with a large tumour in a breast, who has neo-adjuvant chemotherapy, you're invariable, it's recommended to have a mastectomy. In this particular lady's situation, I knew from day one her body image was paramount to this lady and she was, I wouldn't say she was a celebrity, but she was a recognised figure on the television and so obviously her body image was everything to her. And when she came back following her chemotherapy ...

INT: ARE WE TALKING A LOCAL OR NATIONAL CELEBRITY?

Nurse: Local. And she sat in consultation and obviously surgical, surgical procedures were discussed, and the consultant said to her, 'We could potentially do a wide local excision but in view of your original presentation we're not exactly sure of what else is going on within the breast and, under these circumstances ...' she wasn't, she was only small-breasted, '... we would advise you to have a mastectomy.' No way was she going to have a mastectomy, no way, erm, and she had given this serious consideration because she knew that these were the options and that she'd made, you know, she had agreed that she did not want a mastectomy at the end of the day. Her daughter's a GP and her daughter was absolutely horrified that her mother wasn't going to have a mastectomy. So there was obviously some influence from her daughter: her daughter was obviously trying to persuade her to have a mastectomy, and she wasn't going to have a mastectomy. So in the end she did have a wide local excision, although to be fair the consultant did explain to her, 'You know we may not get clear margins, you know that there is a good chance that we may still have to go on and do a mastectomy,' and she was very aware, very honest and upfront with her. And she still wanted to go for a wide local excision first, and that was fine. And she had a wide local excision and she had clear margins and she went on to have radiotherapy. How long that breast will remain safe I have no idea, but only time will tell. But she came in the consultation, had a chat, I took her out into the counselling room and again I had with her, and I understood exactly where she was coming from because of her body image, and I knew that she, no way did she want to embark on a mastectomy. Erm, and as she rightly said to me, 'Once, a mastectomy is a mastectomy, it's done, and that's it, there is no going back, whereas with a wide local excision at least I'm going to have a bite of the cherry, as it were, and if it's not clear then, fair enough, you know, at least I've gone down that road first,' which I thought was perfectly acceptable. So that was one lady ...

INT: CAN I JUST ASK YOU A COUPLE OF QUESTIONS ABOUT ... HOW DID YOU GET ON WITH THE PATIENT?

Nurse: Great, wonderful, I had an extremely rapport with her.

INT: AND HOW DID SHE GET ON WITH THE DOCTOR?

Nurse: Very well, yes, yeah. Yeah, very, very well. Erm ... yeah, because there was a lot of openness and honesty and I'm a great believer in openness and honesty. And she was clearly an intelligent woman, knew her own mind, knew exactly what she wanted, erm, and we tried to work round her, you know, and we did and at the end of the day she's still got her breast at the moment, erm, and that was it really, so.

INT: SO, LOOKING BACK NOW, DO YOU THINK, HOW SATISFIED DO YOU FEEL WITH THE EXPERIENCE OF DEALING WITH THAT PATIENT?

Nurse: I feel, I feel great about that particular situation, the fact that it worked out fine for her and the fact that I was very, very aware that she just did not want a mastectomy, and I took on board what she said to me, erm, and I went along with her decision, and I said 'That's absolutely fine,' I agreed entirely where she was coming from and at the end of the day it was her choice, and she knew the pitfalls, she knew the possible of local recurrence, but she said, 'I want to keep my breast,' and that was fine.

INT: AND HOW SATISFIED DO YOU FEEL THAT SHE IS?

Nurse: I think she's so satisfied in the sense that she had clear margins because when she came back for her results and that was one of the things she was obviously waiting for, and I think she was waiting for us to say, 'Well, actually, you need a mastectomy,' but the fact that we said to her, you know, 'We've got a good clear margin all the way round,' you could see this great big weight come off her shoulders, as if to say, 'I told you so.' [chuckles] But, you know, that was, it was a wonderful for her and it was pleasing for me too because she was happy, which made me happy, you know, she got what she wanted and that's good, it's nice to know that, you know, she had an active part in that decision.

INT: CAN YOU DESCRIBE THE SECOND LADY TO ME?

