

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Doctor)
*VENUE: Low MR unit
*DATE:
*ID: BSO37
*INTERVIEWER: DJW

INT: FIRST OF ALL THANK YOU VERY MUCH FOR AGREEING TO BE INTERVIEWED, I OBVIOUSLY KNOW YOU'RE A BUSY PERSON SO IT'S NICE FOR YOU TO TAKE THE TIME TO DO THIS. I'D LIKE TO START OFF WITH QUESTION ONE WHICH IS ...

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

Doctor: Nine months.

INT: OK, AND THINKING ABOUT THE DAY TO DAY RUNNING OF THE SERVICE ...

Doctor: I understand, yeah.

INT: YEAH? THE SORT OF, YOUR LIKES, YOUR DISLIKES, THE UNIT PHILOSOPHY, THE STRUCTURE OF THE SERVICE, ETC ...

*Q2. CAN YOU JUST GIVE ME AN IDEA WHAT IT'S LIKE TO WORK AS A SPECIALIST IN THIS BREAST SERVICE?

Doctor: Erm, well I have great colleagues. The unit is very organised. We're a bit short-staffed at the minute, everybody is under a little bit of pressure, we've got a lot of patients coming through and we don't have enough medical and support staff. Erm, I think, erm, the unit here was ready for, I don't know, more modern techniques being introduced and some aspects of the service being expanded so that's where I come in.

INT: RIGHT, OK, YEAH. SO WHERE ELSE DID YOU WORK AS A SPECIALIST?

Doctor: Well, erm, this is my first consultant post, I've been a registrar in Nottingham and Edinburgh breast units.

INT: OK, YEAH. OH, EDINBURGH WOULD BE NICE ...

Doctor: Yeah.

INT: DID YOU LIKE IT THERE?

Doctor: Yeah.

INT: YEAH, VERY MULTICULTURAL CITY.

Doctor: Very nice place, yes. Probably a bit cold.

INT: [CHUCKLES] WELL IT WOULD BE COMPARED TO GREECE I SHOULD IMAGINE. YES, SO THINKING ABOUT, IS THERE ANYTHING HERE ABOUT THIS SERVICE YOU THINK PARTICULARLY MAKES YOUR JOB EASY, YOU KNOW, FACILITATES YOUR JOB AS A SPECIALIST?

Doctor: People are approachable. Erm, the breast, the specialist nurses are superb, they have expended their aspects of the service, erm ... things that make my job easy ... erm ... I think that my colleagues have made the job easier and the breast care nurses, otherwise it is, you know, it is difficult if you have a lot of work on a day to day practice. You have to have understanding colleagues that are willing to help, and work in a team.

INT: MM. HOW MANY CLINICS DO YOU DO A WEEK NORMALLY?

Doctor: Er, three.

INT: AND IS THERE ANYTHING, CONVERSELY TO THAT, IS THERE ANYTHING YOU THINK THAT CONSTRAINS, MAKES YOUR JOB DIFFICULT TO DO HERE ... ABOUT THE SERVICE?

Doctor: Right. Erm ... the, well I think the difficulties arise from the fact that we're short-staffed and if there was more staff then we would be able to the, to re-organise things as we want to. It's not possible at the minute. Otherwise, I don't see my job being obstructed in any way.

INT: THAT'S GOOD. BECAUSE YOU DO GET HUGE THROUGHPUT HERE, DON'T YOU? IT'S A BIG AREA, YEAH.

Doctor: Yeah. I mean there's also needs to participate in clinical trials so being overworked it doesn't help to organise yourself and get, you know, because you're always busy and diagnosing and treating people. You do need some time just deal with other aspects like research and expanding in the way of participating in trials.

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

Doctor: Well, erm, I think this question is difficult because everybody has their own style. I think what happens with time is that people who work in a team sometimes get a similar style or a similar, erm, way of approaching things. Not always but, you know, there are some compromises, like a marriage, you know, it's like a wedding, you get people working in a team so people influence one another within the team, so it's likely that we have the sort of same, erm, feelings about how things should be done or similar, or after long discussions you get closer to your beliefs and your styles, but if you're talking about styles of working, styles of operating are always different and we don't get to operate together so that stays the same. Each one has their own style of operating.

