

SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Nurse)

*VENUE: Medium MR unit

*DATE: 29 October 2003

*ID: BCN002

*INTERVIEWER: DJW

INT: FIRST OF ALL THANKS FOR AGREEING TO BE INTERVIEWED, I KNOW YOU'RE BUSY AND IT'S A FAIR WHACK OUT OF YOUR TIME, BUT THANK YOU VERY MUCH. TO BEGIN WITH I'D LIKE TO ASK YOU A FEW QUESTIONS ABOUT YOURSELF AND THE UNIT THAT YOU WORK IN.

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

Nurse: In this breast unit, two years.

INT: TWO YEARS, THANK YOU. AND HAVE YOU WORKED ANYWHERE ELSE AS A SPECIALIST CARE NURSE?

Nurse: I worked in Leicestershire, Glenfield Hospital for ten/twelve years as a Specialist Breast Care Nurse.

*Q2. THANK YOU, SO JUST THINKING ABOUT THINGS LIKE THE PHILOSOPHY HERE IN THE UNIT, THE DAY TO DAY RUNNING OF THE SERVICE, STRUCTURE OF THE SERVICES, YOUR LIKES AND DISLIKES, THAT KIND OF THING, JUST TELL ME WHAT IS IT LIKE TO WORK HERE AS A SPECIALIST NURSE IN THE BREAST SERVICE HERE?

Nurse: Amazingly different from previous experience. I very, very much feel we work as part of a team right across the board from surgeons, nurses, clerical staff, you know, the whole team really does gel, I have no problems going to talk to absolutely anybody about anything at all, and I know they'll take me seriously, I know they'll listen to my opinions, and I know they kind of value what I've got to say. So it's just, it's a really good team and I feel very comfortable working here.

INT: COOL. SO IN TERMS OF THE STRUCTURE OF THE SERVICE, WHEN PATIENTS COME TO CLINIC, AND WHAT-HAVE-YOU, THEY'LL HAVE TIME WITH THE CONSULTANT, TIME AFTER THE CONSULTANT FOR NURSES ETC., CAN YOU JUST SORT OF JUST QUICKLY TELL ME HOW THAT WORKS, WHAT THE SORT OF STRUCTURE OF IT IS?

Nurse: Erm, well, as you say, for the clinic they'll come in, see the surgeon, be told whatever really, whether it's we think something suspicious or you've actually got breast cancer, and go through whatever treatments and options are available. We take, well certainly I take it as how the patient wants to go: some patients want to rush off, some patients want to come through here just to gather their thoughts, but actually not want to know anything further, some people want to know absolutely everything, so I'm actually guided by the patient and what they want to do. And obviously if they want anybody in with them then that's fine, I'll go and sort that out. We give them, or I give them a contact card and I think that's the most important thing that I do because if they want to rush off they know they've got that contact card to get back to us, any time when they feel they're ready to take things further.

INT: AND AFTER THEY'VE BEEN HERE, YOU'LL SEE THEM - IF I REMEMBER RIGHT, I'M TRYING TO REMEMBER WHAT YOU'VE JUST BEEN TALKING ABOUT -

Nurse: Pre-assessment.

INT: YEAH, YOU'LL SEE THEM PROPERLY, TAKE THEM TO PREASSESSMENT FROM HERE.

Nurse: Pre-assessment Clinic, that's right, they get the date to come back for pre-assessment, and as I say we may have contact between time, but then

they'll come back to pre-assessment to see either Mr Holt or Mr Chadwick, and then they'll come in for their surgery.

INT: AND THE CONTACT BETWEEN-TIMES, IS THAT MAINLY BY TELEPHONE OR DO YOU, DO YOU DO ANY HOME VISITS?

Nurse: We don't do home visits here, it can be anything really, a patient can just drop in, they can ring us, on occasion I've actually rung patients up just to see a couple of days afterwards how they are, so it can be any kind of contact really.

INT: OK, AND DO YOU THINK THERE'S ANYTHING HERE THAT PARTICULARLY MAKES YOUR JOB EASIER TO DO?

Nurse: I think just how we're valued in the team and how the team kind of values all of its members. You know, if I had a patient in here and I really felt that she hadn't grasped what was said to her I could have no qualms going next door speak to Mr Chadwick or Mr Holt, say 'Can you come and, you know, talk over things with this lady again because she really hasn't understood anything?' And it's as easy as that really.

INT: AND THE OTHER SIDE OF IT, IS THERE ANYTHING THAT YOU THINK CONSTRAINS YOU IN YOUR JOB AS A BREAST CARE NURSE, ANYTHING THAT YOU THINK DOESN'T FACILITATE THE JOB EASILY?

Nurse: Erm ... not really, I mean, it is so open and honest and relaxed here, erm, as I say, it's totally different from my experiences before apart from, you know, not enough money, not enough hours in the day, that type of thing, I think we give as best service as we're able to here. It's good.

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

Nurse: I think - do you mean all of us, the professionals?

INT: YEAH, MM.

Nurse: I think pretty much we all, I don't say we're rigidly the same but we kind of work on very similar guidelines. We are all open, we are, you know, very relaxed, all very honest with our patients, erm, you know choices are given where, when and if, you know, appropriate. I think that we all work very similarly. I know, you know, for example, that Mr Chadwick and Mr Holt kind of have shared care so, although one does the surgery, it may be whilst patients are inpatient they'll see Mr Chadwick or, you know, either surgeon. And again coming back for results it might be, you know, as much we can whoever does the surgery will see the results but sometimes that doesn't work, but it's not a problem. And Mary and I work like that, we find it very difficult, you know, the big thing in breast care nursing is caseload. What do you, you know, what is your caseload? Well when somebody can tell me what actually defines a caseload, fair enough, so again we have shared care, you know, our patients know both of us, they don't, you know, gravitate to one or the other, they know they can see either of us, and it works very well.

INT: SO YOU THINK THE ACTUAL CONSULTATION AND THE EFFECT ON HOW THE PATIENTS FEEL WHEN THEY COME IN, IT'S WORKING WELL, YOU SAY?

Nurse: I think so, yeah. And part of my kind of thing at the moment is looking at patient narratives as a good way of, you know, looking at how the patient journey's been - I hate that word 'patient journey' - but how

their experience has been throughout our service, and quite a few patients have written me their experience and all of them are very positive. I've said to them, you know, I want to do it bones and all, not just because it's me and you want to please me, just do it bones and all, and they've actually been very good and we've picked up, you know, a couple of things that, if they hadn't have written it, we would never have realised that, you know, things were going on like that. So that's just something that I've got an interest in.

INT: IS THIS LIKE A RESEARCH THING YOU PUT OR WAS IT JUST A KIND OF ...

Nurse: Yeah my degree really.

INT: OH RIGHT.

Nurse: It's just things like names, I mean one lady for example went through the oncology system, chemotherapy system, and she said I wished they'd call me by the right name. What do you mean? Well I know it says 'Marjorie Smith' here for example, but I want to be called 'Doris'. And, you know, it was just as easy, we wouldn't have picked that up. Now I know from my nurse training, I always say, 'What would you like me to call you?' but obviously some people don't. So just at the beginning, I mean she's, the nurses fill in, now what would you like to be called or what would you like to be known as? That was a little thing that had irritated her all the way through her treatment and now it's solved. But we wouldn't have known that if she hadn't told us.

INT: OH WELL, THAT'S INTERETING ACTUALLY.

Nurse: But it's things like that.

INT: THAT'S COMPLETELY SIDELINED, BUT NEVER MIND. I'D LIKE TO MOVE ON A LITTLE BIT TO BEFORE A CONSULTATION WHERE A DIAGNOSIS IS TO BE GIVEN, AND I'D LIKE TO TALK ABOUT WHAT HAPPENS JUST BEFORE CLINIC BEGINS WHERE THE PATIENT'S GOING TO HEAR THEIR DIAGNOSIS, AND FROM THIS POINT IN THE INTERVIEW I WOULD LIKE US TO FOCUS ONLY ON NEWLY DIAGNOSES BREAST CANCER PATIENTS.

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

Nurse: We have a diagnostic MDT meeting on a Tuesday lunchtime and we have clinics on a Tuesday afternoon, Wednesday morning. We have a diagnostic MDT meeting on a Thursday lunchtime - er therapeutic MDT on a Thursday lunchtime but we actually, at the beginning of that MDT, run through any diagnostics that we didn't get through on the Tuesday, and then we have other clinics on a Friday. So pretty much it's like a day or two before.

INT: OK. AND, WELL YOU'RE DISCUSSING PATIENTS PRE-OPERATIVELY AT THAT POINT, YEAH?

Nurse: Mm.

