

SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Nurse)

*VENUE: Medium MR unit

*DATE: 29 October 2003

*ID: BCN001

*INTERVIEWER: DJW

INT: I WANT TO START WITH ASKING YOU A FEW QUESTIONS ABOUT YOURSELF AND THE UNIT YOU WORK IN.

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

Nurse: 1996, January 1996, so it's about 8 years.

*Q2. AND THINKING IN TERMS OF THE UNIT PHILOSOPHY, THE DAY TO DAY RUNNING OF THE SERVICE, YOUR LIKES AND DISLIKES AND THE STRUCTURE OF THE SERVICE, CAN YOU TELL ME WHAT IT'S LIKE TO WORK HERE AS A SPECIALIST NURSE IN THIS BREAST SERVICE HERE?

Nurse: Well it's changed recently, well over the last couple of years, because I've got a new colleague now and we've also got a new department, so the things that were bugging me before have now gone, so I mean it's great, it's great. I mean there's the normal sort of frustrations of working in any large organisation and in the NHS generally, but as far as the team goes and the people I work with, it's great, I really enjoy it.

INT: YOU GET ON WELL WITH YOUR COLLEAGUES?

Nurse: Oh, fantastic, we really have got a super team and very supportive and we all get on really well.

INT: SO IN TERMS OF THE ACTUAL STRUCTURE OF THE SERVICE ITSELF, CONSIDERING LIKE YOU'VE GOT YOUR CONSULTANTS AGAIN, YOU'VE GOT YOUR BREAST CARE NURSES, WHAT ABOUT PATIENTS WHEN THEY SORT OF SEE THE DOCTOR, WHAT KIND OF TIME DO THEY HAVE AFTER THE DOCTOR, DO YOU HAVE THINGS LIKE HOME VISITS? COULD YOU DESCRIBE THAT?

Nurse: No, we don't, we used to do home visits - well I didn't do home visits but the previous breast care did, but we don't do home visits any more. We stopped doing them because it was very time-consuming because of the kind of area we work in, because the screening area goes right out to Buxton, and doing a home visit out to Buxton, you can imagine, is very time-consuming.

INT: MM, SORT OF HALF AN HOUR'S DRIVE IT MUST BE.

Nurse: Well, exactly. So it was decided that, you know, we couldn't, they couldn't provide that service any more, we were a bit worried about, you know, what it would be like without that but it doesn't seem to have given us any problems at all. So all our work is basically hospital-based. And then, sorry, you were asking me ...

INT: YEAH, THE SORT OF STRUCTURE OF THE SERVICE, HOW IT WORKS HERE AND FROM WHEN A PATIENT COMES IN TO ...

Nurse: You want me to tell you what we do?

INT: YEAH, YEAH, JUST ROUGHLY HOW THE UNIT WORKS I THINK.

Nurse: Right, well I mean from our point of view, and we're talking basically about symptomatic patients not about screen patients or both?

INT: YEAH, IT CAN BE BOTH IF YOU CAN.

Nurse: OK. Well the screening patient, sorry symptomatic patients are referred to Mr Holt and Mr Chadwick through the GP, they go to their GP first, then they come to us. The vast majority of patients come through the fast-track clinic, or will be, most of the referrals are sort of considered urgent referrals and obviously have to be seen within the two-week wait, which is another story on its own. So the patients come through to mammography here, they're seen down here. We see about 15, erm, on Tuesday and then probably about another 10, I think it varies, but on a Thursday afternoon sometimes as well. They know that they're going to have a long wait. Originally when we started the fast-track they didn't, they weren't aware of that and it was quite a problem, they got very agitated and worried why they were being kept so long, so we now make sure that they know when they're coming that they are going, it is going to be quite a long afternoon and they're prepared for that and, you know, as they're prepared they don't seem to mind. Erm, we are usually, we're always down here, we try and be in clinic with Mr Holt and Mr Chadwick, from the time the patient first come. Right? Is that making sense?

INT: YEAH, MM.

Nurse: The other person that's in clinic is Julia, who's our Health Care Assistant and she only works with us, she doesn't work in any other clinics, so she knows how we work and she's part of our team, and she's a very significant part of our team. So the patients come in, erm, we try and keep things as sort of relaxed and unhurried and friendly as possible, and since we've been down and we've had this new building, it's much quieter, much more relaxed, and that seems to have filtered through to the patients, and they seem, it just generally seems more laid back.

INT: YEAH, HOW LONG AS THIS BUILDING BEEN UP THEN?

Nurse: It's been up since about, erm, I think it must be, yeah, it was July last year.

INT: MM, 2002.

Nurse: Yeah, yeah. And it really has made a huge difference, we've been a lot happier, and it does seem to, the patients appreciate it. I think it's easy to think that environment doesn't make a difference, but it jolly well does.

INT: WELL, YEAH, I USED TO BE AN ENVIRONMENTAL PSYCHOLOGIST.

Nurse: Oh well, there you are then. OK

INT: YEAH, I USED TO TRAVEL THE COUNTRY LOOKING AND HEALTH AND COMFORT ISSUES IN THE BUILT ENVIRONMENT, SO OFFICE BLOCKS - WE DIDN'T DO MANY HOSPITALS - WE DID OFFICE BLOCKS, THEY'RE BIG, YEAH, THE COMMON ONES, THEY'RE USUALLY BVERY BADLY DESIGNED. BUT ALSO IN PEOPLE'S HOMES AND LOOKING AT POLLUTION ISSUES AND HOW PEOPLE INTERACT IN THE ENVIRONMENT, NOISE, LIGHT TEMPERATURE. IT ALL HAS A MASSIVE IMPACT.

Nurse: Well I've always thought it does but there have been people who've sort of said, 'What difference does it make where you see somebody?' but I think it does, I think it matters as much as how you greet them and how you are with them and just the general ... yeah.

INT: YEAH, YOU SHOULD TRY WORKING IN THE HALLAMSHIRE.

Nurse: I'm glad I don't.

INT: IT'S A NIGHTMARE. ERM, HAS ANYTHING, IS THERE ANYTHING ABOUT THE WAY THE UNIT OPERATES YOU THINK ACTUALLY MAKES YOUR JOB VERY EASY TO DO, IS THERE ONE THING THAT PARTICULARLY STANDS OUT OR MAKES THE JOB VERY EASY OR ...

Nurse: Yeah, I think the, erm, I mean the two consultants we work with, I think if, I mean I know some people work with people who've got shall we say more [??] personalities, in other units, find it quite difficult. I mean our, both our consultants really are very good and will support us and, you know, tell us what's going on as much as they can. And we know how they work, they know how we work, and if there's any problems we talk them through and, you know, if we've got sort of issues about patients need to come to clinic unexpectedly, there's no problem, we just ring them up and say this lady needs to come to clinic, and they say fine, no problems. It just makes it easier, you know. And if we have any problems within the team, any other members of the team, we can sort of discuss it with them and we can work out a way to deal with it makes, it just makes it nicer. I don't think I'd still be here if they were difficult to be honest, and I think, because, it's a very, well it's a stressful job, and if you've got a stressful job and all the emotions involved with that, and then difficult people to work with as well ... I mean I do, I just don't think I'd do it.

INT: YEAH, YES, IT CAN BE VERY DIFFICULT.

Nurse: And I probably, I don't think I would have survived. And, erm, the patients like, seem to like the consultants, and they seem to trust them because they're very open and honest with them. And they've just sort of built us through.

INT: HAVE YOU WORKED AS A SPECIALIST NURSE ANYWHERE ELSE, I MEAN, WITHOUT GIVING ANY DETAILS?

Nurse: I haven't worked as a specialist nurse anywhere else, but I have worked, I've worked in a hospice for a number of years before coming here, and I've also had a colleague to work with who wasn't a very good colleague, who I did find very difficult. So I know, do you know, the difference between easy people and, you know, difficult people.

INT: IS THERE ANYTHING HERE ABOUT WORKING IN THIS UNIT YOU THINK THAT PERHAPS CONSTRAINS YOU IN ANY WAY, THAT YOU DON'T FEEL THAT IT ALLOWS YOU TO DO YOUR JOB THE WAY YOU WANT TO?

Nurse: Erm, I mean the thing is, constraint, things that we can't do anything about like government targets and deadlines and guidelines. Erm, as far as ...

INT: THAT'S THE FIRST TIME THAT'S CAME UP.

Nurse: I mean that's, that's really the most frustrating thing, if we were left alone to get on with the job, erm, and things you have to do, paperwork and, you know, the same things I'm sure everybody feels. One of the issues for us, and I don't know if it's relevant for this, is that we do feel that there's problems in communication between us in chesterfield and the Cancer Centre at Weston Park, it just is, there seems to be a big, black hole in the middle and we have, I mean I don't know if this is what you want to know ...

INT: ANYTHING YOU FEEL THAT [??]

Nurse: Well it does, I mean that is, that is really our biggest bugbear. I mean as I've said we've got a happy working relationship with the people here, but Weston Park's another story, and it's very difficult, very, very difficult.

INT: IS THERE AN EXAMPLE YOU CAN GIVE ME OF HOW THAT IS A PROBLEM?

Nurse: I mean it's mostly with, erm, adjuvant treatment, people who're having chemo, I mean I don't know if that's relevant ...

INT: WELL, IT'S ...

