

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Nurse)
*VENUE: Low MR unit
*DATE:
*ID: BCN037
*INTERVIEWER: DJW

INT: WELL THANKS FOR AGREEING TO BE INTERVIEWED, JUST TO START OFF WITH TH IS, I SUPPOSE, SIMPLE QUESTION,

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

Nurse: Altogether? I've worked here for two and a half years on the ward, which is the breast care ward, and then two and a half years in the breast unit itself, in different, all in different roles, but that's the total.

INT: AND AS A BREAST CARE NURSE, SPECIALIST NURSE?

Nurse: My role at the moment is Senior Nurse/Matron for breast care, so part of that role is to work as a nurse specialist and maintain a patient caseload, but there's another angle to the job as well. So in this post 15 months.

INT: 15 MONTHS, OK. SO,

*Q2. THINKING ABOUT YOUR TIME HERE AS A SPECIALIST NURSE IN THE BREAST SERVICE, CAN YOU TELL ME A BIT ABOUT WHAT IT'S LIKE TO WORK HERE, THINKING ABOUT, YOU KNOW, YOUR LIKES, YOUR DISLIKES, THE UNIT PHILOSOPHY, THE DAY TO DAY RUNNING OF THINGS, JUST TO GIVE ME SOME BACKGROUND ON IT?

Nurse: It's a big, busy unit. Erm ... I find it challenging because every day is different.

INT: WHAT SORT OF CHALLENGES?

Nurse: Challenging, because every patient you meet, everybody brings their own different problems, erm, you know you can be managing crisis to crisis, day by day, or you can have a really smooth day. Every day bring complete, every day you learn something new, you know, every day is not, there's always something else you learn about, I don't think you can, you know, it all, so ... and I like the busyness of it, I like to be stretched and I like to be challenged personally as well, so that's good for me. It's organised, it's an organised unit: the clinic's are well organised and well structured, which I think makes it easier as a specialist nurse working within that because you know exactly where you're going, what's happening and what you're doing. And I feel well

supported as a specialist nurse from management in relation to my professional development, so for me it's an inviting place to work.

INT: OH, THAT'S GOOD THEN, YEAH. CAN YOU TELL ME A BIT ABOUT THE STRUCTURE OF THINGS, HOW THINGS WORK HERE? FOR INSTANCE LIKE WHEN A PATIENT COMES IN, YOU KNOW, WHAT HAPPENS IN TERMS OF THE PATHWAY THROUGH THE THINGS YOU DO, HOME VISITS FOR INSTANCE ...?

Nurse: Right. Do you mean right from, sort of, referral ...

INT: YEAH, JUST A BRIEF, A VERY THUMBNAIL SKETCH STRAIGHT THROUGH, YEAH ...

Nurse: Right, so they could be either referred in, they either come in through symptomatic service, by the GP or via screening service: once they come in, the screening clinics run differently to the symptomatic clinics ... so do you want me to talk to you about each clinic because they're really quite different ...

INT: NO, JUST A [???

Nurse: ... [???] right, to what happens. So the patients go through the process of coming to diagnosis, erm, they're seen in the clinics, a breast care nurse is always present at diagnosis for every patient and we have 100 per cent of that, and then the patients are often, will either go away with information and about surgery, thinking about making a decision about surgery, and will come back to another clinic appointment a week later to discuss their surgery, answer any questions. As a breast care nurse we might have seen them during that week: they might come in informally, just drop in, telephone contact, we don't do home visits ... but you know if they want to come in and talk to us we try, you know, we always fit in time during that time period if they want to come in and go through anything. Then they're given a date for their surgery. When they come in for their operation, we see them pre-operatively and we see them at least three times post-operatively: we try and see them every day other than the day after their operation, because we feel that they don't really need us to bombard with more information or discuss how, I mean they're just often quite sleepy and so we tend to leave them then.

INT: PATIENT INFORMATION PACKS [???] [CHUCKLES]

Nurse: Yeah [chuckles] they don't want that on the first day post-op. So, and then once they're discharged we'll see them again when they come to clinic for their results of their

surgery, which is usually 10 days after the day of the operation, so it's quite soon. But they've always got our contact number, and they have that right from diagnosis, so they can phone us at any point, which they do.

INT: THAT'S GOOD.

Nurse: But we work very much as a team so, if they phone us, it's, they'll speak to any one of us, not necessarily an individual breast care nurse, we don't have our own specific caseloads. And that sort of works well because otherwise some of us would have heavier caseloads than others. Erm, and then they're referred then, if need be, onto the oncology team, and again the oncology appointments are often here, the first appointments, they would be seen in oncology and a breast care nurse would be there at their oncology appointments. They then go to the Royal Infirmary, and this is where there's a bit of a gap from our point of view, to have their oncology treatments and then we tend to see them again in follow-up and in the follow-up programme. So ... that's a very brief overview.

INT: NO, THAT'S FINE, IT'S THE FIRST INTERVIEW, I NEED TO GET AN IDEA OF [???

Nurse: How it all happens, yeah.

INT: YEAH, WHAT HAPPENS, BECAUSE EACH UNIT'S SLIGHTLY DIFFERENT AND WHAT-HAVE-YOU.

Nurse: It's very brief, yeah.

INT: IS THERE ANYTHING HERE YOU THINK THAT ACTUALLY SORT OF HELPS YOU IN YOUR JOB, REALLY SORT OF HELPS FACILITATE THE PROCESS OF GETTING PATIENTS THROUGH, AND WHAT-HAVE-YOU?

Nurse: The outpatient clinic staff do because they know when a patient needs to see a breast care nurse, they know where we are in clinics and how to access us, so they won't let a patient go without making sure, you know, or checking if there's somebody might want to see us about something. And again all the medical staff are good and they know that they won't diagnose somebody without one of us there, so, erm, I think other people having an understanding of our role helps, and that's, and that's quite, you know, that's good. Erm ... I'm trying to think if there's anything else: there's probably loads of things and I can't think of any.

INT: IS THERE ANYTHING YOU THINK ACTUALLY SORT OF SLOWS YOUR JOB DOWN, MAKES IT MORE DIFFICULT TO DO, IS THERE ANYTHING ... I MEAN YOU MENTIONED AS I SAY ...

Nurse: Yes, volume, sometimes it can be the volume of patients, you know, in a clinic, you could have maybe, on some occasions, I mean the most I've probably had in one clinic is 9 patients diagnosed in one afternoon. Now to see them one after the other, if I'm not ready to see the next patient for diagnosis, that slows the clinic down, it makes the patients' waits longer, and it increases patient anxiety. So it's being able to give a little bit of you equally to each patient, and some people need you more than others, you know, so I think volume and I suppose that's always unpredictable, isn't it, in any clinic? That does slow you down or make it more difficult. And I think in Leicester, you know, there's ... we do see an awful lot of cancers: we see more than the recommended, erm, number of cancers that should be seen by a breast care nurse, so we are seeing a lot, so I think that, when you look at our overall figures, it's obvious, you know.

INT: MM, IT IS A BIG UNIT.

Nurse: Yeah, it's a big unit, so, you know, you could always argue manpower and there's never enough, can't you? So, erm, that can slow you down. Some things that can slow you down is, in a clinic particularly, if a patient perhaps comes to clinic and says to you, 'I need a new prosthesis,' now a prosthesis can take you 45 minutes to fit, but they're there in clinic at that time, erm, and you'd love to do it there and then - you can't always - but it's unfortunate if you've got to bring the patient back again ...

INT: YEAH, OF COURSE.

Nurse: ... because that 45 minutes prosthetic fitting is not just about fitting a prosthesis, you're often talking about other issues that sometimes lead on to other referrals as well. So that, those sort of things can slow you down. And the patients that drop in can slow you down, and some days you can have 5 or 6 that drop in when you're in clinic and it's knowing your boundaries and being able to say, 'They'll have to make an appointment this particular time,' but if somebody's got really big anxieties and worries, you don't like to, you know. A bit of us doesn't like to say no to somebody, you know, you can't see them, and they are quite often prepared to wait ...

INT: IT'S QUITE DIFFICULT TO MANAGE YOUR TIME IN THAT RESPECT?

Nurse: Well it is, yeah, yeah, yeah.

INT: I MEAN I DON'T HAVE THAT IN MY JOB [???

Nurse: You know, we all start work at 8.30 but none of us finish at 4.30, ever, not ever, sort of 6 is quite common, and that's because that's when the last patient leaves the clinic, you know, and your cancers are diagnosed at the end of a clinic, and sometimes it's 7, you know, no matter what you're never going to work within your hours, so, you know ...

INT: AND HOW WOULD YOU SAY, YOU KNOW, HOW DO YOU GET ON WITH YOUR COLLEAGUES HERE? I MEAN YOU SEEM TO HAVE QUITE A NICE [???] TEAM ...?

Nurse: Yeah, the breast care nurse, you know, as a breast care nursing team, we work really well together: we're very, you know, every morning sort of half 8 to sort of 9 we'll hand over patients, discuss any issues, and we have a communication board and go through stuff as well. And certainly at the end of a working day we won't leave one person in clinic on their own: there's always two of us, so, you know, if I'm not going to finish till 7 but my colleague finished at 5, she'll wait for me to make sure I'm OK. And it's just that bit of, I suppose, in a way I suppose it's a bit like clinical supervision, but it's not, because it's an informal sit-down, chat and 'How was clinic? Is there anything you want to discuss?' and then you can go home, and it's great. So we work really well together and very close team, communicate really well together. And as a whole I feel we fit and work, you know, we're like the hub really, fit really well within the rest of the team. And I don't think, personally I haven't got any problems with the team as a whole.

INT: MM, AND SO THE MEDICAL STAFF AS WELL PRESUMABLY?

Nurse: Including medical staff, yes.

INT: BECAUSE I MEAN THERE'S A LOT OF YOU HERE ... WELL, 17 IS IT?

