

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Nurse)

*VENUE: Low MR unit

*DATE:

*ID: BCNO40

*INTERVIEWER: DJW

INT: WELL FIRST OF ALL THANK YOU FOR AGREEING TO BE INTERVIEWED, I KNOW YOU'RE ALL VERY BUSY DOWN HERE AND TO TAKE AT LEAST AN HOUR OR SO OF YOUR TIME'S A LOT, SO WE DO APPRECIATE IT. THE FIRST QUESTION'S A VERY SIMPLE ONE, IS THAT ...

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

Nurse: Erm, two years, yes. I also, can I just say this, I do work part-time, I do work just two days down in this breast unit, erm ...

INT: JUST TUESDAYS AND ...?

Nurse: It's Mondays and Tuesdays, and I also do a shift on the breast care ward as well.

INT: OH RIGHT, OK.

Nurse: Yeah, as a flexible shift.

INT: AND THOSE YEARS HAS BEEN AS A BREAST CARE NURSE?

Nurse: It is, yes, I started, yes, it was in the February I started and then I had like about 4-6 months probably being mentored really, so, but yes it is two years.

INT: MM, AND HAVE YOU WORKED ELSE AS A BREAST NURSE?

Nurse: No, no I haven't, no.

*Q2. OK. SO, THINKING ABOUT THINGS LIKE LIKES AND DISLIKES, THE UNIT PHILOSOPHY, THE DAY TO DAY RUNNING OF THE SERVICE, THINGS LIKE THAT, WHAT'S IT LIKE TO WORK HERE AS A SPECIALIST NURSE IN THIS UNIT?

Nurse: Well I find it very enjoyable, it's challenging, we've got a good team here that work very well together and that is just the breast care nurses, but also with the rest of the consultants and the radiographers, everybody in the MDT team really, I think we work quite well together. Erm, obviously you need to know a lot because you need to feed the right information back to the patients, so there is, there is a lot to learn to know, and I feel like I've still got a lot to learn, that although I've been down here for two years, it's still not an awfully long time really, compared to some of the others. Er, so, yes, it's nice, it's good, it's, I enjoy my work, and I find also that working on the ward and working down here gives a good continuation for the patients, because I'm like travelling along the journey with them ...

INT: AH, YES, OF COURSE.

Nurse: ... from the point of diagnosis.

INT: IS THAT, EVERYBODY HERE DOES THAT OR ...?

Nurse: No, no, it's just me ...

INT: IT'S JUST YOU.

Nurse: ... it's just me that does it actually.

INT: [???

Nurse: Well I did work as a nurse on the ward before, I've worked on the ward for a long while, and that is a ward for breast care patients, and then I came down here just to fill in somebody's time really that was pregnant, and then a vacancy came up so I got the job. But it was only a certain amount of hours and I didn't want to reduce my working hours so consequently I got, I kept the job on the ward as well, just part-time to make my hours up. But it is, yes, because it's good feedback for the nurses on the ward as well as down here, and it's a good stepping ladder really for the patients because, like I say, I see them down here at diagnosis and then I meet them on the ward. I mean, I'm in my uniform on the ward and in normal clothes down here and sometimes they think, 'Where do I know that woman from?' and then they 'Oh, yeah, yeah, that's right,' you look different in uniform, don't you? But, yeah, I find it's good for the ladies because they say, 'Oh it's lovely to see you on, to see somebody I know,' because I've met them down here with the doctors, you see. So, yeah, so that's quite good.

INT: THAT'S NICE. AND IN TERMS OF THINGS LIKE TRAINING AND WHAT-HAVE-YOU, AGAIN YOU'VE ONLY BEEN HERE A COUPLE OF YEARS, DO YOU FEEL ALL YOUR TRAINING NEEDS ARE, NEEDS ARE BEING MET AND THINGS?

Nurse: Yes, I do, erm, I do, I've been on lymphoedema training days and I do the lymphoedema clinic now. I'm doing a counselling skills course at the moment.

INT: HOW'S THAT GOING?

Nurse: Fine, yeah, I finish in June, I've enjoyed that actually. Erm ... I'm not seromas [?] yet, which is my next thing to do, I need to start draining the ladies' seromas, mostly the nurses are doing that, but I think because I only work down here two days a week it is quite difficult really to get the time to do it because, you know, my two days here are took up with clinics, lymphoedema clinic, visiting the patients on the ward, erm, and there just doesn't seem an awful lot of time within those two days to do it. I have done part of the All Breast Care Course but that was a few, that was probably about three or four years ago, I just did an overview of that. Er, and obviously I've attended different study days for prosthesis fitting and, you know, different things like that. I can't really think of anything more offhand. But, yes, I do feel that my training needs are being met as much as time will allow really.

INT: AND THINKING ABOUT THE STRUCTURE OF HOW THE CLINIC RUNS, WHEN A PATIENT COMES IN, WHAT'S A SORT OF TYPICE SORT OF PATHWAY? JUST VERY, VERY BRIEFLY, WHEN THEY COME IN, DO THEY GET LIKE A TEST DIAGNOSIS, THINGS LIKE THAT, DO YOU DO HOME VISITS, DO YOU [???] TELEPHONE CONTACT, WHAT'S THE SORT OF GENERAL PATHWAY THEY GO THROUGH?

Nurse: Yeah, right. Well we do, it depends which type of clinic you're talking about because we do a screening clinic here and there's also a symptomatic clinic.

INT: YEAH, THAT'S RIGHT.

Nurse: So ... do you know the difference between those?

INT: Yeah.

Nurse: You do, don't you? Erm, I suppose in lots of ways they are both the same in the fact that all the ladies we give a contact card to, so we're a point of

contact for them if things are looking like they are going to be perhaps diagnosed or they've had an investigation and they're going to come back for results the following week. Yeah, they do get a contact card from us, and they're asked if they've got any problems or questions that they need to ask then they can telephone us and we always do return the calls, even if we're not around we carry bleeps, but if we don't have time to answer them they go through to an answering machine and we do always call them back, we pick the messages up at the end of the day and return the call. Erm, well basically, on a symptomatic clinic, obviously the ladies'll have found something abnormal in the breast, they'll go to the GP and the GP will refer them to the hospital if he thinks need be, there is a criteria for GPs that they fill in and need to know. So the ladies'll come here, they'll maybe have a mammogram on arrival, or they'll maybe see the doctor on arrival, and really it goes from there. If things are still looking abnormal or suspicious they'll go through a series of tests like a core biopsy or a fine needle aspiration to draw some cells off. These cells are then sent up to the Histopathology Lab, they're looked at, and the results come back to us within half an hour. So in a symptomatic clinic the ladies will know before they leave the clinic on the same day if they have got a breast cancer or if it isn't anything. Erm, that, actually that's not always the case because sometimes the fine needle aspiration won't give a good result, a true result, it'll be equivocal: in that case they'll perhaps have to have a core biopsy taken which is done under a local anaesthetic and it takes a little bit of tissue away, but the results take longer for that, so they would have to return the following week for the results of that. Erm, the same really in a breast screening clinic, obviously they've been called back because their mammogram is looking abnormal, so they come back for the second stage of screening, and again they can go through the ultrasound, the core biopsy, the clinical examination by the doctors, but they never a result the same day, they'll have to come back the following week for the results of that. But we do give all of the ladies a contact card and we do talk to them. We've got little rooms that, counselling rooms that we can take them in, erm, and just go through what the doctors have said, answer their questions, and just really, you know, if there's anything they want to know.

INT: MM, DO YOU DO HOME VISITS AS WELL ...?

Nurse: We don't do home visits, no. I think it's probably something that we'd like to do in the future, but at the moment, no we don't, no.

INT: IS THERE ANYTHING HERE DO YOU THINK THAT HELPS YOU DO YOUR JOB, ANYTHING YOU THINK THAT MAKES THINGS EASIER FOR YOU?

Nurse: Er ... well I think working within a good team makes it easier, to get on with the people that you work with, and also the doctors, because you're working quite closely with those during the clinics. I think organisation as well, knowing how things run, and knowing exactly what's what, also helps.

INT: WOULD YOU SAY IT'S WELL ORGANISED HERE, YEAH?

Nurse: I do think it's well organised here, yes, I do. I mean obviously some days we're more hectic than others and things don't go to plan, but they never do in a hospital, do they, and when you're working with people?

INT: [???] in my job.

Nurse: That's right, they don't. But, yes, I do feel like it is a well-organised and well-run unit.

INT: AND YOUR COLLEAGUES, HOW DO YOU GET ON WITH YOUR COLLEAGUES, THE NURSES, THE DOCTORS, AND THAT?

Nurse: Very well.

INT: YEAH?

Nurse: Yeah, very well.

INT: THAT'S GOOD.

Nurse: Yeah.

*Q3. THE NEXT QUESTION IS DO YOU FEEL THAT PROFESSIONALS HAVE DIFFERENT STYLES OR METHODS OF WORKING, AND IF SO, WHAT ARE THESE METHODS HAVE YOU OBSERVED HERE?

Nurse: You mean the doctors, the consultants?

INT: Doctors and ...

Nurse: Right. Erm, yes, I think the doctors, I mean we've got four consultants down here that specialise in breast surgery. Erm, yeah, they have got quite different styles really. Some are quite, there's one or two that are quite easy, quite passive and laid-back - I'm not saying that they don't do their job properly or any thing like that ...

INT: IS THAT TO WORK WITH OR WITH THE PATIENT?

