

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Nurse)
*VENUE: High MR unit
*DATE: 21/10/2003
*ID: BCN025
*INTERVIEWER: DJW

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

Int: Right then, just to start with I'd like to ask you a few questions about yourself and the Unit that you work in. To begin with, I thought I'd ask you a few questions here about how you find working in the Breast Service here. How long have you worked in this Breast Unit?

Nurse: Three years in September just gone.

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

Int: And with regards to you know working here can you tell me what it's like to work here as a specialist nurse in this breast service, thinking about likes and dislikes, Unit philosophy, daily running of the service, how the service is structured, that kind of thing.

Nurse: Right. Well the pointers that I've put down really is on a day-to-day basis I find it rewarding, very rewarding. I guess in comparison to my previous role working on the ward I do enjoy my job. I miss it when I'm not here in terms of long term when I'm not here. For example, last year, you know, I was on maternity leave and I was ready to come back to work, you know, and I missed work and I think, you know, generally, not just the breast care nurses but generally as a Unit we work very well as a team, so...

Int: Yeah, I mean from the interviews I've done so far it certainly seems to be that the Unit philosophy is based round, much round a close-knit team. So in terms of structure of the service, you've obviously got your consultants who patients see and then there'll be time after the doctor with the breast care nurse. Do you do things like home visits or pre-op...

Nurse: Yeah, a patient is seen at the time of diagnosis by a consultant. We're not present when the consultant delivers the diagnosis, which I know certainly one of my other colleagues, Pat, maybe thinks that may be something we need to look at. Then we see the patient individually, a breast care nurse. We do do home visits either in between them coming in for surgery or post-operatively, throughout their treatment journey if you like as the need arises. I would like to think our service is very much patient led in the sense that you know, and this is what I would say to patients, we rely on them to contact us you know, a lot of the time. We try to contact them, you know, in between times on a regular basis but that's not always possible and sometimes their need is, they require support, not at that point when we're contacting them so we see them at the time of diagnosis, then we see them at a pre-assessment clinic. We don't do routine ward visits, again it's upon request. You know, I certainly emphasise that, that we are here, it's part of our role you know, should they require it but we've found in the past that because we do a pre-op visit and we see them post-operatively at results clinic that they didn't, the majority didn't really have that many issues when we went to see them on the ward so we pulled out of that routinely but we are around if they want us to see them, so then we would see them, as I say, at post-operative results clinic then we've just recently got back into oncology clinic now, so any ladies that are referable, referred to the oncologist for additional treatments, a breast care nurse, and we rotate that clinic, attends that clinic and then really that's as far as the routine visits, or the routine contact stops

and the rest of the time it's 'phone contact and/or home visits if necessary.

Int: Right, ok then. Have you worked anywhere else in this capacity?

Nurse: No, no.

Int: So, is there anything about this service here that you think, sort of, makes your job easy to do? Or makes it easier to do than you would perhaps have had a talk with colleagues in other areas and think well, you know. I mean you've mentioned the close-knit teamwork I think.

Nurse: Yeah, I mean I think it's quite difficult to compare sometimes when you haven't worked in another area. I mean, you know, yes we do talk to other breast care nurses when you go on study days or you know, I did the breast care nurses course last year and I think, yes, there are times when you do feel that, ahem, perhaps when you're talking to them that maybe we do have a closer working, ahem team, than perhaps some of the other units. I'm not sure whether that necessarily makes things easier, you know, is an important thing for making our role, or our work easier, I don't know so I think it is difficult to compare when you've not worked in another area.

Int: Do you feel that there's any constraints on you when you're sort of working here and do you think that well, you know like, it sort of prevents me doing the job the way I want to do it?

Nurse: Ahem, I think it's frustrating sometimes from the patients' point of view, you know, I can think of something that's not ideal at the moment is when patients are seen at diagnosis by one consultant, given the results by a consultant surgeon but it may not be that consultant surgeon that operates on them.

Int: Right ok yeah.

Nurse: So continuity wise and sometimes also from the breast care nurses' point of view that continuity isn't always there so we do emphasise working as a team that may sometimes feel that perhaps you're not delivering the service to the level that you would like.

Int: Right, yeah.

Nurse: I don't know.

Int: Ok, right. I mean a very simple sort of question, how well do you get on with your colleagues you know, you seem..

Nurse: I think generally we, we get on very well. We do have two breast care nurses off long term sick at the moment, which has been very difficult for us all. Difficult especially when I was off on maternity leave so it left them down to two and I'm sure that you know they will comment on how that affected them and maybe the service, you know, an impact on the service but certainly the four breast care nurses that we have now is a good team. I think we are able to communicate openly with each other if we've got a problem, whether it be with a patient scenario or with another member then, you know, we talk about that. I don't think there's any, you know, problems in that area.

Int: Oh cool. And the consultants, how do you get on with the consultants?

Nurse: Ahem, the three consultant breast surgeons are very different. I would like to think that personally I can approach them all equally, I

don't have a problem with approaching them, ahem, you perhaps don't have the same rapport with all three, ahem but generally, you know, again I don't have a problem with them. I think, you know, we can go and voice our opinions to them, any problems.

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

Nurse: Again I mean the three consultants are very different and work very differently in the sense of the way that they deliver their information to patients and sometimes that's positive and sometimes it's negative from the patients' point of view. You know, one consultant is very straight to the point, you know, no, 'there, there' sort of thing and ahem, another is very factual which isn't always a good thing, you know, for some ladies either and one in particular is quite sympathetic, perhaps sensitive when delivering you know, a diagnosis of breast cancer to ladies.

Int: So how does that impact upon sort of the consultations if you like? Because you sort of mentioned that you're, if I can get this right, you're not always in with the diagnosis.

Nurse: We're not, we're never in.

Int: Obviously you will have three different consultants and you will have a patient from one of the consultants.

Nurse: Yeah, well what I always do is basically, first of all, find out what's been said you know, I ask the lady what they remember about the information that's been given to them so I basically get them to take me back, you know a little bit and through that consultation.

Int: Do you find that sort of like, process, helpful?

Nurse: I do, yeah I do.

Int: I mean, from the patients' point view...

Nurse: ... and I think, I think, I mean, perhaps this is obviously something that, you know, we're going to be looking at. I think the ladies do, ahem, because first of all it demonstrates how much they have remembered or if they haven't remembered, you know, they'll tell us what they remember and so you can build on that and you know that, you know, you've got your starting point then if you like, so you can either go over it again or start from scratch again and you know, and explain it in more detail or whatever, so I personally find that really helps.

Int: Do you feel it helps building a rapport in some way with the patients?