Nurse: Well, it's just that, well ... erm, when patients are, we see our patients right the way through and then they go to the oncology doctors, they talk about radiotherapy, chemotherapy, then they're taken over by them and they have the treatment, and, erm, the patients will phone us if they've got any problems, but we can't do anything about it and we have to refer back to Weston Park, and we're not getting any support, you know, it's sort of chucked back to us and it's very frustrating because, you know, all the way through, if they ring us with a problem we can kind of get back to our surgeons and say, you know, can we do something about this, or we know what to do. We can't once they get to Weston Park and it means they're just, it just seems the system comes to a stop and there's a big hole.

INT: RIGHT, YEAH.

Nurse: You know. So I think that's, that's quite a bugbear.

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

Nurse: Again, we're talking about the people?

INT: YEAH, AGAIN ...

Nurse: Well, I mean, I think for both our surgeons, I mean they have a sort of slightly different, obviously they're different personalities, so, you know, they've got a different way of doing things in a way, but they're both very open, honest and straightforward. I think, erm, ... it's just sort of personality which is the difference, I think the overall basic philosophy of the way they work is pretty much the same, you know, I wouldn't say there was a vast difference. ... Erm, I mean I'm not sure what you want me to ...

INT: NO, NO, I MEAN ...

Nurse: I think, I think I would say, erm, you know, that they're both, I wouldn't have anything else to say except they're both open and honest and very straightforward with the patients.

INT: MM, I THINK YOU SAID THAT EARLIER, YEAH, YOU SAID IT EARLIER AND THE PATIENTS SEEM TO APPRECIATE THAT, DON'T THEY?

Nurse: Well they do, I mean I know I did a, when I was doing my, I did a dissertation for when I did my degree, and I did a bit on patient information needs and this sort of thing, and one of the things that, well it was like a literature search thing really, going through the literature, and the thing that came out is that most patients preferred an open, honest approach from the consultants, and I really feel it's what they get here.

INT: OH THAT'S GOOD.

Nurse: Bearing in mind the pressures of time.

INT: OH YEAH.

Nurse: You know, I mean it would be great if we had hours and hours to spare but I mean I think they get the best they can get bearing in mind everything else that's happened. And they also get the opportunity to come back at any time and talk more. So, yeah, and, yeah, actually the other thing I notice, which I don't know how, I just don't know how they do it, erm, when they are pressured the patients wouldn't pick it up, you know, I've seen them when they're kind of, erm, must be feeling really frustrated and sometimes I know they are, and the patients come in and they sort of greet them as if they're, you know, the only person they've got to see and give them all the time and make them feel that this is all they've got to do and it's their time and they've got as long as they want.

INT: AH, THAT'S GOOD, YEAH.

Nurse: That's how it comes across anyway.

INT: I'D LIKE TO MOVE ON A BIT NOW TO JUST BEFORE CONSULTATION WEHRE A DIAGNOSIS IS TO BE GIVEN, ERM, I WOULD LIKE TO TALK ABOUT WHAT HAPPENS BEFORE CLINIC BEGINS, WHERE PATIENTS ARE ABOUT TO HEAR THERE DIAGNOSIS. AND FROM THIS POINT IN THE INTERVIEW I'D LIKE TO FOCUS ONLY ON NEWLY-DIAGNOSED BREAST CANCER PATIENTS.

Nurse: Right.

*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, it's held on a Tuesday lunchtime, erm, and if there's any sort of, there's a left-over, you know, that they haven't got the histologies for, erm, we have one on a Thursday afternoon as well: it's mainly therapeutic but we see any diagnostic ones that are left over from the Tuesday meeting.

INT: AND YOU SORT OF DISCUSS YOUR PATIENTS PRE-OPERATIVELY AT THAT MEETING?

Nurse: Oh yes, yeah, yeah.

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

Nurse: Erm ... well ... on a, bearing in mind it's lunchtime ...

INT: YOU'RE HUNGRY.

Nurse: Yeah, well we, no we have, we do have, it's a working lunch, so, and we go from the MDT ... straight through to clinic, and we have, on Tuesday afternoon we have a very afternoon because we have our own nurse-led clinics, we see results down here and we've got a fast-track clinic, so there's a lot going on and there's also a [...] clinic in Suite 1. So I suppose if I was honest my main feeling is, you know, 'Are we gonna get through everything?' and bearing in mind sometimes that we've got work to get through of our own before we get into clinic to see the people who're coming back for results. But we try and work it so that there's one in suite, and one down here. If we're both here it's fine but if one of us is away then it's, it's a bit difficult, and I suppose I feel a little bit anxious that I'm gonna be where I need to be.

INT: AND DOES THAT ALTER BETWEEN HEAVY AND LIGHT WORKLOADS? BY THAT I MEAN IF THERE'S A LOT OF BREAST CANCER PATIENTS COME THROUGH FOR DIAGNOSIS OR ONLY A FEW, HOW DOES THAT CHANGE?

Nurse: Yeah, I mean, if there's a lot you think, 'Oh,' you know, it's gonna a tough afternoon and we try and space them out, we try and space the appointments out so that we've got plenty of time to see them. But some patients will say, 'That's fine, thank you, no I don't need to talk, I'm going home,' you know and they've got a car; and other patients might take longer, and so there's a kind of worry that if we've got a lot and they're all going to take longer, are you going to give them all the time they need and are you going to be back for the next patient, you know, in time? Because we see them, we actually sit in with the consultant when they're getting the diagnosis and then the consultant'll say, 'I'll leave you with Mary or Donna' and, you know, we take them off into the quiet room or whatever and give them, hopefully, as long as they need, which can vary. Some people want to know everything and some people just want to sit and compose themselves.

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

Nurse: Yes, I mean, when we see people in the fast-track clinic, er, if they're having a core biopsy, we always - well we don't but the consultant always gives them an indication if, of what they think it's likely to be. So they may say, you know, 'I'm almost sure this is going to be OK but we just need to prove it,' erm, if there's any area of suspicion they'll say, 'Well, you know, we're not too sure' and if they think it could even turn out to be a breast cancer, which, when they actually say it sounds quite hard but it's important that they know so that when they come back the next week they're not sort of expecting brilliant news and then sort of to be shot down and told it's breast cancer.

INT: YEAH, KIND OF SOFTENS THE BLOW.

Nurse: Yeah, some patients, when we're almost sure it's breast cancer, you know, they do say 'I'm pretty sure this is going to be a breast cancer but we do need to prove it. When you come back next week, you know, we'll discuss it, bring somebody with you,' and they always say, you know, 'We will be able to treat it for you' when it's potentially curable.

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

Nurse: Well, as I've said, you know, if they're coming to the fast-track clinic, they've got a symptom, and most people, as soon as they find anything wrong with their breast, if they find a lump, they've got themselves quite worked up and most of them are convinced it's gonna be something horrible. So they're sort of prepared by the fact they've got a symptom in the first place. But if we are worried, then it's as I've said previously, you know, we sort of say to them, 'You know, this may turn out to be a breast cancer but we will be able to treat it for you.'

INT: SO WHAT ABOUT THE SCREENING PATIENTS, DO THEY DIFFER AT ALL?

Nurse: Erm ... what do we say to screening patients? We tell them if, well it's a little bit different because obviously it's smaller and we need to wait for the results for the biopsy and obviously there's nothing clinically defined, so you're looking at the results of the mammogram, so

they sort of tend to say things like, you know, it is, does look a bit worrying on the mammogram, we need to take ... to prove what it is. And obviously things, in general things that are found on screening are very early and very treatable and they'll sort of say, 'This is why you came for a mammogram in the first place'. Erm ... yeah. And that, erm, I mean it varies, I'm just trying to think, do we say ...? Yeah, I think that's really it, and sometimes, sometimes people might say, 'Well if it is a breast cancer, or you know it is what you say, erm, will I need to lose my breast?' And they sort of say, 'Well, you know, it's unlikely with something so small' or whatever. But it varies according to what the patient asks really. And also, I mean, if it's just calcification then they'll say it could turn out to be, erm, a very early, pre-malignant condition, you know. And we show them the marks of calcium and that, you know, if we need to remove them it's quite a simple thing, you know. It's actually quite difficult when you think about it.

*Q8. PRIOR TO A CONSULTATION WHERE YOU KNOW THAT A PATIENT WILL BE GIVEN A DIAGNOSIS OF BREAST CANCER, DO YOU HAVE ANY EXPECTATIONS ABOUT WHAT THE CONSULTATION WILL BE LIKE AND WHAT WOULD THEY BE BASED ON? I MEAN YOUR SORT OF INVOLVEMENT IN THE CONSULTATION?

Nurse: My involvement?

INT: YEAH.

Nurse: Well I mean, it's as I've sort of described really before, but we'd sort of be in clinic to see what's being said, and the discussion are very much with the consultant and the patient and the relative. I mean sometimes, you know, if it's appropriate to sort of chip in about radiotherapy or stuff like that or appointments, but generally we sit and watch and listen to what's being said. And then if they need to come through here to talk to us we can sort of pick up on any questions and it's not how, it's always, obviously there's things about what's said, but it's also how it's said as well, erm, that I think is important to them. I'm not quite sure what you mean about expectations, I mean, erm ... I mean, I know, I know how the doctor's work, we don't work with any doctors we don't know. We know how they work so we know more or less, we'd be very surprised if they suddenly changed the way they work, you know. Erm ... we always hope that the, I suppose I always hope that whoever's having the bad news has got somebody with them, erm, because it does obviously make a huge difference. We do always advise them to bring somebody with them but sometimes they don't.