Nurse: To work with and with the patients as well, they've got a quite kind of easy, more easy manner than, well, I suppose I'm thinking of one consultant who is very, quite strong, erm, quite direct with the patients and with the staff, and with the breast nurses that they work with. So, yes, the styles are different and also in the way that, after they've diagnosed a patient as well, one or two of the consultants'll bring the patients back the following week to go over things, make sure the patients understand everything, and then perhaps another one won't, you know, they won't bring them back the following week. They could come back if they wanted to but they won't automatically say, 'Bring them back.' Yeah, so the styles are quite different.

INT: AND AMONG THE BREAST CARE NURSES?

Nurse: Yes, again, we're all quite different. I mean I'd probably say, if we were talking about personalities, that I would be more of a passive, erm, passive person [chuckles] whereas, erm, one or two of the others are quite strong. But I think you need that mix in a team, it's different skill mix, isn't it? And I do think you need that to work well together, because what one person's got and another hasn't, it benefits all round really. But ...

Yeah, we have got different styles, but on saying that I do think we do work well together and whatever our styles are we're all very approachable and share things with each other. Because I think you need to do that as well, especially when you're dealing with women with breast cancer, you need to discuss them and what the women need and, you know, their problems really as a team.

INT: OK. I'D LIKE TO MOVE ON TO BEFORE A CONSULTATION WHERE A DIAGNOSIS IS TO BE GIVEN AND I'D LIKE TO TALK ABOUT WHAT HAPPENS JUST BEFORE A CLINIC WHERE PATIENTS HEAR THEIR DIAGNOSIS, AND FROM THIS POINT IN THE INTERVIEW I'D LIKE US TO FOCUS ON NEWLY-DIAGNOSED BREAST CANCER PATIENTS.

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

Nurse: Well, we only have one MDT meeting and that's on a Monday lunchtime. I mean, and then, like, we've got clinics running all through the week. But, yeah, the MDT meeting's held on a Monday and we attend, although maybe we don't play a big part, we are a bit passive in that really, but obviously the pathologist's there, everybody's there for the multidisciplinary team meeting, and they discuss the patients. Er, mainly they discuss the patients that are from the screening really, and, you know, what, their diagnosis and things like that, yes.

INT: SO ARE PATIENTS DISCUSSED PRE-OPERATIVELY AT THAT STAGE?

Nurse: Yes. Yes, they are.

INT: OK, RIGHT, I DIDN'T KNOW WHICH QUESTION TO ASK NEXT. SO, EXCHANGE THE QUESTION ...

*Q5. HOW DO YOU USUALLY FEEL AFTER AN MDT MEETING, WHEN YOU COME OUT AND YOU'VE BEEN THROUGH ALL THE PATIENTS?

Nurse: Well, I suppose obviously you're learning what the results are after their operation because, you know, that's what it's about as well, discussing the tissue after it goes up to the Histopathology and the results depend a lot on what their further treatment is, you know, after the surgery, so I suppose really you feel like, you know something what they don't because they you're gonna meet them afterwards but you know what their results are so really you know a lot of what their treatment's gonna be in the coming month, or whether it's not going to be that. Erm, so but, I mean, obviously you can't let them know that you know what their result are so you don't let them see it. But, yeah, you kind of have got a bit of a secret really.

INT: AND DOES THAT VARY ACFORDING TO THINGS LIKE WORKLOAD, HOW MANY'S COMING THROUGH THE CLINIC, OR ...?

Nurse: ... say it ...

INT: YOU KNOW WHEN YOU'VE GOT, EVERY DAY YOU'VE GOT DIFFERENT WORKLOADS, DIFFERENT AMOUNTS OF PATINTS COMING IN THAT'S GOING TO BE DIAGNOSED, DO YOU FEELINGS SORT OF CHANGE IF YOU'VE GOT A HEAVY WORKLOAD OR A LIGHT WORKLOAD, HOW DO YOU FEEL AFTER EACH SORT OF ONE REALLY?

Nurse: Er, well obviously you're more, the more busier it is ... I don't know, I think you still feel the same really. Yeah, you just accommodate whatever you've got to do really.

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

Nurse: If, so if the doctor thought that it was a breast cancer?

INT: YEAH.

Nurse: Yes, they would kind of give them little hints that it could be serious or things were looking suspicious.

INT: MM, BECAUSE YOU MENTIONED EARLIER, YOU SAID THAT THEY GET THE TESTS, SOME OF THEM GET THEIR RESULTS ON THE SAME DAY WITHIN HALF AN HOUR.

Nurse: They do.

INT: YEAH, SO WOULD THEY BE TOLD THERE AND THEN AND ...?

Nurse: Yes, yes, they would. I think, like, say we've got a symptomatic clinic this afternoon, so the lady, so say the lady comes in, she has a mammogram, the results come back to the doctor and it's looking suspicious on the mammogram or the ultrasound, so at that stage the doctor will then do a clinical examination and a fine needle aspiration, and it may be done in reverse order to that, but those two things would be done. If it got to the stage that a fine needle aspiration was being taken, then obviously the other investigations have looked quite suspicious. So the doctor would then say to them that 'Things are looking a little bit like this maybe could be a breast cancer' and that's why we need to take some cells so they could go to the lab and we could get a definite diagnosis for them, so they would know at that stage that things were looking as if it could be, and then the ladies'd go off, because we have to wait half an hour for the results to come back, so we'd send the ladies off for a cup of tea and then they'd come back and obviously then we'd get the results of that, they're phoned through, and then they would be told, 'Yes, it is a breast cancer.'

INT: AND WHAT ABOUT THOSE PATIENTS THAT DON'T GO TO THE SORT OF HALF AN HOUR ... IS IT A ONE-STOP ...?

Nurse: It is a one-stop clinic, yeah.

INT: YEAH, WHAT ABOUT THE OTHER PATIENTS WHO DON'T ATTEND THAT, IF THERE IS ANY SORT OF SUSPICION?

Nurse: You mean from a screening, a screening programme?

INT: YEAH.

Nurse: Yes, well, again, those ladies, they'll come back, they'll have a recall from the previous mammogram, perhaps have another mammogram, those films will be compared and if things are still looking suspicious then they would probably have a core biopsy, or a final needle aspiration, but we tend to be doing more core biopsies now, erm, for the fact that we can get the ER status from that. But they don't get the results that day, they have to come back the following week. But after they've had the core biopsy, obviously they're in their gown at that stage, I would take the lady out of the room, show her to the changing room, let her get dressed in her clothes, and then would take her in a little off the side of the consulting room and then the doctor would come and discuss everything with her what had gone on in the afternoon and really he would, he would, if it was looking suspicious he would kind of hint to her that this could be a small breast cancer, yes, they do if things are looking suspicious. So they would really go away with that, and they're very worried about it until they come back obviously because they've not got a true answer but they kind of do know that, you know, it could be. But they have got our contact card and, you know, quite a few of the ladies do ring us up and go through things again. Because it is very scary for the ladies when they come to these clinics and they don't always hear everything what you say ...

INT: OF COURSE.

Nurse: Very often ladies that come back to the screening clinic, before we take them in the room where the doctor will go through everything that's happened that afternoon, we do always say to them, 'Have you come with anybody this afternoon?' and if they say yes we usually do, well obviously they want to have that person is as well, but we do say, 'Would you like them to come in?' so they can hear as well what's happening and what's being said. So, you know, because the ladies do tend to sometimes forget because they're scared and they're in a panic and in that situation you don't always hear what's being said. So the ...

INT: I WANT TO MOVE ONTO QUESTION 7 NOW.

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

Nurse: well I've just said, like, that we tell them, haven't I? We give them an idea.

INT: I'M TALKING ABOUT THE ONES THAT COME BACK AND THEY ...

Nurse: Do you mean if, what, how they, do you think if they know, do you mean? Do you mean ...

INT: YEAH, I THINK IF, I SUPPOSE THE FIRST TIME THEY'VE HEARD REALLY THAT THEY'VE GOT A CANCER, DO YOU THINK THAT, I MEAN I THINK FOR THE SCREENING PATIENTS IT'LL BE QUITE A SHOCK ...

Nurse: The screening patients it's more of a shock, it is a more of a shock to the screening ladies, because they have absolutely no idea, because they haven't seen or felt anything abnormal in their breasts, whereas the symptomatic ladies, obviously they have noticed something - whether it be a lump or a dimpling or whatever - but they've actually took themselves off to the doctors because they themselves have noticed something wrong. So a lot of them, deep in their mind, have got an inkling that this could be a breast cancer, because most ladies, it's bandied about in the media and everywhere now about breast cancer, isn't it, that most people are aware of it really. So, yes, it is a shock for the ladies that come to the screening, I think much more so, and so really it's quite good in a way that they don't get the results that day because I think that would be too much to take in one day ...

INT: QUITE POSSIBLY, YEAH.

Nurse: ...to come into a clinic and not dream that you've got anything wrong, and to talk out an hour or so later being told that you've got breast cancer and that you need an operation.

INT: YEAH, IT'S QUITE A SEVEE THING, ISN'T IT?

Nurse: It is, whereas, whereas like I do, I say, the ladies that have attended the symptomatic clinic, a lot of them in their mind they do think, if they've found a lump or they do think, 'Oh, this could be a breast cancer.' So really, they're a little bit already there anyway.

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

Nurse: Erm ... well, the doctors do work in different ways, er, I mean obviously some of the consultants will be very direct and tell the ladies and others will break the news a little bit more gently. Erm, and we know, I know the way, we all know the way the consultants work, so we're prepared, you know, to work with them. We have to kind of adjust ourselves to work with the way they work. So, you know, if you've done, we do the consultants clinics all the while, so we do know their ways of working.