Nurse: Yeah, yeah, at least I think, not thinking of the registrars that work within the team, you know, even, like we're communicating with house officers, you know, and physios, and the bigger picture, and also the community and the outside agencies, because we work, liaise with, you know, the sort of charitable teams out in the community and also the Macmillan nurses, so ... and the hospices. So our communication network's huge.

INT: IT'S MASSIVE.

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

Nurse: Can you just define styles for me?

INT: YES, WELL IT'S JUST KIND OF LIKE, YOU KNOW, JUST DIFFERENT WAYS OF DOING THINGS REALLY, DIFFERENT, ERM, JUST DIFFERENT - IT'S HARD TO GET ROUND THAT WORD STYLE REALLY, ERM, I SUPPOSE IT IS JUST A DIFFERENT WAY OF WORKING REALLY ...

Nurse: Right, and when you're talking about professionals are you talking about everybody within the [???] within the team.

INT: EVERYBODY IN THE TEAM, YEAH.

Nurse: Erm ... I would say, yes, styles of working and ways of working are different within the team, erm, but at no detriment to patient care, it's just the way the clinics are perhaps structured, organised, or the flow through the clinic might be different, so it's much more organisational stuff that's, that makes the style or the way of working different. Erm ... some patients will come to clinic, be diagnosed and have a date for surgery on the same day; some patients in another particular clinic will have diagnosis, go away with information, and come back a week later to discuss, erm, to discuss any questions, go through their choices for surgery if that's feasible, and then given a date for surgery. So the styles are slightly different. Erm ... and people are different, aren't they, anyway, so, which makes the styles different, you know - as in people's personalities are different. So it does make, yeah, the styles different. As a guess, any one of the breast care nursing team will approach and talk to a patient slight ... although we'll be giving, we know we give similar information or patterns of [???] information, but the way we do would be different, so ...

INT: YEAH, OH WELL WE'LL TALK A BIT MORE ABOUT THAT LATER ON.

I'D LIKE TO MOVE ON TO JUST BEFORE A CONSULTATION WHERE A DIAGNOSIS IS TO BE GIVEN, I'D LIKE TO TALK ABOUT WHAT HAPPENS JUST BEFORE CLINIC BEGINS WHERE THE PATIENTS ARE GOING TO HEAR ABOUT THEIR DIAGNOSIS, AND FROM THIS POINT IN THE INTERVIEW I'D JUST LIKE YOU TO FOCUS ONLY ON NEWLY DIAGNOSED BREAST CANCER PATIENTS.

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

Nurse: The breast MDT is every Monday lunchtime. In relation to diagnosis of breast cancer, if it's a one-stop clinic, symptomatic clinic, and an FNA's done that comes back as malignant, the patient could be given their diagnosis before the MDT meeting. If they've had a core biopsy and they'd be coming back to clinic the following week, so an MDT meeting will have happened, and then they'll have had the results a week after. Right it varies on needle testing really and the way that's done and how that fits into clinic.

INT: YEAH. AND ARE PATIENTS DISCUSSED PRE-OPERATIVELY AT AN MDT, ARE THEY?

Nurse: Yes, yeah.

INT: IT JUST HAS A BEARING ON A QUESTION I'M GOING TO ASK.

*Q5. HOW DO YOU USUALLY FEEL AFTER AN MDT MEETING - WHEN YOU COME OUT?

Nurse: It took me a while to think about this, yeah, how do I feel? I feel quite secretive - I've got a big secret, and the reason for that is, I was trying to think why do you feel like that, but the reason for that is I'll know, I've got to know the patients really quite well, certainly some more than others because they're the ones I'll have seen, and I'll be going up, I might have gone to the MDT on a Monday dinnertime, know their results following their surgery, and one particular lady I've seen may have been told, or may have had very difficult, found it difficult to cope with absolutely everything, and you know they've got quite good results. And I'm going in, carrying on, on a level, but I feel like I've got a big secret, sometimes, not all the time. And then the same is, I suppose, the opposite end of the spectrum when you know that somebody's got really quite life devastating results and you've got to carry on on that same level, so I think that's how ... not ... but that's how I feel, yeah. Now sometimes I can go to the MDT and I really don't know the patients that well, some I know more than others, so, you know, I don't feel like that, but if there are particular patients that I've perhaps spent quite a lot of time with before an MDT, then, yeah, you know.

INT: MM, AND DOES THAT VARY ACCORDING TO THE KIND OF WORKLOAD YOU'VE GOT COMING THROUGH THE CLINIC?

Nurse: Yeah, yes, it does, yeah, and varies according to how many newly-diagnosed cancer patients I've seen, yeah.

INT: SO YOU KNOW WHEN YOU SAID YOU CARRYING THIS SECRET, HOW THEN DOES THAT SORT OF, YOU KNOW WHEN YOU COME OUT IN YOUR MIND, YOU THINK, 'I'VE GOT THESE CONSULTATION TO ATTEND,' HOW DO YOU KIND OF LIKE ...

Nurse: I have to shelve it, I have to shelve it, because I've got to be professional and I've got to feel on a level all along and I can't let the patient ever know that I knew that before them, you know, because that would be so unprofessional of me. So, erm, but sometimes, you know, the patient says, 'Oh, do you know my results?' you feel like your lying because you are in a way because you do know their results, but ... not that there's a time or a place that I would ever, you know, breach the confidentiality because it's discussed with the consultant in clinic, and sometimes that could be a Monday and they'll be in clinic on a Thursday, for example. It's not long and I might have only seen them once in between, but, you know, it can put you in sometimes a difficult position, yeah. So I was thinking how do I truly feel, and I think sometimes I feel secretive.

*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: I can only liken this specifically, we all tend to work alongside a specific consultant more than others, so if I liken this to how I see it, if a patient, if it's suspicious that a patient will have a breast cancer at the end of the dia-, you know, end of needle testing and core biopsy, they are told that we're suspicious that it could, the diagnosis could be a breast cancer, and if they want to know what the treatment options are they would be discussed very briefly but told we're only, you know, we don't know for definite, so if we're going down this route and giving you all this information, you might come next week and be told it's not. But it's, we're usually saying this to patients that are going to be told, that have been perhaps a 4 on an FNA but we need the core biopsy to, just as an absolute, 5. If it's going to be somebody where it may or may not be, then we wouldn't be stressing it so much, but they are sort of, so they do come sort of pre-armed to clinic that it's likely that they're going to be told that they have got a breast cancer. And that would be said by the clinician, yeah.

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

Nurse: I think there's a really big difference between screening patients and symptomatic patients. The screening patient is coming to confirm the abnormal is normal - does that make sense? You know, that we've detected the, you know, they see screening as you're detecting and confirming normal, not looking for abnormal, so they come to clinic and ...

INT: BIT OF A SHOCK FOR THEM.

Nurse: ... they can't, because they can't often feel anything because it's so small or it's a DCIS, so, erm, those patients I feel seem psychologically very different to your symptomatic patients.

INT: YEAH, IT MUST BE QUITE A SHOCK FOR THEM, I THINK, IF THEY FOUND OUT.

Nurse: Absolutely, and they come and they've perhaps been examining themselves for, day in, day out, up until their appointment and they'll say, 'Well I can't feel anything,' but it's often so tiny, you know, but it is really, and then really quite devastating - not that it's not devastating to somebody that comes down the symptomatic route, but the lady that's gone to the GP with a symptom quite often has an inkling, or they come knowing that that's what we're looking for and that's why they've been referred. And certainly now, with the 2-week wait, and the referrals being within 2 weeks, the GPs are referring them with a suspected cancer within 2 weeks, patients know the urgency of their referral means the GP - even though the GP's not always said it to them - it could be, you know, because when they're actually asked, you know, if they want, you know, if they think it could be, or, you know, so ... I think some patients do have, have thought about it. Not that they've thought about it, it really is going to happen to them but, you know, they have thought about that it could be. Except the lady I suppose, except the lady that might have had repeated cysts and comes along very blasé, thinking it's yet another cyst, and it's not, and it's absolutely, you know, the opposite extreme.

INT: ACTUALLY I DID A DISCUSSION GROUP ON FRIDAY FOR ANOTHER UNIT AND THERE WAS A LADY SITTING RIGHT NEXT TO ME HAD EXACTLY THAT THING: SHE SAID SHE'D GONE IN AND SAID THAT, 'OH I'VE JUST [???] LITTLE CYST, LITTLE LUMP TH ING THAT I HAD, YOU KNOW.'

Nurse: Mm, and they come in quite blasé like that, don't they? And they're absolutely devastated.

INT: MM, AND I MEAN SHE SAID THAT, YOU'RE QUITE RIGHT, SHE WAS, SHE DEVASTATED, THAT WAS EXACTLY WHAT SHE SAID, SHE SAID 'I JUST BROKE DOWN, COULDN'T BELIEVE IT,' YOU KNOW, SO ... ERM

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

Nurse: ... Yes I do because the patients, erm, I've made contact with the patient from when they're very first come into the treatment room, in to see the consultant, discussed their history. I've seen them when they've been examined and then when they've had an FNA done, so I've already made contact with the patient, and then when they've had an FNA done and they've perhaps gone off for 45 minutes to wait for the results, you can, erm, I suppose just by purely observing the patient's reaction to what's happening, the questions they're being asked, their body language, perhaps gives me some idea of when, if that particular patient's going to be told they've got a breast cancer, how they may react - it doesn't always go, but just by observing I think sometimes you can get a ...

INT: A FEEL FOR IT.

Nurse: A feel for it, or the types of questions the patient might be asking you, erm, other than they're not, the one thing they're not saying is, 'Does it look like I've got a breast cancer?' but they might be asking everything else around it. So I think just that, that gives me an idea of sort of, erm, what the consultation will be like thereafter.