INT: RIGHT, OK. I'D LIKE TO TALK NOW A LITTLE BIT ABOUT BEFORE A CONSULTATION WHERE A DIAGNOSIS IS TO BE GIVEN, AND I'D LIKE US AT THIS POINT TO FOCUS JUST ON NEWLY DIAGNOSED BREAST CANCER PATIENTS.

*Q4. WHEN IS YOUR REGULAR BREAST MDT MEETING HELD IN RELATION TO THE CLINICS BEFORE ...?

Doctor: Two days before the clinic.

INT: IS THAT MONEY OR SOMETHING?

Doctor: Yes, it's Monday and my clinic is on the Wednesday.

*Q5. AND HOW DO YOU NORMALLY FEEL AFTER AN MDT MEETING, WHEN YOU COME OUT?

Doctor: Erm, I feel there was not enough time to discuss things that we wanted, and I don't feel ... well, sometimes it's boring if you discuss too many cases in a very short time, but I don't feel drained or anything like that. I may feel that after a clinic but not after an MDM.

INT: RIGHT, YEAH, MDTS. DO YOU THINK, IS THERE A VARIATION BETWEEN HOW YOU FEEL, BETWEEN WORKLOADS, IF IT GETS PARTICULARLY HEAVY LIKE AFTER A BANK HOLIDAY OR IF THERE'S NOT SO MANY CANCERS COMING THROUGH?

Doctor: Erm, well, the problem is there is pressure about cancer, so it doesn't have to do it, if it's a bank holiday or not, there is always pressure. So you always have to see as many as come through, you cannot let them wait. You cannot put them on a waiting list and you cannot let them wait to see you if you know they have cancer, so ... I see as many as come through. I think the only way where we restrict things is how many patients come through but then there is pressure of who's going to see them in the area, here obviously and elsewhere. And so we are trying to expand our staff and get more staff to do this.

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

Doctor: If there was suspicion but not confirmed on biopsy?

INT: YEAH.

Doctor: I think we would probably discuss the possibilities, depending on how the patient's feeling. You know, if they're terrified, er, then we would probably concentrate on answering their questions and so I would probably say that we will have the results next week and we will discuss them next week, but if the patient, if the patient provokes more, you know, asks more questions about it, then I try and answer the best way I can, so if I do have a suspicion then I'm honest about it and say there is a suspicion and we're doing the biopsy to find out what, you know, for sure.

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

Doctor: How do ...?

INT: IN WHAT WAY, IF ANY, DO, HAVE PATIENTS PREPARE THEMSELVES FOR THE NEWS THEY MIGHT HAVE BREAST CANCER?

Doctor: In what way do the patients prepare themselves?

INT: YEAH, MM.

Doctor: I mean what way do I help the patients or ...?

INT: RIGHT. DO YOU THINK THE PATIENTS IN ANY WAY PREPARE THEMSELVES THAT THEY'RE GONNA BE RECEIVING BAD NEWS?

Doctor: I think they always do, even if they don't, even if you tell them that, I think it's a bad thing to tell them that something is not suspicious or it's not to worry unless we truly mean it.

INT: YEAH, OF COURSE.

Doctor: Erm, because they'll always try, you know, they'll always keep the best news, so if you tell them that's it's, you know, it's unlikely or unusual then you really have to mean it, whether it's, you know, more than 90 or 95 per cent chance that this will be benign. I think if it's equivocal and if we don't know what it is, then I prefer not to say anything, and in that case they do prepare themselves and we do ask them to bring another person when they're here. So they're more or less, most of them are prepared to get news and they are hoping that they won't get the bad news.

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

Doctor: Information from the breast care nurse; information from the clinicians in my clinic that saw the patient in the previous appointment, and if it was me that I saw them, then, you know, I usually write down in my notes, because I cannot, I may not remember everybody, but I usually do within the week. Erm, and so it's information from the previous consultation that the patient had of how this is going to go. But basically the breast care nurse is the main link when there's a [??] different clinician that has seen the patient previously. And then, er, I just take it as it comes when I see them, you know, I see their attitude when I enter the room and everything else, but that's part of the consultation I guess.

*Q9. AND WHEN YOU KNOW YOU'RE GOING INTO A CONSULTATION TO GIVE SORT OF BAD NEWS, HOW WOULD YOU DESCRIBE YOUR FEELINGS BEFORE SUCH A CONSULTATION?

Doctor: My feelings?

INT: MM.