INT: SO YOU'LL BE WITH DIFFERENT CONSULTANT AT ANY POINT, JUST WHOEVER'S IN THE ROOM AT THE TIME, YEAH?

Nurse: Yeah, well I mean ...

INT: YOU DON'T WORK WITH A PARTICULAR CONSULTANT ALL THE TIME?

Nurse: Erm, well, we do quite a lot of the time, yes, I mean I do, there's Tuesday afternoon, I will always do the same consultant's clinic, yeah, because, you know, that is the clinic that's run on Tuesday afternoon and I work here on a Tuesday afternoon. So other clinics are run on set days, erm, so, yes, I mean, it's the screening clinic on a Monday so I do the screening clinic and work, and it's usually the same doctors that do that. Now and again we'll have a change-over because obviously the consultant is in one room but the consultant can't see all of the patients, so they do have other doctors working with them in different suites, yeah.

*Q9. HOW WOULD YOU DESCRIBE YOUR FEELINGS BEFORE SUCH A CONSULTATION, YOU KNOW, WHERE A PATIENT'S GONNA RECEIVE A DIAGNOSIS AND YOU'VE OBVIOUSLY GOT SOME INSIGHT AS TO WHAT THAT PERSON IS GOING TO HEAR? HOW WOULD YOU DESCRIBE YOUR FEELINGS BEFORE SUCH A CONSULTATION?

Nurse: Well obviously, erm, well you've got to be prepared for how the patient's gonna react, and they do all react very differently because people are different, aren't they? And I just think as long as you've got all the information correct and you've been there and obviously you've discussed with the consultant, you know before we go in, what the consultant's gonna tell that lady. Erm, so you're kind of prepared anyway because you know the news they're gonna be given. And then, you know, afterwards, we've got counselling rooms and we would take the ladies in a counselling room and spend some time there with them, asking them if they understood everything what the doctor had said, erm, and go over everything with them and answer any questions that they don't understand and, you know, just support them really through it.

INT: I'D LIKE TO MOVE ON TO ... DURING A CONSULTATION WITH A NEWLY-DIAGNOSED PATIENT ...

*Q10. CAN YOU JUST TALK ME THROUGH WHAT HAPPENS IN A CONSULTATION WHERE DIAGNOSIS AND TREATMENT OPTIONS ARE BEING DISCUSSED? SO IMAGINE, YOU KNOW, THE PATIENT'S JUST KIND OF WALKED IN, YOU KNOW, YOU'RE ALL THERE SORT OF THING, WHAT SORT OF HAPPENS NEXT? JUST TAKE ME THROUGH THAT PROCESS PLEASE.

Nurse: So do you mean where, erm ... say a screening clinic, where the lady's had the investigations the week before, they come back and they do show that a lady's got cancer, so that lady comes back for the results and it is cancer?

INT: YEAH, SHE'LL BE TOLD HER DIAGNOSIS THEN AT THAT TIME.

Nurse: She will be told her diagnosis, that's what she's come back for, yeah. Erm ... well she would, we would bring her into the consultation ... yes she'd come straight in, I'd, actually, I'd just like to say that, really with me only working Mondays and Tuesdays, I'm, I'm not very often in with the actual consultant when the patients do come back for their diagnosis. I'm not in every week with them.

INT: THAT'S FINE.

Nurse: Erm, because it's, like it's Mr Everson's [?] clinic today and he's the consultant, but I won't be doing his clinic, I'll be doing one of the other doctors. And the same at the screening clinic, I don't usually do the consultants, so the patients that have the investigations the week before and they're coming back for their results, and their results are positive, I would not very often sit in with the consultant, but I have done, but it's not ...

INT: NOT A REGULAR THING.

Nurse: every week, no, it isn't. So, erm, from my point of view I would just say that the times I have done it we would bring the patient and their partner or husband back into the consulting room and they would just sit down near the consultant and the consultant would just introduce herself because at that point the consultant may have never even met these people apart from, well, she wouldn't have done really, or he wouldn't have done. And she would just go through what happened the week before about when they came for their investigations, and then they would just really tell them that, unfortunately, it did show that this was a small breast cancer. And then, erm, it's done quite, it's not rushed, it's not done quickly, the consultant would probably stop then and just wait for the reaction of the patient, I mean very often they start crying or, but time is given for them to digest the news really. Erm, and then, after they'd got over the shock of it of whatever they said, the consultant would probably say something to them, 'Well, you know, now we know what it is and we've found out, we need to start discussing what we're going to do about it.' And so then a plan would be drawn up for, you know, well it's almost normally surgery, and so that would be discussed and options, treatment options would be discussed as well. Erm, the consultant would tell them what she thought would be the best surgical option or give them a choice, and then it would be taken from there really. And then they would be given written information by us on which surgical operation they were having, and they would be given that to take home and read. They're not always, they don't always make their mind up that week, a lot of them just want to go home and think about things and then return, you know, the next week to discuss it further, because a lot of them are obviously upset and really just want to go and get home. Erm ... usually that day as well they are sent off to do some, have some blood tests and chest x-rays. Now they are given a choice on that really, if they don't feel up to it after having that bad news, they can come back the following day or a couple of days after to have these tests done, erm, but a lot of them do say, 'No, I'll have it done today, I want to get it over with,' you know, so they'll go for the blood test and chest x-ray and maybe an ECG if they need one.

INT: SO AFTER THEY'VE RECEIVED THE DIAGNOSIS, JUST TO BACKTRACK A LITTLE BIT, IS IT ALWAYS THE CONSULTANT THAT ACTUALLY BREAKS THE BAD NEWS, SORT OF THING?

Nurse: Yeah, yes it is.

INT: AND DO YOU, HAVE YOU OBSERVED ANY SORT OF PREFERRED STYLES OR APPROACHES THAT PEOPLE HAVE DURING ACTUALLY BREAKING THE BAD NEWS? HAVE YOU GOT ONE YOURSELF, WHEN YOU'RE TALKING TO PATIENTS, YOU KNOW LIKE SORT OF, A CERTAIN APPROACH THAT YOU LIKE TO START WITH, OR WHATEVER?

Nurse: I suppose, yeah, I suppose everybody's got their different ways of talking to people, haven't they? I mean I suppose if I, if a lady's just been given a diagnosis and I take her into the counselling room, obviously she knows who I am because I would have introduced myself at a point before that, erm, and I would just probably say to her, so, I don't know what I say, what do I say? I say something like, 'Take a seat, now how are you feeling? Did you understand all what the doctor said to you?' and just take it from there really. Erm ... yeah, I mean, you do notice that surgeons have diff-, consultants have different ways of approaching it as well. Some are very direct and just straight to the point really; and others kind of, not beat about the bush, but kind of work up to it a little bit. But it just takes some people a little bit longer than others to actually hit the point, doesn't it?

INT: THAT'S FINE.

Nurse: I suppose, yeah, we've all got different ways, haven't we?

INT: WHEN YOU'RE IN CONSULTATIONS, WHO DO YOU THINK DOES MOST OF THE TALKING AND WHO TENDS TO ASK MORE OF THE QUESTIONS GENERALLY?

Nurse: The patient, the consultant, you mean the patient-consultant thing?

INT: YEAH.

Nurse: Erm ... I think ... that's hard really, because it depends what the patient's like: some people want to know everything and they've got lots of questions to ask, other people don't want to know, some people don't even want to know, they just say, 'I don't really want to know, I've got no questions, I just want you - it's been found, I just want to get on with it and do what you've got to do,' but like I suppose it depends on the level of people really. But a lot of people do want to know and have got a lot of questions to ask. So sometimes the patient will do a lot of the talking, other times they won't and the consultant'll be doing the talking. So I would say that's quite varied really depending on the patient.

INT: AND WHEN YOU ARE TALKING WITH THEM AFTERWARDS YOURSELF IN A SEPARATE ROOM ... WHO TENDS TO DO MOST OF THE TALKING AND ASK THE QUESTIONS? IS IT STILL VARIED OR DOES IT CHANGE?

Nurse: I think it is still quite varied really. Erm, I mean, obviously, if the patient is, I think you've got to go along with the patients a lot of the time because at that point when they've been given bad news, they may have lots of questions to ask but they may not be ready to ask the questions on that day.

INT: THEY MIGHTN'T KNOW THE QUESTIONS, MM.

Nurse: You know, that's right, they're still in shock really a lot of them, and so they don't, they don't feel like, they can't get their mind together, erm, and so I think you've got to judge what the patient wants at that time really. And at the end of the day they have got our contact card to phone us if they, they have, and we're gonna see them again, we're gonna be seeing them, we visits the patients pre-operatively, we visit them on the ward, and they're gonna probably be coming back the next week as well to see the consultant, so they've got plenty of further opportunity to ask the questions. So, again, it's difficulty really because I tend to go along with how I judge what the patient wants: if they want to talk and if they want to be told everything, then that's fine, we will: but I always ask them as well, I say, 'Now do you want me to go through, through this today, or would you prefer to wait until next week?' and just go along really with what they want at that time.

INT: AND IN CONSULTATIONS DO YOU SEE ANY TOOLS BEING USED, JUST THINGS LIKE X-RAYS, MAMMOGRAMS, DIAGRAMS, ANYTHING LIKE THAT, BEING USED BY THE CONSULTANTS TO EXPLAIN THE DIAGNOSIS?

Nurse: Sometimes the consultants, not very often, not very often have I seen it, they will put the x-rays up on the x-ray machine and point out and things and say, 'Look, this is where this is and ...' yeah. That's, that's all. I mean, erm, sometimes we do do open core biopsies in the consultant room so they're having that done, I mean that's to get a diagnosis.