*Q9. AND HOW WOULD YOU DESCRIBE YOUR FEELINGS BEFORE YOU GO INTO A CONSULTATION WHERE YOU KNOW THAT A PATIENT'S GOING TO RECEIVE BAD NEWS?

Nurse: I've thought a lot about that actually when I saw the question and ... when it's something you do regularly it's actually quite difficult to think what you do feel, because it's sort of all, you know, sometimes automatic. It depends who it is and how, well the first thing I suppose to say is that, you know, I always hope that, erm, I'm going to be able to give the patient what they need in terms of support and, er, information. Sometimes if you know that there's somebody very young or something, you know something a bit out of the ordinary or, there's always patients who, we try and treat everybody the same but inevitably some patients touch you differently than others. And, you know, if it's somebody really young or, you know, if there's something that's ... then you can think, 'Oh gosh, you know, this is going to be really difficult' and feel sort of a bit sad and think, 'Well, there's no point in me being sad because it's not going to help her, I've got to be with her really and give her [...] so yeah, but I mean I guess if I felt too sad then I wouldn't do it. We have to be really

practically because I think patients, it doesn't, it's not always helpful to be too much with the patients and what they feel because then you can't, you can't be involved in that and you can't move them on, which is what they need. Because most people, once they've got bad news, they want one thing - they want to go home really.

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 TYPICAL CONSULTATION WHERE DIAGNOSIS AND TREATMENT OPTIONS ARE BEING DISCUSSED WITH A PATIENT WHO HAS A BREAST CANCER? WHAT WOULD BE THE PROCEDURE IF YOU LIKE?

Nurse: Right, well, erm, the patient will know why they're coming back, as I've already said, they'd be warned. I mean we'd hope it would be, most of them would know, erm ... they both, both the doctors work the same way, I mean they sort of come in, sit down, they don't beat around the bush because what the patient knows is it is yes or no basically. And they sit them down and they tend to say, I mean do you actually want me to say what the [...] say or ...?

INT: YEAH, THAT'S FINE.

Nurse: Yeah, I mean they sort of tend to say things like, you know, 'We've got the results of the core biopsy and, as we discussed last time, unfortunately it has shown that it's a breast cancer, an early breast cancer.' Then they'll sort of talk about, you know, 'But we can treat it,' and it depends, it depends a bit about how, on how the patient responds. I mean some patients just sort of say, 'That's what I thought. Can you treat it for me?' Some people sort of get very emotional, obviously if they're very emotional then you have to deal with that, but as far as discussions about what kind of treatment they're going to have, erm, that's sort of really on a very practical level. I mean sometimes patients will say straight away, 'I don't want any discussion, I want such-and-such,' or they might say, 'Well you're not going to take my breast off because I won't let you.' Or they might say, 'I knew you were going to say this. I know somebody who ... she's had breast cancer, she had a mastectomy, she survived, that's what I want.' And they'll still say, the doctor's will still say, 'That's fine but you do need to have the information and, you know, we do need to sort of explain to you what the options are.' And they go through step by step, they explain that mastectomy, traditionally mastectomy was the treatment for breast cancer, but these days it's always necessary to have a mastectomy, but it is possible if there is a choice obviously to remove the lump. They talk about needing to have clear margins; they tell them about the possibility of needing further surgery, but they do actually give them a percentage and sort of say, you know, 'It is ...' I think something like, I'm not sure what the percentage is actually now, it's sort of about 50 per cent, something like that '... that you won't, but you do need to be aware there could be another operation. That both mastectomy and wide excision are as safe as each other, erm, providing that they have the radiotherapy treatment after the wide excision. OK. They always tell them that it isn't, they say that it's surgery first and then there'll be more treatment after that, most people would lead some drug treatment, but they're not able to tell them what drug treatment they'll need until we've got the results of the histology. They also talk about lymphosurgery and explain that, you know, that is an important factor in planning further treatment. If there isn't a choice of treatment, if it's a very large tumour and it's obviously got to be a mastectomy or if it's some other reason, they'll explain why there isn't an option, in their opinion mastectomy is the safest. Erm ... they also sort of say, talk about, you know, when would they like to have it done and if we've got, we can look in

the diary and sort of find a date for them. Some patients will say, 'Well hang on, I'm going on holiday, can I ...?' I mean not often, but sometimes they do, 'I've got a holiday, can I have my holiday first?' Some patients will say 'Can you do it yesterday?' and we get them in as soon as possible and they always say, make sure that they know that it's not emergency treatment, it's not a sort of biological emergency but, you know, maybe an emotional emergency, and if they want to have it done quickly then, you know, they can come in as soon as we can find a space, which is sometimes even the next week. Do you want me to go into it in more depth?

INT: NO, NO. WHAT I WAS GOING TO SAY WAS, SO AFTER THE INITIAL CONSULTATION WHERE THE NEWS HAS BEEN GIVEN AND THEY'VE DISCUSSED SOME TREATMENT OPTIONS, THE PATIENT, YOU'RE IN WHILST IT'S HAPPENING ...

Nurse: We're in there, so we're sitting at the back, hearing what's being said.

INT: YEAH, ACTUALLY YOU KNOW ...

Nurse: We know the actual ...

INT: THEN ARE THEY LEFT WITH YOU IN THAT ROOM OR DO YOU TAKE THEM SOMEWHERE ELSE?

Nurse: That's the consulting room through there, and this is why we planned it like this, erm, the only thing we haven't got is very good soundproofing, but yeah, what we do, we sort of always bring them through here, even if they just say, 'Well I want to go home,' we sort of sit them down and we, they just, sometimes they can be sitting in there, 'Yes, Mr Holt, that's fine' you know, 'That's fine,' and they come in here and they just whoosh, all the emotions come out. And that's fine. Some people want to talk, some people want information on just about everything - they want to know about chemotherapy, they want to know about - you know, you name it, they want to know. And some people just need to sit and recover, just need to, they don't really want to talk they just want you to sit with them and be with them and, erm, just give them a chance to - I hate using words like 'compose themselves' but basically that's what they're doing.

INT: YEAH, TIME TO THINK IT OVER, LET THE INFORMATION SETTLE IN.

Nurse: Yeah. And, erm, the other very practical thing I think that helps with that, it helps them to move on, is that we try and arrange the pre-assessment visit on that day - I mean we make the appointment on the same day, so they will have been told that, 'Well you'll come in on the same, on the day of the operation, we will need to see you beforehand, and you'll have the opportunity to see us again at pre-assessment and discuss with the consultant, you know, everything we discuss today. OK? So the consultant will be doing the paperwork in there, we'll be here in the patient, there'll be a knock on the door and it'll be Julie and she'll say, 'These are the bits of paper for the pre-assessment' and when the patient's ready - 'cos sometimes patients'll say, 'Well what ...' you know, they'll be sitting there feeling weepy and they'll suddenly think, 'Right, well what do we do next now?' you know, and sometimes we can say 'Well, you know, are you ready to go up to pre-assessment?' So we walk them up to pre-assessment and that kind of moves them on. And I very often find as we're walking up the corridor they seem to just switch back into, 'Let's be practical and get on with it.' So we take them up to pre-assessment, wait till they've got the appointment and just sort of make sure that they remember that we've given them a contact card, that they know where they're coming next time, and say, you know, you ring us if you need us for anything at all.

INT: SO DURING THAT TIME WITH THEM DO YOU USE ANY SORT OF TOOLS, SUCH AS DO YOU DRAW DIAGRAMS OR DO YOU USE ANY KIND OF LITERATURE TO HELP YOU EXPLAINING, WHILE YOU'RE EXPLAINING THINGS TO PEOPLE?

Nurse: No, because the consultants, both of them, by the time they've finished talking with patients, they do all that, they draw diagrams, erm, very carefully, and you know talk about the treatment and why. I mean Mr Chadwick, I think, nearly every single time will sit and draw and say, 'Now it's important,' you know, 'This is what we're going to do' and explain, erm, through the drawing, so we don't really need to do that. And sometimes the patient will say, 'Can I have that bit of paper?' and you let them have it. Mr Holt quite often does it but not always, but it's not something I do particularly.

INT: DO YOU HAVE A PREFERRED STYLE OF APPROACH WHEN YOU COME INTO THE ROOM WITH SOMEBODY? IS THERE SOMETHING YOU WANT TO TRY AND ALWAYS START WITH OR ...?

Nurse: Erm, it depends how they are, I mean, I try to be tuned in to how they're feeling and I think the most, if I had to be honest I'd say the most difficult thing I find is, to pick up on, is to move on to be practical, because my, what I would do is, my training is sort of counselling stuff and I would want to sit down with them and sort of say, you know, erm, just let them have some quiet and deal with their feelings. But I've learnt that doesn't always help them, because it's not the right ... it's difficult to sort of explain really but it doesn't always seem to be the right time. You can, I can do that to a certain extent but then you kind of, it's sometimes more helpful to be practical. So ...

INT: DO YOU THINK YOU'VE GOT SOMETHING THERE BETWEEN SORT OF WHAT YOU, YOU OR THEY PERCEIVE AS YOUR ROLE AS A NURSE AND YOU AS A PERSON?

Nurse: Yeah, yeah.