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

Nurse: Erm, I have spent ages thinking about this and I thought ...

INT: YOU SAID EARLIER, YOU SAID THAT YOU HAD THIS FEELING OF SECRECY [???

Nurse: That, yeah, that's purely with MDT though, and patients that have already had surgery and knowing their results, that's the [???] of secrecy. With these patients, erm, no they've gone off for 45 minutes, we've got an FNA result, for example - I mean this is purely for example - that might say

this patient has got a malignancy, erm ... and my feelings ... it's a ... my feelings ... well I need to be organised, I need to make sure I've got the written information that they want, that I understand what's going to happen, what their options, why they're having ... so my feelings are more geared around being organised so that I'm giving that patient the best of me and the best information to help them understand what's happening to them. So mainly my feelings are very practical feelings at that particular point.

INT: THAT'S FINE. OK, I'D LIKE TO MOVE ON A LITTLE BIT NOW TO DURING A CONSULTATION. I'D LIKE TO START WITH A SORT OF MORE GENERAL QUESTION WHICH IS ...

*Q10. CAN YOU PLEASE TALK ME THROUGH WHAT ACTUALLY HAPPENS IN A CONSULTATION WHERE DIAGNOSIS AND TREATMENT OPTIONS ARE BEING DISCUSSED WITH A PATIENT WITH BREAST CANCER? SO FROM THE MOMENT THEY SORT OF ...

Nurse: Been told ...

INT: YEAH.

Nurse: Well patients are usually seen in the consultation room, dressed, not in their gowns, and usually there's the breast care nurse, clinic nurse and consultant, and they're told by the consultant their diagnosis, and everybody's reaction is different - there's no two alike, you know, and they're given time, you know, some patients, when they hear the word 'cancer' and they don't hear another thing. And between the consultant and myself, you can offer see whether somebody just needs to come out and have some time and let them have a good cry, or you'll get somebody that's very practical and wants to move on and know exactly what's what, so that's done depending on what happens with the patient really and how the patient, or quite often their carer, can react, you know.

INT: IT'S ALWAYS THE CONSULTANT THAT BREAKS THE NEWS?

Nurse: Yes, yeah. Erm ... yeah, you know in some clinics it can be the registrar as well.

INT: AH YES, OF COURSE, YES.

Nurse: Yeah, erm, and they they're just, they're usually told that there are three parts to treatment, erm, which is surgery, drug treatment, who could be chemotherapy or tablets, and radiotherapy, and depending on their specific cancer details they're then, I mean they're talked through in quite

detail, depending on also as well how much the patient is able to absorb or digest - they can appear to but don't often, but then that can be reinforced later - but they're given written information about surgery, erm ... and they're given plenty of time to answer any questions, you know, and sometimes we top part-way through, recap a little bit, and then carry on. That, in brief, that's sort of what happens when they're diagnosed and when treatment options are discussed. And also the patient may ask some questions of the consultant. I quite am more than welcome to contribute to that conversation as well, it's not purely just the consultant that gives all this information, you know, sometimes they want very practical things as well which is where I might come in.

INT: DO YOU FIND THAT CONSULTANTS HAVE PREFERRED APPROACHES TO BREAKING NEWS AND THINGS?

Nurse: Erm, yes I think so, you know, some consultants see the patients in the consulting rooms when they're dressed, with their carer, and some do it in the more like the treatment rooms. Erm, but everybody's different, aren't they, in the way they're able to break bad news, I would say, so, erm, whichever the approach, I mean ... they're all, there's no one better than the other, they're all, you know ...

INT: YEAH, IT'S WHAT SUITS THAT INDIVIDUAL REALLY?

Nurse: Yeah, yeah.

INT: WHAT ABOUT YOURSELF, HAVE YOU GOT A [???] APPROACH THAT YOU TEND TO USE WHEN YOU KNOW YOU'VE GOT TO TALK TO A PATIENT? HOW DO YOU SORT OF ...?

Nurse: Well I like to take the patient away from where they've been, the more clinical room, use the quiet rooms that we've got, like we're in now, and I like to give a patient a bit of time - I don't come straight in - and sometimes they just want a hug, they want a bit of quiet time, sometimes they want a drink, sometimes they don't, you know, and then I'll come and introduce myself, erm, give them a phone number, a contact point, and ask them if they want to go through everything again now or do they want to go through it at a later point and come back and discuss, but quite a lot of them, patients tend to want to go through it again then, because they've not always understood and quite often they'll, I find, if you've managed leave the patient a little while, they might have gone through a very tearful moment and then sat down and discussed it with whoever they're with, and then have some questions.

INT: I SUPPOSE IT GIVES THEM A CHANCE, YEAH, TO GIVE THEM A CHANCE OF FORMING A QUESTION.

Nurse: Yeah, because how can they think of a question if they don't know what they want to ask? It's never happened to them before, it's new, isn't it? And so, erm, I always think it's asking a bit, so my approach is very much like that. And if the patient really can't cope at all, I won't go through anything with them at that particular time, I'll just sit with them sometimes and just let them cry or, you know, be angry, whatever they want to be. And I feel quite comfortable with that and I'm quite comfortable with silence and, erm, whatever they need really.

INT: DO YOU, WHEN YOU'RE CONSULTING WITH PATIENTS, WHO DO YOU THINK TENDS TO DO MOST OF THE TALKING AND WHO ASKS MOST OF THE QUESTIONS?

Nurse: Erm ...

INT: JUST GENERALLY.

Nurse: Generally? Erm, I suppose more 50:50 nowadays, I think patients are just as much informed and come with enough questions as the consultant, I would say, it's, you know, more 50 ... the majority, you know, there are those patients who will just listen, you know I would say more 50:50 really.

INT: AND IS THERE ANY TOOLS YOU USE? BY THAT I MEAN THINGS LIKE X-RAYS, DIAGRAMS, PICTURES, THINGS LIKE THAT.

Nurse: Yeah, you know, erm, some consultants will draw the picture so they can understand - I'm thinking of the patient that, they need to have a mastectomy and that is the only option for that particular patient, they need to understand why, they'll draw a picture of the breast and show them where the cancer is and what it, and if it's multi-focal how that would look in a breast; they'll use the mammograms, put those up; some patients are shown their - if they want to see their histology reports, you know, that this is malignant - they'll ask what type of cancer it is, you know, all these, anything's used really that would help the patient's understanding of what's happening to them.

INT: DO YOU THINK PATIENTS PREFER ANY PARTICULAR KIND OF TOOL?

Nurse: I think they like diagrams.

INT: ONES THAT ARE DRAWN OR ...?

Nurse: Drawn, yeah, that are drawn and explained, because mammograms, you put them up and you know the patient doesn't really understand, you know, and unless you've got quite a lot of time to explain, 'This is what the breast looks like, that's normal, that's not,' and because of the way the breast is in the mammogram machine, if it's sort of [???] view, it doesn't make sense to the patient quite often, you know, this is what the view is, so I do think they quite like diagrams.
Mm.

INT: SO WHEN YOU'RE ACTUALLY IN THE CONSULTATION, I MEAN, WE'VE DISCUSSED YOUR FEELINGS AT MDT, AND BEFORE THE CONSULTATION, NOW YOU'VE GONE THROUGH THE CONSULTATION, WHAT'S GENERALLY OUR FEELINGS IN THAT SITUATION?

Nurse: To be honest, I'm going from one patient diagnosis of cancer to another, so my feelings, my true feelings, personal feelings don't come out. Sometimes too I can't even think about them until the end of clinic because I'm ready thinking, 'Now, I need to get organised and ready for the next patients,' if there is a gap - and it does happen - I'll go into the consultation room, the consultant will be there, and if it's been a very difficult patient to diagnose, we'll sit there together. And sometimes he'll say, 'Shall we stop? Shall we have a cup of tea? How do you feel?' and we'll talk about how we felt. 'Well that was difficult, wasn't it?' and I can go in to the consultation room at any point and say, 'Can I have five minutes? I just need to stop,' because I'm only human, you know.

INT: THAT'S RIGHT, YEAH.

Nurse: And so ... and that can happen, you know, if I wanted to say, 'Can we go out for five minutes of fresh air?' we could do that, you know, I don't feel, I wouldn't feel uncomfortable stopping the clinic because I couldn't, wasn't ready to take the next patient on board, and go through, because otherwise I wouldn't be able to give to that patient the right bit of me, the right bit of information. So ... erm, it varies really, I think it varies, depends how I feel that day, if I'm feeling on top form or not; erm, it varies, I think it's harder when the patients that have got like situations to yourself - for example for me it's when involves their children - and if it's people you know, because I've had people I know, and that's hard, professionally known, you know, or otherwise. So that's always, you know, that's harder.

INT: YEAH I GET THAT, I'VE HAD THAT EXPERIENCE MYSELF, I MEAN I WORKED WITH CONSUMERS AT SHEFFIELD, AND YOU KNOW VARIOUS [???] AND SOME OF THEM, YOU KNOW, ONE OF THEM'S JUST BEEN

DIAGNOSED WITH RECURRENCE IN HER LUNGS AND REAL, REALLY SAD, AND OF COURSE I'VE GOT TO KNOW THAT PERSON VERY WELL, BEING TO CONFERENCES TOGETHER AND DONE MEETINGS TOGETHER, AND ALL OF A SUDDEN IT'S, IT'S NOT A PROFESSIONAL RELATIONSHIP, IT' SORT OF BUT IT'S NOT, THEY BECOME MY FRIEND THEN.

Nurse: Mm, it's difficult, yeah.

INT: YEAH, IT IS, AND SORT OF, IT'S LIKE IT'S MY FIRST EXPERIENCE OF IT REALLY BECAUSE I HAVEN'T BEEN IN THIS SORT OF AREA VERY LONG, BUT ...