INT: AND WHAT ABOUT YOURSELF WHEN YOU'RE ACTUALLY TALKING THE PATIENTS AFTERWARDS, DO YOU USE ANY TOOLS SUCH AS PICTURES, DIAGRAMS, PHOTOGRAPHS, WRITTEN INFORMATION, ANYTHING LIKE THAT?

Nurse: We've got written information, yes, yeah, we give them written information if they've been diagnosed, that's for them to take away. So, yeah, they'll have written information, erm, yeah, we just give them written information. We have got booklets about cancer as well which we give sometimes and that goes through the journey and it's not just about cancer it's got lots of other information about outpatients and the whole journey of what will happen. Yeah, we give them that as well.

INT: SO THAT, OF THOSE THINGS, WHICH DO YOU THINK PATIENTS FIND THE MOST HELPFUL? DO THINK THERE'S ANYTHING THEY PARTICULARLY FIND HELPFUL AND WHY DO THEY FIND IT HELPFUL?

Nurse: Well obviously they find the written information helpful because they can take it home and read when they're ready to read it, you know, when their mind is more settled and they've accepted the news and their mind's clearer, so they can read it and they, it does give them a description of what's going to happen with their operation. Just ... it's only a brief description really but it does inform them of what is gonna happen. I also think the contact card which we give them is quite helpful because they don't feel so alone: they know that we are there at the end of a phone, you know, if they've got any problems, and very often they do phone up and are crying and upset, and I do think, I do think that's good, that contact card, because I do think we're there if they need us. And we do make, we do point that out, we don't just say, 'Here's a contact card,' we do go through it and tell them that, you know, that's what we're here for, if they've got any problems or further questions, do phone us, use the contact card because it's out contact between them and us really.

INT: YEAH. WE TALKED A BIT ABOUT YOUR FEELINGS AFTER THE MDT AND BEFORE YOU GOING INTO A CONSULTATION, AND KIND OF GONE THROUGH THE CONSULTATION PROCESS NOW TO THE POINT WHERE YOU'VE SPOKE TO THE PATIENT AND THEY'VE NOW GONE, WHAT ARE YOUR FEELINGS AFTER SUCH A CONSULTATION WHEN BAD NEWS HAS BEEN BROKEN TO THEM ETC?

Nurse: Well, I think sometimes you can be, you can feel a bit drained actually at the end of the day.

INT: EMOTIONALLY.

Nurse: Yeah, you can. You can, because it's not nice to be with people that are being given bad news obviously, and, you know, depending which, how people react, it does have an effect on you as well. And I think also people circumstances as well can have an affect on you, you know, maybe, I know age doesn't come into it, but if you've, you know, if you've diagnosed, you've been with a youngish person that's been diagnosed that day that's got little children, and you know be told that she's got breast cancer, that can hit you probably, sometimes, not always, more, you know, than an elderly person really, just because of life circumstances, and, you know, you just think, 'Life's unfair really to some people more than others.'

INT: IT'S THE SAME SORT OF THING WHEN YOU INTERVIEW PEOPLE, PATIENTS, YOU KNOW, BECAUSE YOU DO GET TO ASK THEM A LOT OF IN-DEPTH QUESTIONS AND YOU DO GET TO KNOW [???] OVER A COUPLE OF HOURS REALLY, AND YOU KNOW YOU LEAVE AT THE END OF DAY AND YOU THINK, YOU GET HOME AND YOU THINK, YOU THINK, 'WHY AM I LIKE THAT?' YOU KNOW, I HAVEN'T DONE ANYTHING APART FROM ASK PEOPLE BUT OF COURSE IT'S THE EMOTIONAL THING.

Nurse: It is, it is.

INT: YOU'RE JUST THERE WITH THAT PERSON ALL THE TIME AND, YOU KNOW, TRYING TO UNDERSTAND AND AT THE SAME TIME TRYING TO DO A JOB. IT'S QUITE DIFFICULTY [???]

Nurse: It is, it is very draining actually, yeah.

*Q11. CAN YOU TELL ME ABOUT ANY ADDITIIONAL TIME THAT YOU USUALLY HAVE WITH A PATIENT AFTER THE PART OF THE CONSULTATION WHERE THE DOCTOR'S BEEN PRESENT? YOU'VE SPOKEN TO THEM AND THEY'VE GONE HOME, WHAT KIND OF CONTACT DO YOU HAVE WITH THEM AFTER THEN, BECAUE YOU CAN HAVE A UNIQUE HEAD HERE, HAVEN'T YOU BECAUSE YOU'RE GOING TO SEE SOME OF THESE PEOPLE ON THE WARD AS WELL, AREN'T YOU?

Nurse: I am, yes [chuckles] I am.

INT: SO TELL ME A BIT ABOUT THAT.

Nurse: Right, well, obviously, if they don't use the contact card and don't phone us up the next point of contact will be when they are admitted for their surgery, unless they come back the following week. If they're diagnosed one week, sometimes they do come back so we do see them again, but not always. So the next point of contact, unless, as I say, unless they phone us, would be when they are admitted to the ward, which is usually the day before their operation. And we would go and see them, we'd make a point of seeing the ladies before they go down for their operation, and we spend time with them, we give them, if they're having nodes taken away we give them an arm exercise leaflet because they need to do arm exercise post-operatively. So we go through that with them, and we'd also just ask them if there's any more questions, do they understand everything what's happening, are there any more questions that they want to ask, is there anything they don't understand, so that would be the next point of contact with them a lot of the time, yeah.

INT: SO WHEN YOU SEE THEM, AND I'M THINKING NOW ... SORRY WERE YOU GOING TO SAY SOKMETHING?

Nurse: No I wasn't, no.

INT: OK, YOU KNOW WHEN YOU SEE THEM OUT OF CIVVIES, OUT OF CIVVIES, IN YOUR UNIFORM SORT OF THING, HOW DOES THAT GO THEN?

Nurse: Do you mean when I see them down here, do you mean when I've my uniform on ...

INT: YEAH, WHEN YOU'RE ON THE WARD, YOU SAY ...

Nurse: Oh, when I'm on the ward and I'm in my uniform?

INT: YEAH, HOW DOES THAT GO?

Nurse: It goes very well actually. Yeah, it does, because when I first started working as a breast care nurse and had this like dual role, I thought, 'I don't know whether this is really gonna work or not' because it's like having two heads in one way: I know it's all under the same umbrella of breast cancer but it's very different working in the clinic to working on the ward, very different. And I was quite unsure of it at the beginning. But it's worked very well and it's got a lot, it's got far more advantages than disadvantages really.

INT: SUCH AS?

Nurse: Such as the way, for the patients, and I can, I tell the nurses a lot of what happens down here and so a lot of things that they don't understand about how patients' diagnoses are reached and, you know, I can go through that with them. I've also, I did develop a booklet about the breast care clinic and all

what happens, so it goes through everything and that's on the ward for them to read. Erm, it's about diagnosis and FNAs and follow-up clinics and what happens in a screening clinic, what happens in a symptomatic clinic, how the patients reach hospital, because really when you work on the ward you don't know any of that. I know when I worked on the ward I often used to think, 'Well how did they get to that stage?' Or 'How did ...' you know, [???] and ER positive status, and all things like that, you don't really know, and why some ladies are started on Tamoxafen and not others, and lots and lots of things really. So I did make a booklet which I think has been quite useful to a lot of them up there. So, yes, it's worked, I feel it's worked quite well really, yeah.

INT: HAVE YOU GOT A COPY OF THAT BOOKLET I COULD HAVE LOOK AT?

Nurse: Yes, it's up on the ward, yeah.

INT: CAN I GET A COPY OF SOME KIND? CAN I HAVE A COPY? IS IT POSSIBLE TO HAVE A COPY?

Nurse: Erm, well it's got quite a lot of pages in, it's not. When are you coming back to the hospital?

INT: TOMORROW.

Nurse: I'm off tomorrow.

INT: WELL I'LL BE BACK PROBABLY NEXT WEEK AT SOME POINT.

Nurse: I'll get it from, I'll get it from the ward, I'm working on the ward on Friday, I'll bring it home with me and I'll bring it down to the clinic on Monday.

INT: YEAH, IS THAT ALL RIGHT?

Nurse: I'm not on next Monday, I'll bring it on Tuesday.

INT: YEAH, OK.

Nurse: Yeah, I'll bring it on Tuesday for you.

INT: YEAH, I SUPPOSE I WAS GOING TO ASK YOU TWO THINGS ABOUT THIS, WAS THE PATIENTS THEMSELVES, YOU'VE TOLD ME YOUR PERSPECTIVE OF SEEING THE PATIENTS, HOW DO THEY REACT TO YOU, YOU KNOW, IF THEY KNOW YOU FROM THIS CLINIC HERE, THEN THEY SEE YOU IN A UNIFORM AND THAT LIKE, DO THEY REACT DIFFERENTLY TO YOU THERE?