Doctor: Erm, well, erm, I think I'm not, you know, after, when we get used to the service we don't get sort of soiled[?] by the, you know, how we should be feeling, I think I just concentrate on what's the best way, what is the best treatment to recommend to the patient, I try not to be part of it. However I do empathise with them where they're feeling so, I do respond to their feelings when they get the bad news. So, and I do respond to what they want to know. Others have questions, others just want to cry and stay alone for a while, so I do respond to that but I try not to include myself in the sort of emotional ... although, although sometimes, you know, especially when you have very young patients that may have advanced or terminal disease then I think that's difficult, or recurring disease. And it's, I mean, yeah, it doesn't affect me, it doesn't influence my decision or my recommendation or my discussion, but I do sometimes empathise with what they feel. I just try to keep myself out of it and forget about it as soon as I go out the door.

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

*Q10. CAN YOU JUST SORT OF, JUST IN GENERAL, CAN YOU PLEASE TALK ME THROUGH WHAT HAPPENS IN A CONSULTATION WHERE DIAGNOSIS AND TREATMENT OPTIONS ARE BEING DISCUSSED WITH A PATIENT WITH BREAST CANCER?

Doctor: Yeah, right. Again, I would say the standard, the routine consultation would be to discuss, to go through what happened the previous time they were there and if there was a diagnosis to repeat that, if there wasn't a diagnosis then just go through what has happened before and then discuss the result. And when the result is a cancer result then I do say that there was cancer cells, or there was cancer, and I do use the word cancer when I give them their result. And then I just wait for their response and some people, as I've said, will want to know more about what is to be done next, some others just want to stop and cry, so I do respond to their feeling after that. And if, if I do feel at the end that they need more information, and they do get to speak to the breast care nurse afterwards and they do get information leaflets, and if I think they will need a second consultation I sometimes arrange a second consultation before surgery. Otherwise I arrange for a date for their surgery and then I see them just prior to surgery to see if they have any more questions or if there's anything they need to change. But the breast care nurse is an important link because some people may have concerns in between. The breast care nurse will

pick that up and will let me know and when I know I will arrange to see them again if I think there is a gap and they need to be seen again.

INT: AND DURING THE CONSULTATION IS THERE ANYBODY ELSE APART FROM YOURSELF AND THE PATIENT IN THE ROOM?

Doctor: There's a breast care nurse always, sometimes there's a medical student or one of the junior staff. Erm, but I'm never alone. I'm always with a breast care nurse when I discuss this. And, as I said, plus there maybe some junior staff, one of the junior staff or one medical student, so it's, we're three people in there in the room.

INT: AND DOES THE PATIENT BRING ANY RELATIVES IN OR ...?

Doctor: They do, yes, they always bring relatives or friends. And, what was the thing, erm ... what else takes place in the consultation is, what I discuss I try to put it in a way of what we recommend and I try and use the word 'may' or 'could' or 'would' rather 'have to' so 'we have to try this', or 'we recommend that we try this' and 'this is likely' so I give them the choice to say, you know, to ask if there's, if they think there should be any alternative, but I do mention what the recommended optimal treatment is.

INT: RIGHT, OK, YEAH. AND WHEN YOU ARE SORT OF DISCUSSING THINGS LIKE DIAGNOSIS, TREATMENT OPTIONS, DO YOU USE ANYTHING, ANY TOOLS LIKE X-RAYS, DIAGRAMS, PHOTOGRAPHS, DO YOU DRAW PICTURES?

Doctor: I usually draw. I usually draw, but I also use the diagrams on the consent forms. But I usually draw. I mean in other aspects of my clinics, discussing with the patients, I may use photographs but not on a newly diagnosed breast cancer patient, not on the first consultation where the bad news are broken.

INT: YEAH, MM. AND DO YOU SPEND ANY ADDITIONAL TIME WITH THE PATIENT AFTER THAT CONSULTATION?

Doctor: Erm, I, sometimes the patients have more questions and I may need to see them again on the same day, otherwise additional time when I see them prior to their operation, unless it's, another consultation will be prompted either from the breast care nurse or myself if I think they need it. Erm, otherwise after this consultation they will stay with the breast care nurse and have a discussion with her, and then I will see them prior to surgery.

INT: IN YOUR EXPERIENCE ...