INT: BECAUSE [...] WHAT YOU JUST SAID IS TWO THINGS THERE, YOU'RE JUST TRYING TO EMPATHISE AS A PERSON AND TO UNDERSTAND HOW THAT PERSON FEELS, AND THEN THERE'S A PART OF YOU WHICH IS SORT OF SAYING, 'BUT, YEAH, I'M ALSO A PROFESSIONAL AND I NEED TO SORT ...'

Nurse: Yeah, and I mean I've, erm, yes, I think ... I think I've realised that what the patients need from me, yes they do need obviously empathy to a certain extent but you can, I think, at this stage you can overdo it because what they need from me is practicalities because, erm, they need to my job is to sort of move them on and help them through this, and there's other people who can sort of, they can turn - that sounds awful, I don't mean that the way that sounds - but you know what I mean? That my role is to help them through this, it's like, you know, 'I'll hold the light and you walk it' kind of thing, it's my job to hold the light, not to sort of sit with them in the darkness. Oh ... you know, you know what I mean, I find it really difficult to describe these things because we're talking about feelings and they're often hard to ... but, yeah, I think, I think it's the practical, trying to be practical and move them on is the best help, and I think that's what they appreciate.

INT: SO DURING THIS TIME THAT YOU SPEND WITH THEM WHO DOES MOST OF THE TALKING DO YOU THINK? WHO ASKS MOST OF THE QUESTIONS?

Nurse: It depends on the patient.

INT: GENERALLY DO YOU THINK?

Nurse: I think, I think, who does most of the talking? Erm, I suppose I'm giving information but I don't really like the way that sounds. I don't think, erm ... I suppose generally I do. There isn't always a lot of talking that happens, erm, so I suppose I'd be saying to them 'Well what we need to do next is such-and-such, have you any questions?' Erm, sometimes I think I talk too much but, yeah, I would say so. I don't think, I think they've had enough information already and they can only take in so much so I think the thing to do is to just let them gather themselves and move on practically.

*Q11. SO CAN YOU TELL ME ABOUT ANY ADDITIONAL TIME YOU USUALLY HAVE WITH A PATIENT AFTER YOU'VE SEEN THEM? THEY'VE COME THROUGH FROM SEEING THE CONSULTANT AND YOU'VE HAD TIME WITH THEM HERE AND THEN YOU WALK THEM TO PRE-ASSESSMENT I THINK YOU SAID, MAKE AN APPOINTMENT, SO AFTER ALL THAT'S HAPPENED THEN WHAT KIND OF CONTACT DO YOU HAVE WITH THE PATIENT AFTER THAT ... GENERALLY?

Nurse: Well, we used to see everybody in pre-assessment but basically, by the time they've been through pre-assessment and done all the stuff they have to do up there, they've had enough, so, and also there's a limit, limitation of space up there and we're basically in the way and not really being very helpful, so what we've said is, unless somebody actually says to us, 'Oh, will you be there?' we don't go up: what we say to the nurses up there, any of our patients who want us or you think need to see us, give us a shout and we'll come up, and we also say this to the patients. We say, you know, 'We won't be in the pre-assessment clinic but we are on call so just tell one of the nurses if you want us.' So we would be available for pre-assessment: sometimes patients will phone us, not always, well far from always, but sometimes patients will phone and say, basically, I mean it doesn't happen very often but, you know, 'Can you just, can I come and see you, can you just tell me, can we go through again what was said yesterday?' or if they're having a mastectomy they may say, 'Can I see some breast forms?' or 'Can you tell me what's gonna happen afterwards?' and they may want to sit and go through everything that's been said. So, and it's sort of an open door policy: you know, we give them the card, the ball's in their court, we don't know how they're feeling, but sometimes if patients are particularly, if it seems appropriate and they're particularly distressed or something, I might say to them, 'Well look,' you know, 'Here's our card, we'd really like to know how you're getting on. Perhaps you'd like to give us a ring in the morning?' And they do, erm, I used to ring them at one time, I used to ring them all, and it wasn't appropriate, it just wasn't appropriate. So we don't do that, so we leave the ball in their court really.

INT: AND HOW LONG IS IT TILL THEY COME BACK AFTER THAT?

Nurse: Well they'll be coming in then: they're usually coming in within, usually within a fortnight.

INT: RIGHT AND DO YOU GET TO SEE THEM PRE-OPERATIVELY ON THE WARD THEN, YEAH?

Nurse: They're coming in the day of the operation so no, we don't, we don't see them again pre-operatively unless we're asked to. When I go up to see them pre-operatively I don't think I'm doing them any favours because they don't really want to talk, they don't know what to say. Sometimes if I'm seeing some post-op patients on the ward and a pre-op patient's around I'll sort of say hello, but it's, erm, it's just a sort of social chat, they're just, because they're very near to going to theatre, and they just, it's just not on.

INT: AND DURING ALL THIS TIME FROM THE MOMENT OF GOING TO THE CONSULTATION ROOM UNTIL THEY'VE HAD THEIR OPERATION, ARE YOU AWARE OF ANY INFLUENCE, ANY THIRD PARTIES SUCH AS FAMILY, FRIENDS, ANYTHING LIKE THAT?

Nurse: Oh very much so, yeah.

INT: CAN YOU DESCRIBE SOME OF THOSE TO ME?

Nurse: Well I think some patients are very influenced by, well first of all by their own experiences of breast cancer, if they've had anybody in the family who's had breast cancer or a close friend, or any cancer, that has quite an impact on how they deal with things. Erm, and people may say to them, 'Oh you should have this operation, you should have that operation' or 'This'll happen to you, that'll happen to you.' And it does sort of influence very much how they deal with things. They may have sort of, one of the things we get is sometimes people say, 'Ah well, I thought, I didn't know what the scar would look like, I thought I was going to have a big hole and So-and-So said, "Oh, you know, it's going to be like this, it's going to be like that"' and they worry about that sort of thing. They're also influenced by what's in the media, very much so, because there's always a lot of mis-information in the media about breast cancer. We sort of try and tell them to keep away from that. Erm ... sometimes they'll be influenced by another healthcare professional, they might contact Breast Cancer Care because we offer them written information, so they might contact Breast Cancer Care, they might want to see, talk to other people who've been through breast cancer, erm, so that might have had an influence on them. ... What's, they might have been on a website and come up with loads and loads of research from, [chuckles] wherever, and, yes, wanting to know why we're not doing it this way. Er ... some patients will go to their GP and talk to the GPs, not all of them. I think that's ... it's difficult really because it's, I think people are influenced by so much because you can't get away from breast cancer, so they're bound to be influenced. And if you speak to anybody, erm, every, you know, everybody seems to be an expert on breast cancer, and everybody's got opinion, and so if they talk to people, erm, tell them what's happened, then somebody's going to give them an opinion and tell them what they ought to be doing. Sometimes people are quite distressed by what other people say, erm, sometimes people say that 'I was fine until I started telling other people: I'd decided to have operation a, and they said, "Oh, you shouldn't have had that, fancy having that, fancy having a mastectomy," or "Fancy not having a mastectomy" "Oh you don't want to have radiotherapy, I know somebody ..."' you know, and all this sort of thing, and it can upset people quite a lot.

INT: IT CAN BE QUITE CONFUSING I THINK AS WELL.

Nurse: Very confusing, yeah.

INT: IN BETWEEN FIRST HEARING THEIR DIAGNOSIS THAT THEY HAVE CANCER, HOW LONG DO YOU THINK IT IS FROM HEARING, FROM THAT POINT TO THE POINT WHERE YOU THINK THAT THEY'VE ACTUALLY MADE UP THEIR MINDS? JUST GENERALLY, HOW LONG DO YOU THINK IT TAKES THEM TO MAKE, PATIENT TO MAKE THEIR MIND UP ABOUT WHAT TREATMENT THEY'RE GOING TO HAVE?

Nurse: I think some people have a gut feeling and they've made their mind up before they walk in the door, no matter what. It depends on the, how they are. I mean bearing in mind they're in within a fortnight usually, I think usually by the time they come to the pre-assessment, which would be about a week or so afterwards, I think they've usually made their mind up. Some don't. I think most people are happier when they have made their decision. So I would say probably not very long actually, thinking about it: I think most people have got a pretty good idea before they leave here

what they're going to do and most, I think that most people don't actually change their minds. Some people don't make a decision, I mean there's no pressure to make a decision and both the surgeons say, you know, 'If you don't want to make the decision until you go down to the theatre,' you know, 'till the day of the operation, that's OK.' They're not pressured, and they always give them time to make that decision. And even if they make the decision then [...] they say, 'You know what you said, Mr Holt, Mr Chadwick, you know, this is the operation I want and I've heard what you said, but I'm telling you that's what I want,' they'll always say, 'Well I still think you should go home and let the dust settle and think about it because, you know, erm, you need to think about it and discuss it with your family' and whatever.

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

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

Nurse: Well, some people know nothing except what, you know, ancient myth and ritual has taught them from the past, and they've got all sorts of weird ideas: some people know an awful lot, and some people in between. Some people know, you know, are very well informed because they've been on the net: some people think they're well informed and don't, well they are quite well informed but they're not, they don't really know as much as they think they do about what's going to happen. Erm, and I think it varies, I think generally most people are reasonably well informed but, well actually I don't, I don't think that's true. I think most people know about breast cancer from women's magazines, [...] most people think it's a death sentence, or they do when they get the news, yeah.