Nurse: I've got three patients, for example, that, who are mothers, whose children are in the same class as one of my children. So I stand in the playground wanting to be a mum, but I've got three patients. And it's up tot hem whether they can talk to me, and they will do, and one particularly does and one of them's quite, I know quite well, you know, that I haven't seen through the whole journey and I didn't see them at diagnosis, but they'll still come to you for a bit of information or they come up to me the other day and said, 'It's five years since I was diagnosed, isn't that great, I've moved forward, I'm five years on,' you know, but they needed to tell me that in the playground. And I think sometimes that's hard, you know, so I suppose people in your social groups or like situations, yeah.

*Q11. CAN YOU TELL ME ABOUT ANY ADDITIONAL TIME YOU USUALLY HAVE WITH A PATIENT AFTER THE CONSULTATION WHERE THE DOCTOR HAS BEEN PRESENT? YOU MENTIONED TELEPHONE CALLS, YOU DON'T DO HOME VISITS, DO YOU?

Nurse: We don't do home visits.

INT: OUTPATIENTS? DO YOU POST-OP ?

Nurse: Any, erm, when I'm in outpatients anyway, whatever, you know, if a patient wants to see us, as I said before, the outpatients nurses are really good and if the patient, if they can perceive that the patient's upset or there's anything, they will come and find a breast care nurse, or one of the doctors will, you know, they'll come. So we will see them in outpatients, erm, they can come in formally, they can either drop in - we don't like to say to them, 'Arrange to come and see us,' because they always think they're seeing us in a really busy clinic and that's what we do. So we just, you know, if they want to come by and drop by and discuss anything and, you know, quite a few do. So they can come informally or formally if they want to plan and come to see us. Erm, as I say we see them on the ward prior to surgery and certainly

they're in for a maximum of 7 days so we'll have seen them at least three times during their inpatient stay including, as well as the pre-operative visit. Erm ... we'll ring them at home, as well as the patients ring us. Erm ... I'm trying to think if there's anything else ... if a patient comes into the ward that might have a wound infection or wound problems, for example, and the house office will have seen them or they've got a [???] or they'll call us and we'll go up to the ward and see them. So, and they could be on other wards, you know, they've been admitted to a medical ward with a problem, but we're asked to go and see them from a breast care point of view. Could be a, perhaps an old patient or something like that. So ... there's quite a lot of contact, mm.

INT: AND WHAT, I MEAN WHAT SORT OF INFORMATION MIGHT YOU GIVE?

Nurse: Oh and the other one is the support group, that's the other one.

INT: AH, RIGHT, YEAH.

Nurse: The support group that runs once a month, and we go for the sort of first hour and a half, so we see patients there. There's not a doctor present there, but, you know, that's another contact.

INT: YEAH, SO WHAT SORT OF INFORMATION DO YOU TEND TO GIVE ON THESE OCCASIONS?

Nurse: Whatever they, you know, they'll come in, whatever their questions are really. Sometimes there aren't any questions, they just want to come and sit and ...

INT: TALK.

Nurse: ... talk to you, yeah, yeah. And that's fine too, you know, they might just want to come and say how they're feeling or, and if they haven't come for anything and you're wondering, 'Well, I wonder why they wanted to come,' sometimes they want to come to feel reassured, or if it's been a little while since they saw somebody, it's just that contact as well, contact. And also it's not a member of their family, it's somebody else seeing them. So, erm, if they want, if they come with specific questions they might want specific written information to support that, or websites to go and look at and what, where could they find this about, something about, you know, if they want to look at something in more depth, where could they go. And, erm ... so quite a few you can be a resource for them.

INT: JUST THINKING A BIT NOW ABOUT THE PATIENT DECISION MAKING, WHEN A PATIENT'S BEEN GIVEN A DIAGNOSIS, HOW LONG DO YOU THINK, OR WHEN DO YOU THINK THAT PATIENT GENERALLY TENDS TO MAKE THEIR MIND UP? I'M TRYING TO THINK OF A TIME LIMIT.

Nurse: Generally?

INT: I MEAN SOME'S GOING TO DO IT STRAIGHT AWAY, BUT WHAT DO YOU THIBNK IS THE GENERAL SORT OF TIME LIMIT?

Nurse: ... It's difficult to generalise really because everybody's so different. Erm ... but I would say generally, the majority of patients given a choice, would know what they want immediately. And by personal experiences, the majority of people, or the majority of patients if they can avoid a mastectomy would, and that's jut my, purely my experience?

INT: WHAT YOU SEE, YEAH. OK, WE'LL COME BACK TO THAT, THERE WAS A QUESTIONNAIRE AGES AGO WHEN WE WERE DOING THIS SORT OF PILOTING, AND IT'S ALWAYS STUCK WITH ME BECAUSE I THINK THE NURSE THAT WE ACTUALLY INTERVIEW AS THE PILOT SORT OF SAID, 'IN MY EXPERIENCE IT'S THIS,' AND SHE HAD THIS VERY DEFINITE TIME LIMIT OF WHEN THINGS ... [???] THINGS ARE DIFFERENT, BUT I JUST THOUGHT, HAVE BEEN ASKING THAT NOW. ERM, I'D LIKE TO TALK ABOUT PATIENTS' INFORMATION NEEDS NOW.

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

Nurse: Erm ... patients'll tend to come thinking, 'If I've got breast cancer I'll need to have a mastectomy.' It'll depend on their personal experiences, whether they've got a family member - whether it's a good personal experience or not - or more often than not somebody always knows somebody that's been through, or had, or knows of somebody that's had breast cancer. And that will depend on whether that was a good outcome or not as to how they, as to what they know about it. And certainly, you know, if somebody comes along and their grandma had surgery and had a mastectomy they'll have had a very radical bit of surgery and they'll see it as very, erm, it was all very hush-hush and taboo mentioning breast cancer those years ago, so, erm, and ... they have really sort of got fixed hair loss as well, you know, they know that does it mean having a mastectomy and losing their hair. I think that's sort of how I see, the majority of patients would sort of already know or, you know.

INT: DO YOU FIND THAT WHAT PATIENTS KNOW OR DON'T KNOW, DOES IT MAKE FOR A HARDER OR AN EASIER CONSULTATION PROCESS OR ...?

Nurse: Erm, I think some of the, sometimes there's myths that you need to put straight and it's building that trust and that relationship up with a patient that you are dispelling myths rather than trying to say, 'Well, no, that's not right,' and, you know, that it, because some patients have really got set ideas on, based a lot on personal experience really. Erm, so it doesn't, doesn't always help. But it's always in the media and ... like today, or was it yesterday, yesterday's paper, 'Bilateral mastectomy if you've got family history.' Now I've not had the phone calls yet but, you know, the media has a big influence, like with HRT. Deodorants - that was a question I've had this week. So it's not always good because it's not always evidence-based, is it, the things they're reading about and hearing, and hearing too frequently.

INT: I THINK PART OF THE PROBLEM WITH THE MEDIA IS OF COURSE THEY WANT STORIES THEY'RE GOING TO SELL. AND WE'VE HAD THAT DOWN SHEFFIELD, WE HAD A TERRIBLE THING LAST YEAR WHERE THE LOCAL RAG CAME OUT WITH, 'IF YOU LIVE IN SHEFFIELD OR SOMETHING YOU HAVE THE WORST CHANCES OF SURVIVAL IF YOU'VE GOT LUNG CANCER.' I WAS THINKING, WELL, HANG ON A MINUTE, THIS IS NOT A VERY GOOD, WE'RE MISSING OUT HERE ...

Nurse: Yeah, anything, that's right, yeah.

INT: THEY'VE JUST SEEN ONE FIGURE AND REPORTED IT.

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

Nurse: At diagnosis I would say a very common thing they'll ask is 'Has it spread?' and 'How big is it?' I think they want to know how life-threatening it is at diagnosis. And that's the biggest bit of information I'll see patients really wanting.

INT: WHEN YOU'RE DISCUSSING THE SORT OF THINGS RELATED TO THEIR DIAGNOSIS, IS THERE ANYTHING THAT PATIENTS PARTICULARLY UNDERSTAND WELL? IS THERE ANYTHING YOU START TO TELL THEM AND THEY KNOW ...

Nurse: Say that to again, sorry, slowly.

INT: WHEN YOU'RE DISCUSSING DIAGNOSIS AND YOU'RE TALKING ABOUT THESE DIAGNOSIS ISSUES, IS THERE ANYTHING THAT PATIENTS SEEM TO JUST IMMEDIATELY SORT OF TAKE IN, YOU KNOW, THEY DON'T HAVE ANY PROBLEMS WITH ...? IT'S A HARD QUESTION TO ANSWER THAT, I KNOW, BUT THERE'S THE CONVERSE QUESTIONS COMING AFTERWARDS ...

Nurse: Erm ...

INT: IS THERE ANY INFORMATION THAT YOU THINK THEY'RE PARTICULARLY FAMILIAR WITH OR THEY UNDERSTAND VERY QUICKLY?

Nurse: I think they understand about surgery and quite often, and we're talking that people will, they tend to very generalised about people that have surgery first, aren't we? We've not talked about people who've had chemotherapy first or anything like that. So, you know, as we've talked all the way through, we've generalised about people that have surgery first, but they often understand that it will involve an operation, and that seems to be very acceptable, you know.

INT: DO YOU THINK THAT'S BASED ON THEIR EXPERIENCE OR ...?

Nurse: Yeah and, yeah, they tend to know that, you know, if you've got breast cancer you tend to have an operation. And commonly think they have to have a mastectomy, mm.

INT: IS THERE ANY INFORMATION YOU THINK THEY DON'T UNDERSTAND VERY WELL, THAT'S VERY POORLY UNDERSTOOD ABOUT DIAGNOSIS?

Nurse: About diagnosis? Mm, difficult one. I can't just think of anything off the top of my head.