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

Nurse: It all depends really. Erm, Tuesdays MDTs can be quite rushed purely because of the pressure of clinics, you know, we have our own nurse-led clinic starts at 1 o'clock and, you know, you kind of want to stay there to hear the results of biopsies and what-have-you but pressure of clinic sometimes doesn't allow that. Therapeutic MDT, sometimes extremely frustrated, erm, sometimes you get newly-diagnosed breast cancer patients

for example needing neo-adjuvant treatment and they always, always seem to be a great debate between Oncology and the surgeon. You know, surgeons have referred somebody, you know, their cancer's inoperable, they need neo-adjuvant treatment to reduce the cancer size. But for some reason Oncology just kind of give them a really hard time and in the end have agreed but you just come out of their thinking, 'Oh if they've said they can't operate why doesn't he accept that?' So you sometimes feel quite frustrated [chuckles].

INT: YEAH I CAN TELL. DOES THAT FEELING CHANGED IF YOU'VE GOT HEAVY OR LIGHT WORKLOADS, AND BY THAT I MEAN IF THERE'S MORE BREAST CANCER PATIENTS COMING THROUGH OR LESS BREAST CANCER THAN USUAL?

Nurse: The frustration bit?

INT: MM.

Nurse: Erm, I don't think it's frustration at the patient I think it's just frustration at personality really. Erm, you know, as soon as I get down to clinic I just kind of think, well OK, that's over and done with now, we're starting something afresh and that's how I try and look at it really. I don't try to let what overflows, you know, what I felt previously overflow into something that's completely new.

*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: Erm, yeah, I mean, if for example they've had all the tests and, basically because we do like a one-stop here, they have all the tests, once they've had the tests they come back in and see the consultant and, if he feels that it's suspicious he'll tell the patient, he'll say we've done all the tests, the mammograms, erm, you know, it looks suspicious and we've done the needle tests, now hopefully it'll tell us one of several things: yes, this is a breast cancer; we haven't got enough material, we need to repeat; or no, it isn't. So, yes, if there are suspicions they are noted at that point and the patients are aware of that. We usually bring, well I usually bring the patient in here and say, you know, what have you understood by what Mr Chadwick or Mr Holt has said? Some people will say, I don't know, they think it's a cancer, and I'll say OK, then but you do understand we need to get the results to know for sure. Some people are kind of right off track, I mean that's the type of scenario where I'd go back and say to Mr Holt or Mr Chadwick, they really haven't understood, do you want to come and just explain things again?

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

Nurse: Erm, I think it's difficult because we see different types of patients. So for example most symptomatic patients, I think a lot of patients will come with their lump or their symptom and they'll automatically think they've got breast cancer until somebody tells them otherwise. I think some of the ladies we see through the screening programme are very different because obviously they haven't, the majority of them have no symptoms, so a lot of them are quite shocked and behave quite differently when they're told that, you know, you see this tiny thing here, well actually we think it might be a breast cancer. So I think it's quite hard.

INT: YEAH, QUITE A SHOCK.

Nurse: Yeah. As I say, if you've got a symptom, or most ladies'll think, when they come in they say, 'Oh I thought it was something to worry about,' well actually, you know. I think it's OK. So I think because they've got something to focus on they're perhaps having thought about it being a breast cancer to start with, but, you know, without any symptoms the screening ladies do take things quite differently really.

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

Nurse: I probably, the expectations I have will be purely because I know how the surgeon for example works, so I know how it's basically gonna be structured, but thereafter I don't really have any preconceived ideas because at the end of the day I don't know how that patient's going to react. So I just kind of watch and take the lead from them, you know, some patients are very matter of fact and 'I'm OK fine' and that's OK, some patients are very upset. So again if they wanted somebody in with them, that's fine, if they want tissues they get them handed over, you know. I don't think you can predict how people are going to behave, and therefore I don't really have any preconceived ideas about it, I just take the lead from them, how they react really.

*Q9. AND CAN YOU DESCRIBE YOUR FEELINGS BEFORE SUCH A CONSULTATION WHEN YOU'RE GOING TO GO IN WITH A PATIENT WHO'S GOING TO RECEIVE BAD NEWS?

Nurse: Erm, I try to be myself, I try to be honest and open. Obviously very, you know, supportive and, you know, that's what my job is, that's my role. It's very difficult: I remember I had one experience, it wasn't myself, it was a colleague at another hospital, and the patient said, 'I knew there was something wrong because she came through the waiting area and didn't smile at me,' and things like that. So I mean if I go through and, you know, I see the patient, I still, I talk to them and I'm, you know, just very ordinary, very as I was when they saw me the last time. I've never had anyone say, 'Do you know my results yet?' so that's very fortunate. But certainly, erm, I just kind of know that my job is there to support them, and I shall feel for them however they react when they get the news and that's it really.

*Q10. I'D LIKE TO DURING A CONSULTATION OF A NEWLY-DIAGNOSED PATIENT. CAN YOU PLEASE TALK ME THROUGH WHAT HAPPENS IN A CONSULTATION HERE WHERE DIAGNOSIS AND TREATMENT OPTIONS ARE BEING DISCUSSED WITH A PATIENT WITH BREAST CANCER FROM THE START THROUGH THE ACTUAL ...?

Nurse: Right, well before the patient comes in I'll be in there with whomever, Mr Chadwick, Mr Holt, and they'll say, well we would know the result because we would have known it at the MDT, so we'll know what the result is. The patient will come in, they'll sit down and Mr Holt will explain that we've got the results of their biopsy and it was a breast cancer. And the patient will react however, like I say, if they've come in on their own we ask them if they want anybody to come in, and sometimes they do, sometimes they don't, that's their choice. Then either surgeon will explain what that diagnosis means and what options of treatment there are available, you know, if that's the case, and they'll go through, they'll spend a lot of time with the patient going through in detail about types of treatment available. Not only the type of surgery but maybe the adjuvant treatment afterwards, and explain why as well. They do spend an awful lot of time with the patient explaining everything in great detail. If the patient doesn't quite understand or is upset they'll hang back a bit, obviously if somebody's tearful you can't take a lot in, so to a certain extent they read and take the lead from the patients. Sometimes

they'll say, 'Look, you ...' you know, 'I've told you enough for the moment, go next door, calm ...' not calm down, but '... have time to think about what I've said, gather your thoughts together and if you want me to go on further that's what we'll do.' Once everything's been talked about, they always say, you know, 'You don't need to make any decisions now, just take your time, we can make a provisional date ...' because a lot of patients just want to know when and, you know, when's it all gonna be done. So we can make a provisional date now, so that's when they come in here and I'll sit down with them and talk to them. Once they take the lead from there, if they want to go through everything, erm, that's fair enough: if they just want to rush off they do. It's entirely individual. Usually I kind of say to patients, 'There are two things that, you know, I want you to remember: firstly, you know, it's nothing you've done or not done to get this, unfortunately breast cancer is a very, very common female disease; and secondly the aim of, you know, the surgeons and the nurses and everybody here is to offer you and give you the best treatment possible to keep you well and safe,' because I have had quite a few patients sit in here and say, 'Oh well I've got this because I did this as a child,' or this happened to me or what-have-you. I worry about that because I think they'll have enough to cope with with the diagnosis of breast cancer without heaping a whole load of guilt onto them. And, you know, people don't realise how common breast cancer is and really it isn't anything that they've done or not done, it's just it's very a very common female disease. And quite a few people, you know, quite a lot of the patients say 'Actually, that's really helpful,' so, but at least it gives them something to go away with that they can think, 'Well, it isn't my fault and, yes, I do need to get on and sort this, and they will do the best for me.' But, like I say, after that some people just want to rush off, some people want to sit and chat and know about absolutely everything, so I take the lead from them pre-admission and that kind of thing.

INT: AND WHEN YOU COME IN HERE WITH A PATIENT DO YOU HAVE LIKE A PREFERRED APPROACH THAT YOU WANT TO START WITH WHEN YOU COME IN?

Nurse: Erm, it just varies really, I don't have kind of a set thing. Very often, if they're a couple, you know, husband and wife or whatever and they're just hugging, I'll say, 'Look I'll just leave you alone for a, you know, couple of minutes together,' because I think it's, some people can't, if they need to let go of their feelings or whatever, sometimes they can't do it with a third person in here so I just go away for a couple of minutes and let them kind of do what they need to do. And then I come back in and again just see what they want to do. I explain, you know, who I am, but I mean they would have met me the week before, I just explain my role here is to support you, your family and whoever, throughout all this and, you know, I just want you to briefly explain, you know, let me know that you understand what's been said, because it would be awful if they went away with total misconception about what's been said. So I kind of just go through that with them. But again if they truly say, 'I just want to go,' I'll say that's fine, you've got our card, please ring us, or please ring me up in a couple of days and we can go through it then. And you can either talk on the phone or come back here and we can go through it all again. It's different every time. Some people just say, 'Why have you brought me in here?' and I say, 'Well it's just a chance for you to gather your thoughts but if you don't want to stay that's fine,' [chuckles] it's very different.