Doctor: But I would be the second, sometimes I am the second person that sees them after the bad news have been broken, so many, if not most of the times the way the system works here, when I see them as a surgeon to discuss surgical treatment, I will be the second person after they've had the bad news broken.

INT: SO WHO WILL HAVE BROKEN THE BAD NEWS [???

Doctor: But as I am the surgeon, if I break the bad news the automatically talking about options, treatment options, then I am the right person to talk to them about surgery and they will ask me, they will expect me to discuss this. The other is the clinical assistant and the associate specialists. So when they see new patients and they diagnose them, they discuss the results together with the breast care nurse again.

INT: RIGHT, OK, AND THEN THEY PASS TO YOURSELF TO ...

Doctor: I see them the following week, yeah.

*Q11. IN YOUR EXPERIENCE WHAT DO YOU THINK PATIENTS TEND TO KNOW ABOUT BREAST CANCER AND ITS TREATMENT OPTIONS BEFORE THEY COME TO SEE YOU?

Doctor: It depends if the consultation is the first consultation where the bad news have been broken. If, some, very few will have a friend that's had breast cancer so they will know of treatment options, most of them don't. If they have seen somebody before me then they will know more about treatment options but, erm, I will have to expand on this when I see them. Many of them, erm, have heard that breast cancer needs chemotherapy so they will always ask, many of them will ask [???] chemotherapy. Erm ... and some of them may have already had, if they have seen somebody before me that have broken the bad news, they may have already received the leaflets discussing treatment options and surgery and side effects from surgery, so, and they will have heard that they may, following surgery they may need chemotherapy or radiotherapy or hormonal treatment.

INT: OK ...

Doctor: So it depends who sees them first. If somebody hasn't had experience, you know, if it's their first appointment where the bad news aren't broken, then, erm, you know, very few of them will have, will know details. If they haven't had the news from a clinician prior to, prior to seeing myself, then most of them would have gone on the, many would go on the internet, most of them would have asked somebody or discussed it with the family, and some, and another lot, you know, another third would probably not discuss anything further but just want me to tell them what the best thing to do is, and they wouldn't want any information, wouldn't, sometimes they wouldn't read the leaflet even.

INT: THINKING ABOUT THE ONES THAT COME TO SEE YOU FOR THE FIRST TIME TO GET THEIR DIAGNOSIS OF BAD NEWS, DO YOU THINK THAT THEIR LEVEL OF KNOWLEDGE AND UNDERSTANDING ABOUT BREAST CANCER AND THE TREATMENT OPTIONS, DOES IT, DO YOU THINK IT MAKES FOR A HARDER OR AN EASIER CONSULTATION, IF THEY KNOW A LOT OR A LITTLE?

Doctor: The level of ...?

INT: SORT OF KNOWLEDGE OR UNDERSTANDING OF [???]

Doctor: I think the level of knowledge makes it, the higher the education the more difficult I think.

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

Doctor: Because the highly educated people tend to want to know more and they, and because, you know, they have to learn more within a short period of time, they get confused sometimes so they need us to clarify a lot of issues, whereas people who are not very well educated, they will just follow what we see, they will read the information we give them and they will either make a decision or ask us to make a decision without asking for more. So they will concentrate on the consultation, whereas people who are highly educated they will check more, other options, go on the internet, may discuss more, so they get more confused. But this doesn't necessarily mean that they're going to have worse outcome or anything like that, or worse treatment. But I think it's more difficult for them because they get into more, sort of, in that way it's more difficult. But in terms of accepting the disease I think it's all the same for everybody.

INT: OK.

Doctor: And in terms of making up their mind about this, making decisions or ... they want to make decisions, they're more likely to want to be able to make decisions on their treatment, but they are the ones that may be getting more confused because they have to take, read, and take in all that information. So [???] that's what I'm saying.

*Q12. WHAT DO YOU THINK ARE THE MOST IMPORTANT PIECES OF INFORMATION THAT PATIENTS NEED OR WANT TO KNOW ABOUT THEIR DIAGNOSIS?