Nurse: Mm, I don't know that they react differently, sometimes they seem a bit confused about, 'I know your face but where do I know you from?' because you do look different when you're in a uniform to when you're in your clothes. A lot of them say, 'Oh, I remember you from clinic, you were with me when I was diagnosed, and, oh, it is nice to see you again,' so, yeah, I think most of them ... are glad to see a face that they've already met because it's quite traumatic, because that's the big part of them, isn't it, when they enter the ward and they're going for their operation, it's the build-up, isn't it, from when they've first been diagnosed, the build-up is to them getting into hospital for their operation? So it's quite daunting for them to walk on the ward. So it is quite nice when she see me because I've already met them before, and so I'm familiar to them. And so, yeah, they like that. I do tend, I do tend to keep my roles quite separate, erm, when I'm, as a breast care nurse when we go up on the ward to visit the patients they see us in a different role then because they see us that we've got time for them, maybe 5 or 10 minutes we'll spend with the ladies each day, but they know that that time is for them alone, because we're

not a nurse on the ward and we're not answering telephones and there's not other patients calling us or visitors asking us questions or doctors wanting us. So when they see a breast care, breast care nurse walk on the ward and we go to them, they know that they've got us for that 5 or 10 minutes because we're not going to be called off because we've got not a nurse's uniform on, we're not going to be answering telephones. But obviously when you're a nurse on the ward it's very different because you've got to give a bit of yourself to the whole of the ward really, erm, and everybody else, and patients and doctors and everybody. So I do, I do keep the roles quite separate. I don't, if I'm on the ward I'm on the ward as a ward nurse.

INT: DO YOU FIND THEY ASK, DO THEY ASK YOU QUESTIONS, SAY, 'OH YES, YOU KNOW, YOU WERE WITH ME WHEN I WAS DIAGNOSED BLAH-BLAH-BLAH,' ASKING YOU QUESTIONS?

Nurse: No, not, not very often. Because really by that time I think they're very well informed the ladies that come here, so you know I do think by the time it comes for their operation they do understand what's going on, because they have been well-informed really. I mean obviously they will ask you the odd thing, yeah, I'll, I'll go through it with them. And obviously if, if the breast care nurses have not been - say a lady was being discharged that day and the breast care nurses, for some reason they've not had a visit from the breast care nurse, now the day before discharge, we go through and also give them another leaflet called, a seroma leaflet, because - I don't know whether you know anything about seromas, but it's the build-up of fluid that ladies can get on discharge from hospital when they've had their drains taken out. Not all ladies'll get it but some will, so we give them all, all ladies that have nodes taken out, we give them all - and a mastectomy as well - we give them a leaflet saying that they may have a collection of fluid and if they do get one they need to know what to do about it, so we give them a leaflet with phone numbers on and telling them why they might get a collection, what it's about, and if they get it what to do about it. So they all go home with that. But if a breast care nurse has not been up on the ward and it just happens occasionally that the lady's being discharged that day but she's not got a leaflet, then obviously I would give them a leaflet, I'd make sure and say, 'Have you got your seroma leaflet?' I mean, but then again the other ward nurses would as well, you know, make sure that they've got everything what they need to have before they go. So, yeah, I do tend to keep the roles separate but they are kind of combined as well, if you know what I mean.

INT: YEAH, THAT'S INTERESTING THAT BECAUSE, AS I SAY, IT'S QUITE UNIQUE [???] I'D LIKE TO MOVE ON TO QUESTION 12 NOW, STARTING PATIENTS' INFORMATION NEEDS.

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

Nurse: Oh gosh. Well, again that depends, doesn't it? A lot of ladies, erm, will go on, they use the internet a lot, don't they? They read it in the mass media. A lot of people know people that have had breast cancer and will get an awful lot of information from them - whether it's the right or wrong information - but they will so they'll think they know a lot and what the options are from other people, but, you know, it's not always the right, the right way to go about getting the information. And then other ladies'll be quite naïve about breast cancer, they won't really know an awful lot about it. I suppose really, I suppose it's maybe the older ladies that would tend to not know so much about it, about ... they know breast cancer, but they wouldn't about the treatment and the options so much as younger ladies, I wouldn't think, because they wouldn't be so computer-literate, older people, they don't go on the internet as much and find out. Whereas somebody that was like that, they'd just be searching the, searching the internet for treatments and different options, and so they'd know a lot about it when they came. But not everybody would. It just depends. And it

depends, like I say, from other people as well, it depends if they've known anybody that's had breast cancer, or what they read in the papers or ...

INT: DOES A PATIENT'S LEVEL OF KNOWLEDGE ABOUT CANCER AND ITS TREATMENT OPTIONS, BREAST CANCER AND ITS TREATMENT OPTIONS, DOES IT SORT OF MAKE FOR A HARDER OR AN EASIER CONSULTATION PROCESS, DO YOU THINK? IF YOU GET SOMEBODY WHO'S GOT A LOT OF INFORMATION ...

Nurse: Yeah, well it can be harder I suppose really, because ...

INT: IF THEY'VE GOT A LOT OF INFORMATION?

Nurse: Yeah, yes it can.

INT: IN WHAT WAY?

Nurse: ... not harder, but they'll kind of go through everything with you and expect, sometimes you can't answer everything with breast cancer, you know, sometimes things are not so black and white but I think patients tend to think that they are, and so it can be harder that way that they've come with all this information what they've gathered and so they think the information they've gathered, it's got to be this or this or this and, you know, it's all black or white, and it's not always like that. So that's, that's quite hard really. But then, I suppose, it's hard in the other way that a lady that's quite ignorant and has not got any knowledge about it, it's hard to make her understand all the different things about breast cancer and the variations of it. So it's quite hard in both ways I suppose for people that have got a lot of knowledge or a little knowledge, it can be just as difficult one way or the other really.

INT: DO YOU THINK INCORRECT KNOWLEDGE IS THE WORST CULPRIT [??]

Nurse: Well I do, yeah, yeah. Yeah, it is, and some people do have incorrect knowledge, and a lot of time it's from other people I find. Well, not a lot, but sometimes it is, you know, because like ladies have said, 'Oh my friend had breast cancer and she's had this done and she's had that done, and she'll say to me, "Now you'll have this and you'll have that,"' but they don't realise, you know, just because they've got breast cancer, they think it's all the same, but,

INT: IS ISN'T, IS IT?

Nurse: Yes, not at all, you know, and so it's difficult to say, but your friend, your friend's position may be totally different to your position, but they can't kind of see that, and you don't know what their friend's position was or, you know, all right you might know she's got breast cancer but there's a lot more to it than just saying 'breast cancer'.

INT: YEAH.

Nurse: So, yeah, it is difficult really.

*Q13. WHAT DO YOU THINK ARE THE MOST IMPORTANT PIECES OF INFORMATION PATIENTS NEED OR WANT TO KNOW ABOUT THEIR DIAGNOSIS AND WHEN DO THEY GENERAL RAISE THOSE PIECES OF INFORMATION?

Nurse: Erm ... a lot of times when they're diagnosed they want to know the information if they're in that frame of mind, but if they're not they'll raise a lot of issues sometimes on the ward after their operation, a lot of the ladies will. It's usually after their operation they're moving further down the line then, they've got their operation over with, and they're moving further towards the results and things like that, and so ... it is about, yeah, it's about the

surgery really and what's gonna happen to them and ... and the written information, it's just a whole lot of things really what they want to know. Sometimes they travel too much down the line.

INT: YOU MEAN AHEAD OF THEMSELVES, YEAH?

Nurse: A lot of ladies are awfully head of theirselves, they want, you know, and I tend to say to them, you know, 'You've got to take one hurdle at a time really' because if you don't it's a bit too much to handle, you know, because from diagnosis you've got to, you've had your diagnosis, now your next hurdle really is your operation, but you've got to give yourself chance to get over your operation and don't, you know, don't travel any further down the line until you've got over that really, because you don't really know what your further treatment is until you get your results.' So, you know, 'Don't let your mind play overtime and go that way because, you know, you won't, your mind can't cope with it if you do.' So I tend to try and let them just go slowly and a bit at a time really, because they need time after their operation just to get over their operation, you know, and feel, start feeling all right again.

INT: AND A SIMILAR SORT OF QUESTION HERE

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

Nurse: ... Well the treatment, the treatment being surgical treatment do you mean?

INT: MM.

Nurse: Well obviously they want to know that, that's important, they've obviously got to know that before the operation because the treatment options are discussed obviously before then. Erm, so that's the most important really I think, you know, do they need a mastectomy or a wide excision or what. So that's before the diagnosis. So I'd say, mainly the treatment, yeah, and it's discussed obviously before diagnosis because they've got to know what operation they're having.

INT: SO, THE KIND OF, THE TYPE OF TREATMENT THEY'RE ACTUALLY GOING TO END UP, YEAH, WHETHER IT'S GOING TO BE A MASTECTOMY, BREAST CONSERVATION?

Nurse: That's right, yeah, yeah.

INT: DO YOU THINK WHEN YOU TALK TO PATIENTS, OR WHEN YOU HEAR PATIENTS TALKING TO THE CONSULTANT ABOUT THINGS LIKE DIAGNOSIS AND TREATMENT OPTIONS, DO YOU THINK THERE'S ANY INFORMATION WHICH SEEMS TO JUST SINK IN VERY QUICKLY TO THEM YOU KNOW, THEY SEEM TO UNDERSTAND IT VERY WELL, THEY DON'T NEED TO, THEY DON'T NEED TO RECAP ANYTHING? THEY KNOW WHAT YOU'RE SAYING AND THAT? IT'S A DIFFICULT A QUESTION TO ANSWER THAT BECAUSE YOU DON'T, YOU TEND TO NOTICE MORE INFORMATION THAT PEOPLE DON'T UNDERSTAND, RIGHT? IF THEY'RE UNDERSTOOD IF YOU TEND JUST TO FORGET ABOUT IT BECAUSE YOU THINK THAT'S GONE IN. I JUST WONDERED IF YOU HAPPENED TO NOTICE ANYTHING, INFORMATION THAT, SOMETHING YOU SAY TO SOMEBODY AND THEY JUST, YEAH, IT'S JUST CLICKED, I KNOW THEY'VE GOT THAT.