INT: GENERALLY WHEN YOU'RE IN HERE CHATTING WITH PATIENTS, WHO GENERALLY DOES MOST OF THE TALKING AND GENERALLY ASKS MOST OF THE QUESTIONS?

Nurse: It can be anybody. Erm, I usually kind of start off things but sometimes patients, sometimes patients can be very quiet and the relatives

ask questions. That's a bit disconcerting, I feel, because sometimes, it's all very well the relative might want to know but the patient might not, and ...

INT: IF THEY'RE GONNA DIE.

Nurse: Yeah, things like that, and what's gonna happen to my wife, or ... I can tell you that but if your wife is not ready to hear that just yet, you know, it's inappropriate to talk about things like that. I don't perhaps put it like that but, you know, I say general questions I can answer but really, you know, it's your wife that we're talking about here and she might not want, she might not be ready to, to, you know, go that step yet, so. But anybody can ask questions, you know, daughter and whatever, 'Is this gonna effect me?' you know, a whole host of people.

INT: WHEN YOU'RE TALKING ABOUT THINGS LIKE DIAGNOSIS AND TREATMENT ISSUES, DO YOU USE ANY TOOLS, DIAGRAMS, PICTURES, ANYTHING LIKE THAT?

Nurse: No, no. Not for the newly-diagnosed, no. I mean on, occasionally, that's not quite true, occasionally people have said to me, 'What will my scar look like?' for example, if they've got a, if they're gonna have a mastectomy, or even before, if they've got a choice, so I kind of explain that, but we've got some diagrammatical pictures in the books over there - they're not brilliant but at least they kind of show a patient what in a diagram their scar may look like. So, yes, on occasion I'll use those.

INT: DO YOU FIND PATIENTS FIND THAT SORT OF STUFF HELPFUL OR ...?

Nurse: Some do, some don't. Erm, often the pictures - again, I mean, they're only diagrams, it's not a realistic picture of what their scar will look like.

INT: NO, OF COURSE.

Nurse: And at the end of the day we could show them a whole host of scars and nine times out of ten their scar still won't look like it. So, but sometimes they want, you know, occasionally they've asked could they have a look at books, that's fine.

*Q11. CAN YOU TELL ME ABOUT ANY ADDITIONAL TIME YOU SPEND WITH A PATIENT AFTER YOU'VE MADE THEM [...] ?

Nurse: After the doctors?

INT: YEAH, SO I'M TALKING ABOUT POST-DOCTOR, BUT YOU MENTIONED YOU WELCOME TO [...] THE CLINIC, YOU SAID, IS IT PRE-OPERATIVE CLINIC?

Nurse: Yes, I mean not often. Not often, I mean sometimes we endeavour to get on the ward pre-operatively but often the ladies come in - I mean that's essentially why we have pre-assessment, because when they come in for their surgery they're not on the ward that long before they're whisked down to theatre. So we would tend to see them certainly in the pre-assessment clinic. If they want to come and see us in between time they do, we give them this contact card. And in the clinics, for example, you know if they came back just for an extra clinic visit to go over things, we'd see them then.

INT: AND WHAT SORT OF THINGS WOULD YOU DISCUSS AT THOSE STAGES?

Nurse: Again take the lead from them, whatever they want to talk about. Some people, they're not quite clear in their mind about what surgery they

want so: 'Can you run through things again for me?' 'Somebody's, her great-aunt down the road had this, why aren't I having that?' I mean it's one of the things I also say to the patient, unfortunately, you know, you're gonna meet a whole host of people that have experience of breast cancer or know somebody that has. If you hear anything that you're unsure of or upsets you, whatever, you know, please give us a ring and, you know, let us go through it again because, you know, breast cancer treatments have changed, they are different around the country - although they're not supposed to be - and, you know, what happens to one lady is not likely, you know, may not be the same for you. It's individualised care for you, so if there's anything that you hear that is concerning you or worrying you or you're not having it but Mrs Such-and-Such down the road did, please come back and talk to us about it. So I think that's quite disconcerting as well.

INT: THROUGH ALL THIS TIME YOU SPEND WITH THE PATIENT, DO YOU GET ANY IMPRESSION THAT THERE IS ANY INFLUENCE FROM LIKE THIRD PARTIES? BY THAT I MEAN NOT HERE, OR YOURSELF OR ANYTHING LIKE THAT?

Nurse: I lot of people want to look in the internet - that's a great one. Erm ... experiences beforehand, relatives, Breast Awareness Month is always a contentious issue because there's always things on the TV and magazines, all over you. I think there are a lot of influences from the media and from literature, women's magazines and what-have-you. Some people have medics in the family or people that they can refer to. Some people send their siblings off, or children off to go and look at stuff on the internet, so I think they can be of influence. I know with a lot of our patients that have gone onto the internet, I say, if you're going to look at internet sites please first of all look at British ones because, you know, a lot of the sites on breast cancer are American and treatments and protocols are different, different sites, and there are some really good sites that we've got books for here and stuff like that. We direct them towards those rather than anything that might scare them or they might get the wrong impression of.

INT: FROM THE POINT OF VIEW OF WHEN THEY FIRST GET THEIR DIAGNOSIS AND THEY'VE HEARD THEY'VE GOT CANCER, HOW LONG DO YOU THINK FROM THAT POINT DOES IT TAKE - GENERALLY I'M SPEAKING ABOUT - HOW LONG DOES IT TAKE PATIENTS TOMAKE THEIR MIND UP ABOUT WHAT TREATMENT THEY'RE GONNA HAVE? JUST FROM WHAT YOU OBSERVE.

Nurse: Quite, quite a few patients know what they want there and then, they'll say, 'Right, I know what I want, I want this,' and irrespective of them saying that we say, 'OK, that's fine, but, you know, please do take time to think about it, don't, you know, although you've said this now, we're not gonna hold you to it, we want you to have time to think about it.' Pretty much by the time they come back to pre-assessment most people have made their mind up what they want. I mean Mr Holt and Mr Chadwick both say, 'I don't need to know your decision until you go down to theatre,' but most people have made their mind up by pre-assessment clinic. So that's usually a week.

INT: AND ALL THIS TIME YOU SPEND WITH THE PATIENT, HOW, WHAT ARE YOUR FEELINGS ABOUT DISCUSSING THESE SORTS OF ISSUES SUCH AS DIAGNOSIS AND TREATMENT OPTIONS?

Nurse: Erm ... I'm quite happy to talk to them. I always, erm, I'm very honest with patients for, you know, when patients are struggling for example about, you know, how can one be the same as the other, I do bring in the fact that, you know, there has been a lot of research and, you know, wide local excisions, as long as you get clear margins plus you give the radiotherapy, is the same in terms of survival as a mastectomy. That's why

there is a choice and that's why it comes down to personal preference because at the end of the day any decisions that are made, the women are going to live with them for the rest of their lives, and it's not my breast and it's not my decision, it's not what I want, it's how they feel and what they want. And I'm quite comfortable talking about that but at the end of the day it is their decision. I mean some people say, 'Well, my husband would want this,' or 'Such-and-Such would want that,' and I say, 'Well, fine, you know, discuss these things with your family, but at the end of the day it's your breast, it's your decision, and you are the only that, you know, will live with the consequences of the options, the decision that you've made, you're at the end of it.'

INT: I'D LIKE TO TALK NOW 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? YOU'VE MENTIONED SOME PEOPLE HAVE BEEN ON THE INTERNET AND THINGS, BUT JUST GENERALLY, WHAT DO YOU THINK ARE THE THINGS THAT PATIENTS TEND TO KNOW ABOUT THEM, THEIR TREATMENT OPTIONS?

Nurse: I think, I think it really does vary tremendously. Some people know absolutely nothing about breast cancer, they don't know anything about options. A lot of people have heard about mastectomy but some people really haven't got a clue, erm, you know, someone says, 'Oh, radiotherapy, that's where your hair falls out,' or they've got information but they're not correct in their assumptions and things ...

INT: YEAH, MISINFORMATION.

Nurse: Yes. Whereas some people know absolutely everything. I think the majority kind of fall in between, but I really do think it varies tremendously from person to person.

INT: AND DO YOU THINK PATIENTS WITH A HIGH, LIKE, LEVEL OF KNOWLEDGE, DO YOU THINK THAT MAKES IT HARDER OR EASIER TO COMMUNICATE WITH SOMEONE OR HAVE A CONSULTATION WITH THEM?