INT: SO DO YOU THINK IT MAKES IT HARDER OR EASIER TO HAVE A CONSULTATION WITH SOMEONE WHO KNOWS A LOT ABOUT THESE THINGS, OR ANY HARDER OR EASIER BECAUSE THEY KNOW LITTLE, OR WHAT?

Nurse: I don't think ... gosh, I don't necessarily think it's what they know, I think it's what they know, I think it's what their personality is. I mean some people deal with things by being quite ... aggressive is the wrong word to use, but you know what I mean, it's sort of, they'll sort of say, 'Well, yes, of course I know that, Doctor,' and they don't want, you know, 'I ... this is what you're going to do and this is what I'll have,' and can be quite opinionated and don't want to listen, are unable to listen to what's being said. So they can be quite difficult. But then the other people are difficult, other people who don't know anything and will sort of say, 'Whatever you say, Doctors, is OK' and you might think, well, oh that's easier because we can just say, 'Well this is what you ought to have,' but if there's a choice then it truly is their choice and they have to make that choice. And I guess what we say to those patients is ... well probably to any patient, but particularly to the ones who are having difficulties making their minds up and when there truly is a choice, I would say, 'If there's any doubt in your mind you're probably better opting for the lesser option, ie the wide excision because you can then change your mind after and have a mastectomy [chuckles] but if you've had a mastectomy you can't go back and have a wide excision.' So I'm not sure that it makes a lot of difference what they know: I think it's how they deal with it. Does that really answer the question?

INT: YEAH, THAT'S FINE. I'M ASKING IN YOUR EXPERIENCE ...

Nurse: Yeah, I mean I don't find, I really don't find dealing with people who know, who know a lot or don't know a lot, it's more about how they are as people.

*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: Well, straight away they want to know that it can be treated: they want to know that they're being, going to be dealt with by a team who know what they're doing, they want to have confidence in the people who're looking after them. They also need to know, they want to know what the treatment is, when it's going to happen, and they need to know the full story. They often say, 'Well, will I need chemotherapy? Will I need radiotherapy?' And that happens at the first visit, so I think they need to know the full story of what all the treatment's going to be as far as we know, and what the journey's going to be, you know, that it's not sort of - surgery, that's it, finished - they need to know that it's going to be further treatment. And they need to know that there's some questions that we can't answer at this stage and why we can't answer them. And they need to know the landmarks along the way.

INT: SO WHEN DISCUSSING DIAGNOSIS, WHAT DO YOU THINK PATIENTS UNDERSTAND WELL ABOUT WHAT'S TOLD TO THEM, DO THEY SEEM TO TAKE SOMETHING IN THAT YOU DON'T NEED TO REPEAT ANYTHING AND THEY SEEM TO DEMONSTRATE THE KIND OF UNDERSTANDING THAT ...?

Nurse: I need to see this - can you just - which page are on?

INT: IT'S PAGE 4 OR SOMETHING LIKE THAT. IT'S QUESTION 13.

Nurse: OK. Well, yeah ... well that they're going to survive. Are they going to die, can they be treated, has it spread.

INT: AND IS THERE ANY INFORMATION YOU THINK THAT THEY UNDERSTAND POORLY ABOUT DIAGNOSIS?

Nurse: Yeah, it's difficult to get their head round the idea about how complicated the treatment is and that it's not ... you know breast cancer treatment you could say is not sort of a one-off event, it's an ongoing process and it's a long, often quite tedious, tiring journey, and you're talking - if they're having chemo - of months of treatment. Because very often they think, 'Right, Doctor, get it off and then I can get back to work.' Well for some people, yeah, but, you know, usually not, usually not. And I think they find that very difficult and they also find it difficult - oh the other question that always comes up is, particularly with wide excision, 'If you open me up, Doctor, and you see it has spread, will you do the mastectomy then instead of the wide excision? Why can't you tell, you know, why do you have to wait for the pathologist to tell you that the margins aren't clear? you know, 'Why do I have to ...' and we have to sort of talk to them quite a lot about that and they find that quite difficult to understand. But that's when the diagrams come in very handy that the doctors do. I think they find that difficult and they find the concept of having to wait for their results difficult. They also find, I think, people don't understand the difference between radiotherapy and chemotherapy and talking about local treatment and systemic treatment, and also that whatever other treatment they have is adjuvant treatment, it's not necessarily treating the cancer, it's treating the risk, and that's quite tough to understand.

INT: SO THINKING ABOUT TREATMENT OPTIONS NOW ...

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

Nurse: ... Well they need to know ... they need to know, you know, what the operation is, they need to know when they're going to come in, they need everything ... I think they need to know from the beginning, I think I really would repeat what I've already said, you know, that they need to know the full range of treatment and I think they need to know it from the start. I think the thing that people have said in the past is that, 'Well the first time I came you told me I needed this treatment, and I've had that done, I've had the surgery, and now I've come back you tell me I need a bit more surgery and you didn't tell me that the first time, and now I've come back again and I've had the surgery and you tell me I need chemotherapy - why didn't you tell me all that at the beginning?' So I think it's important that they know from the beginning that they have, that it's going to be, you know, a long haul and that there's going to be a lot of different treatments. I think what they need to know most is which is the bit that comes first, what am I going to do, what's the next thing I've got to do, you know, sort of like a treatment plan. So, OK, this treatment may take six months but what you've got to do now is the bit that's in front of you: the next thing we need to do is to give you the appointment for the pre-assessment and then we need to get the operation sorted out, and then we'll keep you informed about the next step as and when it happens. That's what I think, and they need to know that, when they're going to be seen after the operation as well, that we'll tell them the results within a certain length of time.

INT: I'D LIKE TO MOVE ON A BIT NOW TO WHAT A PATIENT IS OFFERED ...

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

*a. ONLY BREAST CONSERVATION SURGERY. ANY INSTANCES WHERE YOU THINK YOU'D OFFER ONLY BREAST CONSERVATION SURGERY?

Nurse: Well, I mean, I understand the question but, even if you offer only breast conservation surgery, sometimes people will say, 'I don't want breast conservation I want to have a mastectomy' so for example, if it's a small, particularly screen detected tumour, something like that or DCIS or something, you obviously wouldn't be talking mastectomy, but even then, you know, some people would still say, 'Sorry, Doctor, I want a mastectomy.' I mean we tend to say that, you know, if it's a small lesion and we could get a good cosmetic result, we'd sort of say, 'Well, you know, you wouldn't need to lose your breast,' but sometimes people would say, 'Well, I know, but I don't want to live with a breast that's had breast cancer in.' So I mean we don't go round saying, promoting mastectomies, but you know it does always come up, not that you can have mastectomy if you want it, but traditionally the treatment would have been a mastectomy, that would well be over-treatment, and this is why it could be over-treatment because this is the size of the lump as we see at the moment, this is how it looks on the mammogram, so providing we can remove that small area with an area of healthy tissue round it, you don't need to lose your breast. But some people still say ... yeah ... a mastectomy.

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

Nurse: Erm, large tumour, small breasts; heavy nodal involvement; centrally placed tumour; anything that they felt, the surgeons felt they couldn't get a good cosmetic result, then they may say, 'Well we could remove ...

sometimes patients will say, 'Well could you remove the lump?' and they say, 'Well, yes we could but, you know, we wouldn't be very happy with the cosmetic result and there wouldn't be much breast left.' Anything obviously coming through the skin.

INT: OF COURSE NOT.

Nurse: If it was DCIS and it was diffuse, obviously multifocal, erm ...that's about it really, sort of large tumour small breast; patient choice; multifocal, coming through the skin, I think, I haven't missed anything out.

*c. AND CAN YOU DESCRIBE THE FACTORS THAT LEAD YOUR TEAM OFFER A CHOICE BETWEEN MASTECTOMY & BREAST CONSERVATION SURGERY?

Nurse: Well in all the cases we've already talked about. I mean if the doctors, if it was, they'd need to be sure they could get a good cosmetic result. If they could get a good cosmetic result and this is where I'm going to bring the oncologists in, because if you've got, we find particularly it's quite a difficult area, the surgeons may be quite happy to do a wide excision, if you've got a very small area in a large breast, and then they radiotherapy, you know, if they need radiotherapy, the radiotherapist would say, may well say, 'Well I can't, I'm not prepared to do radiotherapy to that woman's breast because it's too big,' so then we're left with a sort of problem about, you know, do you say to the patient, a patient that's got a very small, early tumour, 'Well sorry we've got to do a mastectomy ...' which seems crazy, 'because you're not suitable for radiotherapy,' or do you then say, 'Well maybe we'd start of with a wide excision, hopefully you could be in a position where you don't need radiotherapy.' Sometimes we need to send them along to see the oncologist first, and that's really quite difficult. I'm sorry I've lost my thread ... can you?

INT: YEAH, THE QUESTION IS WITHIN THE CONTEXT OF THE UNITS' GUIDELINES AND PUBLISHED RESEARCH, PLEASE DESCRIBE THE FACTORS THAT WOULD LEAD YOUR TEAM TO OFFER A PATIENT A CHOICE BETWEEN MASTECTOMY AND BREAST CONSERVATION SURGERY? AND YOU WERE SAYING ABOUT COSMETIC RESULT, RADIOGRAPHERS, ONCOLOGISTS.