Nurse: Yeah

Int: Yeah, ok. I'll move on to before a consultation where a diagnosis is to be given. I'd like to talk about what happens just before the clinic begins where patients are given to hear about diagnosis. From this point in the interview I would us to focus only on newly-diagnosed breast cancer patients.

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

Nurse: Right. We have two what we call 'results clinics' where patients are given diagnosis of breast cancer and those are a Tuesday morning and generally a Friday morning or afternoon, that clinic there is at the moment so Tuesdays, ladies that are going to attend the Tuesday results clinic are discussed on a Monday lunchtime MDT. Now because of the logistics and the hours that I work I'm not present at that MDT because I don't work on Monday ahem, which maybe doesn't always help me from that point of view ahem and then Friday's results, ladies attending Friday's clinic are discussed at Thursday's MDT. There's always a breast care nurse present ahem, we all try to attend where possible.

Int: And patients are discussed pre-operatively at that MDT yeah?

Nurse: Yes, yeah.

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

Int: So if you attend an MDT how do you usually feel after that MDT meeting?

Nurse: When I attend on a Thursday? Ahem, I think it depends on who's, on the patients that are discussed, the outcomes, ahem. I feel well informed, you know, about what's going to be happening. I feel that, you know, that we all know what's going to be happening to that lady then. You know, we've all agreed on what's going to be happening. Ahem, I think sometimes, you know, you (long pause) feel quite emotional towards. I don't know, I, quite recently if there were ladies of similar age to me, and whether it's because I've recently had a child and when they've got children as well, sometimes, you know, those things are included in the MDT, their age and, you know, a little bit about their background ahem, you sympathise with them or empathise with them more.

Int: Yeah, right, yeah. Do you have variable workloads? Is there times when it gets heavy, you know, is it a light workload or?

Nurse: Ahem, yes, I mean, yeah, it varies throughout the year to be honest, I mean we, even our workload as it comes, you know, as it comes through the clinics and again, you know, we're all generally present at those results clinics so whatever's coming through we share out but there are busy times throughout the year and there are quiet times and sometimes it can be yeah, quite heavy.

Int: And when you've got a heavy period of patients coming through do you think that changes how you feel or do you notice your feelings changing from different workloads?

Nurse: I think, yeah, I guess it does in a way. I think sometimes you're not, I mean you know, sometimes for example, on a Tuesday, we've had ten results patients through and you know, if there is a breast care nurse on leave or whatever, and you've got three, four patients to see, you feel almost as if it's a bit like a conveyor belt and even though, yes, you're delivering the same information, I do feel that you're perhaps a little bit withdrawn if you like, step back a bit and you don't perhaps get as involved with those as maybe you do with, when you've got more time with them you know.

Int: Is that because you feel that there's a, that you have to get on or is it...?

Nurse: I think it's a combination really, I think yes, because you know that you're going to be seeing somebody else quite soon but also I think on a day to day basis you almost feel that you have to do that to be able to go on, you know, to keep going otherwise if you get involved with everybody that walks through the door it would be very difficult to do your job.

Int: Do you find it draining emotionally or something or...?

Nurse: It can be, yeah.

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

Nurse: Sometimes, ahem, in particular, I would say this doesn't help very often with screening ladies but in particular symptomatic ladies, so ladies that already have been to their GP because they suspect something is wrong then I guess if they ask the questions to the radiologist or the consultant then the seed might be planted that, and you know, I have you know, I wouldn't do it personally myself 'cos they wouldn't routinely see us at that point unless the consultants or the radiologists felt that it was necessary. If they were particularly upset or they wanted to discuss the 'what happens if it is?' you know, the words like 'suspicious' might be used or you know 'we need to investigate this further' or you know, those sorts of things so that there's an error of doubt really, yeah, yeah.

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

Nurse: (Long pause) ahem, again I think really the answer to that is the same as the first, the last question, in the sense that if it's generally the symptomatic ones you know, they may be prepared in the way that, you know, this area's suspicious.

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

Nurse: Ahem, well I think we know how our consultants work and the way that they deliver the information or the diagnosis to patients. We've all, in our induction periods coming into the Unit, sat in with the different consultants so you know, we have an idea about what's going to be said and how the consultation might be going. So I think it's dependent on the consultant as to how the consultation will go and what will be said.

*Q9. HOW WOULD YOU DESCRIBE YOUR FEELINGS BEFORE SUCH A CONSULTATION?

Nurse: I don't know really. Ahem, I don't know, I don't know, ahem. It's not something I've thought about really, is how you're feeling before, you know, yes you are sympathetic towards the ladies. The way that I perceive my role is if you can make a difference, you know, if you can make them understand, if (pause) if you can make that path or that journey if you like, any easier, yeah, by what you do, then that's got to be a plus so I don't know how exactly I feel before a consultation. I don't, you know, it's part of my job, so I don't really, I don't particularly, you know, feel anxious or uptight, or nervous about what's going to be said, or

anything like that. You know, I feel quite laid back about what I'm going to be doing or quite confident should I say, you know.

*Q10. PLEASE TALK ME THROUGH WHAT HAPPENS IN A CONSULTATION WHERE DIAGNOSIS AND TREATMENT OPTIONS ARE BEING DISCUSSED WITH A PATIENT WITH BREAST CANCER.

Int: Yeah, ok. Ahem, I'd like to move on a bit now. During a consultation with a newly-diagnosed patient can you talk me through what happens in a typical consultation where diagnosis and treatment options are being discussed with a patient with breast cancer here?

Nurse: Right, well what I will reiterate again at this stage is that a breast care nurse isn't present so, you know, we don't know exactly the ins and outs, only from prior when we've sat in with the consultants but usually what's discussed is, you know, the consultant will discuss the results of the biopsy because generally that's what they're coming back for the results of, is the results of the core biopsy or an FNA and, so he'll deliver those results and then really say what we need to do about that. Usually they'll discuss risks and benefits of the surgery to them as they have to do now as part of the consent procedure and now, if there are options to be given, then they'll give them those options. As to how much detail they go into again depends on the consultant surgeon.

Int: Yeah, of course. So typically who is sitting in the room when a patient's receiving a diagnosis?

Nurse: It would be the patient, possibly a relative or whoever they've brought with them and the nurse assistant.

Int: And when, obviously they'll come in then to you and the consultant, so when you, you know, you're going into the room to meet this patient perhaps for the first time or whatever, do you have a preferred style or approach that you start with when you go in?