Nurse: I don't know, I think it's quite individual. You know we get some patients, you know, they walk in and say '... oh well, actually I'm a nurse,' and I don't know why they say that, but as if that's going to make a great deal of difference, and, yes, they may have been a nurse, but paediatrics or what-have-you, erm ... we all joke about, oh, the social workers or nurses or teachers are always difficult to treat and, you know, difficult to look after, but I think any patient, you know, you need to assess their level of knowledge and if it's not so great actually inform them and guide them. If it's incorrect you need to correct it, so I think you just have to play on how the patient, what the patient presents as their level of knowledge. You know, you do need to correct it if they're going along the wrong lines because at the end of the day their option decisions are going to be based on their level of information so it does need to be correct.

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

Nurse: Well, first of all, they all kind of, like, as I said earlier, 'Am I gonna die?' 'Is this gonna kill me?' 'What's gonna happen?' Erm, certainly once they've had their diagnosis they do need to know the treatment options if, you know, or what the correct treatment is. So, you know, some patients might not have an option of treatment, they might need to have to have a mastectomy and that's explained to them why, as opposed to, you know, why

they haven't been given a choice. But, you know, it's just whatever they want to know. They need to know what their relevant treatments are but maybe not all the treatment, sometimes just patients want to take it one step at a time, so they need to kind of know what the next step is and, 'What do I need to know to plan for the next step?' in which case we tell them.

INT: DO YOU THINK THERE'S ANYTHING, WHEN YOU'RE DISCUSSING DIAGNOSIS, DO YOU THINK THERE'S ANY INFORMATION THAT PATIENTS PARTICULARLY UNDERSTAND WELL WHAT'S TOLD THEM?

Nurse: Erm, I don't really understand what you mean.

INT: WELL, SORT OF INFORMATION THAT YOU, YOU JUST KNOW AS SOON AS I'M GOING TO SAY THIS THEY'RE GONNA, GONNA GO STRAIGHT IN, I'M NOT GOING TO HAVE TO GO OVER THIS AGAIN. IT'S NOT ALWAYS EASY TO REMEMBER THAT SORT OF THING, IT'S PROBABLY EASIER TO SAY, WELL, WHICH THINGS ARE NOT REMEMBERED VERY WELL, BUT I'M TRYING TO GET THE THINGS THEY DO REMEMBER.

Nurse: Well most people remember they've been told they've got breast cancer, erm ... again, like, some women, you know, they're told their options of surgery but really in your case you have to have a mastectomy because x, y and z. Sometimes they come through and say, 'You know, can you just explain why, because Mrs Such-and-Such, or I know you can just have smaller surgery,' so sometimes that needs to be reiterated. Erm ... I think assimilation of kind of information is difficult and you only know over the time what's been taken in and what hasn't.

INT: ARE THERE ANY THINGS YOU CAN THINK OF THAT WERE UNDERSTOOD JUST GENERALLY POORLY?

Nurse: What treatment's needed afterwards. Erm, and I don't think, I don't think that's usually due to a level of intelligence, I just think, you know, if you're told you've got breast cancer, for an awful lot of people that's enough, anything else said after is just, goes way over their head, and is forgotten or just not taken in, because, like I say, when you're told you've got cancer you think, 'Oh my God, am I gonna die? What does this mean? Am I ever gonna see my children grow up?' and all that kind of stuff, so I don't think it's because of lack of intelligence, I just think it's something that, they just haven't heard [chuckles] because of what they've been told before.

INT: THERE'S QUITE A CONNOTATION ATTACHED TO THAT WORD, CANCER, STILL.

Nurse: Yeah, yeah.

INT: I USED TO DO RESEARCH IN LUNG AND COLORECTAL CANCER AND I'VE HAD VERY SIMILAR STORIES, SO IT'S, THEY TAKE A BLOCK STRAIGHT AWAY AS SOON AS THEY HEAR IT, THEY DON'T WANT TO KNOW ANY MORE ...

Nurse: And it's whether some people, it's like they hear and they say, 'Gosh, you do use the word cancer a lot,' and I say, 'Well at the end of the day cancer is cancer and people know what cancer is,' you know, if you say a tumour, tumours can be benign, they can become, you know, they can be harmless, they can be serious.

INT: OR A GROWTH.

Nurse: Or, yeah, any other connotation can have different implications and different people will take on whatever they think is right, whereas a cancer is a cancer is a cancer.

INT: YEAH.

*Q14. WHAT DO YOU THINK ARE THE MOST IMPORTANT - SIMILAR SORT OF QUESTION - WHAT DO YOU THINK ARE THE MOST IMPORTANT PIECES OF INFORMATION PATIENTS NEED OR WANT TO KNOW ABOUT TREATMENT OPTIONS?

Nurse: 'How long?' 'When?' you know, time duration, 'Can I fit it in with what's going on around me already ready?' 'Can I leave it?' some people 'Well actually I'm going on holiday for a couple of weeks, can you do it when I get back?' and things like that. Most people I have to say want it done, like, yesterday, so ... and quite glad that we say, you know, 'We can get you in within the next couple of weeks.' So, and how long they're gonna be in hospital, 'How long will it be before I get all the results and know what's happening next?' that type of information they quite readily want.

INT: AND IS THERE ANYTHING ABOUT THOSE TREATMENT OPTIONS YOU'VE DESCRIBED THEY UNDERSTAND POORLY, ANYTHING THEY JUST DON'T TAKE IN AT ALL?

Nurse: I think sometimes they don't get the options about, you know, 'Well he said I can have, you know, the smaller operation or a mastectomy, you know, why?' and so ...

INT: JUST WHY THE CHOICE, YEAH.

Nurse: Yeah, why have they got choice. And some people say, 'Well I don't really know, he's the doctor,' that doesn't, I don't think that tends to happen much now, there's certainly some people say that, you know, 'How am I expected to choose when I don't know anything about it?' and I feel it's our, you know, our responsibility to actually inform the patients that, you know, there is a choice and why there's a choice, and to actually, yes the doctor does know best but if there was a best option the doctor would be saying 'You should have this because it is the best option,' you know, whereas the two options he's described to you both are equal in terms of you living to be a hundred, for example, therefore, that's when your own personal choice comes into it. So sometimes you have to reiterate that, but most people understand.

INT: I'D LIKE TO TALK NOW ABOUT WHAT A PATIENT IS ACTUALLY OFFERED.

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

*a. ONLY BREAST CONSERVATION SURGERY. ARE THERE ANY INSTANCES WHERE YOU CAN REMEMBER ONLY BREAST CONSERVATION SURGERY BEING OFFERED?

Nurse: ... Erm ... I think very occasionally we've had a couple of ladies on the screening programme where the size of the lesion or the DCIS or whatever has been exceedingly tiny, like 2 or 3 mms. Options of treatment have been discussed but the clinician has said, 'Well actually a mastectomy in this case may be over-treatment.' Is that kind of the thing you want?

INT: YEAH, YEAH.

Nurse: That's the only thing I can think of.

INT: RIGHT, YEAH.

Nurse: Erm, I know ... but I can't think of anything where somebody said, 'Well actually what you should have is a wide local excision.' Certainly the other way round, but not ...

*b. YEAH, WELL THAT IS, THAT'S USUALLY, IT'S QUITE EASY TO SORT OF, YEAH ... BUT AFTER I SORT OF GO THROUGH THE, THERE'S A COUPLE OF OPTIONS I WANT TO GO THROUGH. THE NEXT ONE IS LIKE, WHAT WOULD, CAN YOU DESCRIBE THE FACTORS THAT WOULD LEAD YOUR TEAM TO OFFER A PATIENT ...ONLY A MASTECTOMY? WHAT WOULD BE THE FACTORS THERE?