Nurse: Yeah ... yes sometimes a patient would say, 'I hear what you're saying ...' but they totally refuse to, they could, if they sort of say, 'I'm not having a mastectomy,' then obviously they'd try and do a wide excision for them, which doesn't very often happen.

*d. SO WHAT FACTORS WOULD LEAD YOUR TEAM TO OFFER A PATIENT ANY OTHER TREATMENTS?

Nurse: Where are we ...?

INT: NUMBER 15.

Nurse: I'm sorry, I've just lost it at the moment.

INT: NUMBER 15.

Nurse: Yeah, and the question is ...

INT: OFFER A PATIENT ... AH, SORRY, THIS HAS BEEN MISSED OUT ...YEAH, THERE'S FOUR CATEGORIES, THERE IS ONLY BREAST CONSERVATION SURGERY, ONLY MASTECTOMY, CHOICE BETWEEN MASTECTOMY AND BREAST CONSERVATION, AND I WAS

ASKING YOU ABOUT ANY OTHER TREATMENTS. SO WHAT FACTORS WOULD LEAD YOUR TEAM TO OFFER A PATIENT ANY OTHER TREATMENTS?

Nurse: Do you mean for surgery or for ...?

INT: SUCH AS RADIO, CHEMOTHERAPY, THINGS LIKE THAT, AND BEFORE OR AFTERWARDS.

Nurse: Right ... well, I mean, obviously the results of the - we're talking about results here, aren't we?

INT: Mm.

Nurse: I mean they all go on to see the oncologist, the only ones that don't if they're obviously very, very low MPI and it's just Tamoxifen, they don't always go on to see the oncologists so we just would give them Tamoxifen and they'd be discussed at the MDT to make sure the oncologists are happy. Chemotherapy depends, you know, we work according to the guidelines, which, you know, I'd find difficult to talk about really without having them in front of me. I mean I don't know how much you actually do you want me to go into, but I mean most people have some sort of follow-up treatment and would go on to the oncologist - obviously anybody who's had a wide excision would certainly go on to talk about radiotherapy and nodal involvement and the MPI would dictate what further treatment they had, whether it was hormonal treatment or chemotherapy, whether they're ER negative, ER positive, and as I'm sure you know - I don't know if you've seen the guidelines - but they're quite complex and it would be sort, I mean we work according to those. I mean obviously if patients have, you might find a patient falls into a certain category and she'd have treatment, on paper she'd have treatment A and they may not be fit enough say for chemotherapy so obviously then, you know, you've got to look at the whole patient, I mean you're not going to kill them but you don't want the treatment to kill them if they've got other medical conditions, obviously you have to take those into account. And some people will say, 'I don't want chemotherapy,' or some other people will say, 'Oh my God, why aren't you giving chemotherapy? My friend down the road has it and she had chemotherapy, why can't I have it?' you know. But generally we, obviously we sort of stick to the guidelines and if there's any reason to sort of, you know, not to do what it says on the paper, we still, they still discuss with the patient what the options are and why a different treatment's recommended.

INT: THE LITERATURE SUGGESTS THAT PATIENTS IN VARYING DEGREE OF INVOLVEMENT THAT THEY WANT WHEN MAKING DECISIONS ABOUT SURGERY, WHAT SURGERY TO HAVE, SOME PATIENTS WILL WANT FULL CONTROL OF THE DECISION MAKING PROCESS AND SOME WILL PREFER THE SHARE THE CONTROL, WHILST OTHERS WILL PREFER THAT THEIR PROFESSIONALS TAKE FULL CONTROL ...

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

Nurse: Yes. Yes I do. I don't know how else it could be. I mean I haven't any experience of working as a breast care nurse in another unit, so I don't know how they work, but I don't honestly know how we could give them any more choice that they've got. I mean they're given all the information; they're given a chance to come back and discuss it again; they're given plenty of time and I don't know what else we could do really.

*Q17. THINKING ABOUT YOUR EXPERIENCE WITH PATIENTS THAT YOU SEE HERE, CAN YOU LOOK AT THIS, THERE'S FIVE BULLET POINTS BELOW THERE AND CAN YOU TELL

ME, DURING CONSULTATIONS, WHO GENERALLY MAKES THE FINAL DECISION ABOUT WHAT SURGICAL TREATMENT TO HAVE?

Nurse: The patient. I mean, if we're talking about choices, you know, I mean we are talking about choices here, aren't we?

INT: Mm.

Nurse: I mean if it's a choice, the patient. In fact sometimes when I listen to what the patients say, the patients are sort of leading, you can feel them almost wishing, them saying, 'For goodness sake, don't leave me to make this decision, tell me what I need.' And you think, you know, they're going to say one thing or the other, but they don't. So we always leave the patient to make the decision. So I think the patient has final decision.

INT: IS THAT THE FIRST ONE OR SECOND ONE - THERE'S TWO - THE PATIENT TENDS TO MAKE THE FINAL DECISION REGARDING TREATMENT THEY WILL HAVE, OR THE PATIENT TENDS TO MAKE THE FINAL DECISION ABOUT WHAT TREATMENT THEY WILL HAVE AFTER SERIOUSLY CONSIDERING MY OR CONSULTANT'S OPINIONS?

Nurse: I would say that patient tends to make the (2) and I wouldn't say it was my opinion, I would say it would be the consultant's opinion.

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

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

Nurse: Well I've looked at this and I found it really, really difficult.

INT: CAN YOU THINK OF ANYBODY WHO YOU THOUGHT [...] ACTIVE OR HEADSTRONG IN SOME WAY ABOUT MAKING THEIR DECISIONS, SEEMED TO KNOW EXACTLY WHAT THEY WANTED.

Nurse: Straight away?

INT: MM. CAN YOU TELL ME A LITTLE BIT ABOUT THOSE PEOPLE WITHOUT REVEALING ANY CONFIDENTIAL DETAILS?

Nurse: Well we had a patient yesterday who I think has made, I mean she's gone away to think about it but I mean, because that's what we've suggested she does, but my opinion is she's made her decision anyway.

INT: SO WHAT HAPPENED WHEN THEY CAME INTO CONSULTATION? HOW DID IT GO?

Nurse: She was given, she was expecting it to be breast cancer because she'd been told last week that there was concerns, and she'd come with her partner or husband, and she'd been told, yes it was a breast cancer and now we need to talk about treatment. She was told that, it was Mr Chadwick, and he said 'Treatment, sort of, there's quite a lot to discuss, you will have some questions but I need to sort of explain to you what the treatment involves and what the options are and then you can ask the questions or you can stop me along the way,' so he always starts by saying, you know, traditionally that mastectomy was the only treatment for breast cancer and then he says 'Of course it works, but, as I'm sure you know, sometimes it can be over-treatment and it may not be necessary to lose the breast. There's no difference in outcome, they're both as safe as each other otherwise we wouldn't be offering you a choice, but providing certain conditions are met ...' so he did all that. And then she said, 'Well I've talked about this and I want to have a mastectomy, I don't want to have to go to Weston Park, I don't want to travel.' So Mr Chadwick said, 'Well travelling doesn't have to be a problem because we can provide transport.' And she said, 'Oh well I haven't got a car.' 'No, we can provide transport,' and she said, 'I don't want to travel. I want to have a mastectomy.' And he went all through, he wasn't sort of deflected, he went through every, each step of both options and at the end of it she still said, 'I don't want to go to Weston Park, I want to have a mastectomy.'

[Interruption in recording]

INT: THAT'S IF, SO IF YOU CAN JUST PICK UP THE STORY ...

Nurse: Right, oh you said, yeah, what was she like in there, in there she was, and you asked me what she was like in here ... well a couple of times when she was talking to Mr Chadwick she did kind of turn round and particularly talking of cosmetic stuff, and she did to say to him, 'Well what will I look like,' and he said, 'Oh maybe we've got some pictures we can show you,' and, you know, I said, 'Oh well we can come through afterwards.' And she sort of went to go that way through the other door, and I said, 'Well why don't you just come in here, sit down a minute' and she, you know, 'And I can just, need to give you some information about pre-assessment.' And she breezed in here, she sat down and she sort of put her head in her hands and was upset and her husband was comforting her and I said, I just sort of felt that I was in the way, so I sort of said, 'I shall leave you alone for a couple of minutes,' which I did. She wasn't sort of distraught, I mean it wasn't sort of emotion, fury or, you know, deep sobbing, it was just what you'd expect really. And they just wanted some time to say whatever they wanted to say to each other and give each other a bit of comfort. So then I came back in and she was asking about what the mastectomy scar looked like and could she see pictures, and I said, 'Well ...' I mean normally I don't show people pictures, but I did actually have a very positive image, so I sort of explained what it would be like and I showed it to her ... and she said, 'Oh that's better than I thought, and of course I felt quite strange doing that because they don't normally show pictures, and then she said, 'Oh well, I know everybody'll look different,' and I said, 'Yeah, this is one person's scar, but basically that's where it goes, so you see there's no holes or anything like that.' Then she wanted to talk about breast forms, could she see what they were like, she thought she was quite heavy breasted but in fact in our terms she wasn't particularly, so we showed her the breast forms and she said, 'Oh, yeah, not too bad.' She had a bit of a weep and I told her that, I think we arranged the pre-assessment, went up to pre-assessment, went up to pre-assessment and I said, 'Look, you know, we're not going to be phoning you, you've got our contact card, if there's anything at all you want to know, even if it's just, you know, what did, what was it all about, you know, did I hear it right - whatever it is, give us a ring: ball's in

your court' sort of thing. And I think I also said, you know, 'You do need to go home and think about this, you don't have to make the final decision,' and she sort of intimated that she had already and that there was no way she was going to have radiotherapy or travel.