Nurse: Yeah, I mean, I guess everybody has their same sort of spiel, if you like, that they use. The ladies are actually brought over to our counselling rooms generally by the nurse assistants and what we would generally do is, or what I would certainly do is come in, introduce myself, say who I am and what I do in the sense that what I usually say is, you know, 'I'm Karen, I'm one of what they call a breast care nurse. The idea of seeing me today is just to expand a bit more on the information that you've been given to you today'. And then what I'd usually do is just leave them for a few minutes, you know, help, get them to make themselves a drink and just compose themselves for a few minutes and pop over and have a chat with the surgeon to find out exactly what information has been given to them ahem, and the surgeons would generally then go through what, you know, what they've said to them. A little bit about the breast cancer and what options they've been given.

Int: And does how you approach a patient from then on, once you know the information they've received, is that sort of, does it change, because you obviously have different working styles here from the consultants, does that somehow shape how you're going to then approach the patient to take them through something.

Nurse: No, no I wouldn't say so. I don't, from that respect it doesn't matter what options they've been given because, you know, again, I would, once I come back in the room I would sit down with the lady and that's when I would say, you know, can you just take me through what the surgeon said

to you and we'll go from there and on the basis of that, I'll expand on that and go into more detail.

Int: Right, ok. When you're actually talking to a patient at this stage who does most of the talking and who asks most of the questions do you think?

Nurse: I think it depends on the type of patient, to the type of lady that you've got and sometimes the type of relative that you've got in the room as well 'cos they, or friend or whatever, ahem, generally it's me that does most of the talking, ahem, but I would like to think that it's led by the patient. Now there is a certain amount of information that we have to give them at this point but because we see them at pre-assessment and they've got our contact, we don't have to bombard them with every inch of information, we give them written information to take away with them and some ladies will say 'well hang on you know, I don't want to know all of that, you know, I just want to know the very least and be on my way' or 'I don't want to talk about it today' and in those instances you might say 'well can I give you a ring tomorrow or what about if I pop and see you', 'cos a pre-assessment clinic might be a week away so you know, again, give them the opportunity that, to see us again, if we felt it was necessary.

Int: Do they ever talk about clinical trials, does anyone ask about clinical trials or...?

Nurse: No, not generally unless the surgeon's mentioned it but certainly in my experience I've not, it's not been a question that's been asked routinely, no, no.

Int: Ok, ok, just that the project I did before ... When you're actually talking about, you know, to the patient about, after the consultation sorry, do you use anything like any tools or anything such as you know x-rays or diagrams, do you ...

Nurse: We have the triple assessment form, we have the breast packet with all the information in, in the consultation, in our consultation, so we have all the information there and if it's relevant, like for example if they've been given a choice and you want to expand on that more you can go through why they've been given a choice, you know, it might be because of the size of the breast cancer, because of the size of the breast, so you could work through that with them. I don't use it routinely all the time ahem, like, you know we have prostheses as well and softies, so we could show them those if they wanted to. We have various other bits of specific information about different types of breast cancer so yes we do, but you know, I wouldn't say I do it routinely. I try to look at the individual.

Int: Do any patients find these sorts of things particularly helpful?

Nurse: Yes, yeah, I think so and that's why I would say, you know, I will try to base it on the individual and give them the option about, especially you know, like the visual aids of the softies and the prosthesis if, if a mastectomy is an option or a choice, or is an only option then, you know, if they wanted to see them at this point I would show them. If they didn't, then I wouldn't you know.

Int: And sort of, you know, once you've been talking to this patient now for a while, how are your feelings then about discussing these issues?

Nurse: Again, you can usually judge how well it's going from them, you know. I'd like to think that I can assess somebody's non-verbals as well as well as verbal communication fairly well, you know, you can usually tell

from them how well it's going, how much they're taking in and how much more they want to know, you know, ahem, and I always reiterate on a number of occasions throughout the consultation that, you know, we can go through this as many times as they want, you know, we can go through this, not necessarily obviously at this point again, but at pre-assessment or pop out to see them or whatever to try and make sure that by the time that they make their decision about the treatment that it's, it's informed, you know.

*Q11. PLEASE TELL ME ABOUT ANY ADDITIONAL TIME YOU USUALLY HAVE WITH A PATIENT AFTER THE PART OF THE CONSULTATION WHERE THE DOCTOR IS PRESENT?

Int: So we've talked about the time after the patient, after they've seen the consultant. Can you tell me any additional time you usually have with the patient. I think you've mentioned telephones, and I think you've mentioned pre-assessment?

Nurse: Yeah, pre-assessment clinic.

Int: And is the pre-op on the ward?

Nurse: No we don't see them, ahem, we don't do a ward visit pre-operatively or post-operatively routinely.

Int: By request?

Nurse: Yeah.

Int: That's right, yeah.

Nurse: And, or again, on occasions, I would judge the lady, assess the lady and I would say to them if I felt it was appropriate, I'll pop and see you, you know, whilst you're on the ward. If you've got a particularly anxious lady or you've got a lady that's asking an awful lot of questions, lots of things really, you know, I would say 'I'll pop and see you no the ward if that's ok, you know, get permission from them if they think it's 'Oh yes, I'd like that' you know, or whatever, so.

Int: You mentioned that you don't routinely do home visits.

Nurse: No.

Int: I mean, obviously I interview patients in the home myself, so it's kind of, and I've been at one or two home visits in preparation to, because I don't, I'm not a breast specialist or anything, I'm a researcher, ahem, I'm very interested in sort of the home visits really, can you talk sort of talk me through what would be a typical sort of home visit.

Nurse: Again, dependent on the individual you, I tend to find that we don't get very many home visit requests prior to surgery, ahem, it tends to be post-surgery at any point really, in particular if they're for additional treatment, ahem, and the requests can be for different sorts of reasons. Most commonly, I guess, they're not coping, you know psychologically and emotionally. The reality is starting to hit. A lot of ladies will say, you know 'I'm on a bit of a roller coaster at the moment, I feel like it's happening to somebody else' and then all of a sudden they'll reach a point, and it can happen at any time, you know, it's generally post surgery though where you know, they'll hit a point and think 'Oh, hang on a minute. What exactly has been happening to me' you know and they have a whole host of questions, ahem, whether it be about their diagnosis, about their prognosis, about their whatever treatment they're

having, about their follow-up care or what happens when all this is done, you know. So, or ladies that come at the very end of treatment and want to discuss reconstruction, breast reconstruction.

Int: So, but, pre-operatively...

Nurse: Very rarely...

Int: Very rarely... and what sort of things might generate the request there?