Nurse: The factors that only offer a mastectomy, erm, if it's a large cancer in a small breast; if it's involved, if the cancer's involving the nipple or situated right behind the nipple; erm, if the cancer's known to be multifocal; erm, patient, you know, if the patient chooses it. Some patients - especially some of the older ladies we've had - desperately, desperately want to avoid radiotherapy for whatever reason, be it the trek up to Weston Park, be it personal experience that means they don't ever want to Weston Park because somebody died there or they've had a bad experience there. And, although we explain that, you know, although you have a mastectomy, there's still a small chance you'd need radiotherapy, erm, you might get away with not needing it, and, you know, if they're desperate to avoid radiotherapy they'd opt for that. I can't think of any more. If they're, I suppose if they've got any other co-morbidities that perhaps a mastectomy would be an easier option for them whereas a wide local excision, if the margin's weren't clear they'd then need to have a further anaesthetic, which might, you know, if they've got heart disease or whatever, be a risk to them. That might be another ... I think on a couple of occasions that that's occurred, you know, the surgeon's said, 'Well if you really want, you know, if you really want to go down a wide local excision route then that's what we'll do.' The kind of thing we have here which I've never experienced before is the, erm, importance that's placed on technical suitability for radiotherapy. So for example if you've got a, quite a large-breasted lady with a tiny, tiny lesion on, you know, an outer part of the breast, erm, where I was previously wide local excision, no problem at all, but if a lady wanted to go for a wide local excision they then have to go and see the oncology just to make sure that it's technically suitable for radiotherapy. If he, you know, if he decides that actually radiotherapy isn't technically suitable, then that lady would be advised to have a mastectomy. And that was, where I was previously, that, [chuckles] that didn't ever coming into, ladies, if they wanted a wide local had them and had radiotherapy irrespective of the breast size. So that was something that was new to me here. Erm, which can be, we have had occasions when you've had a lady that's had, you know, a 44, I don't know, G breast, that is technically unsuitable, and a mastectomy for somebody that was perhaps 2 or 3 mms tumour, cancer, whatever, DCIS. And that's, that's quite hard to, certainly quite hard on the woman, to have such a big breast removed for something that is so, so small. You know on a couple of occasions I've brought ladies back to speak to the clinicians again because there's always the option, well in theory you could argue that we could remove it with safe margins, erm, if you accept that there might be a risk of it coming back locally without radiotherapy, then you wouldn't have to have it. But invariably, because they've already had the oncology opinion that's said it won't be safe unless you have the breast removed. So they tend to go that way, which is, we've had two ladies like that and I've brought both of them back to see Mr Holt and Mr Chadwick just to go through things because, you know, then they say, 'Yes, but it's so tiny and you ask, you know, you're now saying I need my whole breast removed, which is a big breast.' That's hard.

*c. AND COULD YOU PLEASE DESCRIBE THE FACTORS THAT WOULD LEAD YOUR TEAM TO OFFER A CHOICE BETWEEN MASTECTOMY AND BREAST CONSERVATION SURGERY.

Nurse: They, I mean, providing the cancer's anywhere on the outer, outer aspect of the breast, patients will be given a choice. Even, you know, I

have known patients where, you know, perhaps the cancer's a bit near the nipple, a bit bigger than one would ideally choose to do a wide local excision and perhaps was borderline, the surgeons would say, 'Well it's probably borderline but if you want me to do it, you know, accepting that (a) we might have to go back a second time to clear margins, or the cosmetic appearance may not be acceptable, erm, but I'll still do it if you want.' So where there is a genuine choice then they will give the choice to the patient.

*d. AND COULD YOU PLEASE DESCRIBE THE FACTORS THAT WOULD LEAD YOUR TIME TO OFFER A PATIENT ANY OTHER TREATMENTS.

Nurse: Any other treatment? What, neo-adjuvant treatment, stuff like that? Yeah. If something's an inflammatory breast cancer or a really, really bi, I mean inflammatory breast cancers tend to be involved in and occupy most of the breast anyway, they would always offer neo-adjuvant treatment for that, again with full explanations about the fact that inflammatory cancers are quite rapid and at the end of the day it's not only the breast that we need to sort out but any micro metastases around the body with chemotherapy. Also chemotherapy could be used to shrink the cancer down in the breast so then after that it would be operable, but usually still with a mastectomy rather than a wide local excision to get good clearance and to ensure you've got all the cells. Erm, fungating breast cancers or if they're stuck, you know, cancers stuck to the chest wall, they might be offered radio-, well certainly offered an opinion for radiotherapy first. Erm, that's all I can think of really.

*Q16. OK, FINE. THE LITERATURE SUGGESTS PATIENTS VARY IN THE DEGREE OF INVOLVEMENT THEY WANT WHEN MAKING DECISIONS ABOUT WHAT SURGERY TO HAVE: SOME PATIENTS WILL WANT FULL CONTROL OF THE DECISION MAKING PROCESS, SOME PREFER TO SHARE THE CONTROL, AND OTHERS WOULD PREFER IT IF THE PROFESSIONALS TAKE FULL CONTROL. DO YOU THINK PATIENTS ARE GETTING THE DEGREE OF CHOICE THEY WANT?

Nurse: I think they are. I think a lot of patients are surprised that we offer them a choice, erm. I think still a lot of the patients expect us to say, 'This has happened and you will go and have this done to you.' I really think a lot of patients are surprised that they're given a choice. But certainly I think here the patients are, you know, where choice is applicable they're always given it, certainly always offered it.

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

Nurse: I would say the patient.

INT: IS THAT THE FIRST ONE OR SECOND ONE, THIRD ONE?

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

INT: YEAH?

Nurse: I've put something here, 'The patient tends [...] the patient tends to make the final decision about which treatment they will have after,' and I've crossed out 'seriously considering my opinion' and put 'listening to the options available to them.'

INT: OK. LISTENING TO THE OPTIONS AVAILABLE TO THEM. OK.

Nurse: I don't give them my opinion about what they should want, I give them the options that have already been discussed with them.

INT: OK THANKYOU. ERM I WANT TO TALK A BIT ABOUT COMMUNICATING WITH PATIENTS WHO HAVE BREAST CANCER NOW. AT THIS POINT I WOULD LIKE YOU TO TAKE ABOUT YOUR EXPERIENCES COMMUNICATING WITH PATIENTS, IN PARTICULAR I'D LIKE US TO FOCUS ON PATIENTS IN WHOM, FOR CLINICAL REASONS, MASTECTOMY IS NOT THE ONLY OPTION. RESEARCH HAS IDENTIFIED THAT PATIENTS WITH BREAST CANCER TEND TO FALL IN ONE OF THREE DECISION MAKING STYLES: THESE ARE ACTIVE, COLLABORATIVE AND PASSIVE DECISION MAKERS. IN THIS FINAL SECTION I WOULD 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 FINAL TREATMENT DECISION.

*Q18. I'D LIKE TO START WITH SITUATIONS INVOLVING ACTIVE DECISION MAKERS WHICH WE HAVE DEFINED HERE AS PATIENTS WHO TEND TO MAKE THEIR OWN FINAL TREATMENT DECISIONS EITHER WITH OR WITHOUT SERIOUSLY CONSIDERING THE SPECIALIST'S OPINION, OR TO USE YOUR WORDS, ERM, LISTENING TO THE OPTIONS AVAILABLE. FIRSTLY I'D LIKE YOU TO THINK ABOUT A SITUATION WHERE YOU'VE HAD WITH A PATIENT WHO WAS PARTICULARLY ACTIVE ABOUT MAKING DECISIONS. I DON'T WANT YOU TO REVEAL ANY CONFIDENTIAL DETAILS OBVIOUSLY, BUT IF YOU CAN TELL ME ABOUT THE EXPERIENCE YOU HAD WITH THEM UP TO THE POINT WHEN THEY MADE A DECISION ON WHAT TREATMENT THEY WERE GOING TO HAVE. SO CAN YOU THINK OF PATIENT WHO YOU THOUGHT WAS, GIVEN THESE DEFINITIONS, WAS QUITE ACTIVE?

Nurse: There is, I mean there's one patient but I don't know whether it's appropriate or not but as soon as she walked in the room she told us that she had breast cancer, she hadn't had any tests or anything, but she told us she had breast cancer, she came armed with a whole kind of stack of papers about breast cancer and its treatment - I would say most of them from the US but, hey-ho - and she said 'I will undergo your tests, well I'll have a mammogram and I'll have needle test but that'll be it, and whatever the outcome, if it's a breast cancer I want both breasts removing. [chuckles] And that was it.

INT: [chuckles] THAT SEEMS ODD TO ME. [?]

Nurse: She told us that she was a nurse and she knew all about it and, fine, and that was what she wanted.

INT: SO WHAT HAPPENED THEN?

Nurse: She under, she had a mammogram, she had a needle test, we told her that, yes, it was likely to be cancer, and she says, 'Well you don't need to wait for the answer, erm, I want both breasts removing.' So we said, 'Well, we need to get the answer first, we can't carry on treatment until we've got the answer.' And basically I brought her in here and she wouldn't budge, you know, she was adamant that that's what she was going to have and, you know, 'I'm a nurse, I've read all about breast cancer, I just want my mastectomies and to get on with my life.' And that was it. And that's what she did. And I have to say she caused an awful lot of trauma and heartache.

INT: AND WHEN THE RESULTS CAME BACK DID THEY CONFIRM?

Nurse: Yeah, she had breast cancer.

INT: YEAH.

Nurse: And clear ...

INT: DID SHE HAVE A CHOICE OF WHAT TREATMENT SHE COULD HAVE HAD?