Nurse: The second lady was under a different consultant altogether and she had a wide local excision and it came back as incomplete margin - not particularly big-breasted lady but again quite glamorous. And she had incomplete margins because she had a lobular type of carcinoma which you can't always know where the edges are, it tends to, it's undefined, you know, you can't feel the actual edge of it like you can with a barn-door breast cancer. So we weren't entirely sure where the edges were, and she was offered a mastectomy. I took her into the cupboard, she was absolutely devastated, and her partner was there, he was actually quite ... I wouldn't say aggressive, abrupt, I think was the word I'd use, abrupt, he was quite abrupt. And she said, 'Why can't I just have a little bit more removed?' and Miss ... sorry I nearly said the lady's, the consultant's name there. [chuckles]

INT: OK IT'S ALL CONFIDENTIAL, GO ON.

Nurse: The consultant actually said to her that, 'Yes, we could do a wider excision but your breast'll probably be quite distorted and the shape would not be acceptable to you, and so we would advise you to have a mastectomy.' Well, again, this lady did not want a mastectomy and she went and sought a second opinion from this consultant who this other lady, the first lady ... so she went and sought a second opinion. And this consultant said, 'I could do a wider excision but there may be some deficit in your breast, but I can't guarantee I'll give you clear margins again.' So in the a sense the consultant, the second consultant was offering her a wider excision with the knowledge, again, we might not give clear margins and, yes, there may be some deficit in your breast,' whereas her originally consultant was sort of pushing towards a mastectomy because it's a lobular carcinoma, probably won't be able to get clear margins, so you're probably going to end up having a mastectomy anyway. This lady stayed with the second consultant and the consultant did do a wider excision and she had clear margins and she had the most beautiful shaped breast afterwards, so she didn't have a huge deficit at all, and she was absolutely thrilled.

INT: I BET SHE WAS.

Nurse: Absolutely thrilled. So, again, I was pleased for her and, going back to the MDT meeting I was in there when this came up about having clear margins and I could have cheered because I was so pleased, you know, that this lady had clear margins, and I know how upset and distressed she was getting at the prospect of having a mastectomy. And I saw her fairly recently and she's still pleased as punch that she's still got her breast left, so ...

INT: AND YOUR RAPPORT WITH HER, DID YOU GET ON WITH HER?

Nurse: Oh brilliant, yes, absolutely.

INT: SO WERE YOU THERE AT THE ORIGINAL CONSULTATION?

Nurse: Not the, not the first consultation when she was diagnosed with breast cancer but when she came back for her results following the surgery I was there and obviously again I'd made contact with her up on the ward, I had seen her on the ward when she had her original, first operation. Again, very good rapport with her. Nice lady, as I say her partner's a bit abrupt but, we can cope with those.

INT: AND DO YOU THINK THAT SHE GOT ON WITH THE DOCTOR WELL?

Nurse: Her first consultant, no, not at all, not at all, they just didn't, the pair of them just didn't like each other, you could tell. And she actually said to me, 'I never, ever want to see that person again.' Erm, and she was quite, you know, quite clear in her mind, 'I never want to see that person again.' And you could tell from the consultant that they didn't like her either.

INT: THINKING ABOUT THE TWO THAT YOU'VE TALKED ABOUT, HOW SOON DO YOU THINK YOU KNOW WHEN YOU'RE ACTUALLY, WHEN YOU'RE TALKING TO AN ACTIVE DECISION MAKER? YOU MIGHT NOT ACTUALLY THINK ABOUT IT IN TERMS OF AN ACTIVE DECISION MAKER, BUT YOU KNOW WHAT I'M TALKING ABOUT, YEAH?

Nurse: I think they know more or less straight away, because those sort of people often have thought about this before they even come and they often have already made a decision. And when they go in and see the consultant it's either confirmed what they thought all along anyway, erm, but come what may they often have made the decision one way or another, you know, 'I don't want to lose my breast' or, you know, 'That's it, I just want rid and I'll go along with a mastectomy.' So often they have made, these active decision makers are often very aware of their decision beforehand.

INT: AND WHEN YOU REALISE THAT YOU'VE GOT THIS KIND OF DECISION MAKER, HOW DOES THAT THEN, YOU KNOW, SHAPE YOUR APPROACH TOWARDS THAT PERSON?

Nurse: It doesn't make any difference to me personally at all, because at the end of the day it's their decision, and if they've already made their decision then that's fine, that's entirely up to you. The ones I do find difficult, well not so much difficult but obviously need a lot more dealing with, are those who are unable to come up with a decision, who find it difficult to make a decision, 'Do I have a mastectomy, do I have a wide local excision?' They're the ones you need to go through things again, over and over again. So ...