INT: I MEAN ONE OF THE THINGS THAT'S BEEN RAISED BEFORE WAS THE ISSUE OF CHOICE, SOME PEOPLE, SOME CONSULTANTS HAVE A PROBLEM GETTING THE WHOLE IDEA OF CHOICE OVER TO PEOPLE.

Nurse: Yes, I suppose, that's, you know, they often think, erm, 'Well, you're the expert, you tell me,' yeah, you'll get ... er, I think people are more and more, that's not so difficult. There are some patients that would much rather the consultant, the God say, as they see it, don't they? They've got them on a pedestal, 'You're the expert, I'm not, you tell me.' Yes, so choice is hard for patients.

INT: ANYTHING ELSE YOU CAN THINK OF?

Nurse: That's hard?

INT: YEAH.

Nurse: There's perhaps, this is hard is , they want it doing tomorrow.

INT: OH, RIGHT YEAH.

Nurse: And that leaving it a week, are they going to come to any harm? Because it's diagnosed, it's in their body, they want it out, so I think that's hard for patients. Mm. And at diagnosis a lot of ladies, when their first thoughts, 'How am I going to tell ...?' never mind what's happening to them, but 'How am I going to tell ... my Mum, my husband if they're not there, my children, my friends,' you know, they turn into this person that, you know, very maternal role, that worries about everybody else other than themselves initially. Mm.

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

Nurse: How soon they can have it, yeah, which I mentioned, you know, [???] well how quick is all going to happen. How long it will all take from beginning to end - it's a big piece of their life that then becomes partially, you know, having treatment. And these are often raised again at diagnosis really, you know, once they're told about, talked through everything, they want to know when they can start and these are all quite often raised at diagnosis .. or, after they've been diagnosed with the consultant and they'll come in with the breast care nurse and talk, and they'll often ask questions then. And when will we know whether they will or won't need chemotherapy; will or won't need radiotherapy because that obviously makes a difference to how long it will take.

INT: THAT KIND OF INFORMATION, DO YOU TEND TO RELEASE IT AS AND WHEN IT'S NEEDED OR DO YOU GIVE THEM THE INFORMATION ALL AT THE BEGINNING AND SAY ...?

Nurse: No, it varies from individual to individual because some patients don't want any written information, they don't want to know a single thing and want to just come in and have an operation, and you do it each day, bit by bit. And some patients want to know absolutely everything: they want to know relevant websites or [???] have already done a bit before they've come along. So very, very different. So ... and I'll just, I will give information but, as breast care nurses we have records, we have our own documentation so I can go and pick somebody's record up and know which bits of information they've had and if you flip the reverse side over, it'll say when they've had it and what ... so eventually everybody'll have caught up with each other and all had, certainly there are set bits of information that everybody's going, we need them to have, to know about for example how to access the saroma [?] service and what a saroma is. So everybody needs

that information, but when they get it could vary, but they will all get it ... yeah.

INT: I'D LIKE TO MOVE ON NOW TO WHAT KIND OF TREATMENT PATIENTS ARE OFFERED. THIS IS A GREAT QUESTION ...

*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, IN THE FIRST INSTANCE ...

*a. ONLY BREAST CONSERVATION SURGERY?

Nurse: [Chuckles] Only breast conservation surgery ... erm ... that would depend on where the tumour is within the breast as to whether that would be the best option for the patient. Specifically if it was in, on the outer perimeter of the breast.

*b. AND WHAT ABOUT ONLY A MASTECTOMY, OFFERING ONLY MASTECTOMY?

Nurse: Only mastectomy ... erm would be, depending on the tumour size in relation to the size and shape of that person's breast, so small breast, large tumour, that'll indicate a mastectomy if they've not had chemotherapy. Erm, if it's multi-focal. If they've already had surgery to that breast or had radiotherapy, so the mastectomy would be possibly the only option because they couldn't have any further radiotherapy to that area. Erm ... that's all I can think of off the top of my head, but I know there's more. [chuckles]

*c. AND WHAT ABOUT THE FACTORS THAT WOULD LEAD YOUR TEAM TO OFFER A CHOICE BETWEEN MASTECTOMY & BREAST CONSERVATION?

Nurse: Erm ... patients that have a choice, I mean, if it's suitable to do a wide local excision on, as in it's small enough - I didn't say about mastectomy perhaps if it was very central, involving the nipple as well and quite large - but then back the other way, if they had a choice, erm, again it would be where it was within the breast, size in relation to the woman's breast, and that they could do wide local excision. If it's possible to do a wide local excision then the woman is also entitled to have a choice of a mastectomy, if that's what they want as well. So ... I think quite a lot of our patients sit in that.

*d. AND WHAT ABOUT ANY OTHER TREATMENTS?

Nurse: So chemotherapy [???] neo-adjuvant chemotherapy, large tumour taking up the majority of the breast tissue,

inflammatory carcinoma, if it's fungating ... erm ... there's loads more and I can't think, I've got a complete mental break ...

INT; [???

Nurse: Yeah, if they've had radiotherapy, erm ... or for example if it's fungating and the best way to treat was radiotherapy first. Erm ... again that would involve very much the oncologist. Erm ... and I suppose the one thing I've not mentioned, if there's a, is in prophylaxis, and mastectomy if there's a significant family history and psychologically the patient's been through, you know, lots of different, they've been seen by the psychologist and they've really want a prophylactic mastectomy, and, you know, those who've got a significant family history might have a mastectomy.

INT: I'LL MOVE ON A BIT NOW TO ...

Nurse: And I've not even mentioned reconstruction, have I? They keep coming to me now [chuckles].

INT: THE LITERATURE SUGGESTS THAT PATIENTS VARY IN THE DEGREE OF INVOLVEMENT THEY WANT WHEN MAKING DECISIONS ABOUT WHAT SURGERY TO HAVE. SOME PATIENTS WANT FULL CONTROL OF THE DECISION MAKING PROCESS, SOME PREFER TO SHARE CONTROL, OTHERS PREFERS THE PROFESSIONALS TO TAKE CONTROL. THE FIRST QUESTION I WANT TO ASK YOU THERE IS ...

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

Nurse: I think so but I think people would, some patients would like reconstruction sooner than is possible, but they get - if a choice is feasible, you know ... [???] if a choice is feasible then they are given that choice, yeah. OK? So, yeah, I do think, you know, yes.

INT: OK. I WAS GOING TO SHOW YOU A CARD HERE BUT YOU'VE GOT THESE FIVE CHOICES HERE, SO ..

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

Nurse: It would be the top one, patients tend to make the final decision regarding the treatment ...

INT: AND I'D LIKE TO SPEAK NOW ABOUT COMMUNICATING WITH PATIENTS WHO HAVE BREAST CANCER AND AT THIS PARTICULAR POINT I'D LIKE TO TALK ABOUT YOUR EXPERIENCES COMMUNICATING WITH PATIENTS. IN PARTICULAR I'D LIKE YOU TO FOCUS ON PATIENTS IN WHOM FOR CLINICAL REASONS MASTECTOMY IS NOT THE ONLY OPTION. SO RESEARCH HAS IDENTIFIED THAT PATIENTS WITH BREAST CANCER TEND TO FALL IN ONE OF THREE DIFFERENT 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 FINAL TREATMENT DECISION. I'D LIKE TO START WITH THE SITUATION WITH AN ACTIVE DECISION MAKER, AND FOR THE PURPOSE OF THE STUDY WE DEFINE ACTIVE DECISION MAKERS AS PATIENTS WHO TEND TO MAKE THEIR OWN FINAL TREATMENT DECISIONS, EITHER WITH OR WITHOUT SERIOUSLY CONSIDERATING THEIR SPECIALIST'S OPINION.

*Q18. FIRSTLY, I WOULD LIKE YOU TO THINK ABOUT A SITUATION YOU'VE HAD WITH AN ACTIVE PATIENT, WITHOUT REVEALING ANY CONFIDENTIAL DETAILS OBVIOUSLY, PLEASE TELL ME ABOUT YOUR EXPERIENCE WITH THEM UP TO THE POINT WHEN A TREATMENT DECISION WAS MADE. DID YOU HAVE CHANCE TO THINK OF SOMEBODY?

Nurse: Yeah I did, actually. Do you want me to talk to you a bit about the patient first?

INT: YEAH, NOT [??] BUT JUST GENERALLY.

Nurse: Yeah, well this particular patient is a 48-year-old lady that had, came to clinic with lumps in both breasts and on one side was a fibroidanoma [?] but on the other was diagnosed with a breast cancer. She was suitable to have either a wide local excision or a mastectomy and was told this at diagnosis, and she was adamant that she didn't want a mastectomy, so she was very strong in her views and went away from clinic with written information still on both types of surgery, even though I remember giving her this information leaflet on the mastectomy thinking, 'I know she's said she doesn't want one: should I have done that?' but I felt I had to give her both - she could have just said that on the spur of the moment without really thinking about it. She took both bits of information and came back to clinic the following week, having been on the internet, with a list of about 20 questions for the consultant and some questions for me, and was just very strong, very clear, knew exactly what she wanted and what was happening to her. It was her body, this is her breast cancer, and she was going to have done to it what she wanted. But she would have listened had there been any - if it had had to have been a mastectomy she would have understood

that, and she understood the risk that if we did a wide local excision there's always a risk of the margins of the wound not being free from cancer cells and that need, there's always a risk of further surgery on incomplete margins, although that's not a high risk. And so she went ahead and had a wide local excision, but I would call her very active in her decision making: she was very clear, very strong, very vocal all the way through, and she didn't need any further surgery. She had a small grade one cancer, so no nodal involvement, so for her she knew she'd made the right decision. And she knew that because she'd found out all about the different grades of cancers, what happens if the nodes are involved, and how size is, what the size of breast cancers mean and the implications for that. So, yes, I would call her very active in her, you know ...