Nurse: She did, yeah, but, no, she wanted bilateral mastectomy and that was it.

INT: OK. ERM, HOW, THE QUESTION WAS HOW DID YOU GET ON WITH THE PATIENT?

Nurse: She just caused a lot of, I mean, she revealed after a while her kind of true colours which were bordering on psychotic, er, but she was still adamant that that was the surgery she was going to have, and that was it. Erm, and basically she's never darkened our door - well certainly not the breast care nurses' or the breast clinicians' doors again.

INT: WAS SHE A BREAST CARE NURSE HERSELF OR JUST A ... ?

Nurse: No, no, no. I don't know what type of nurse she was. She certainly wasn't a breast care nurse. Erm, she, I think she did something to do with urology or whatever, I don't know.

INT: HOW WERE YOUR FEELINGS ABOUT THAT SITUATION?

Nurse: Erm, it was a hard time. She was, this is going to sound terrible, she only kind of revealed her true, to anybody else, you know, when she was here, she left this room saying that I was the best person in the whole world and she'd had superb treatment and she was going to write to the hospital saying what brilliant care she'd had. Several weeks later she was swearing and causing so much trouble on the ward you wouldn't know that, hospital managers had to come in and talk to her, and it was just unbelievable and, you know, I'd say bordering on some kind of psychiatric referral.

INT: COULD YOU TELL ME, WAS THERE ANY INFLUENCES APPARENT, YOU KNOW, WHEN YOU WERE CONSULTING WITH HER, JUST TO WHY THIS DECISION WAS BEING MADE AND ...?

Nurse: She told me at the time that she, she had a lot of illnesses, and she just couldn't afford to have something else. She just wanted rid of it, she couldn't afford for it to come back and, you know, we'd try and explain well breast cancer can come back, not particularly in the other breast but certainly it can come back systematically, so having both breasts removed would never remove that risk. She didn't care, that's what she wanted, she didn't want to be worried by anything else to do with breast cancer, she just wanted it over and done with. She was starting her art degree in September and she just wanted to get on with that and get on with her life. It was absolutely unbelievable [...]

INT: ACTUALLY THIS MIGHT SOUND A STRANGE QUESTION BUT I'M GOING TO ASK IT ANYWAY, HOW SATISFIED WERE YOU WITH THE EXPERIENCE OF DEALING WITH THAT TYPE OF DECISION MAKER?

Nurse: To my mind that's an extreme, [chuckles] a very extreme case.

INT: YEAH, IT SOUNDS QUITE EXTREME.

Nurse: I mean we have had, we have had other women who are quite forthright in what they want, they do understand very clearly the implications of the decisions they're making. You know, we've had some women who for example are very much into complementary therapies so, 'Yes, I'll go so far, doctor, but then after that I want, you know, to include my type of therapies, my type of medicine and ways of dealing with things,' and that's fine, I'm quite, you know, quite OK with that. At the end of the day if

they want to be, have treatment that they have faith in, then that's fine. So you know I mean the first lady was quite extreme, but certainly other women that have been quite active, that's OK. Some people come in and think they know everything and perhaps sometimes don't, so I think that's where our, you know, job is to say, 'Well, yes, I hear what you're saying but you actually haven't got that quite right,' You know, there was quite a misnomer about, 'If I have a mastectomy breast cancer will never come back in that breast.' Well that's clearly not right. And rather than kind of continue that wrong, erm, attitude, you know, I would say, 'Well I hear what you're saying but there is still a small risk that breast cancer can come back either in the scar or in the chest wall because maybe, you know, it only takes one cell to be left behind.' 'Oh, I didn't realise that, I thought once I had a mastectomy there'd be no chance it could come back.' So things like, you know, correcting people's, erm, information or knowledge so they can make the right decision, I think that's important. And sometimes when somebody's been so forthright they haven't always got the correct, their active participation hasn't always been, you know, judged on the right information.

INT: AND THINKING BACK TO THE LADY YOU FIRST DESCRIBED, HOW SATISFIED DO YOU THINK SHE WAS WITH THE EXPERIENCE?

Nurse: As far as, I didn't have anything to do with her after that, as far as I'm, if that's what she wanted, that's what she was happy with. Well she wasn't happy with the scars but I think that was more personality than, erm, surgical technique. The scars were two of the best I've ever seen. Erm, but she's, I don't know is the honest answer.

INT: OK. WHEN YOU'RE THINKING ABOUT ACTIVE DECISION MAKERS GENERALLY, AT WHAT POINT DO YOU THINK YOU BECOME AWARE THAT YOU'RE SORT OF DEALING WITH SOMEONE WHO'S OBVIOUSLY QUITE KNOWS EXACTLY WHAT THEY WANT, OR HOW WOULD YOU DECIDE, OR WOULD YOU DESCRIBE AS AN ACTIVE DECISION MAKER? IS THERE ANYTHING YOU CAN PICK UP ON, HOW DO YOU SOON DO YOU THINK YOU PICK UP ON IT?

Nurse: I think if they make a decision and actually stick to it, erm, you know we've had some ladies that have said, 'All I want's a mastectomy,' and so long as they're clear in their reasons why they want it and understand the reasons behind it, then I think that's fine. I think we have had some women who say, 'Well actually I want a mastectomy' and then half an hour later say, 'Well no, perhaps I want this,' and, you know, I think, 'Well, yes, you're trying to be active but you're actually changing your mind quite a lot of the time here so that's not helpful to you really.' I think those that, you know, decide what they want and stick to it, based on their judgements and their relatives and the correct knowledge and information, I think.

INT: DOES THAT CHANGE YOUR APPROACH TO THAT PARTICULAR PATIENT WHEN YOU KNOW WHAT TYPE OF DECISION MAKER, IF YOU KNOW THEIR AN ACTIVE DECISION MAKER?

Nurse: Erm, not really. I mean, I don't know if it makes me spend less time with them, I don't think it does, because I still think, erm, although they're active in the decisions they're making, they still need the support, they still need, you know, information about what's going on or what's likely to happen to them. So I don't think it, I don't think I change. I don't think I give them any less and I don't think I treat them any different, differently to anybody else, you know, anybody else I see. You know, I kind of, I will acknowledge that that's their decision and, you know, why ever they made it or however they've come by it, that's their decision, but I still think, if they need our, you know, need my support or

need my information or whatever, then they get in. I don't think I would treat them any different.

INT: I'D LIKE TO MOVE ON A LITTLE BIT NOW TO TALK ABOUT SITUATIONS WITH COLLABORATIVE DECISION MAKERS. FOR THE PURPOSES OF THIS STUDY WE DEFINE COLLABORATIVE DECISION MAKERS AS PATIENTS WHO TEND TO SHARE FINAL TREATMENT DECISION RESPONSIBILITIES WITH THEIR SPECIALIST OR SPECIALISTS.

*Q19. THIS TIME I WOULD LIKE YOU TO THINK ABOUT A SITUATION YOU HAVE HAD WITH A PATIENT WHO WAS PARTICULARLY COLLABORATIVE ABOUT MAKING DECISIONS. AGAIN, DON'T REVEAL ANY CONFIDENTIAL DETAILS, BUT TELL ME ABOUT THE EXPERIENCE WITH THEM UP TO THE POINT WHEN THEY'D MADE A TREATMENT DECISION. IS THERE ANYONE YOU CAN THINK OF THAT YOU COULD USE AS AN EXAMPLE OF A COLLABORATIVE DECISION MAKER?

Nurse: ... I should think quite a few of our patients are collaborative decision makers. Erm, maybe I think it's these, the type of patient that's collaborative, take more time about what they, think about a bit more about their decision options. Maybe, perhaps need our input, my input a bit more to go through the options or choices that they have.

INT: IS THERE ANYONE THAT YOU CAN THINK OF IN PARTICULAR THAT YOU COULD USE AS AN EXAMPLE?