INT: I'D LIKE TO MOVE ON SITUATIONS WITH COLLABORATIVE DECISION MAKER, PATIENTS WHO TEND TO SHARE FINAL TREATMENT DECISION RESPONSIBILITIES WITH THEIR SPECIALISTS.

\*Q19. IT'S SIMILAR TO WHAT WE'VE JUST DONE, I'D LIKE YOU TO TALK ABOUT A YOUR EXPERIENCE WITH A COLLABORATIVE DECISION MAKER UP TO THE POINT WHERE A TREATMENT DECISION WAS MADE, AND AGAIN, YOU DON'T HAVE TO REVEAL ANY CONFIDENTIAL DETAILS.

Nurse: Yeah, erm ... again there's a couple of ladies, very very similar really. Hadn't really got any clear idea of surgery, and the consultant, once they explained they'd got breast cancer, said to them, you know, 'There are these options,' and invariably they say to the doctor, 'Well, what would you choose?' And they often would say, this particular consultant, said, 'Well, it is, if you, if you want to keep your breast you can do, you don't have to have a mastectomy unless you, for whatever reason, decide you feel more comfortable with that, but it is suitable for a wide local excision followed by radiotherapy and that is quite acceptable.' And they're happy with that because at the end of the day most women don't want to lose their breast and they, but, you know, these women have said, 'Well, yes, I'm quite happy with that arrangement because I don't want to lose my breast and if I'm guided by you, if that's what you

suggest, then I was hoping you would say that, and that's fine.' And, you know, they were happy to do that really. I can't really expand any more than that really to be honest.

INT: NO, THAT'S FINE, THAT'S OK. WERE THEY BOTH UNDER THE SAME CONSULTANT?

Nurse: No.

INT: NO, DIFFERENT CONSULTANTS, YEAH?

Nurse: Yes, yeah.

INT: AND HOW DID YOU, WERE YOU THERE BOTH AS A BREAST CARE NURSE, HOW DID YOU GET ON WITH THEM?

Nurse: Again, fine, absolutely fine. There are very few women I don't tend to get on with, I have to say. Erm, you know, I tend to get on, well I like to think I get on with the ladies very well really. But, yes, absolutely fine, you know, you know, you listen to the ladies what they have to say and you're guided by, you know, what the consultant says in clinic and also you listen to what the patients have to say and what they feel comfortable with at the end of the day.

INT: AND DID THEY GET ON WELL WITH THE DOCTORS AND THE CONSULTANTS?

Nurse: Yes, oh yes, yes they did, yeah.

INT: WERE THER ANY EXTERNAL INFLUENCES DO YOU THINK THAT WERE APPARENT IN THOSE TWO INSTANCES?

Nurse: One of the ladies, I think it was her older sister had already been through the system of having breast cancer and she had a wide local excision and radiotherapy and she was fine, and so she already had an idea that that was a good surgical procedure and she knew that her sister had done all right, so what's good enough for her sister was probably good enough for her. So ...

INT: AND THAT'S, THEY BOTH HAD WIDE LOCALS DID YOU SAY?

Nurse: Yeah, yes, so she was happy, you know, she was happy with that. The other one I'm not so sure whether there were any external influences really. I think she just wanted to keep her breast really and so she, really she was pleased that the consultant had said, you know, 'Very suitable for a wide local,' and she was happy with that. So ...

INT: AND HOW SATISFIED WERE THESE LADIES AT THE END OF THEIR EXPERIENCES?

Nurse: Yeah, yeah.

INT: AND WHAT ABOUT YOURSELF, WERE YOU SATISFIED WITH THE ...?

Nurse: Yeah, yeah, absolutely, yeah, yeah.

INT: HOW SOON DO YOU THINK YOU KNOW YOU'RE TALKING TO A COLLABORATIVE DECISION MAKER? I THINK THIS IS THE HARDEST ONE OF THE THREE, TO BE HONEST.

Nurse: It is, that's why I'm thinking ...

INT: THE OTHER TWO STAND OUT I THINK, THESE TEND NOT TO IN MY BOOK ANYWAY.