Nurse: Mm ... yeah, it is difficult really. Yeah, I can't really think of anything at the moment off the cuff.

INT: IS THERE ANY INFORMATION YOU THINK IS PARTICULARLY UNDERSTOOD POORLY?

Nurse: By some people, yes, I think they don't, when we go through their operation and we explain to them that they'll have drains in and the length of

stay and why they've got to stay in that long, and about the node surgery ... there is an awful lot of information that we give them. And I do think there is some of it that they don't understand. I think the main thing, I suppose the main with a lady is, I think is, a big thing is ... if it's a mastectomy ... then I think that is more traumatic for a lady, if she's having a mastectomy, than a wide excision, because I suppose, because every day she's gonna be looking down and seeing that she's got no breast, so it's a constant reminder of what she's had, whereas a lady that's had a wide excision, sometimes it's a brilliant scar and hardly noticeable, and there's no deficit in the breast as well. So that lady can quite forget, can't she, whether she's had it or not. But ...

INT: DO YOU THINK THAT, DO PATIENTS UNDERSTAND THE FACT THEY'VE GOT CHOICE VERY WELL?

Nurse: Yes. Yeah, they do. Yeah, they do. I mean a lot of times they don't have a choice, they don't all, you know, yeah there are a lot of times they don't have a choice.

INT: OK. I'D LIKE TO MOVE ON NOW TO WHAT A PATIENT IS OFFERED. DO YOU WANT A DRINK OF ANYTHING OR ...

Nurse: Well, do you?

INT: I'M ALL RIGHT, BUT IF YOU WANT A DRINK OR SOMETHING, COFFEE OR SOMETHING ...

Nurse: Yeah, I think I will. Switch it off and I'll go and make one. How long have we been talking?

INT: AN HOUR.

Nurse: We never have, have we really?

INT: YEAH.

Nurse: An hour? I can't believe that. Do you want a drink?

INT: YEAH, GO ON, I'LL HAVE A CUP OF COFFEE ...

[Interruption in recording]

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

*a. ONLY BREAST CONSERVATION SURGERY

Nurse: Only breast conservation?

INT: ONLY BREAST CONSERVATION SURGERY.

Nurse: The factors?

INT: MM, YEAH.

Nurse: Well, the factors would be, erm, the size, the size of the lump according to the size of their breasts, where it was in the breast, er, what the patients wanted ... what else?

*b. WHAT FACTORS WOULD LEAD YOUR TEAM TO OFFER A PATIENT ONLY A MASTECTOMY?

Nurse: Only a mastectomy?

INT: MM.

Nurse: Oh, obviously, if the consultant thought, sometimes ladies that have DCIS, which is ductal carcinoma in situ, which is really what we would class as pre-cancer cells, sometimes those ladies need a mastectomy which is hard for the ladies to get their head round really because in one breath they're being told by the consultant that they haven't got a cancer, they've got a pre-cancer condition, but then in the next breath they'll tell them 'But you need a mastectomy because it's multi-focal,' and so, you know, sometimes those ladies need a mastectomy. Also they would advocate a mastectomy obviously if it was a very large lump in small breasts because they would explain to the ladies that that is what they needed for safety's sake, and also because of the deformity that they would have in their breast after it was taken away. Also if it's, if it's quite central to the nipple as well, and that's again, it's quite deformities breast really. And the size of, the size of the lump, maybe what kind of cancer they thought it was. Sometimes if the consultant did think that a lady needed a mastectomy because the lump was so large, sometimes if a lady really didn't want a mastectomy, sometimes they, or they do try, they do give chemotherapy first as an adjuvant treatment to bring the size of the lump down and that would enable them to sometimes do breast conservation. Er ... but, yes, I can't think of anything else offhand at the moment. They're the main reasons that I can think of.

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

Nurse: Again, where ... erm, a lot of ladies, some ladies don't have a choice in what they can have obviously, some ladies are given, all ladies are given a choi-, all ladi-, I mean, it's difficult but ladies, lots of times the consultant'll say to the patient, 'Right, well, you know, your lump's only so big and it's situation there and, yes, erm, we can do a wide excision, we can just remove that part of the tissue and, you know, it'll just be that part of the tissue that's removed.' Sometimes the ladies, 'Or you can have your breast removed if you would feel, if you would feel safer,' and so sometimes the ladies, even though they don't need to have a mastectomy, one or two ladies would have a mastectomy even if the consultant said that, 'Yes, breast conservation would be all right with just removing the tissue,' but they would feel safer with a mastectomy because in their mind the whole thing's gone then. Er ... I mean if ladies have a wide excision, which is just the lump removed, they also see, as the completeness of treatment to have radiotherapy a an after-treatment. For some ladies, one or two, not often, but some ladies don't want to go through that radiotherapy as well, so, and if they have a mastectomy they don't need radiotherapy as well - one or two will, depending on what the results are, but, you know, normally if you have a mastectomy you don't need radiotherapy. So, what was the question, why did you ...?

INT: WHAT SORT OF FACTORS LEAD THE TEAM TO OFFER A PATIENT A CHOICE BETWEEN MASTECTOMY AND BREAST CONSERVATION?

Nurse: Again, it's the position, the size of the lady's breast, patient's preference ... size of the lump, things like that really, a variety of things but, you know, patient's preference does come into it, if they can have it, the choice.

*d. OTHER TREATMENTS [NOT ASKED]
Here

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

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

Nurse: Yes. I do. It's al-, well, they're not always given a choice because some patients need a mastectomy to control the disease, so it's obviously not what they choose, it wouldn't be their choice, but it's really a necessity because of the degree of where it is or, you know, what they've got. So, but I do think on the whole they do. I mean sometimes ladies, the consultant does go along with saying, you know, I think it would be, for safety's sake I think it would be better if you had a mastectomy, and I suppose there are one or two ladies that really don't want a mastectomy. But they understand they implications if they have a wide excision that, following a wide excision, they've got to have clear margins and, you know, if those margins are not clear, then they've got to have more surgery, and that'll be another factor. I should have said this earlier, but that's also another factor in they are told that, that if, you know, if ladies are having just a wide excision, they do understand about the clear margins, very much so, before that decision is made. That they do understand that there is always a possibility that, if there's not a clear margin round that tissue what's removed, that they will need further surgery. And there's no way they can tell whether the margin's are clear until that tissue goes up to the pathology lab.

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

Nurse: Well I think the patient does really.

INT: IS THAT NUMBER ONE OR TWO? SORRY, THE TOP TWO, WHICH ONE?

Nurse: ... Well when you say, 'After considering my opinion,' you're talking about the doctor here aren't you?'

INT: WELL, YEAH, THE SPECIALIST'S OPINION.

Nurse: Yeah. ... Well I think number two. Yeah, I do, because they do seriously consider what the consultant's got to say, and they do take their advice, but they do make the final decision, but, yeah, it is after, obviously after lots of discussion with the consultant. Yeah.

INT: I'D LIKE TO TALK A LITTLE BIT ABOUT COMMUNICATING WITH PATIENTS WHO HGAVE BREAST CANCER NOW. AT THIS POINT I'D LIKE YOU TO TALK ABOUT YOUR EXPERIENCES COMMUNICATING WITH PATIENTS AND IN PARTICULAR I'D LIKE US TO FOCUS ON PATIENTS IN WHOM, FOR CLINICAL REASONS, MASTECTOMY IS NOT THE ONLY OPTION. OK? RESEARCH HAS IDENTIFIED THAT PATIENTS WITH BREAST CANCER TEND TO FALL IN ONE OF THREE DIFFERENCE DECISION MAKING CATEGORIE: THESE ARE ACTIVE, COLLABORATIVE AND PASSIVE. AND IN THIS SECTION OF THE INTERVIEW I'D LIKE TO ASK YOU A FEW QUESTIONS ABOUT HOW YOU FIND COMMUNICATING WITH THESE TYPES OF PATIENTS DURING THE CONSULTATION PROCESS THAT LEADS TO A FINAL TREATMENT DECISION. I'D LIKE TO START WITH SITUATIONS WITH ACTIVE DECISIONS, AND FOR THE PURPOSES OF THE STUDY WE DEFINE ACTIVE DECISION MAKERS AS PATIENTS WHO TEND TO MAKE THEIR OWN FINAL TREATMENT DECISIONS, EITHER WITH OR WITHOUT SERIOUSLY CONSIDERING THEIR SPECIALIST'S OPINION.

*Q18. FIRSTLY, I'D LIKE YOU TO THINK ABOUT A SITUATION YOU HAVE HAD WITH A PATIENT WHO WAS ACTIVE ACCORDING TO THAT DEFINITION ABOUT MAKING DECISIONS, AND WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, CAN YOU PLEASE TELL ME ABOUT YOUR EXPERIENCE WITH THEM UP TO THE POINT WHEN THEY MADE A DECISION WHAT TREATMENT TO HAVE. DO YOU HAVE AN IDEA OF A PATIENT IN MIND THAT WAS QUITE ACTIVE?

Nurse: I have, yeah, I have, yes.

INT: OK, IF YOU COULD JUST SORT OF TELL ME ABOUT THEM ...