Nurse: Well there's one lady, but I don't know if she fits into newly-diagnosed. She is a lady who had a very strong family history when I first met her two years ago and she had quite a lot to think about because she did have a very strong family history and we diagnosed her with localised DCIS, and she was very much given the options of a wide local excision, a mastectomy, bi-lateral mastectomy, you know, because of the family history, bi-lateral mastectomy plus immediate or delayed reconstruction. And that was an awful lot for her to think about because she wasn't only thinking about the pre-cancerous side of things but also the family history side of things. And it took her quite a while, she came back several times to talk it over not only with myself but Mr Chadwick, erm, and there was a lot of talking about, 'Well yes there's the family history but at the moment we're only deal with ...' not 'only dealing with', but 'We're dealing with DCIS,' so you could argue it hasn't become a full-blown cancer yet, but then this could be the option or the opportunity to actually sort things out once and for all not only from the disease process point of view but from the family history point of view. There was a lot of discussion with her, erm, there was a lot of guidance because she didn't, she had just so many factors to consider and she actually came to me and said about, 'Well I've decided, I've listened to what you've said, I've listened to all the options, I'm quite young, I don't want to lose my breasts just yet so what I'd quite like to do is have a wide local excision.' And we accepted that because we'd been through on numerous times, you know, the various factors, the various issues that she had to consider, especially the fact that she had more issues to consider than most. And that was her decision and, yes, that was perfectly fine. Bless her! She's come back to our follow-up clinic a couple of times and she's been fine, but recently on a surveillance mammogram she's now got in that breast, erm, invasive disease. So now she's two years on and again she's thinking about what she should have done. And, you know, but the wide local excision option now isn't really there, it's either a mastectomy, bi-lateral mastectomy, bilateral ... whatever. So she's kind of back at stage, where she was two years ago, but she says, 'Well at least I've had my breast for two years.' She said, 'I appreciate if I'd had a mastectomy two years ago we wouldn't be in this situation now,' and I said, 'Well you know, maybe you would, you know, mastectomy doesn't get rid of it all totally, so you know it's an unknown, you know, we don't know.' But I think, I think you'd call her collaborative, there was a lot of, erm,

decision making and heartfelt rendering, and it took her a long time to make her decision and I think it was a very considered decision and it had to be. She's taken a long time making her decision now but she's actually, she wants to visit her daughters and her daughter opinion, who, she's in Germany, so it's taken a bit longer than it would otherwise, but she's, erm, going down the possibly having bilateral mastectomy and maybe reconstruction, but she's got, I mean she's in Germany as we speak at the moment, she'll be back in a couple of weeks, and I know she'll go and see Weston ... Northern General plastic surgeon, whatever, and I know she'll come back and she'll want to talk to Mr Holt and Mr Chadwick or myself again. So, I mean she's also had a lot of other things going on like, you know, people saying to her, 'Oh well you've got to have your ovaries removed now and a hysterectomy' and stuff like this and, possibly that's an awful lot to take on board for her. I mean she's been there once and now she's got to go through it again. But it will take her a while to sort it all out, and I know she will sort it all out because that's how she was before. But she does come back to us and, you know, it's not as if she wants reassurance or clarification, I don't, she just wants to go through just to make sure at the end of the day she's making the right decision for her. That's the only one I can think of that springs to mind.

INT: AND HOW DO YOU GET ON WITH HER?

Nurse: She's fine, she ... she often says to me, 'Do you think I'm doing the right thing?' and I say, 'I can't really answer that because at the end of the day, you know, you've been there, done it, written a book one time, and that was your decision, and you could say, well maybe it wasn't the right decision then but I would say it was the right decision for you at that time, and at the end of the day you've got to make a decision now.' I mean you can't, whatever the decision is, you hope it's the right decision at the time. Nobody's got a crystal ball and nobody will know for sure whether it's the right decision, but so long as you're comfortable with the decision at that time and you're for whatever reasons you're happy with, then that's the right decision.

INT: SO HOW DO YOU FEEL ABOUT HOW THINGS WENT?

Nurse: I felt OK. You know, as I say I've not heard from her for a couple of weeks but I know she'll ring because that's how it was before and I know she'll ring again, and I know she'll want to come back just to, just to tell us what happened for example with the plastic surgeons, she'll come back and say, 'Well this has happened, this has happened, so after all this, I know you said this, this and this, but, you know, I've considered everything and this is what I want to do.' And she'll do that.

INT: WAS THERE ANY, DURING THE CONSULTATION PROCESS WITH HER, WAS THERE ANY INFLUENCES APPARENT?

Nurse: From us?

INT: FROM ANYBODY.

Nurse: When she was in the room and we told her that breast cancer had now become invasive, she said, 'Well I suppose now's the time I've got to have both breasts off,' and her husband, well clearly shell-shocked, I mean he knows this has been on the cards, as she has known, you know, she knows her family history for example is a time bomb, and that's how she's felt about it. She said, 'Well I suppose we'll have both breasts ...' and he said, 'Hold on a minute, [chuckles] don't, you know, hold on a minute, you know, I know these guys have got more to talk to you about, just hold on a minute.' So he's clearly an influence, the daughters are clearly an influence on her ...

not, not by saying to her, 'Mum, you've got to do this, you've got to do that,' but certainly they're her daughters, she carries the gene, she knows there's a big chance they'll have the gene, and I think she wants to do things right for her but in collaboration with her daughters. It's ... it's quite weird I think. How do I clarify weird? I know it's the right thing for her to do, she needs to do this, you know, because she said to me, 'Well I've got to go and see my daughter, I'm going to see her in Spain in a couple of weeks, will that be all right?' And I said, 'Well I'm sure it will but I will go and speak to Mr Holt because I know if he went it would be a detriment to your health he would say no.' So I went back and he said no, that's fine, you know, it will be fine, and he came and he said, 'Yes, nothing will happen in the time that you're spending with your daughter.' So now that she knows it's safe she's OK and she'll go with it. But I know she has to do it. If we said to her, 'You've got to come in tomorrow,' she would feel uncomfortable. She's, and she actually said, 'I'd feel awful if I had a mastectomy and then I'd to go and say to my daughter, "Well actually it came back and now I've got no breast."' So I know she has to do it and I know once she's done what she needs to do to find, you know, to get all the information together and to be settled in her own mind, then she'll make the right decision for her.

INT: HOW SATISFIED DO YOU THINK THE PATIENT'S BEEN WITH THE EXPERIENCE SO FAR? IT'S VERY HARD ...

Nurse: Mm ... the experience of, what, her breast cancer coming back or the, everything?

INT: WELL I THINK FROM THE INITIAL SORT OF DIAGNOSIS FIRST TIME ROUND TO ... BECAUSE OBVIOUSLY SHE'S MADE A VERY, VERY CONSIDERED DECISION REALLY.

Nurse: Yeah. She's very, she's, to say she's, I mean to say she's all together, she's very, I mean she fell apart in there and she cried and cried and cried. But she's kind of ... she knew it was always on the cards, she was kind of expecting it. In her words she's always had great support - I mean I've actually done the follow-up clinic and, you know, she sits there and she says, 'Oh they want me to have this, this and this, what do you think?' you know, and I said, 'Well, it's not my decision but because you've got, carry the family, you know, the breast cancer gene, these are things that people are just saying you might need to consider, you know, maybe not at this time but in the future.' She's very eager to, she wants us I guess to reaffirm that she's doing the right thing, which is fair enough but, you know, I can't tell her what she's doing is the right thing because it's her decision, it's not my decision, but I can kind of explain to her why people are offering these things. And she, you know, she's always thanked me for that, she says, 'Donna, I know you can't tell me what to do and I know,' she says, 'But thank you for explaining to me why this is happening or why they want me to do this.' So she's kind of, she's kind of all together. She kind of knows that she's, she shows all the emotions of, you know, 'God, it comes back' and this, that and the other, which is, you know, what I would expect her to do. But I know once she's done it in her and once she's done what she has to do she'll be, she'll just get on with it like she did before.

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

Nurse: Erm, it may be when they just sit down and take time, rather than make any decision there and then and being adamant about what they want to do, when they actually take time to consider all the options and to consider what people are saying to them, erm, I suppose it's a bit of 'What doctor knows is best,' it's not really that it's just they will consider,

you know, 'OK I've got this, you need to talk to me about what my options are and then I will listen to you but then talk, think about what the options are and then go with what I think is the right way for me to go out of what you've told me.' I don't think it, I think probably it's not somebody that'll say, 'Well I'm having this and that's it.' Erm, it doesn't mean that they're not going to take control over their decisions or they're not going to be, but they actually take time to listen and to talk and to take con-, not considered opinion, but considered advice and information.

INT: AND DOES IT SORT OF, BEING AWARE OF THE FACT THAT YOU'RE DEALING WITH A COLLABORATIVE DECISION MAKER, DOES IT CHANGE YOUR OPINION, YOUR APPROACH SORRY, WITH THAT PERSON?

Nurse: Erm, no, not really, I mean, like I say, for the active one, you know, maybe they may not need my input but it's there if they want it. Certainly with a patient who I think was a collaborative one, she ... not sort of reassurance that she wanted, it was just, information and I suppose clarification, but that's not even the right word. I can't really explain what I mean, but, erm, you know, somebody who'll talk to you or what-have-you and just, 'OK, that's fine, I know enough now.' Or, you know, 'You've answered my question, I'll go away and consider it,' and then maybe they'll ring up or talk a couple of days later. 'I understand that now, I just want to know a bit about this.' And maybe the process is a bit longer, I'm not sure, maybe there's more contact between myself and the patient. Er, I'm not sure really. Just thinking of the two women, certainly the one that I considered active just, you know, she came in, that was it, gone, whereas, the couple of other, you know, the other patient I consider collaborative, do want a bit more input just because they want to kind of listen to what's been said, take on board everything that's been said to they're able to make, you know, an informed decision.