Nurse: Pre-operatively, as I said before, in particular if, you know, if you saw somebody at a diagnosis and they wanted to bolt really, you know, on odd occasions you do get that and ahem, at that point I would say 'right, ok, just go' you know, I wouldn't even attempt to go through any information with them. Let them go, 'I'll ring you up and pop out and see you if that's ok'.

Int: Right, yeah

Nurse: You know, and then basically give the same consultation that you would normally give following a diagnosis but in their own home when they've had two or three days, which, ahem, can maybe be more advantageous than seeing them at, you know, when they've actually just been given a diagnosis from the surgeon.

Int: And do you, thinking about all these times that you see patients after they've seen the consultant, is, do you notice any influence of third parties such as family members or anything like that?

Nurse: Oh yeah, yeah. Ahem, again, very much so depending on who you've got with them, ahem, and that's why maybe in some respects, and these are, I guess, things that I picked up through the breast care nurse course I did last year, ahem, that sometimes it might be more beneficial to see the lady on a one to one because then you, if you have got a relative or a friend that's very outspoken the poor little you know, patient can't get a word in edgeways or it's the patient, it's the relative or the friend asking the questions but the patient's not really finding out what they need to know, you know, so sometimes it's not always beneficial having a third person there.

Int: Ah, ok. Between receiving the diagnosis and actually deciding on what treatment they're going to have, how long do you think it takes on average for patients to decide what treatment they're going to have, from when they've heard the diagnosis?

Nurse: I think most, most ladies, ahem, it very much depends on the individual and, because I was going to say I think most would already have gone out of here almost making, have made a decision. I would never take that decision from them at this point. I would always say 'Go away, have a read, have a think, if you want to know anything else you can pick up the 'phone' and give them the opportunity to make the decision at the pre-assessment clinic. But a lot, a lot of ladies will say 'well actually I've already made my decision'. Now that decision may be based on a number of things, outside influences, again, relatives, friends, consultants, the information that we've given to them.

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

Int: Ok. I'd like another one now. How about patients' information needs? In your experience, what do patients tend to know about breast cancer and its treatment options before they see you?

Nurse: I put in general, either little information about breast cancer or sometimes often misleading information, you know, like some ladies will assume that either all of their breast had to be removed, you know 'I expected if it was breast cancer that I would have to have my breast off and that was it, nothing else'. Or on the reverse of that, the other end of that is some ladies will come and say 'I really expected actually just to be able to have that area removed and you know, retain my breast'. So, I'd say, you know, in general, quite misleading information.

Int: Where do you think that misleading information comes from? Do you think it's something they've found themselves or?

Nurse: Yeah, the media, or the people. You often find when you see a lady a second time when they've talked about it to others 'such and such said this' most ladies will always know somebody, or somebody that knows somebody that's had a diagnosis of breast cancer 'and they had this, and they went through this' and 'why aren't I having this?' or you know 'why have I got to have this and they didn't' so you have to explain, you know, all of that to them and the reasons why this is the options for them, that every case is individual.

Int: So, if you've got a patient who knows a lot about breast cancer and its' treatments and assuming the information's right, do you think that makes for, how does that make for a consultation, do you think it's easier, harder?

Nurse: I think it's easier with a lot of respects, ahem, you know, coming in with a lot of knowledge, ahem, I don't see there's a bad thing at all, I think it's great. You know, I think it gives them some control of what's happening to them, the fact that they have been and you know, read about breast cancer, read about the different types, the different, you know, options, whatever and so you can explain that to them.

Nurse: I think sometimes that can make a consultation difficult but, ahem, I think as long as you explain it clearly why that isn't option, you know, why this is so in your case and why this is what's happening to you is 'cos it's you, you know, then generally the patients will accept that.

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

Nurse: I think in that respect I wouldn't want to put everybody together, you know, in one pot and say everybody needs this. It does very much depend on the individual and a diagnosis of breast cancer affects people differently and affects their lives differently and some people, for example, 'well how is it going to affect my work?' You know, 'I do this' you know, how much time?' and that's all that they want to know, or that seems to be their most important issue, so ahem, I think you have to base your information on the individual.

Int: When discussing diagnosis with these patients what do you think they typically understand well about what's told them. Something you're going perhaps to need to go over again?

Nurse: (Long pause) Ask me that again while I'm thinking about it.

Int: When you're discussing diagnosis with these patients, is there any information you think that patients seem to understand really well and get just first time or?

Nurse: Again, I'd say that varies from person to person. If there's a lot of things to be discussed like for example if they're given a choice of surgery you may need to repeat it on a number of occasions and explain it in more detail so.

Int: Is choice you find something patients find hard to come to terms with?

Nurse: I think it's perhaps not so much from the surgery point of view but definitely from the post-op treatment, especially when you're talking about radiotherapy and you know, that generally radiotherapy and wide local excision comes as a package and it's trying to explain that to them. You know, some ladies might go for a mastectomy because they're reducing their risks of not requiring radiotherapy. I've found that a lot. I've found that a lot you know, and it's trying to re-emphasise that really and clarify that, that it's still a possibility even if you choose a mastectomy that you still may require radiotherapy.

Int: Is there any other information you think might be understood poorly generally, typically?

Nurse: Well again, the radiotherapy. You know, if you talk about that often they might think it starts straight away, post surgery. I think additional treatments I would say perhaps. I don't like to go into too much detail unless it's asked because I do think and you can tell with the ladies they start getting overloaded then, you know. So I give them the options again, you know, 'Look I can tell you all about this, give you as little or as much information as you want about these additional treatments but I think especially where there is a choice to be made about surgery that you're giving them a lot of information to begin with and then to start talking about possible post-op treatments they start to get overloaded generally.

Int: Ok, ??? next part of the next question, so we'll just move on.

*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

Int: The next section is what the patient is offered. Within the context of the Unit's guidelines and published research, please describe the factors that would lead your team to offer a patient only breast conservation surgery.

Nurse: I think there should be no instances where somebody is offered only breast conservation surgery and certainly again, from my point of view, I always say to the lady, you know when you're asking them about what information they've been given from the surgeon and what they remember about the information, I always talk about a choice because mastectomy is still a choice, you know, even though breast conservation on the basis of the results, ahem, may be advised by the surgeon, ahem, I would reiterate that there is still a choice but it's quite sensible, reasonable because of all the results and I would go through the results with them again if they wanted me to, to opt for breast conservation surgery.

*b. ONLY A MASTECTOMY

Int: And what factors would lead the team to offer a patient only mastectomy.

Nurse: The size of the breast cancer in relation to the breast.

*c. A CHOICE BETWEEN MASTECTOMY & BREAST CONSERVATION SURGERY

Int: Size ratio?