Nurse: OK, this lady was one that I dealt with, I think it was probably, it was the end of last year. She was a symptomatic lady and she was 40 years of age. She'd got a strong family history of breast cancer, she'd got two sisters who'd both had breast cancer and they were aged 34 and 36. They were both still well and alive. So, this particularly lady who I saw, she had been attending the family history clinic here because of her family connections with breast cancer. She presented with quite a sizeable lump in a small breast and so the consultant felt that a mastectomy would be best but he was prepared to do a wide local excision if she strongly, if that's what she strongly wanted. She didn't want a mastectomy. So she was, her husband was present with her and he was quite supportive, well he seemed very supportive: I think she'd got two children, I can't remember how old they were, I know she'd got a daughter as well. But she was really, did not want a mastectomy. So after she was diagnosed and had a long discussion with the consultant, she went away very upset and really was most undecided: gave her the written information on both. Came back the following week, still very undecided, couldn't make her mind up, so she had two further visits to discuss, and the consultant pointed out that the reasons he thought mastectomy would be best was because (1) it would reduce further risk if she had a mastectomy, and also, because of the strong family connection, it would be better. She didn't want further surgery and she was told that if she had a wide excision, no clear margins, it would be further surgery. She was quite strongly opposed to coming back into hospital to have further surgery. Although she knew it may not happen she knew there was a chance that it may. Erm, and also he did tell her that, because of the size of breast and the size of the lump, she would have quite a deficit in that breast. So she knew, she knew all the reasons why he steered her towards a mastectomy, but she did, she did struggle to make a decision. But in the end she did make a decision and she did have a mastectomy. So I thought she was quite active in what she wanted really. She didn't go along with him, with what he thought best: all right, she did in the end but it took her a long while to think about it and, you know, to consider everything, and at the end of the day I suppose he would have still done, he would have done a wide excision if she'd have wanted it, but it was a grade three and I think there were, I think there was one node involved. Er ... she did go on to have chemotherapy and I forget whether she had radiotherapy or not, she may have done, even with a mastectomy, but she certainly had chemotherapy. So she probably, she made the right decision really as well, but I classed her as being active in her decision really.

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

Nurse: Very well, yeah, she was a nice lady. Knew what she wanted. She's got a younger sister as well, er, and obviously she was worried about her younger sister: she'd also worried about her daughter, erm, because that was three of the sisters out of the four that had developed cancer at a young age really, well, yeah, all three of them were young. So, but, yeah, got on very well with her. I've seen her since and she's coping very well.

INT: WAS THERE ANY OTHER INFLUENCES OUTSIDE OF THE CONSULTATION THAT WAS APPARENT?

Nurse: Well, yes, I mean, she'd had long discussions with her sisters as well as she did talk, I don't really know what was said, but obviously they'd been down that path. And to be quite honest I don't think that either of those had had a mastectomy, I think they'd both had wide excisions. So, yes, she'd had long discussions with them, so, you know, they'd been quite involved, involved with her as well, because I think they were a close family anyway. Yeah.

INT: LOOKING BACK NOW, HOW SATISFIED DO YOU THINK YOU ARE WITH THE EXPERIENCE OF THAT CONSULTATION, THE OUTCOME?

Nurse: Erm, well I felt we were there for her, you know, when she came back for, we were always there, we were always willing to spend time with her, and she did take a long time to make her mind up. I mean I can remember going into the counselling room with her and maybe spending, we'd be there for half an hour, with her husband as well, and there were tears, she was crying, and he more or less said, 'She finds it so difficult to make a decision that, really, we ought to push her into making one,' but I mean that didn't happen. She did make her own mind up at the end of the day. Yeah, I think she was, once she'd made her mind up, she felt better. I mean she was fine when she came on the ward. Yeah, I think once she'd made that decision, it took a long while to make it, but once she'd made it she could cope with things from then on.

INT: AND HOW SATISFIED DO YOU THINK SHE WAS WITH THE SITUATION AND THE OUTCOME OF THE CONSULTATION ETC?

Nurse: I think she was satisfied with it, yeah, I do. Mr Everson spent a long while with her, he never pushed her into anything, yeah. He never, you know, never steered, he told her what, he told her why he thought a mastectomy would be best, but then you've got to give people your opinions, haven't you, I mean he is the consultant. But you never, ever, never pushed her directly into making a decision at all, it was always left to her.

INT: WHEN YOU FIRST MEET A PATIENT, YOU KNOW, IN THAT CONSULTATION ROOM, HOW SOON DOES IT TAKE YOU TO REALISE IF THEY'RE AN ACTIVE DECISION MAKERS OR NOT? I KNOW YOU PERHAPS DON'T THINK OF THEM AS AN ACTIVE DECISION MAKER, BUT, YOU KNOW, HOW SOON DO YOU REALISE THAT THIS PERSON ...

Nurse: Quite soon, yeah.

INT: AND WHAT'S THE GIVEAWAY DO YOU THINK THAT HIGHLIGHTS IT?

Nurse: By the way she presents herself, by the way, when she's given the diagnosis, the questions she asked. Just things like that really. You could just tell that she was quite, she wasn't strong because she crumpled and, you know, went to pieces, but she was strong in other ways about she knew what she wanted and what she didn't want. And you could really tell, there was like a stubborn streak in her, I suppose, of, you know, having her way and she would not be pushed into it. And you could just tell from ...

INT: SHE WAS QUITE WEAK SORT OF EMOTIONALLY BUT STRONG MENTALLY ...?

Nurse: Yeah, she was, she was, yeah, quite determined. And it did come through that she was like that, that she wouldn't be pushed although it was a traumatic time - she needed time, she needed that time to know that she was making the right decision. And I suppose, like, she'd had a lot to do with breast cancer, hadn't she, as well, because it had been in her family? So ...so, you know, she'd dealt with it with her sisters really, so it wasn't an actual new thing to her, but to happen to you, I think, it was traumatic, yeah. Yeah, she was strong.

INT: DO YOU THINK THAT ONCE YOU REALISE A PERSON IS A PARTICULAR TYPE OF DECISION MAKER, DO YOU THINK IT SHAPES HOW YOU APPROACH THAT PERSON OR CONSULT WITH THAT PERSON?

Nurse: Probably, yeah, it does. Well I suppose you've just to go with them, you've still got to be there for the advice and just react, you know, to how they feel, you know, as long as you're giving them the right information, as long as they understand what's going on ...

INT: SO WHEN YOU KNOW YOU'VE GOT A PARTICULARLY ACTIVE PERSON, HOW WOULD YOU SORT OF, YOU KNOW, WHAT WOULD BE GOING THROUGH YOUR MIND, HOW DO I DEAL WITH PATIENT? SORT OF THING.

Nurse: Well it would really because at the end of the day she has got, they have got to make their mind up. But the choice, you know, as long as they've got informed, as long as they're informed, it is their body, you know, so they have got all the rights in the world to make their own decision, be it the right or wrong one really I suppose. So, you've got to be quite strong with them, I think, you can't, you know, because you are working with them, so you know you can't just sit back and you be the passive one and let them, just because they are active, you've also got to be active in what you believe, although you're not pushing them, you've still got to be active in your knowledge and feed them that, you know, what you know, although you're not, you're not making the decision, and I wouldn't dream of making anybody decision, but ... yeah, it's hard really.

INT: I'D LIKE TO MOVE ON AND LET YOU THINK ABOUT A SITUATIONX WITH COLLABORATIVE DECISION MAKERS, PATIENTS WHO TEND TO SHARE FINAL TREATMENT DECISION RESPONSIBILITIES WITH THEIR SPECIALISTS.

*Q19. AGAIN, WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, CANTELL ME ABOUT AN EXPERIENCE YOU'VE HAD WITH SOMEONE WHO WAS QUITE COLLABORATIVE?

Nurse: Yeah, I've thought of one. It's not, it's not actually a straightforward one really but, erm, it was one that came to mind so I thought I'd use it. It's a lady who, she's 75 years of age actually, and she was diagnosed with breast cancer in 2001. Because, actually I think she may be a bit older than 75 now, because of her age, very often the ladies are commenced on Tamoxafen and kept a close eye on and that will often control the disease in elderly people. That happened with this lady. She was commenced on Tamoxafen, seen regularly in the clinic, clinically the lump didn't really shrink down a lot but didn't get any bigger, so it kind of stayed stable. So, because it wasn't reducing in size, they switched her medication to [???] so she was on [???] for two years, but came back to clinic every few months, clinically examined, ultrasound or whatever every so often, and she came back to follow-up clinic a little while ago, not too long ago, and the lump was getting bigger. So [???] wasn't working either, so she'd had Tamoxafen and [???] so the time came that really surgery ought to be considered now because that was the next best thing. So she was offered a mastectomy or a wide excision and she was very undecided as well, erm, but I, I would say she was collaborative because she went along with what the doctor said, yes, you know, what he thought was best, and there were things which she considered as well. She was, obviously the clear margins were a big concern because she didn't want further surgery and she did keep going back to that, and she really wanted us to tell her, you know, that the margins would be clear, [chuckles] but you can't, you can't do that. Also she disliked the thought of having radiotherapy, she didn't want to spend five weeks going down to the Royal every day, I think maybe they've got transport problems, and so that was another consideration as well. And also her age, because she was like heading towards 80, if she needed further surgery and another anaesthetic, that's another thing that she didn't really want. So she did consider those

things, but in the end I think she still kind of put it in his hands and she had a mastectomy. So, but I would, she was quite collaborative about it - undecided but in the end went along, after some thoughts of her own about what I've just said, but went along and agreed with the surgeon that, yeah.

INT: HOW DID YOU GET ON WITH THE PATIENT?

Nurse: OK. Yeah, she had her husband with her as well. She was really quite, very very upset when she was told that she needed surgery, and yet before, I mean she'd been, she'd had breast cancer for maybe, nearly, it must have been three years I would think, and she'd questioned when she was first diagnosed why she wasn't having surgery. Erm, 'Ooh, why am I not having surgery and lots of other ladies do?' but then when it, when that, the medication didn't work and she needed surgery, she kind of turned the tables a bit and said that she didn't really want surgery, why did she have to have surgery, but I suppose she was a few years older then and she, I suppose, she never really thought that it would get to her having surgery. But she was nice, she was tearful, she was shocked, she was shocked that she needed surgery. Yeah.