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

Nurse: I had a good relationship. Patients like that are really challenging, lovely, you know, bring me a long list of questions and, you know, I don't profess to know everything and nobody does, and people comes with lots of, quite often internet information that's, I don't know, not always right, is it, some of it? So you're able to put them straight, but I'd rather tell them to go and look on this website or that website as well as look as wherever else they want to. But, no, I admired her, you know, she knew, she was, yeah, very clear in what she wanted and she was sticking with it. And if she'd have had to have a mastectomy in the end that was fine, but I think she'd have had three goes at clearing margins before she'd have even got there. Her femininity was of high importance, she was in quite a new relationship, so her sexuality and her sex life was really important to her, so she didn't want to be without her breast. And that was very clear, you know. So ... yeah.

INT: AND WERE ANY OTHER INFLUENCES APPARENT FROM THIRD PARTIES OR ANYTHING FROM OUTSIDE ...?

Nurse: No, her partner was very supportive and said, 'Well, you know, I'd still love you even if you didn't have your breast,' you know, it wouldn't, that, it was up to her, and he was very clear he was, 'You decide.'

INT: WAS HE THERE AT THE CONSULTATION?

Nurse: Yes, yeah, but I would say she was a very strong personality, if that's the right word, but you know quite a strong character, yeah.

INT: LOOKING BACK, HOW SATISFIED DO YOU THINK YOU WERE WITH THE EXPERIENCE OF THE CONSULTATION?

Nurse: Oh, completely, yeah, I was completely happy with it, yeah. I felt we'd answered every question she'd got: we'd given an opportunity to ask the questions, she'd come with a list, they were all answered, so I think she was as informed as she could be. So I was completely happy with it.

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

Nurse: Oh I think, yeah, yeah, because she didn't need to have anything else done and, you know, it had not gone into her lymph nodes which a lot of patients tend to hang on to, so I would think, yeah. 1

INT: AT WHAT POINT, THINKING A BIT MORE ABOUT ACTIVES IN GENERAL, BUT AT WHAT POINT DO YOU THINK YOU KNOW YOU'RE DEALING WITH AN ACTIVE DECISION MAKER? I MEAN YOU MIGHT NOT EVEN IN TERMS LIKE THAT, BUT YOU GET THE IDEA, THIS PERSON'S THEY'RE VERY, KNOW THEIR MIND AND WHAT THEY WANT.

Nurse: I think sometimes you can see right at initial consultation, just with their body language and just the way, erm, a consultant will ask the first question and the way they respond to it, you know, sometimes they can appear quite angry, irritated or agitated, erm, and will always what and why are you doing that, and ask a lot of questions as you go through, but that doesn't always go but, yeah.

INT: AND ONCE YOU HAVE THAT SORT OF AWARENESS HOW DOES THAT THEN SORT OF SHAPE YOUR APPROACH TO THAT PERSON?

Nurse: Erm ... no different than it would shape a lot of our approach to other patients in that I know that this person will need to be equally informed as anybody else. They might want more from me because they come back with more questions, but I hope they're perhaps questions that ... they've looked into, I don't know, perhaps looked more around the type of breast cancer whereas another patient might not have even explored that. They might want to know their survival statistics, another patient might not even want to go there, you know, but they come with slightly deeper or slightly different angle to the questions. And sometimes they can be the type of patient that will question the surgeon's level of expertise and want to know their credentials before, which, you know, does happen. I've seen many a time them being questioned about their credentials before ... they say, 'Can I trust you to do this?' So quite a strong, strong person.

INT: SO LOOKING BACK NOW AT THAT SORT OF CONSULTATION, THE EXPERIENCE WITH THAT PATIENT, SO HOW DO YOU FEEL THAT IT ALL WENT?

Nurse: Well I think it went, you know, I was quite satisfied with the way it went. I'm glad we gave this lady a week to come back with more questions because I think if we'd have planned for surgery on that particular date that we saw her with a decision, I would question whether we'd needed to, you know, sometimes I think people need time to read information and gather, and this lady did because she came back with lots of questions. And I think if we'd have not given her that time I wouldn't have been completely satisfied. But I know I'm able to say in the consultation or say to the consultant, 'This lady needs a bit of time to think about things,' or to go and do their own research, because then they feel, this type of person's often in control, you know, this woman needed to be in control of what was happening to her, nobody else, be it the expert or not, this lady was in control, yeah.

INT: OK. I'D LIKE TO MOVE ON TO A SIMILAR SITUATION WITH A COLLABORATIVE PATIENT AND FOR THE PURPOSE OF THE STUDY WE DEFINE COLLABORATIVE AS PATIENTS WHO TEND TO SHARE FINAL TREATMENT DECISION RESPONSIBILITIES WITH THEIR SPECIALIST.

*Q19. SO AGAIN, WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, CAN YOU PLEASE TELL ME ABOUT YOUR EXPERIENCE WITH A PATIENT YOU HAD UP TO THE POINT WHEN A TREATMENT DECISION WAS MADE?

Nurse: This lady is a 63-year-old lady who, cancer was detected through the screening programme. The previous lady I discussed was symptomatic. This lady came through the screening programme, and at the initial consultation, once she was told her diagnosis, this lady was coming in all along thinking she was going to have a mastectomy, she wanted a mastectomy. Yet her, the nature of her cancer, size of the breast, it was all, she was quite suitable to have a wide local excision. And if it was small enough it would have had to be marked as well with a needle localisation. So I couldn't understand why she immediately wanted a mastectomy and in the consultation I felt quite uncomfortable that this lady was just going to have a mastectomy and I wanted to explore with her why she had decided to do that. So, you know, I was able to say to the consultant, 'Well can I chat to this lady for a little while, take her away into the quiet room ...' which I did and said to her, 'So, you've said you'd like a mastectomy, what's your reasons for that?' and it was because she didn't want to, she couldn't have transport to the other hospital to have her radiotherapy, should she need to have radiotherapy.

So she hadn't got anybody that could take her and she couldn't afford taxies. So I then said to her, 'If I told you that we could arrange transport, how does that make you feel?' And she said, 'Oh, I'd have the other operation.' So I think, so then I made some phone calls, so I wanted to then say to this lady that, you know, we can definitely arrange transport - which I knew we could do - I wanted her to know that that was a definite thing, but that she might have to wait and a bit more time might have been taken out of her with the volunteer driver system, but I went away and came back with more information for her and said, 'But I think you need to think about it,' you know, because 'Is that what you really want?' Also her daughter had started in a new job and she was going to be doing the childcare so that was another ... and the daughter was with her at consultation and she was saying, 'It doesn't matter, I can get a childminder, it really doesn't matter,' you know, 'You have the operation you want to have.' So we went back in to see the consultant after that in the same outpatients visit and so she went away then with written information and went away for a week and came back and, during the week she'd phone me and asked me questions about both types of operation, how long she'd be in hospital for, which is equal lengths of stay really; what she'd be able to do afterwards or not do, what radiotherapy was about. So I then posted her some written information about radiotherapy that she would have within the week to help her understand that a bit more, but I talked to her in quite a lot of detail about it. And she came back in and I didn't, it was then purely with the consultant, she discussed everything with her and decided to have a marker wide local excision and [???] which she had done. And I feel she made that decision in collaboration with myself particularly but also the consultant, her family and with the people, the travel, arranged the travel to and from the hospital as well. I think it needed all, she needed to be, to have all that information to make that, you know, and I just thought it was really sad that a woman would chose to have her breast removed because she thought she couldn't get to have the treatment. But was there an underlying reason? Was that the pure reasons or was there anything else? And there wasn't. This lady had that surgery and she's really glad. She didn't need any further surgery, she had no nodal involvement, small tumour, grade two, and she's had radiotherapy and it was fine. And she had, you know, and during radiotherapy I made telephone contact with her on three occasions to make sure the transport was working and that it was all right and it was working for her and her family, and it was. And I've seen her in follow-up and I have to say, you know, I was really, you know, I felt, I thought, 'No, that was right, and she made the right decision.' But she talked all the way through about how she was feeling and what she was thinking and why and she was

very open, but she would always listen from the other side. And, you know, there's me saying to her, 'Well if I say to you I can provide transport ...' I wanted to reassure her, 'Ring this number and they'll organise it,' and she did, so, yeah, so that was, I would say she was shared.

INT: SO YOU GOT ON QUITE WELL THEN WITH HER?

Nurse: Yes, yeah, yeah.

INT: WAS THERE ANY OTHER INFLUENCES APPARENT, DO YOU THINK?

Nurse: No, I think she was concerned, her daughter was a nurse and she was concerned that her daughter was going to be starting a new job and if she was going to have radiotherapy that would be a bit longer in treatment and she would have to help with the childcare, but she organised her radiotherapy for the end of the day and her daughter was working in the mornings, so she had the child to look after in the mornings, which was fine, then went for radiotherapy at the end of the day. And I said to her, 'You can work it all around time,' which she did, and that worked as well. So that was perhaps one influence. But, no, it was purely - she's a very independent lady; she lost her husband quite a long time ago and there's just her daughter that is her next of kin, but very, very independent, and I don't think she wanted to rely or depend on anybody, but she was able to rely on the ambulance service to, the volunteer transport, and managed that well. So, yeah.

INT: SO LOOKING BACK, HOW SATISFIED DO YOU THINK YOU WERE WITH THE EXPERIENCE OF THAT CONSULTATION?

Nurse: Oh I was very satisfied because I knew I was able to bring that lady out and say to the consultant, 'I think I need to spend some time with this lady,' you know, but also the consultant turned round to me and sort of looked at me and I know the look that sort of said, 'This lady can't make a decision today, we need to talk to her a bit more,' you know. It's like the non-verbal that goes on between you and the working relationship you have with the consultant, isn't it? You know what's what, so, yes, so, no, I was, erm, this lady could have gone and had her breast removed and maybe lived to regret it, I don't know, but she was ...