Nurse: Yes, if it's multifocal. Not necessarily if there's lymph gland involvement. I have known on occasions, you know, even if there's lymph gland involvement, that they would still offer breast conservation surgery. Ahem, position, but again, you know, even if, yeah, yeah, position. I was going to say even if there's nipple, or you know if it's situated behind the nipple, then we may sometimes still offer breast conservation, but they may advise towards a mastectomy because of the cosmetic distortion.

Int: Is there a? Can I say I'm just trying to pick up on my knowledge so far? Would it be any, would there be any difference between is it ductal and lobular? That kind of thing?

Nurse: Ahem, well, you see they don't always get that information from a core as in the type of breast cancer so, no, possibly not.

Int: Right, ok.

Nurse: If it's DCIS that's different but if it's invasive ductal or invasive lobular, possibly, but I think that they would still take into consideration everything else.

*d. OTHER TREATMENTS

Int: Right, ok. And what factors would lead the team to, well, we've talked about choice between mastectomy and breast conservation so what factors would lead the team to offer a patient any other treatments?

Nurse: Any other treatments?

Int: Radiotherapy, chemotherapy, things like that.

Nurse: Right, so is this post-operatively then?

Int: Mmhh, yeah.

Nurse: Right, ahem, it would depend on the results discussed at the MDT and usually an oncologist is present at the post-op MDT. It would depend on their MPI so you know, it would depend on vascular invasion, lymph node involvement, what surgery they've had, so and that's why I said before, breast conservation generally, mostly, is supported by radiotherapy, although there is certainly a trial going on about that in, we're looking at the over 65's and whether or not to give radiotherapy post breast conservation and DCIS is the other area where radiotherapy and breast conservation may be up for discussion. So generally it's on the basis of all the post-op results; size of the breast cancer, type of the breast cancer, lymph node involvement, vascular invasion and the surgery, type of surgery and the EL status.

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

Int: The literature suggests that patients vary in the degree of involvement they want when making decisions about what surgery to have. Some patients want full control in the decision making process, some prefer to share and some prefer the consultant to take full control. Do you think that patients are getting the degree of choice they want?

Nurse: Do I think patients get the degree of choice they want?

Int: Yes

Nurse: Ahem (long pause). I think generally, yes. There may be instances where they are swayed towards one type of treatment than the other, and one type of surgery than the other and this is, I guess where you then start to, when you are networking with other units and other breast care nurses and you know that if they were treated somewhere else they might be given more choices in relation to like for example, neo-adjuvant chemotherapy to shrink a tumour down to make it suitable for breast conservation and rather than mastectomy being their only choice. We don't do that very often so... It's difficult to answer that one because I think yes, in relation to the guidelines that we follow but you know that, you know, sometimes in other areas they are given more choices.

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

Int: Right, ok. So I think you, actually, I've just got a card here I was going to show but you've got the responses in front of you so. I mean the thing about your experiences with patients you see please look at the responses there and tell me during consultations who generally makes the final decision about what surgical treatment to have.

Nurse: Who generally makes the final decision? The patient.

Int: There's five choices here. Have you ringed one of them?

Nurse: Oh right, ok, yeah, sorry. It was the top one 'The patient tends to make the final decision regarding the treatment they will have' and I've just added to that 'following verbal written information from the consultant surgeon and to the breast care nurse as well as outside influences'.

*Q18. FIRSTLY, I WOULD LIKE YOU TO THINK ABOUT A SITUATION YOU HAVE HAD WITH A PATIENT WHO WAS ACTIVE ABOUT MAKING DECISIONS. WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, PLEASE TELL ME ABOUT YOUR EXPERIENCE WITH THEM UP TO THE POINT WHEN A TREATMENT DECISION WAS MADE.

INT: AND AT THIS POINT I WOULD LIKE TO START WITH SITUATIONS WITH ACTIVE DECISION MAKERS AND YOU HAVE A DEFINITION THERE OF ACTION DECISION AKERS, FOR THE PURPOSES OF THIS PROJECT, PATIENTS WHO TEND TO MAKE THEIR OWN FINAL TREATMENT DECISIONS EITHER WITH OR WITHOUT SERIOUSLY CONSIDERING THE SPECIALIST'S OPINIONS.

*Q18. FIRSTLY I'D LIKE YOU TO FIRST THINK ABOUT A SITUATION YOU'VE PERHAPS HAD WITH A PATIENT WHO YOU, ER, THOUGH WAS ACTIVE IN TERMS OF THAT SORT OF

DEFINITION AND, WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, CAN YOU PLEASE TELL ME ABOUT YOUR EXPERIENCE WITH THEM UP TO THE POINT WHEN A TREATMENT DECISION WAS MADE.

Nurse: Mm, I can't particularly think of one person, or one scenario of one patient individually, but I think of that particular type of patient ...

INT: RIGHT, OK, MM.

Nurse: ... and, erm, in general I would say that, you know, they are the ladies that you can tell aren't really interested in the information that you're, you know, attempting to give them.

INT: RIGHT, OK.

Nurse: And, erm, they've already made their decision before they've even walked through the doors, in the sense that - and again I would say this tends to be perhaps easily identifiable with symptomatic ladies because they've already had time to think about, 'What if this is a breast cancer?' you know, and, erm, it may be those that have then been out and, you know, read the information, erm, you know, accessed more information. Erm, they've come in really, not listening to the information that's been given to them, already made their decision anyway.

INT: YEAH, MM.

Nurse: Erm, so, you know, I can think of a few, a few instances where ...

INT: CAN YOU TELL ME ABOUT ONE OF THEM?

Nurse: Well, er ... you know, I would say that just really, when you're attempting to give them the information you're not really getting anything back from them, you know, you're, when you're trying to explain things you're not really, it's difficult to assess whether they're understanding what you're getting, what you're telling them. You're not getting much verbal and much non-verbal contact from them, because they don't really want to know because they've already made the decision.

INT: MM, RIGHT. DO YOU FEEL THEY'RE HEARING BUT NOT LISTENING?

Nurse: Yes, absolutely, yeah, absolutely, because they've already done their, you know, their reading, so, erm ... and that's fine, you know, that's fine.

INT: AND ARE YOU, ARE YOU AWARE OF WHAT KIND OF INFLUENCES DURING, ARE APPARENT DURING THAT, CONSULTATION WITH THAT TYPE OF DECISION MAKER?

Nurse: Erm, outside influences?

INT: ANY INFLUENCES, YOU KNOW, APPARENT.

Nurse: I'm just trying to think of, you know, one particular ...

INT: MM, YEAH.

Nurse: ... I think cosmetic is a major influence, you know, ...