INT: YOU SAID EARLIER ON THAT SHE'D SAID 'I'VE TALKED ABOUT THIS' ... I PRESUME THAT WAS WITH, DID YOU SAY HER HUSBAND WAS THERE?

Nurse: Mm.

INT: WOULD THAT BE RIGHT OR DID THAT NOT COME OUT?

Nurse: What that ...

INT: SHE SAID SHE'D TALKED ABOUT IT.

Nurse: She said she'd thought about it and she also said she knew somebody, I'm sure she said that, you know, but she and her husband had talked about it, we didn't sort of really get into that. She just said she'd decided that that was what she wanted to do. And I did say, you know, we did say again, you know ... oh yeah, I know what, I do remember actually, I said to her, 'Well, it's very easy ...' she was saying 'I want a mastectomy,' I'd got the breast form in my hand, and I said to her, 'Well you know you may well decide to have a mastectomy because it means you don't have to go to Weston Park and you can avoid the five weeks of treatment and travelling ...' but we both, Mr Chadwick said it several times and I said it as well, erm, the five weeks will come to an end, you know, it does end - yes, it's a difficult five weeks, there's lots of travelling, it does come to an end. If you have the mastectomy that's fine and in the cold light of day it's often, sorry, you know, when you're feeling very emotional and you've got a diagnosis of breast cancer, it's often a gut reaction to say, 'Just cut it off, get rid of it' but remember you're going to wake up from the operation - I don't think I quite put it like that, but you know basically you've got to think how you're going to feel afterwards - are you going to feel, 'Well, did I really need to have this done?'

INT: WAS SHE A YOUNG OR OLD PATIENT?

Nurse: She was ... forties, no in her fifties I think. Spring chicken. Yeah, she was in sort of mid-fifties I would say, yeah.

INT: AND APART FROM THE WESTON PARK RADIOTHERAPY THING, WAS THERE ANY OTHER INFLUENCES APPARENT ON HER DECISION, DO YOU THINK?

Nurse: Well, she didn't say ... but I always get the feeling that, sometimes, there's two things: one is 'Cut it off, doctor, and then it's gone' and there's another sort of underlying thing which people feel that if they don't have a mastectomy, they're chickening out and she should, this is the price they've got to pay for being cured, and that it's just a kind of sense you get that, I'm not sure if I got it with her or not, but I do think it is an issue for women, for some women, particularly sort of ... I was going to say hardworking women - I don't mean that but, just, there is a sense that, 'Right, I've got breast cancer so therefore I need to have a mastectomy and if I have a mastectomy everything'll be all right, if I go for the vain option then it'll come back and it'll be my fault because I've been vain, so therefore I should have the mastectomy.' It's like, you know, 'this is the price I have to pay for a cure.'

INT: I'VE HEARD THAT BEFORE.

Nurse: And it felt, I think there's a bit of that.

INT: LOOKING BACK AT THE EXPERIENCE, HOW SATISFIED WERE YOU WITH HOW THAT CONSULTATION WENT?

Nurse: You mean for my bit of it, or the whole thing?

INT: THE WHOLE THING.

Nurse: The bit that was in there was OK: I wasn't too sure about showing her the picture and I wasn't sure, thinking about it, erm ... yeah, I suppose it was OK actually. I think sometimes, I suppose the queries I've got in my mind are that we got quite involved talking about breast forms and things, maybe if we hadn't talked about that we could have talked more about different types of surgery again, but it was what she wanted, and it was patient-led, so [chuckles] I suppose ... yeah.

INT: DO YOU THINK, HOW SATISFIED DO YOU THINK SHE WAS WITH THE EXPERIENCE? NOT, OBVIOUSLY SHE'S GOT BREAST CANCER, BUT I MEAN IN TERMS OF THE CONSULTATION AND THEN THE TIME WITH YOU?

Nurse: I think she was OK. I think, I mean as far as she could be. I mean when we were walking up the corridor to the pre-assessment, I actually couldn't remember the way out and, erm so I walked up to pre-assessment and waited with her and sort of said, I don't know why it helps but it does actually help, I feel as if when we walk up the corridor - because one of the questions they say is, like they're hanging on, 'So where do I come to this pre-assessment? When I come to pre-assessment where do I go?' And I say, 'Well we're going to make the appointment now and the place we're going to make the appointment is the place we're coming to. And I'll walk up with you, it's on the way out. Where did you park your Car?' and they can't, you know, kind of, try to focus on that. So I walk up with them and it's something about when I say to them, 'This is where we're going to make the appointment and this is where you will come when you come to pre-assessment. That's the way out, you remember walking through there.' It kind of seems, I don't know why, it just does, it seems to [...] and let them back down to reality, whatever.

INT: AT WHAT POINT DO YOU THINK YOU KNOW THAT YOU'RE TALKING TO SOMEONE WHO IS QUITE AN ACTIVE DECISION MAKER, WHEN YOU FIRST MEET THEM?

Nurse: That's a really tough one. Well, I suppose, God,

INT: YOU'LL SLEEP TONIGHT [LAUGHS]

Nurse: How do I know they're an active decision ...? Well by their body language I think, very often, they come, sometimes they come sort of in and the way they, they way they are when they come, the way they greet you, the way they greet the doctor, how ... how confident they are. Did you say, sorry, how do I feel or did you say ...?

INT: NO I SAID AT WHAT POINT ARE YOU AWARE THAT YOU'RE TALKING TO AN ACTIVE DECISION MAKER?

Nurse: As soon as they open their mouths really, and ... I don't know if that's true but that's what I feel I want to say. And again, you see, we will have remembered them from the week before, so you've got an idea of what they're going to be like. So, yes, I think, pretty much.

INT: AND WHEN YOU REALISE THAT THEY'RE THIS, OBVIOUSLY, I DON'T KNOW IF YOU THINK OF IT IN TERMS OF ACTIVE DECISION MAKER, BUT THAT'S THE TERM WE'RE USING SO I'LL STICK WITH IT, DOES THAT CHANGE YOUR AWARENESS, DOES IT

CHANGE HOW YOU APPROACH OR COMMUNICATE WITH THAT PATIENT, DO YOU THINK, 'I'VE GOT QUITE AN ACTIVE PERSON HERE, QUITE A HEADSTRONG PERSON, [...] HOW'S THAT CHANGE YOUR APPROACH TO THAT PERSON?

Nurse: I'd be, yeah, it does change the approach because obviously you've got to meet them, I was going to say you have to be tougher, not, you have to be kind of more, I think people like - I know what I want to say, people like that they'll pick up if there's any, if I'm not confident in what I'm saying, if I'm sort of not, you know, very, not exactly bouncy but confident and very, give sharp answers and don't waffle. You know, they don't want to know ifs and maybes, it's sort of saying, they ask you a question, they want an answer, they don't any, they just want that question answered, they don't want anything else. They're probably quite a challenge. They don't really ... I don't know, that's what I think, yes, I think they're more of a challenge.

INT: THERE'S A LITTLE BIT LEFT, BECAUSE THE LAST COUPLE OF QUESTIONS YOU'VE ALMOST ANSWERED ANYWAY TALKING PREVIOUSLY. SO I'D LIKE TO MOVE ON TO, I'D LIKE YOU TO THINK ABOUT THE SITUATION WITH COLLABORATIVE TYPE DECISION MAKERS, AND FOR THE PURPOSE OF THE STUDY WE DEFINE COLLABORATIVE AS PATIENTS WHO TEND TO SHARE FINAL TREATMENT DECISION RESPONSIBILITIES WITH THEIR SPECIALIST OR SPECIALISTS.

*Q19. I'D LIKE YOU TO THINK AGAIN ABOUT A SITUATION WITH A PATIENT WHO YOU THINK WAS COLLABORATIVE AND AGAIN, WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, JUST TELL ME A LITTLE BIT ABOUT YOUR EXPERIENCE WITH THEM FROM THE MOMENT YOU FIRST MET THEM, IN CONSULTATION, HOW IT WENT WITH THEM.

Nurse: It's actually quite difficult to think about a particular patient because there's so many of them. I think most people, I think we get more collaborative decision makers these days.

INT: IF YOU CAN'T THINK OF ANYONE IN PARTICULAR JUST TELL ME HOW YOU FEEL COMMUNICATING WITH THEM GENERALLY, IF THERE'S NOT ONE PARTICULARLY SPRINGS TO MIND.

Nurse: Well I would say, you know, you get somebody who's sort of asking questions and really wants information and maybe wants to listen to what we've got to say and asks questions sort of, as we are sort of just on a one to one, and isn't ... I think maybe with an active decision maker sometimes I kind of feel going back that people maybe, you know, they may be trying to sort of catch you out, you know catch me out, 'Oh well, she doesn't know that, she's not very good,' kind of thing and, you know, where as these collaborative patients really want to know what you think and they want to know your experience; they want to know what your opinions are, and they often sort of say the hardest question in the world to answer, 'Would you do, what would you do?' And, you know, then you come up with old thing, 'Well, you know, I don't know what I'd do because I'm not in that situation and my decision may be totally different than yours. What's right for me may not be ...' I find these the easiest people actually to deal with because they're interested in, they want to know what we know and I know, and want information, but they've also got their own ideas as well, and they want to make the final decision. And very often these are the people who'll sort of say, 'Ooh, you know, is that Breast Cancer Care down there or, you know, have you got any more information? Can I talk to somebody? Have you got any reading, written information?' So, you know, I do that with them.