INT: SO DO YOU THINK SHE WAS SATISFIED WITH THE OUTCOME?

Nurse: Yeah, oh definitely. I mean she even, she [???] that.

INT: OH THAT'S GOOD, YEAH. AND NOW YOU'VE HAD A CHANCE TO SORT OF REFLECT ON THAT SITUATION, HOW DO YOU GENERALLY FEEL THINGS WENT ...?

Nurse: I was really pleased with this particular patient, that's why I brought this patient's information in with me because I've used in this my own personal reflective practice.

INT: OH RIGHT.

Nurse: Because I actually feel that this patient said a lot about the importance of my role. Because the patient could have sat in a consultation, been diagnosed, and gone and had a mastectomy and not seen a breast care nurse. And it's the breast care nurses that know the practical, a lot of the practical arrangements as to what happens. So I managed to find time, sort out transport and all those issues out, and my question is, had I have not been there, and had there not been a breast care nurse, would anybody else have done that? You know, because, I don't know, so I've used that, you know, as an example and said, 'Well, I felt very valuable in my role and I felt I was able to give the patient a broad bit of information and also give her the contact numbers so that she could be independent, go and phone these numbers and say, "I believe you organise the transport to the Royal Infirmary - when do I need to let you know? What sort of time do I need to be ready?"' She could find all those bits out for herself, which she needed to do, but used me as a ... not used me, but I was there as her resource to do that. So, no, I was quite OK with that one.

INT: AT WHAT POINT DO YOU THINK YOU'RE AWARE THAT YOU'RE TALKING TO SOMEONE WHO'S COLLABORATIVE? IT'S A TRICKY ONE THAT ...

Nurse: Yeah, tricky questions, these are the hidden questions you're asking me. I don't know. I think at some point during the consultation or ... I think you can sense that the patient might be just listening, not hearing you but listening to you; takes things on board and then comes back with questions. So part-way through the consultation I would say, yeah. But it's not something I would have ever looked for.

INT: NO, YOU MIGHT DO AFTER THIS?

Nurse: I might do, but I haven't ...

INT: DOES THAT SORT OF AWARENESS THAT THIS PERSON, I KNOW IT'S DIFFICULT TO SAY THIS BECAUSE I MEAN OBVIOUSLY YOU DON'T TEND TO THINK AS YOU SAY IN TERMS OF THESE TERMS, BUT DOES THAT

SORT OF, HAS IT SHAPED YOUR APPROACH TO THAT PERSON, YOU KNOW, HOW YOU DEAL WITH THEM LATER ON?

Nurse: Erm ... shaped my approach ... well again, a bit like the previous lady, I know that I need to be keeping them really well, you know, well-informed, and I think a patient that has that collaborative approach is going to ask you lots and lots of questions still, but also listen to what you're saying. Erm ... so I think as long as I, you know, keep them well-informed really as we go through, and again questioning their reasons for thinking like that or feeling like that, which I did with this lady, you know, I did go and ask her why she felt so strongly that she wanted a mastectomy. Which I don't necessarily do with every patient, but I knew something, you know, to be told it was a very small cancer and it just, I think perhaps it's very much experience, but to be told it was a small cancer and it could be removed and it needed a marker wire because it was that small to identify it, then there must be a reason why this lady wanted a mastectomy, you know. To find out it was because of transport.

INT: I'D LIKE TO MOVE ON TO THE LAST ONE WHICH IS THE PASSIVE DECISION MAKER AND JUST TO READ IT OUT, PASSIVE IS PATIENTS THAT TEND TO WANT TO LEAVE THE FINAL TREATMENT DECISION TO THEIR SPECIALISTS EITHER WITH OR WITHOUT THEIR SPECIALIST SERIOUSLY CONSIDERING THEIR OPINION.

*Q20. AGAIN IF YOU CAN THINK OF A PASSIVE DECISION MAKER, TELL ME ABOUT YOUR EXPERIENCES, AND AGAIN WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, UP TO THE POINT WHEN A TREATMENT DECISION WAS MADE.

Nurse: Right. This lady is 46-year-old lady who presented in clinic with a lump in her breast and was diagnosed with a core and drag and the drag [???] showed that it was cancer. Very ... a small breast cancer, 7mm, and she was told that it was suitable to do a wide local excision or she could also consider a mastectomy. Immediately, I mean this lady also, interestingly, had her Mum going through treatment for breast cancer, who was partway through radiotherapy at the time of this lady's diagnosis: her Mum had had wound infection, had also had a mastectomy and needed radiotherapy. And I would think, this lady's husband was a very strong, dominant character in the consultation: it was as if it was, 'This is my breast, not my wife's breast' type of consultation. He was obviously very angry: you could sense the anger, but it made her more and more withdrawn during the consultation, and you just got the feeling that within their relationship he was a very dominant person. And so, when she was given a choice, she said, 'Well, you know ...' he said, 'Oh, she's never been very

good at making any decisions about anything in life,' so I guess he did them all, he made them all. And 'She couldn't make a decision and she couldn't make a choice, you tell us what you think we ought to do.' The consultant would say, or did say, 'Well we could a wide local excision, it's small enough to do that, but some women do want to have a mastectomy for various reasons, and you need to think about, you know ...' but again the husband came back with, 'You're the expert, you tell us.' And the consultant would say, 'Well, no, you need to really take away some written information, have a think about it, come back the following week with some questions and go from there.' So after that consultation I, I actually left them quite a little while, thinking, 'Well, do they need some time together?' because I couldn't decide whether she was completely switched off emotionally and didn't really hear a lot of what went on, but he was very fired up. So I left them for a little while. In the meantime somebody had made them a drink, and then I came back in and that little while probably was about 15 minutes, and when I came back in he was much calmer but she said very little the whole time. And part of me wondered if she was quite depressed anyway, you know, even before, at the very beginning. So then I sort of asked her a little bit about her Mum to see if I could get information from her around that, but I think her Mum's experience from her perspective, from this patient's perspective, had been very negative because of her wound infection and having to have a mastectomy. And her Mum was very large-breasted and it was a large tumour as well, so she'd found that hard to cope with her Mum. Her Dad had died the previous years so she's, you know, got a lot of sort of family, bereavement within her family, and then coping with Mum's breast cancer, that she couldn't even think about herself and what to do with herself. She really couldn't make any decisions. So at that particular time I didn't, I felt that I couldn't give them any more information, or help them in any way, any more at that particular point, and I got the feeling that, she was sat right on the edge of the chair, she just wanted to go. So this lady, her husband took written information away and they left the clinic, but I felt really uncomfortable, you know, that I'd not done my job well enough. So the next day I then phoned and they arranged to come in and it was arranged rather than drop in, and I said, 'It might be a good idea to come and talk, how do you feel about that?' and they said, she actually said, 'No, I'd like to.' I said 'Do you want to bring your husband with you or are you can come in on your own, what are you going to do?' I said, 'Sometimes it's better to have somebody else to listen,' but wondering if she'd be better without her husband at that particular time. Anyway she came with her Mum and it was a little bit about what had happened to her Mum, the discussions we had, but then

we were able to talk about her, and she just couldn't make a decision, she said she's just been one of those people in her life that, she was obviously a very 'glass half empty', very low person, never been able to make decisions, you know, can't choose a carpet, can't choose anything, you know. That's just her nature. So you might think she's the sort of person that, and that's why she wants somebody else to tell her that's what she needs to do. So the lady then came back to clinic the following, on the following, later on that week, and saw the consultant, really still not a lot clearer, and I sort of went a lot round body image issues with her, what her relationship was like with her husband, you know, trying to sort of get her to perhaps think about what a breast means to her, and this lady then had, went in to see the consultant and the consultant said to her, 'Well, you know, it is small, we can do a wide local excision, take some of the nodes, there is a chance of having it, you know, with the margins, with everybody not being clear, there's no other reason, there's no reason to take your breast off unless that's what you really, really want,' and then she sort of said, 'Well I don't, if I've not got to have it off I don't want it off.' So that, in a way, the consultant rephrasing it helped her make a decision. So without being told that that's what we were going to do, so she did make a decision in the end, but it was very difficult to get her to think about it. So that's what she had done. Unfortunately the margins were incomplete and there was lots of DCIS in the margins and so she did go on and have a mastectomy and she did have an episode of collapse, emotional collapse, erm, between the two operations, and she just found it very difficult to cope, collapsed on the floor at home, her husband was very distraught and phoned and, you know, we got the Macmillan nurses very involved in this family, right from the very beginning I referred her to Macmillan nurses though. She was one of these ladies that you knew needed, needed that bit more support. And a lot of the issues were round her husband, they were farmers, her husband was out on the farm the whole time and she was at home, and she was in the house on her own all day with nobody to talk to and, you know, felt very isolated, very lonely. So we've, Coping with Cancer were brilliant, you know, other agencies have really helped this lady and she's sort of now part-way through chemotherapy and is, I can't say coping, but is managing the best she can. But this is a patient that I've got my eye on, you know, you think, we'll be watching out for this lady and we're all aware ... I mean there are some of those patients that you just wonder whether they were depressed to start with and there was something wrong to start with, or, I don't know, but, you know, so ... but couldn't make any decisions about anything. And I think chemotherapy was difficult because the benefit, there's 4 per cent benefit from chemotherapy but should she

have it or shouldn't she have it, and she went through all the decision making again for herself.

INT: SHE'S HAD A RIGHT OLD TIME, HASN'T SHE?

Nurse: Yeah, so it's not been, yeah, so I would say very passive, yeah.

INT: HOW DID YOU GET ON WITH HER THEN?