INT: WHAT IT'S GONNA LOOK AFTERWARDS, YEAH.

Nurse: ... what their appearance is going to be cosmetically. Erm, yeah, if you've got a very, a particular vain person that I think no matter what you were gonna tell them they weren't gonna have their breast off.

INT: RIGHT, OK.

Nurse: That would be their absolute worst, you know, and on a couple of occasions, you know, a couple of ladies have said to me, 'I would rather die than lose my breast,' but thankfully they have been offered a choice anyway.

INT: MM, RIGHT.

Nurse: So it's clear that, you know, they've already made their decision before they've walked, you know, walked through the doors, but if ... if it had have been that, you know, mastectomy was gonna be their only option, it would have been very difficult, it would have been a different sort of consultation.

INT: YEAH, OF COURSE, YEAH. YEAH, WELL WE'RE JUST TALKING ABOUT [???

Nurse: Yes, but, these had been given a choice, yeah.

INT: AHA. AND SORT OF, YOU KNOW, LOOKING BACK AT THESE SORT OF EXPERIENCES WITH THESE DECISION MAKERS, HOW SATISFIED ARE YOU WITH THINGS GO?

Nurse: Erm, I think it is, it's very difficult because, as I say, you know, you're not really getting a lot back from them. And so, because their decision is already made, and they don't really want to hear what you've got to say, erm, it's not very satisfying. But, so long as they have come to the decision because they, you know, they've read whatever information - it might not be the information that you've given - but so long as they've, you know, come to that decision because they've looked into it, erm, then that's almost like, it's almost done the job for you ...

INT: YEAH.

Nurse: ... if you like, you know. So, er, but they are ... they're difficult to get into, you know, those patients.

INT: YEAH.

Nurse: I keep using the term 'patients' and 'ladies,' I notice that. Yes.

INT: YOU SAY IT'S NOT, YOU SAY IT'S NOT SATISFYING, CAN YOU ELABORATE A LITTLE BIT ON WHY YOU THINK IT'S NOT SATISFYING?

Nurse: Erm, I think it's just, it's just quite frustrating, I think. Erm ... I don't know, you just kind of feel that, er, well ... you just feel that you can't give them the support that you perhaps would to the other two types of patients, because they don't want that support. And that's fine, and you have to respect that.

INT: OF COURSE, YEAH.

Nurse: Erm, but it's just difficult, you know, I think when you come out of that consultation you, you feel it didn't go as well as you wanted it to, you know, and sometimes, you know, you can confer with other colleagues and ... you try, it's almost like you tried to get into them, you know, you tried to get through to them and you couldn't.

INT: MM, OK.

Nurse: Yeah.

INT: AND WHAT POINT, YOU KNOW, WHEN YOU'VE COME INTO THE ROOM TO THIS, MEET THIS PATIENT, AT WHAT POINT ARE YOU AWARE THAT YOU'RE TALKING TO SOMEONE WHO IS QUITE AN ACTIVE ...?

Nurse: Who is ac-, yeah.

INT: ... QUITE AN ACTIVE DECISION MAKER?

Nurse: I think probably from very early on, especially, you know, when I do use that at the start of the consultation, you know, 'Tell me what you remember about what the ...' I think it, in the way that they deliver that back ...

INT: RIGHT, YEAH.

Nurse: ... erm, would, would add to that, 'Well actually, you know, the surgeon says this but I've already made my decision anyway.'

INT: YEAH.

Nurse: You know, 'This was the decision I was going to make anyway.' So, erm, from quite early on, you know. And I, I would still say to them, 'Well, you know, OK, so you've already made your decision, but do you want me to run through anything else with you?' Still give them the opportunity ...

INT: OH YEAH, OF COURSE.

Nurse: ... still give them the same service that you would give to the others, but then if they don't, then you respect that.

INT: RIGHT, YEAH.

Nurse: I would still offer them the information to take away with them and still, you know, offer the contact, but, erm, and it may be that they may value that support further on.

INT: MM, AND HAVE YOU, CAN YOU RECALL ANY INSTANCES WHERE, YOU KNOW, YOU'VE SAID YOU MEET THE PATIENT THEN YOU GO AND SPEAK TO THE SURGEON ABOUT WHAT'S BEEN SAID, HAS THERE BEEN INSTANCES WHERE THE SURGEON'S KIND OF PRE-WARNED YOU THAT, LIKE, WELL, THIS PERSON SEEMS TO BE, YOU KNOW, QUITE DETERMINED WHAT THEY WANT OR ...?

Nurse: Erm, yeah, er, I think, erm, yeah. When you go, you know, when you first go to see the surgeon, erm, before you've met the lady, erm, sometimes the surgeon might say, 'These are the options open to the lady, but actually she's already made her decision because, you know, she's had time to think about it anyway. She, erm ...' and that's fine.

INT: MM, YEAH.

Nurse: But that wouldn't change, I'd like to think that wouldn't change, you know, the way that I would perceive that lady in any way.

INT: RIGHT, YEAH. AH NO, NO, I JUST, I WAS INTERESTED TO SEE IF, YOU KNOW, WHAT KIND OF THE FEEDBACK [???] TEAMWORK [???]

Nurse: But I think it they ... I'm sure an active, an active patients would be picked up by both, you know, by both the consultant surgeon very early on and by myself very early on because an active person tends to be very outspoken and, you know, that's how I perceive an active person to be anyway.

INT: ... PATIENTS WHO HAVE BREAST CANCER.

Nurse: Yes.

*Q19. THIS TIME I WOULD LIKE YOU TO THINK ABOUT A SITUATION YOU HAVE HAD WITH A PATIENT WHO WAS COLLABORATIVE ABOUT MAKING DECISIONS. AGAIN, WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, PLEASE TELL ME ABOUT YOUR EXPERIENCE WITH THEM UP TO THE POINT WHEN A TREATMENT DECISION WAS MADE.

Int: thank you. right well the next one's going to be collaborative patients who are... we have a definition of a collaborative patient here which his 'patients who tend to share the final treatment responsibilities with their specialists'. i would like you to think about a situation you have with a patient who's collaborative about making decisions. Again, if you don't want to reveal any confidential details that's fine. Tell me about your experience with the patient up to the point where the treatment decision was made.