Nurse: I think, I really, I really think probably ... is at the time of consultation, I think you do tend to pick up a lot at the time of consultation

because the active ones stand out a mile anyway because they often tell you what they want and what they don't want, and they're often schoolteachers in my opinion [chuckles].

INT: I CAN'T BELIEVE THAT!

Nurse: Erm, yeah, you often can put them in pigeonholes really, to be honest. You can suss them out straight away more or less at the time of consultation, yeah. Well I can anyway, I can't speak for the others, but ...

INT: I'D LIKE TO MOVE ON NOW BECAUSE I'M AWARE THAT TIME'S SLIPPING AWAY, TO TALK ABOUT SITUATIONS WITH PASSIVE DECISION MAKERS, PATIENTS WHO TEND TO WANT TO LEAVE FINAL TREATMENT DECISIONS TO THEIR SPECIALIST, EITHER WITH OR WITHOUT THEIR SPECIALIST SERIOUSLY CONSIDERING THEIR OPINION.

\*Q20. SIMILAR TO WHAT WE'VE DONE BEFORE, NO CONFIDENTIAL DETAILS OBVIOUSLY, JUST TELL ME ABOUT YOUR EXPERIENCE WITH THAT PERSON OR PERSONS UP TO THE POINT WHEN MADE A TREATMENT DECISION.

Nurse: Yeah, I often find there's quite a lot of those because they don't know what to do. I mentioned it before, you have a lot of ladies that come, especially elderly, that are 'Quite happy along by what you think, Doctor,' sort of situation, and they really don't know what is the best, best option for them, and so they would be more than happy - if they could, you know, the doctor would say, 'Right, well I think you ought to have ... Right, we'll have a mastectomy, or ... We'll just remove the lump then' - they'd be quite happy with that, and in fact some women actually get quite anxious if the options are left to them, they get really upset and think, 'Well, I can't make a decision, I don't know what to do,' and often in that sort of situation you have to sort of guide them and say, 'Well, look, how would you feel if we said you needed a mastectomy?' 'Well if that needed to be done, doctor, well then that needs to be done and that'll be ... you know, I'm guided by you, Doctor, because you know best.' [chuckles]

INT: SO DO YOU HAVE A PARTICULAR PATIENT IN MIND HERE?

Nurse: Well there's one particular lady who was elderly actually and she sat there, hardly said a word, and you could tell - I wasn't quite sure really whether she understood in the sense that I don't think she was quite the sharpest in the drawer, if you get my drift - and she sat there and she was going, 'Yes, Doctor ... No, Doctor ... Yes, Doctor ...' and I thought, 'Is she really taking on board what's being said here, and I took her out into the cupboard and I said, 'Did you understand what the doctor said?' and she said, 'Yes, but ...' she said, 'I don't know what I'm supposed to do.' And she says, 'I know I've got to have an operation, but I don't know what operation I'm going to have.' I said, 'Well, you know, that's why, you know, the doctor did explain, we've got these two options here, it's very much what you feel.' 'Well, can't you make the decision for me?' 'cos they haven't got a clue, you know, it's not like buying a tin of beans, 'Shall I have Crosse and Blackwell or Heinz today?' you know, you're talking about these, you know, life-changing situations for some people and ... and this poor lady couldn't decide and so it was the situation, 'Well, let's put it this way: we can just remove the lump if you want to and keep the rest of the breast, and you have radiotherapy - how would you feel about that?' 'Yes, that doesn't sound too bad, does it, Doctor?' 'What about if you had your whole breast removed, how would you feel about that?' 'Well I don't really want to lose my breast ...' so then again they've more or less said what they want by saying that really. And so in the end we had to guide her quite strongly as to one way or another, and she was quite happy with that, the fact that we'd guided her, and in a way although ...

INT: SO DID SHE GO FOR THE ...?

Nurse: She went for the wide local excision. So although in a way, she made her own choice but indirectly by saying what she did, by saying she didn't really want to lose her breast. And we said, 'Well you don't really have to if you don't want to, but we can just remove this lump for you,' and she was happy with that. But there are a group of patients who really don't know what to do, and they are very difficult to deal with sometimes and you really, although you want to say, 'Oh have a wide local excision and be done with it,' you know, that's sorted, you can't say that, you have to work with the patient so in a sense they have to come up with their own decision. But we do get there in the end.