INT: THE LAST ONE I'D LIKE TO MOVE ONTO IS THE PASSIVE DECISION MAKER, THE PATIENTS WHO TEND TO WANT TO LEAVE THEIR FINAL TREATMENT DECISION TO THEIR SPECIALIST, EITHER WITH OR WITHOUT THE SPECIALIST SERIOUSLY CONSIDERING THEIR OPINIONS, OR LISTENING TO THE ADVICE THEY'VE BEEN GIVEN.

*Q20. FINALLY IN THIS SECTION, I WOULD LIKE TO DEAL WITH A SITUATION WITH A PATIENT WHO WAS PARTICULARLY PASSIVE ABOUT MAKING DECISIONS, JUST AS WE'VE BEEN DOING. DO YOU HAVE ANYBODY IN MIND OF A, WHO YOU THINK IS A PARTICULARLY PASSIVE DECISION MAKER?

Nurse: ... Erm, I can't, I mean I know we have seen quite a few but I can't think of one at the minute. I mean we often do have women that say, 'I can't make a decision at all: you'll have to, you'll have to help me, or what-have-you.' Certainly one of the lines that the surgeons say is, you know, 'If you really can't decide between the smaller surgery, you know, wide local excision or mastectomy, I would advise you to have the smaller surgery because at the end of the day it might well be that when we get the full histology the margins are clear, everything's fine, you won't need anything further surgically. But obviously if the histology comes back and the margins aren't clear, then, yes, you need to go on and have a mastectomy, but you've not lost anything but at least we know that that is a decision that you would have needed to come to in the first place. So you've not lost anything by doing that apart from it's just, it is two anaesthetics and there are two trips to hospital.'

INT: SO HOW DO PATIENTS, YOU KNOW, HOW DO THEY PERCEIVE, OR ARE THEY SATISFIED WITH THAT? IS THAT HELPFUL DO YOU THINK?

Nurse: Yeah, a lot of patients. Yeah, it does help them, the patients that certainly - I mean it doesn't happen all the time by any means - but

certainly the patients say, 'Well actually that's a good way round it because at least, at least when the histology comes back, if the margins aren't clear then I'll know I would have had to have a mastectomy in the first place, whereas perhaps if I'd chosen a mastectomy before, in the first place, I'd always wonder if I'd have got away with the smaller surgery.' So that does tend to help them, and it also I guess confirms in their mind that, yes, they might need to have one operation or they might need to have two, but certainly they're OK with that before they, you know, they kind of go to theatre and make any final decisions or what-have-you.

INT: SO LOOKING BACK TO THE EXPERIENCES WITH PASSIVE DECISION MAKERS, HOW SATISFIED ARE YOU WITH THE WAY THINGS GO? WHAT ARE YOUR FEELINGS ON THOSE SORT OF CONSULTATIONS?

Nurse: Erm, maybe sometimes a little frustrated because certainly I bring people in here and they say, 'Oh I really don't know what to have, you know, I'm not the doctor, I don't understand.' So I say, 'Well, you know, if I talk to you a bit more about the options of surgery, give you that help?' 'Well it might.' So I go through it, you know, I think quite concisely and clearly and, erm, some patients - well one patient I do remember she said, 'Oh yes, I understand that and I know what I'm gonna have,' and a couple of days later she rang up and she said, 'Donna, I really haven't made my mind up yet.' And I said, 'Well is there anything I can do to help you make your mind up?' 'Well, no, I don't know anything about breast cancer and, you know, I don't feel I ought to do this.' And I'm thinking, 'Hang on a minute, both Mr Chadwick and Mr Holt spend a good time with their patients, a very long time, draw pictures and all sorts, you know, to help them with the decision-making. I know I spent time in here going through it all again,' and then for her to ring and say, 'Well actually I really can't do it, I don't know anything about it,' I guess I felt a bit frustrated after that. But, it must be hard for patients who really, you know, it's a hard decision, it's a hard thing for them to come to terms with breast cancer, never mind then having to decide what surgery to have, and I suppose I just reiterate what Mr Chadwick and Mr Holt say, 'Look, if you really can't make your mind up, perhaps the best way to go is to start off with the smaller surgery because, you know, it may well be that that's all you need surgically-wise, whereas perhaps if you go for a mastectomy at this stage you might always regret and wonder if you could have got away with the smaller surgery.' I mean I talk to them about, 'How would you feel if you had your breast? How would you feel if you didn't have a breast?' 'Well it doesn't matter.' So that doesn't even help kind of, make them think, 'Well actually perhaps I would like to keep it, or 'No, I wouldn't.' So I think that's, it does frustrate me a bit, but then on the other hand, like I say, it's, it's hard to cope with a diagnosis of breast cancer never mind to make decisions that are gonna affect the rest of your life. So I can kind of see where they're coming from.

INT: HOW OFTEN, HOW SOON DOES IT TAKE YOU TO COTTON YOU'RE TALKING TO A PASSIVE DECISION MAKER? HOW SOON DOES THAT BECOME APPARENT?

Nurse: Probably from quiet early on when we're in there.

INT: AND THE KIND OF CLUES ARE, ARE WHAT REALLY?

Nurse: Well just verbalising, you know, 'I can't decide, I don't know what's best,' erm, that kind of, or they, you know, they look to whoever and say, 'Well what am I supposed to do? I can't decide. I don't know what's best for me.' Stuff like that.

INT: AND THEN ONCE YOU'VE GET THAT AWARENESS SIMILAR TO THE OTHER TWO, HOW DOES THIS SORT OF SHAPE YOUR APPROACH TO THAT PATIENT?

Nurse: I guess it makes me think, you know, I need to spend time with this, this patient, this woman, because it is important that she, erm, does make some, you know, does, you know, does get the information that she needs to make whatever decisions. Erm, I guess, you know, I, you know, like with all my patients, I say, 'Look, you don't have to make any decisions now, but go home, think about it, if you want to come back you can do, if you want to ring up you can.' And it gives them inroads into, 'OK, well I don't have to do it now, but I might not.' But like one patient it just didn't work at all and she just, bless her she couldn't make a decision, so she came to pre-assessment and Mr Chadwick said about 'Have you made a decision?' and she says, 'Well I can't, I just don't know,' she says, 'The only thing I can think of is I'll do what you said and have the smaller operation first,' which is what she did. And it worked [chuckles] so that was, margins clear, fantastic.

INT: OK LAST GROUP OF QUESTIONS, I'M SURE YOU WANT TO GET AWAY, AND I'VE GOT THE M1 TO BRAVE YET ...

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

Nurse: Life, past experience, what they read, what they see about on the television and in magazines. Probably, pre-conception but sometimes often mis-pre-conceptions like I said earlier like 'Well if I have a mastectomy that'll be it, it'll never come back,' erm, family members.

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

Nurse: Erm ... I'm sure, you know, as surgeons and breast care nurses, we have, we've got to have some influence on them just by the fact that we're talking to them about options in the first place. Erm ... yes, certainly we all, the surgeons and the nurses as a team, we all sing from the same hymn-sheet type scenario, so, whether you're active, passive or collaborative, you know, you need some kind of information from us. So just by the mere fact that we're explaining the options, explaining the information that they need to make the decision has got to be some kind of influence on them. I wouldn't say anybody says, 'I think this is best, you know, you've got to have this because it's my opinion' at all, but I think purely because they're here, you know, they want the information of us to make a decision, so that has got to influence them.

INT: I'M GOING TO THROW A QUESTION RIGHT AT THE END HERE, A COLLEAGUE'S JUST SAID TO ME, I THOUGHT IT WAS QUITE A GOOD ONE. IF YOU HAD THE POWER AND MONEY TO CHANGE ONE THING ABOUT THE SYSTEM HERE, WHAT WOULD IT BE?

Nurse: ... I don't know. There's so many. [chuckles] ... I don't know.

*Q23. NO? ERM, IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD OR TALK ABOUT WHAT WE'VE BEEN TALKING ABOUT TODAY?

Nurse: No.

INT: OK. THANK YOU VERY MUCH FOR YOUR TIME. ERM, IT'S BEEN A VERY GOOD INTERVIEW, VERY INTERESTING, AND I APPRECIATE YOU'RE VERY BUSY, THANKS FOR TAKING TIME OUT FOR THAT.

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