INT: SO OUTSIDE OF THE UNIT, WHAT SORT OF INFLUENCES DO YOU THINK WERE APPARENT?

Nurse: I don't know really. I don't, I don't think she had many influences outside. Erm, she was quite elderly so she was quite, quite naive in a way. I don't think she'd have, I don't she'd have been the type of person to try and find out news from the internet on up to date treatments and options. I don't think she would have been that type of person and, as I say, she did, she did attend the clinic and was kept an eye on quite closely because she was on medication for the cancer, and so I, you know, she just, I think she felt the lump a lot herself and she was always asked when she came back did she think it was getting any bigger or smaller, you know, so she was quite involved really. But I don't think she maybe had much influence from outside, not that I can think of anyway.

INT: AND LOOKING BACK HOW SATISFIED DO YOU THINK YOU WERE WITH THE EXPERIENCE OF THAT CONSULTATION AND DEALING WITH THAT PATIENT?

Nurse: Erm ... it was OK, it was quite difficult really because, as I say, she was so shocked when she was told that she needed surgery, you know, I think maybe she thought that the tablets'd always work, and that's what she'd stay on for the rest of her life, to keep this under control. And I suppose after three years you would think along those lines, wouldn't you, really, that, you know, things were jogging along nicely, and that'd be it? So it was quite difficult to make her understand that, you know, surgery was the next step really. And I think she thought she was perhaps too old to have surgery, but I mean she was quite a healthy 76-year-old, she'd got no, no major medical problems and, you know, I said to her 'We've had ladies that have been 90 on the ward and got through breast surgery very well,' you know. She was quite shocked at that I think. But, so it was, it was like quite difficult bringing her round that, you know, so she would need surgery and she would be all right. So, but she was, she was all right in the end, yeah.

INT: HOW SATISFIED DO YOU THINK SHE WAS WITH THE OUTCOME AND THE CONSULTATION?

Nurse: Well I think she was satisfied, yeah, I think she was. She'd been guided mostly by the doctor and gone along with him, but she was satisfied.

INT: HOW SOON DO YOU THINK YOU REALISE YOU'RE DEALING WITH A COLLABORATIVE PATIENT? WE'VE TALKED ABOUT ACTIVE PATIENTS, HOW ABOUT COLLABORATIVES?

Nurse: I think by things what they're saying really, yeah. They tend to hold back and say, 'Well, what do you think, Doctor?' or ... yes, it's just really by their actions and what they say. Yeah.

INT: AND AGAIN DOES THAT SORT OF SHAPE HOW YOU'RE GONNA APPROACH THAT PATIENT FROM THEN ON?

Nurse: I suppose it does, you take kind of a different attitude, yeah, because the collaborative, it's been a two-way thing anyway, you know, she's had a, yeah, she's gone along with the doctor and they've worked it out together really, so she's come to a decision with the help of him. It's been a two-way process, which, you know, she's obviously happy about. Because, you know, it's been, it's not just been her choice, it's been his as well, but she's been happy with the choice. So, yeah.

INT: THINKING ABOUT THE ACTIVE PATIENT YOU DESCRIBED AND THIS ONE, HOW WERE YOUR FEELINGS AFTER THOSE TWO CONSULTATIONS? OR ACTUALLY THE EXPERIENCES OF DEALING WITH THE PATIENT.

Nurse: Well, they're hard in different ways.

INT: IN WHAT WAY, CAN YOU DESCRIBE THAT?

Nurse: Well the active one it's kind of a bit exhausting at the end of the day because she's, she's so active and vocal in what she wants, and, you know, you've got to ride along with that with her. So that's mentally draining, but also I suppose the collaborative lady is also, because she's ... you've needed to make sure that she's happy with what she's got and understands everything, because it's not, she's not been that active in it, she's been halfway there but you need to know that she's been happy. So they're both different, but both, it's hard to say which one's the hardest for me as a breast care nurse really. Both different and ...

INT: OK. I'D LIKE TO MOVE ON TO THE LAST ONE, WHICH IS SITUATIONS WITH PASSIVE DECISION MAKERS - THESE ARE PATIENTS WHO TEND TO WANT TO LEAVE FINAL TREATMENT DECISIONS TO THEIR SPECIALIST, EITHER WITH OR WITHOUT THEIR SPECIALIST SERIOUSLY CONSIDERING THEIR OPINIONS. AGAIN,

*Q20. AGAIN THINK OF A PATIENT WHO WAS, YOU BELIEVE, PASSIVE, AND WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, PLEASE TELL ME ABOUT YOUR EXPERIENCE WITH THEM UP TO THE POINT WHEN THEY MADE A TREATMENT DECISION.

Nurse: Right, well I have thought of one, again it's a young patient, she's 36 years of age and she's got two smallish children, married. In, she had, in November of 03 she had a wide excision and that was what was, that would have been fine, the doctors said, you know, that it wasn't a choice - well it would have been a choice but they said that that would be enough, you know, she could have a wide excision. Obviously she was told about close margins and everything. Erm, and when the results came back, she had a wide excision, and when the results came back the margins weren't clear. So then she was offered either a wider excision or a mastectomy, and she chose the wider excision. I went to see her on the ward after, when she'd come in the second time for the wider excision and she was more upset at having the second lot of surgery than she was the first. I think she thought it would be all over the first time, she could go back home and get on with her life with the children, and that would be it. So She had the wider excision, when she came back for the results of the wider excision, they found that there was further tumour and also vascular invasion. So she's now, this poor girl, is now having chemotherapy and, after the chemotherapy's finished she's got to come back in for a mastectomy. So that is, that's awful really, you know, for all what she's gone through at such a young

age. But I always felt that she was quite passive in her approach to it all. I don't know whether it's because she was young - maybe, I do think perhaps age sometimes has got a lot to do with it. Maybe in her life she'd not had a lot of dealings with breast cancer or knew little about it, and maybe not probably, almost certainly not had any, I don't think there was any breast cancer in her family, and I'm sure none of her friends or acquaintances had ever had breast cancer because of her age really, 'cos she's quite young, she's very young in fact, and there's not many young ladies like that. So I don't think she'd had any dealings with it or maybe breast cancer had never touched her life before and maybe she'd never even thought of it, you know, she was young, married, two you children. Things like that don't enter your head really when you're young, do they? You don't, you know, it's like, when you get older and things happen, it's just life experiences really what, and as you're getting older you know that you're more prone to disease, but at her age I would think that she'd never even thought about anything. So she couldn't be active because she'd not got any knowledge of it, what was happening really, so she put it all in the hands of the doctors and really said, you know, 'Do what you've got to do.' But, you know, I suppose, she was offered the second time what to have and I presume she chose the wider excision if she was offered both, I wasn't there at that time, at that, you know, when she saw the doctor at that stage. Erm, but, you know, looking back it's a pity that she didn't choose the mastectomy because she's gonna end up coming back in a few months for a mastectomy, so this'll be her third operation, and I would imagine she's really quite, quite traumatised by it now.

INT: WAS THERE ANY EXTERNAL INFLUENCES APPARENT?

Nurse: Not that I know of. No, I don't, she's got a husband and he was, he was supportive. She was quite, erm, she was quite an easy-going girl and really when I visited her on the ward I thought to myself, 'You don't seem too troubled by what you're going through,' but she put on that face of, she was always smiling and as I think, 'Do you really know what, you know, what's happening, what you're going through?' She did, I'm sure she did, but it was just this outward app-, outward thing with her, that you never really knew, you know, there were, I never saw her cry or anything. So, you know, I would class her as being passive really.

INT: DID YOU GET ON WELL WITH THE PATIENT?

Nurse: Yeah, she's lovely. In fact she's, my friend outside of work it' a friend of hers actually. Mm. So, but I never knew, I never knew the patient before, but my friend knew her quite well, they'd worked together.

INT: SO LOOKING BACK NOW HOW SATISFIED DO YOU THINK YOU WERE WITH THE EXPERIENCE, THE WAY IT WENT DEALING WITH THE CONSULTATION ETC FROM YOUR PERSPECTIVE?

Nurse: Well, I suppose she's, I suppose the consultation went all right, I just think things have just gone wrong. She had her wound infection after the first operation and she had the district nurse to manage the wound, so things never really went right for her from the word go, you know, she was on antibiotics, she'd had this wound, she's just be so, so unlucky, you know, nothing's gone right for her really. I'm sure the consultations were fine and, you know, everybody did what they thought was the right thing at that and, you know, the choice was hers at the second operation, and obviously because she was young I suppose ...

[Interruption in recording]

Nurse: ... I think at the end of the day she chose the wider excision hoping that would be the end of it and because she's young she didn't want to lose her breast and so for her that decision was right at that time.

INT: RIGHT, WE'LL STOP THERE, IT'S NOT A PROBLEM, BECAUSE THE LAST COUPLE OF AQUESTIONS AREN'T PARTICULARLY CRUCIAL ANYWAY. I JUST WANT TO QUICKLY DE-BRIEF YOU, OK? RUN THROUGH A COUPLE OF THINGS. DO YOU HAVE ANY QUESTIONS AT THIS STAGE.

Nurse: No. Not that ...

[End of recording]

.....

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

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?

Here

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

Here

*Q24. THE REST OF THE TAPE HERE...

Here