Nurse: I think in some respects they're quite easy ones to think of because quite a lot of ladies fall into that so Tuesday, this Tuesday I saw a lady who was offered a choice so, consultation goes, you know, very well, in the sense that you know, you get the feedback from them, what they understand, what they remember about what the consultant said to them, they, you can tell that they are actively listening to what you are saying to them, they are asking questions that they want to know the answers to you know. They, you can, you get good eye contact, you get good non verbals from them, you can just tell that they're very interested in what you're saying, you know, they're taking on board the information on board the information that you're giving them. I'm not saying that they're taking on all of the, you know, information by any means but they're trying, you know, attempting to take on board the information that you're giving them, you know, so you, so they go out of there hopefully, they've asked all the questions that they want to know at that point. You've given them a certain amount of information about the reasons for the choice of surgery, explained both surgical procedures, you know, in brief to them or in detail, depending on how much they want to know. Give them the opportunity to ask questions at any point which they often do. You know, they'll think of questions, will ask questions as they think of them. Give them the written information to go away with and generally by the time they come back to pre-assessment they've made the decision.

Int: Right, yeah, that's good. Ahem, sort of a personal point here. How did you get on with that particular patient?

Nurse: Well, yeah, yeah.

Int: Had you met them before or not? No?

Nurse: No, no.

Int: And how did you perceive that the patient got on with the consultant?

Nurse: Ahem, let's think of the consultant. Ahem, ok I think, ahem in the sense that I think they understood what information had been given to them by the consultant. (Long pause) Yeah, sometimes, ahem, I don't think

this lady did, but sometimes they have taken the advice from the surgeon in the sense of 'well, I haven't really considered a mastectomy because the surgeon's advised on wide local excision' and I would just elaborate on that a little bit more just by emphasising that there is always a choice but as I said before, quite a sensible, reasonable decision to make.

Int: And what was the final decision that this person made? Did they... ?

Nurse: Well, they are swaying towards, it's a needle marker wide local excision and this was an assessment they did whilst they were screening the lady so hadn't anticipated anything at all. No, when she first came in actually, when she first came into the consultation she said, actually when and she said this to me, you know when the word cancer was first mentioned she was all for having the breast off, straight away but now that it had been explained she couldn't really see the point in having a mastectomy but this lady has got a lot of other issues in the sense of she's due to be moving house, exchanging contracts next week, due to be moving house out of area but I'm, you know, I've tried to explain that really that shouldn't influence your decision in surgical choice because this is something that you've got to live with and additional treatments can be planned elsewhere, you don't necessarily need to be performed here. So I think this lady will probably go for a needle marker wide local excision but I wouldn't, I'd never take a decision from them there and then even if the consultant writes on the consent form and writes on the TCI form that, 'wide local excision' I would always say to the lady you know, you don't need to make a decision today because they don't and this lady's coming back to pre-assessment next week when her decision will be made.

Int: Looking back, how satisfied are you with the experience of this lady so far?

Nurse: Ok I think, because, especially as, you know, at the end of the consultation, you know, I always sort of end on really 'Is there anything else you want me to go through with you, any more questions?' and you know she said 'No, you know, I think you've been very good, you know, you've been very informative' so getting that feedback from them I think you feel that, well in that case I think that it's gone well, you know, so I would hope from that, that in that respect then you've given them all the information that they want to know at this point and you know, you just re-emphasise that, well ok, we're not seeing you for a week, you've got our contact, you know, you can ring us.

Int: And from their perspective, how do you think, how satisfied do you think they are with the experience so far?

Nurse: I think very satisfied. Yeah, yeah, from the feedback that they gave, you know.

Int: And at what point do you think you're aware, when you walk into a room, that you're talking to a collaborative person, do you think it hits you immediately as an active person or does it take a bit longer or?

Nurse: Yeah, probably takes a bit longer I think. Probably takes a bit longer.

Int: Are there any particular cues that get, you've mentioned a few things earlier on but ...

Nurse: I think, yeah, the fact that they are, you can tell that they're listening to what you're saying, you know, they're nodding in all the right places, they're giving you the eye contact, they're asking

questions without prompting. They're, so you're giving them the information that they want to know so I think the fact that you're getting joint, it's not necessarily me doing all the talking then in that, you know, in that instance so, so you feel it's a joint consultation rather than me doing all the talking and delivering all the information, so I think it is shared.

Int: And so at the end of this experience, this initial consultation, how do you feel, how did you feel when that patient went away?

Nurse: Satisfied.

Int: Yeah?

Nurse: Yeah, yeah, good, yeah, I think you just, I think you just feel that 'well, that went well' and you know, ok, diagnosis of breast cancer, so not good to start with, as all consultations start that way, you know, ok not great but hopefully at the end, you know, you've clarified things, you've explained the diagnosis to them, you've given them the information so hopefully things aren't as bad as they first assume, you know when you first see them. That word 'cancer', you know, so...

Int: Yeah, huge connotations...

Nurse: Yeah, absolutely, yeah.

*Q20. FINALLY IN THIS SECTION, I WOULD LIKE YOU TO THINK ABOUT A SITUATION YOU HAVE WITH A PATIENT WHO WAS PASSIVE ABOUT MAKING DECISIONS. AGAIN, WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, PLEASE TELL ME ABOUT YOUR EXPERIENCE WITH THEM UP TO THE POINT WHEN A TREATMENT DECISION WAS MADE.

Int: Okey doke. I'd like to move on to the third category here which is dealing with situations with a passive decision maker and our definition here is 'Patients who tend to want to leave final treatment decisions to their specialists either with or without the specialists considering their opinion'. In this section, again, I'd like you to think of a patient that you've met, that you've dealt with, who was passive about making decisions and again without revealing any confidential details please tell me about your experience with them up to a point when they made some treatment decision.

Nurse: Ahem, I can think of an instance of a lady offered a choice, husband was present and daughter was present and it was very much, I think taking on the information, taking in the information but not really making sense of it and looking at husband, looking at daughter, saying 'should you?'...

Int: She was?

Nurse: Yes, what would you do? You know, what would you do? Or 'what do you advise?' and, so sometimes they can be quite difficult and I would never advise, I would never say what I would do 'cos I think, it's impossible to do that or it's impossible to put yourself in their shoes because it's not you that's just had that diagnosis but I think in this instance this lady was guided by her husband's advice.

Int: So how, what were the, how did her husband and daughter react to that apparent request for the information?

Nurse: Well, she asked you know, she looked at her husband 'What do you think?' said to him "What do you think?" and he said "Well, you know"

and they were all a knowledgeable family, he I think was a judge, not that that makes any difference in any way at all but, you know, just things that you remember I guess that associate you with that lady and he said "Well, you know, if you're telling us that there's, 'cos the scenario or the way that I explain when the choice is given is I often talk about you know, the past research where you're comparing those that have a mastectomy to those that have a wide local backed up with radiotherapy and the long-term results are the same so you know, I will avoid, use that, and explain that to them, the family and so then the husband replied "Well, you know, if you're saying that by having the breast off you're in no way reducing the risks any further and you're saying that", you know he's interpreted that as being almost unnecessary to do that, then he said "I think you should go for the smaller operation", you know, the wide local excision and so she agreed with that but again, I didn't take the decision from her on the day, you know, I said 'Please go away and read the information, ring me again if you want me to go through anything with you but I think she was very much guided by her husband.