INT: AT WHAT POINT DO YOU THINK YOU KNOW YOU'RE TALKING TO A COLLABORATIVE DECISION MAKER?

Nurse: Erm, I think usually you can pick it up from the consultation with the ...

INT: LISTENING INTO THE ...

Nurse: Listening in to what's being said, you kind of get an idea. Sometimes you can get caught out and you can think, 'Oh, yeah,' and you get something totally different. Not often but I think normally just by watching, and when you've watched a few you kind of, you know, can make a judgement about what they're going to be like.

*Q20. AND THE FINAL CATEGORY IS PASSIVE DECISION MAKERS, AND I'D LIKE YOU TO THINK ABOUT SITUATIONS WITH PASSIVE DECISION MAKERS AND WE DEFINE THOSE IN THIS STUDY AS PATIENTS WHO TEND TO WANT TO LEAVE THE FINAL TREATMENT DECISION TO THEIR SPECIALISTS EITHER WITH OR WITHOUT THEIR SPECIALISTS SERIOUSLY CONSIDERING THEIR OPINION. HAVE YOU GOT ANY, A PATIENT PARTICULARLY IN MIND THAT YOU THOUGHT WAS PARTICULARLY PASSIVE?

Nurse: Well we have, yeah, I mean very often people say, 'But you're the doctor, why don't you tell me what I should have done?' You know, 'Why don't you know? Why are you giving me a decision?' And I mean, in answer to your question, I can't think of anybody at the moment - well I can actually, yeah, I can, and they're very difficult because they will do, use every trick in the book to get you to tell them what you think, and it's very hard not to sometimes. You just sort of end up saying, 'Well, why don't you do this ...' you know, because they really, really don't want to and they are generally quite often, if you get sort of an older person who's quite passive and sort of - not always but - wants the doctor to tell them what to do because that's what doctors do. And then, 'Well if the doctor won't, this nice nurse will tell me what to do, she's knows, she's smiling at me so she'll tell me.' 'What would you do if it was you?' you know.

INT: SO THIS PERSON, WHAT WAS THEIR STORY IF YOU LIKE, WHEN THEY CAME TO CONSULTATION HOW DID IT GO AND ...?

Nurse: I'm thinking of a patient a while ago: well I mean ... we just totally, first of all when you get people who understand what's being said and just can't get their head round the fact that it's their decision.

INT: DID THIS PATIENT HAVE A CHOICE?

Nurse: Yeah, yeah. Oh, yeah, yeah. And then you get other people who just don't understand what's being said and just want the doctor, who say, 'Whatever you say, Doctor' you know. And then you say, 'Well there is a choice and it is your choice,' and it's very hard because you almost feel, well, obviously, just tell them what they think.

INT: HOW SOON DO YOU KNOW YOU'RE TALKING TO A PASSIVE, OR YOU'RE COMMUNICATING WITH A PASSIVE DECISION-MAKER?

Nurse: Well, again, you know, as soon as they walk in the door really, and also you would have, we would have seen them the week before hopefully anyway and would have some idea about what they're like. And you go on body language and experience and, you know, as with the others, sometimes you get caught out but not often.

INT: WHAT KIND OF BODY LANGUAGE DOES THAT TYPE OF DECISION MAKER GENERALLY HAVE DO YOU THINK?

Nurse: You know, kind of a little bit ... deferential, kind of, you know, quite hunched up, not very confident, often clutching something ... eye contact, not particularly good eye contact, or sometimes you get the eye contact and it's, they're quite tearful. I suppose in all fairness I'm thinking of older people but it isn't always older people.

[Interruption in recording]

Nurse: ... round and sort of have somebody with them who's [...]

INT: ONCE YOU KNOW THAT YOU'RE TALKING TO A PASSIVE DECISION MAKER DOES IT CHANGE YOUR APPROACH IN ANY WAY?

Nurse: Yeah, yeah.

INT: IN WHAT WAY WOULD IT CHANGE?

Nurse: I mean I like to think I'm fairly, well I hope I'm fairly easy-going and gentle, but you know I tread very carefully - I wouldn't want to say anything or do anything that would indicate I thought they should have - I mean if we're talking about preferences - choices of treatment. I wouldn't want to give them, say anything that would indicate I thought they should have this, that or the other treatment, although it might be quite tempting, but I wouldn't. And again, as I've said already, if I really, if I was really put in a corner with somebody like that, I'd always say to them, 'Look, you know, if we're talking about choices of treatment, unless you're absolutely sure you want a mastectomy, opt for the lesser option because at least you can, you know, backtrack on that one.' But, yeah, I feel they're actually quite, they're difficult in a different sort of way because they'll, they could interpret the slightest contraction of voice or, you know, movement as sort of 'Oh, she really thinks ... Did you see the way she looked when she said that?' you know. They pick up on that, so that's a bit worrying.

INT: THE LAST COUPLE OF QUESTIONS ... WE'VE TALKED A BIT ABOUT SORT OF INFLUENCES ON PATIENT DECISIONS AND WE SPOKE A LITTLE BIT EARLIER ABOUT THAT, I WANT TO SKIP PAST 21 BECAUSE YOU'VE KIND OF TALKED A LOT ABOUT THAT.

Nurse: Talked too much.

INT: YEAH, NOT TOO MUCH, YOU SPOKE VERY WELL.

*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?

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

Nurse: The surgeons. Well, I mean, we're talking about, you know, when we know that we've got all the, you know, what the mammogram looks like and we're talking about people who talk to patients presumably, not what happens in the back room, we're not talking about histology or talking about pathologists, we're talking about ... I would say the surgeons. But also, yeah that's why, I've answered that question, yeah, I would say the surgeons.

INT: WHY DO YOU THINK THAT IS THEN? WHY DO YOU THINK THEY HAVE THAT KIND OF INFLUENCE?

Nurse: Because they're the people who've got the relationship; they are the person that the patient is coming to see; they've been to their GP and the GP's said, 'I'm going to refer you to the Breast Clinic, you're going to see Mr Holt or you're going to see Mr Chadwick, or it will be Mr Holt and Mr Chadwick. They'll be able to help you.' And that's the person they're expecting to see and that's the person who they listen to, you know, I mean this is their consultant, he's the expert. And because of the way they are with the patients, the patients have confidence in them. And I'm not say, I mean I'm saying that as ... no that's fine, I'm leaving it at that. And when I say 'influence' I don't mean 'unduly influence,' I just mean that, you know, yeah ...

INT: NO, THIS IS JUST YOUR OBSERVATIONS REALLY.

Nurse: Yeah because I mean they spend a lot of time with them and they, because I know in some places they just say, 'Right you've ...' I mean I've had somebody say, 'Right, you've got breast cancer, Sister here will tell you what we're going to do,' but these two don't do that. They say, they go through all the options with them and discuss things in detail, so, yeah ...

INT: THIS WON'T BE ON YOUR SHEET, IT'S A QUESTION THAT WAS SUGGESTED TO ME BY A COLLEAGUE, BUT I THOUGHT IT WAS QUITE A GOOD ONE SO I'M GOING TO JUST THROUGH IT IN HERE AT THE END ... IF YOU HAD THE MONEY AND POWER TO CHANGE ONE THING ABOUT THE SYSTEM HERE, WHAT WOULD IT BE?

Nurse: Well this is nothing to do with any political considerations or ... well it's the oncology bit, I think it's with the oncology bit.

INT: IS THIS THE WESTON PARK??

Nurse: Yeah, I think. Erm, more time of course, you know. Er, different facilities; more staff. I mean you could go on for ever.

INT: WHEN YOU SAY 'MORE STAFF' WHAT PARTICULAR STAFF WOULD YOU BE THINKING OF?

Nurse: Well I suppose, I mean, if you're talking of an ideal world, I mean, clinics wouldn't be rushed, 2-week wait wouldn't be as it is, everybody would have loads of time and wouldn't be going from clinic to clinic. I mean, I'm sure you know, we have clinics, so many clinics a week that, you know, life is just one long clinic and you just wonder how they cope - well I mean we find it pressured but I mean they're the ones who are really on the front line. How they cope with it. So I think less pressure, and extra, maybe an extra - I mean I wouldn't change the consultants we've got but you kind of think, 'Well maybe if there was either less patients or more doctors, it might take the pressure off a bit.'

INT: SHARING THE WORKLOAD TYPE OF THING.

Nurse: Well sharing the workload, yeah, absolutely.

INT: I MEAN AMONG MORE PEOPLE RATHER THAN THE SAME ONES.

Nurse: Yeah, yeah. But I mean the main, if everything else was staying the same as it was with the same people, then I'd say the oncology bit, you know, better links with the oncologists, erm, and our working relationship is sometimes quite difficult there. I think there'd be better patient care as well.

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

Nurse: Not really, I think I've probably talked enough.

INT: IT'S QUITE AN EXHAUSTING [...] ISN'T IT?

Nurse: Yeah. Is that OK?

INT: THAT'S FINE, THANK YOU VERY MUCH FOR YOUR TIME, I KNOW YOU'RE VERY BUSY.

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