Nurse: I got on really quite well with her. It took a while to get to know her because she was just very quiet, and every time she came there was somebody that would speak for her, and I just wanted to see her on my own but without saying that to her, because I wanted her to feel that was right for her, you know? I can't say to somebody, 'Come on your own,' because most people bring somebody, but eventually, you know, I did get to ... and when I phoned she'd speak but then her husband, you know, somebody else would come on, either her husband or her Mum, but there were too many people interfering in what was happening to her.

INT: WHAT WAS THE RELATIONSHIP BETWEEN HER MUM AND HER THEN, WAS HER MUM QUITE ... ?

Nurse: Her Mum's a very strong, dominant character as well, a bit like her husband, who was very vocal about when she'd sit talking and saying, 'Oh, you know, well I got this infection after a mastectomy and so ...' this, that and the other. It wasn't, and I had to be very careful that we're talking about this particular patient and not her Mum. So, yeah. Very sad, very, you know ... yeah.

INT: YEAH, IT SOUNDS LIKE ... SO WAS IT, APART FROM HER MUM AND OBVIOUSLY HER HUSBAND WAS QUITE STRONG, WAS THERE ANY OTHER INFLUENCES APPARENT DO YOU THINK?

Nurse: Erm ... no. She didn't really seem to have any friends or, you know, that she talked of, or she'd got two children but didn't talk about them particularly.

INT: WERE THEY SMALL OR WERE THEY GROWN UP?

Nurse: Teenage, but younger, you know, younger end of teens. Mm.

INT: SO, LOOKING BACK, HOW SATISFIED DO YOU THINK YOU WERE WITH THE EXPERIENCE WITH THIS PATIENT?

Nurse: Initially I found it really quite difficult with this particular: I brought it in, really quite a difficult patient. I did find it difficult, erm, because I wanted this lady to say that's what she wanted, not 'This is what I want because my husband told me I've got to have it,' or, you know, I wanted her to be able to think about what she wanted.

INT: [???] MORE TIME IN HER LIFE, YEAH.

Nurse: Yeah. And there were obviously other underlying issues in her relationship as well, and I just thought, you know, but initially I didn't feel, I kept thinking, 'What else can I do? Where else can I go? What other contacts have I got? What other agencies could I use that would be beneficial without bringing too many in?' And also getting her consent to it as well, you know, it's all right saying, 'I'll refer you to a Macmillan nurse,' but you know that might not be what she wanted. But it did and it worked and she has somebody that goes out to her home and she has quite a good relationship with that Macmillan nurse and Coping with Cancer have been and done reflexology and massage. So, and that's been something for her. But she needs, she just needed to, you saw a change, you know, and when she was in on the ward it was great because I really got to know her a bit more, got more time with her, but initially I was very ... not that I felt uncomfortable, I felt uncomfortable that she wasn't, that this was about her husband and not about her.

INT: HOW SATISFIED DO YOU THINK SHE IS WITH THE EXPERIENCE SO FAR, WHAT KIND OF FEEDBACK DO YOU GET FROM HER?

Nurse: Well I wouldn't think she was that satisfied really because at the end of the day she has had more surgery, and that just pushed her lower, really. So, erm, she's seen her Mum go through problems and I think she thinks she'll just do the same, you know. And she's one of those people that is like that anyway, you know, very negative about a lot of things. So I think she would say 'I'm a negative ...' she's a negative sort of person in her outlook of what's happening, so maybe would be, wouldn't be completely satisfied because of that.

INT: AT WHAT POINT DO YOU THINK YOU ARE AWARE THAT YOU'RE TALKING TO SOMEONE WHO'S PASSIVE, DO YOU THINK?

Nurse: Again, sometimes I can, even during the initial consultation: no eye contact, don't ... or look at the husband or their partner or whoever they've come with for answers, rather than answer the questions themselves. 'How long have you had this problem?' husband or partner will answer, you know, and that's what he did. And, I don't know, as I say

sometimes you can, even, maybe even at diag-, you know, at that initial consultation, or even at diagnosis, when you're talking about decision making. So quite soon on.

INT: AND DOES THAT, AGAIN, SHAPE YOUR AWARENESS TO THEM, CHANGE YOUR APPROACH TO THE PERSON IN A SORT OF WAY?

Nurse: It doesn't change my approach but in the sense of ... I suppose what it does change is the way, well it did change my approach in that I knew this lady needed time and it's then, I have to be confident to go back to the consultant and say, 'This lady can't make a decision, you know ...' it's about being confident, isn't it, in what you do some sometimes, and saying, 'This lady can't make a decision, she needs time. I know you want to do her next Tuesday, but ...' you know, 'You can't, because I need to talk to her some more, she needs to make her own decision and it's got to be the right decision.' As with anybody really that can happen, you know, erm, but I needed, in this lady in particular situation, I was more conscious that I needed to let her husband calm down before I went to talk to them, rather than what was happening to her. Because he was so angry, I thought, 'I don't want to confront that anger, I want to talk to her,' so, not that I didn't want, I would have confronted it but, you know, it wasn't about, I needed to see how she was thinking or feeling and get to know her a bit as well as her husband, but he was so dominant.

INT: SO HOW OVERALL, THINKING BACK NOW, HOW ARE YOUR FEELINGS ABOUT THAT SORT OF EXPERIENCE?

Nurse: Erm ... my overall feelings, did you say?

INT: MM

Nurse: Erm ... part of me thought, 'What else can I do? What more can I do?' erm, so perhaps I didn't feel that I could, I'd done enough, or maybe I had but, you know, I kept thinking, 'What else can I do to help this lady?' really and, you know, you sort of cover all different avenues, but there's that bit of me somewhere that's saying, 'Is there anything else I could have done?' you know. So, which leaves me not completely satisfied with the outcome.

INT: YEAH, OF COURSE. I MEAN YOUR THREE EXPERIENCES HAVE BEEN VERY INTERESTING BECAUSE I MEAN YOU HAD AN ACTIVE DECISION MAKER WHERE YOU DIDN'T REALLY FEEL YOU COULD DO A LOT FOR THE LADY, DO YOU KNOW WHAT I MEAN? YOU HAD THE COLLABORATIVE WHERE YOU REALLY FELT YOU GOT ON REALLY WITH THEM AND YOU REALLY FELT THAT YOU COULD DO A LOT AND IT ALL KIND OF WORKED OUT.

AND THEN YOU HAD THIS THING WHERE, WHERE YOU'D DONE A LOT I THOUGHT, YOU'D REALLY PUT YOURSELF OUT AND THEN SORT OF GOT RIGHT TO END AND THOUGHT, 'IS THERE ANYTHING MORE I COULD DO TO TRY AND HELP THIS PERSON?' IT'S VERY INTERESTING.

Nurse: Mm, mm. I think it's because this lady stayed flat at the very, even at the end, even though, you know, emotionally you could see she was flat, and that's why she's one of them ladies that, you know, I'm conscious that I've, I'll be watching, watching out for in follow-up because, my guess is that there'll be some sound depression somewhere, there'll be more to come.

INT: LAST COUPLE OF QUESTIONS. THE LITERATURE TELLS US THERE'S A VARIETY OF INFLUENCES ON PATIENTS MAKING DECISIONS ABOUT SURGICAL TREATMENT.

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

Nurse: In the wider sense, erm, patients' personal experience, who they know, do they know somebody that's had, you know, if they go out with a diagnosis they go talking to somebody else and say, 'Well I know somebody that's had done and they were fine,' so they go, you know, they might go with that. Media I think has a massive implication in it completely, the internet. Erm, even more, you know, you see that more and more. And the partner and their relationship.

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

Nurse: The surgeon, the consultant.

INT: MM, WHY IS THAT THEN DO YOU THINK?

Nurse: Because I still think, erm, the public see the surgeon as the ultimate, you know, the person, the God, the person on the pedestal, you know, I think it still happens in a lot of cases, and they're the expert and they're the ones that are going to be doing the operation, so, erm, I think they can have the biggest influence personally.

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

Nurse: Perhaps other things that influence patients sometimes, I think a culture, an ethnicity, if you think about Leicester's high Asian population, 25 per cent of the Leicester population's I think Asian, South Asian. And I think their culture and cultural needs can affect their decision making.

INT: CAN YOU GIVE ME AN EDAMPLE OF THAT?

Nurse: I can give you an example in that, and I can't think which specific ethnic group, but I know some women, it depends on which, if we're talking about breast cancer in women, but the women, if it's a younger woman in a forced marriage rather than arranged, erm, that brings to consultation their husband and the mother-in-law that they live with, it can be, erm, quite often there are, you know, we need, we obviously need interpreters and things, but it can be, erm, the influence of the mother-in-law about what operation the young woman would have rather than the husband or the patient themselves. And also there is, there are some ladies that will not have a mastectomy or choose not to if that's the ideal operation because they are not seen as going whole into later life, when they move on to the next life, they're not classed as being whole, whereas to have a part of the breast removed is not so difficult, but to have a complete mastectomy, they're not seen as being whole. So I do think in Leicestershire we have to be conscious that culture can have an influence. Erm ... and I think just generally, you know, my general experience that people given choice, when they, would much rather have a wide lower excision above mastectomy if they could.

INT: IF YOU HAD THE POWER AND MONEY TO CHANGE ONE SYSTEM ABOUT THE SYSTEM HERE, WHAT WOULD IT BE?

Nurse: Ah!

INT: YOU CAN'T GIVE YOURSELF A WAGE RISE.

Nurse: That we would be ...power and money ... if I had the power and the money that breast in Leicester would be one big directorate of its own and it would all be housed in one centre, and screening and symptomatic would be one complete, the service would be one. Mm, and all in one, including reconstruction, everything, in one centre of excellence rather than across sites.

INT: HOW MANY DIFFERENT SITES IS THAT? THREE? TWO?

Nurse: There's three sites in Leicestershire but breast is effectively on two sites.

INT: THAT'S RIGHT, YEAH. WELL THAT'S THE END OF THE INTERVIEW.

Nurse: Good [laughs]

[End of interview]