Int: And what was her daughter's reaction to all this then?

Nurse: I think her daughter agreed, yeah, yeah. I mean they all want...

Int: Was the daughter a young, very young or middle-aged?

Nurse: Yeah, middle aged, yeah, yeah. The lady actually, well, was over 65 so when she went down to oncology to discuss radiotherapy in actual she decided, now again, that's not her being an active person, that's I think her husband making the decision on the basis of the information that was given 'cos interestingly she decided that, well if we're doing this trial to look at the benefits of whether or not to give radiotherapy in this instance with your results, very good results post surgery, that why have it anyway? Instead of going into the trial to be randomised, why have it anyway, so she actually opted not to have a course of radiotherapy.

Int: Ah, right, ok.

Nurse: So...

Int: And that again was her husband sort of being influential?

Nurse: Yeah, yeah, I would say so, definitely, yeah. She was quite a timid lady, quiet lady and so, she was listening to what you were saying and the information that you were giving but as I say, I don't think really taking it in or not really maybe fully understanding or whatever and as much as you try, you know 'Would you like me to explain this again to you or in more detail?' or you know, 'Is there anything you don't...' you don't really get, you know, I get the feedback from her that yeah, I understand but I don't, but I still can't make my mind up, you know, I still don't know what to do and so if she asks various opinions I, you know, can't give my, you know, advice, I give it on the basis of you know, the research and the results and what the surgeon's given to them as well and so she turns to her husband and I think you know, that's where she got her answer from.

Int: And how do you feel, how did you get on with the patient then, that person?

Nurse: Yeah, I get on well, yeah. I mean she was a lovely lady. I wonder how the consultation would have gone if she had been on her own, you know.

In: Yeah, of course.

Nurse: And whether the outcome would have been different. I don't know.

Int: Have you had an experience with a passive type patient where you've been by yourself?

Nurse: No, no because you very rarely get that you see. Not that, you know, certainly not that I can think of. You very rarely get that.

Int: And how do you perceive that the patient got on with their consultant? Do you think they had a good consultation?

Nurse: Yes, yeah, yeah. Again, I think they'd been able to ask the questions that they'd wanted to ask and they'd got the information that they needed from the consultant so yeah, ok.

Int: Looking back, how satisfied do you think you were with the experience of this lady?

Nurse: Ahem, ok, I mean - those are the ones that you're not getting through to as well as with the collaborative ones you know, and I guess it does depend on the support that they've got from others and who they can consult elsewhere to enable them to come to a decision so like I say, it would be interesting if you were counselling them on their own, with them on their own.

Int: And how satisfied do you think they've been with the complication of the choices?

Nurse: Well, I mean, I know that they've been very satisfied. They've written a letter of thanks to the team, that, you know, I guess that's why she sticks out in my mind. A letter of thanks for all the support that they've had and you know, so they've been very happy but this is the husband that wrote the letter.

Int: Ah, ok.

Nurse: You know.

Int: Right, ok. Ah well, it's still nice to get a letter though isn't it?

Nurse: Yeah, yeah, but I think he is the collaborative one. I wouldn't say active. He is the collaborative - well, is he active because of when they discussed the trial?

Int: Were you present then when he actually asked about it?

Nurse: No, I wasn't.

Int: At what point do you think you're aware that you're talking to a passive decision maker. Do you think this is quite soon or?

Nurse: Yeah, again I think, well, probably part way through the consultation. They don't tend to have that many questions because it's almost as if they don't really know what questions to ask. You get the impression that they're very much guided by you as to.

Bleep on tape and short pause then continues...

Int: Well I would think so, I mean I wouldn't think it's just going to end and not right

Nurse: Ok.

Int: I have been known to press the wrong button before...

Nurse: Oh bug...

Int: Oh yeah, no I did, I did an interview with a surgeon once, got a really, really good interview with this surgeon, quality surgeon and I came to the end and I'd pressed the wrong button and it just stopped and I checked the disc again and nothing had written, a whole 45-minute interview gone.

Nurse: So what did you do? Get him to do it again?

Int: No, no. I had a few notes I had to go for that but that was it, 'that's cocked it up' he says ????? Ok.

Nurse: Yeah, I think the greatest influence is how others perceive a woman in the sense of having two breasts, but that's a very big thing and to lose a breast is a big thing, a very big thing. So I think certainly younger women, the majority of younger women, if there's a choice to be offered, will go for a wide local excision to preserve the breast. So vanity, cosmetically, socially, to me I think are the biggest things.

*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?

Int: And thinking within the context of the unity 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 very much dependant on the advice that's given at the time of diagnosis so the consultant surgeons have the greatest influence by far, yeah.

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

Int: And finally, is there anything else you'd like to add to what we've been talking about today. We've covered quite a lot of ground.

Nurse: We have. I don't think so.

Int: No? You sure?

Nurse: Yeah, can't think of anything.

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

Int: Well I've got a little question right at the end here a colleague suggested to me. I think it's quite an interesting one. It basically says 'If you had the money and power to change one thing about the system here, what would it be?'

Nurse: Right. Did you ask Joe this one?

Int: I did and I'm asking you this one. It just suddenly came up at the end of a...

Nurse: To just change one thing?

Int: Yeah, you've got the total money and power to change one thing about the system here what would that be?

Nurse: There's two things I can think of.

Int: Ok, tell me two things then.

Nurse: Well, one thing I think is, is from the breast reconstruction side. It would be very nice to have the money, the facilities to have a consultant reconstructive surgeon working together to perform more immediate breast reconstruction. To be able to offer more options with regards breast reconstruction, immediate breast reconstruction so I'd very much love to be able to offer that service. And the other, and I'm not really sure that this comes down to money but is just, it's a shame when ladies do see one surgeon with the results and see another to do the operation.

Int: So the continuity thing...

Nurse: ...the continuity, yeah. So I'm not sure whether that's just logistics or whether that is a money thing, yeah. But the reconstruction I think is an important...

Int: Ok, thank you very much for being interviewed. I know you're busy and it's quite a lot of time out of your schedule but I must...

Nurse: You can take us out for a big slap-up meal.. that's all of us by the way!