INT: HOW DID YOU FEEL THAT THINGS WENT WITH THAT PATIENT? HOW WERE YOUR FEELINGS AT THE END OF IT ALL?

Nurse: All right actually, erm, often when you see the patients on the ward and obviously there's a group of women on there, there's such an awful amount of women on there, you can have up to about 15 patients, breast patients, on the ward in a week, and they obviously talk to each other, and often you find that, if you've got quite a few of the mastectomies who're coming in at the time, you often find that the women who've had wide local excisions they think, 'Well have I made the right decision because there seems to be an awful lot of women who've had a mastectomy?' or the other thing is, if there are women who have come in for their second procedure, you know they've previously had a wide local excision, haven't got good, clear margins so they need to come in for a mastectomy, and again it makes them feel uneasy, 'Have I made the right decision?' and I know this particular lady said that to me, she said, 'This woman, you see that woman over there, you know, she's coming in for her second operation,' and suddenly you could tell she was, she was thinking, 'Have I made the right decision here?' But we sat down and we went through it all again with her and why some people have to come in and have another operation. But she was OK with that, with that information, she was fine. But sometimes it can make them feel a bit uneasy. And also if women have developed a cancer in a breast again, in the same breast, and then obviously they need a mastectomy, and again some of the women will say, 'Well she's got a second cancer in her breast, and should I have had a mastectomy and then that won't happen?' So it's again ...

INT: GOING BACK TO THE SAFETY ISSUE AGAIN.

Nurse: ... you have to unpick the pieces again. So ...

INT: AND DID YOU GET ON WELL WITH THIS PATIENT?

Nurse: Yeah, yeah, she was a little sweetie, bless her, yeah, she was lovely, yeah.

INT: HOW DID SHE GET ON WITH THE CONSULTANT, ALL RIGHT?

Nurse: I think she was a bit timid by them, er, she was a bit of 'Ooh ...' you know, but you've got to remember with the older generation they're the culture where you've got to sit there and don't question the doctor and you don't say anything. But she was a little sweetie, she really was, yeah, yeah.

INT: LOOKING BACK NOW, HOW SATISFIED DO YOU THINK YOU WERE WITH THE WHOLE EXPERINCE?

Nurse: OK. Absolutely fine, yeah.

INT: AND WHAT ABOUT HER, HOW SATISFIED WAS SHE, DO YOU THINK?

Nurse: Yeah, yeah, I've seen her fairly recently and she often waves at me. Yes, she's fine, absolutely fine.

INT: AT WHAT POINT DO YOU BECOME AWARE YOU'RE TALKING TO A PASSIVE DECISION MAKER?

Nurse: Again I think that's at time of consultation.

INT: SO YOU THINK IT STANDS OUT VERY ...?

Nurse: Yeah, yeah.

INT: WHAT SORT OF THINGS DRAW YOUR ATTENTION TO IT?

Nurse: ... I think they often admit that they don't know what to do at the time, when you take them off into the cupboard and you give them the written information and discuss things with them, erm, and they often will say, 'Well, I don't know what to do,' or 'What do you think is the best?' They try and question you about what you feel, so what they're wanting is for you to tell them what to do. And you can't tell them what to do. I mean they know what they want to do.

INT: OK, LAST COUPLE OF QUESTIONS ... THE LITERATURE TELLS US THERE ARE A VARIETY OF INFLUENCES ON PATIENTS MAKING DECISIONS ABOUT SURGICAL TREATMENTS ...

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

Nurse: I think it's family and friends, erm, and their pre-existing knowledge and understanding of the disease or if, for example, they've had family or friends who've been through it, that's all they know. So if they know somebody who's had a mastectomy who's had chemotherapy and has died, that's all they know about and their experiences of cancer. Erm, also the media, especially if somebody dies, you know, Paul McCartney's wife, Linda McCartney for example, was it Sandy Shaw that died, you know, all these people, high profile have died of breast cancer, and unfortunately they don't always focus on those that have had it and survived, you know, and unfortunately, you know, it causes a lot of anxieties. And the websites as well because people are quite, erm, quite tuned into the website and getting a lot of information off there really, and a lot of it is either American or it's outdated and it's not necessarily relevant to what we do here.

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

Nurse: I think it's first the consultants and then us, breast care nurses, definitely.

INT: AND WHY DO YOU THINK IT'S THAT WAY?

Nurse: I think it's because the consultants are the ones that are discussing the surgical options with them and I think secondly it's because it's, afterwards, that we then have the most contact with the patients and are, erm, our level of contact is high with them and the fact we spend more time with them with the consultants going through everything again with them. So I think it's a combination of the two, but certainly the consultants have their influence first, because they'll always wanted to be guided by 'a doctor', not necessarily 'a nurse' it's 'a doctor'.

\*Q23. 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 OR DIDN'T COVER OR ANYTHING?

Nurse: I did actually write one or two things down here, but I think I've already discussed them, erm, [???] anyway.

INT: YEAH, THAT TENDS TO HAPPY ... IT COMES OUT BECAUSE YOU CAN'T WRITE DOWN EVERY SINGLE QUESTION YOU NEED TO ASK, WHATEVER. ANY [???]

Nurse: Some of the doctors, and I have to say it's not many, erm, in certain situations don't even mention mastectomy, because if it's a tiny tumour in a big breast they won't even mention mastectomy, they will just say, 'This is very suitable just to remove your cancer with a margin of normal breast tissue followed by radiotherapy.' Sometimes, in some situations, mastectomy is not even mentioned. Sometimes when it is mentioned it's, 'You can have a mastectomy if you feel more comfortable to do so, but you don't have to, this is very suitable for a wide local excision.' So in a sense they're guiding them indirectly in a way, aren't they?

INT: OF COURSE, YEAH. WELL IN THE FIRST INSTANCE VERY HEAVILY.

Nurse: Absolutely, absolutely. Erm, and it's interesting how women will opt for a mastectomy for the wrong reasons, because, like I mentioned before, they think it is safer to have a mastectomy than it is a wide local excision, and often it is up to us as the breast care nurses then to go and speak to the women and say, you know, 'Let's go through these options,' and if they say 'I want a mastectomy,' I often say to them, 'Can you just explain to me why you feel more comfortable having a mastectomy?' and if they say, 'Well, it's gonna be safer, isn't it, living longer, if I have a mastectomy and I haven't got the risk of it coming back?' and then you have to clarify that position, and say, 'Well, actually, that's not quite true ...' and that one is just as safe as the other, you know. So it's getting that message across, which is really important and there are times I've had to clarify that with patients, you know, you don't, you know, have to have a mastectomy because you think it's safer, erm, so I think we, you know, it's important that we as breast care nurses we make sure that we get that message across because they could be having mastectomies for the wrong reasons really.

INT: ANYTHING ELSE?

Nurse: No.

\*Q24. ONE LAST LITTLE ANECDOTAL QUESTION HERE, IF YOU HAD THE POWER AND MONEY TO CHANGE ONE THING ABOUT THE SYSTEM HERE, WHAT WOULD IT BE?

Nurse: I think it would be so the patients aren't waiting too long for their results from the surgery. When you speak to patients the most common anxiety levels that they have is waiting for their results.

INT: FROM THE ACTUAL SURGERY?

Nurse: From the surgery.

INT: SO HOW LONG WOULD THAT TAKE?

Nurse: It varies on the consultant, from consultant to consultant because some can wait two weeks for their results and that's just not acceptable. And we know that ...

INT: WHY IS IT VARIED?

Nurse: It's because it depends where, when the clinic falls, for example if a patient comes in on a Tuesday and have their operation on the Tuesday, often they home the following Tuesday. Then they come back the following Tuesday for their consultation for their results and so therefore it's two weeks from their surgery. If, for example, a patient comes in on Wednesday, they'll go home the following Wednesday and then they come back the next day, the Thursday, to another, to a different consultant who does their clinic on a Thursday, for their results, so their time is a lot less than some of the other consultants, it's just the way it falls actually. And I argued that the women that go home on the Tuesday could, there is no reason for them to come down to clinic and have their results on the Tuesday of that week when they go home, why they have to wait another week, and they said it's because of the notes and all the admin. I said, 'That's nonsense, that's not fair on the patients, you can't expect patients to wait another week, it's just not fair.' I wouldn't like it. And you speak to them and you, it is always waiting, it's a waiting game, it's waiting for their results, and that's something they worry about more than anything is waiting for their results. And I just wish we could, there was as system where we could give them their results much quicker.

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

[End of interview]