Doctor: It's difficult. I think it's very individual what ... others would want to know about surgery and the effects, you know, the cosmetic outcome; most of them would want to know the general outcome, however that's never easy to determine from the first consultation so that's an easy one basically for us because ... but they do I think all like to hear what is our expert, you know, what, what sort of level of risk do we put them when we see them. We say, again, as I say, it's very difficult because we have different cancers [???] if it's a small screening one then it's most likely that they are, the general outcome would be good, so we do try to, erm, say that we think it's treatable because it's small. If you have someone in with a bigger lesion and whatever, then you prefer to discuss the details afterwards. What else is there for them that they want to know? Erm, well they want to know if it's going to affect their, their life pattern, their working patterns, mothers are worried about their children, everybody will want to know how long they're going to live ... and many will ask that. Erm, well some would want to know if they have other treatment options but in most cases we know that the optimal treatment is surgery.

*Q13. AND THINKING ABOUT TREATMENT OPTIONS, YOU KNOW, DO YOU THINK THAT, WHAT DO YOU THINK ARE THE MOST IMPORTANT PIECES OF INFORMATION PEOPLE WANT TO KNOW ABOUT THEIR TREATMENT?

Doctor: As I said, the cosmetic outcome from their surgical treatment. If it's a medical treatment, the side effects. And, you know, as far as cosmetic outcome is concerned they want, most of them would want to know if they will be able to keep their breast with the same sort of treatment effectiveness. And as far as adjuvant treatment is concerned I think most people would be worried about losing their hair [???] Again as far as the image, the [???] image is concerned.

INT: WHEN YOU'RE TALKING ABOUT THINGS LIKE DIAGNOSIS AND TREATMENT OPTIONS, IS THERE ANY, ANYTHING, ANY INFORMATION THAT YOU GIVE THAT YOU THINK, ERM, IS GENERALLY NOT UNDERSTOOD VERY WELL?

Doctor: From what sort of ... sorry?

INT: WHEN YOU'RE TALKING ABOUT TREATMENT OPTIONS AND DIAGNOSIS, ETC, DO YOU THINK, IS ANY INFORMATION THAT YOU PERHAPS GIVE TO PATIENTS THAT THEY GENERALLY DON'T UNDERSTAND, FIND IT DIFFICULT TO ...?

Doctor: I think difficult, difficult to the patients to understand is, er, to say that if the surgery has been adequate, for example when we do a wide local excision, that the margins are clear, some people interpret this as that the cancer has been removed and they are clear, and they cannot understand that at the same time there is a risk that there may be systemic disease that may recur at some point. I think that's a difficult piece of information for them to take in. I think the bits that have to do with surgery are relatively straightforward so they do understand, if they have the adequate information and leaflets and pictures, they do understand how they're going to look after a mastectomy and how they're going to look after a wide local excision and, you know, what sort of stitches they are going to have and what complications may occur, I think that's easy. But the difficult thing is to take in your options and why there is a possibility of recurrence even if we say that we don't need more surgery, you

know, that it has been removed. That's a difficult piece to take in. Another difficult piece to take in is when they have ductal carcinoma in situ - again to take in that, if you haven't had a mastectomy, then there is a risk of local recurrence which is higher than the risk of local recurrence with a mastectomy for patients who've had DCIS. But, it's unlikely to affect their survival.

INT: I'D LIKE TO MOVE ON NOW TO THE KIND OF TREATMENT OFFERED, A PATIENT IS OFFERED.

*Q14. WITHIN THE CONTEXT OF THE UNIT'S GUIDELINES AND PUBLISHED RESEARCH, CAN YOU PLEASE DESCRIBE THE FACTORS THAT WOULD LEAD YOUR TEAM TO OFFER A PATIENT...

*a. IN THE FIRST INSTANCE ONLY BREAST CONSERVATION SURGERY?

Doctor: The size of the tumour in relation to the size of the breast; the evidence from the imaging of widespread disease that is confirmed on the histology; the evidence of multi-centric disease, which means two tumours in two different quadrants of the breast, sort of [???] is a big distance between them in which case breast conservation is not possible, because we would need to remove half of the breast and it wouldn't look nice afterwards anyway; I'm not particularly worried about the tumour being close to the nipple, I find that sometimes I can excise it without removing the nipple, or even if I do remove the nipple areola complex with the tumour, or if it's central then, depending again on the size of the breast of course and size of the tumour, I don't think the cosmetic outcome is really bad, they just have a slightly smaller breast, so, without a nipple. And I think most women prefer that than just losing their breast completely. So the proximity to the nipple areola complex is not a contra-indication for offering breast conservation treatment, even if they have to have their nipple removed.

*b. AND CAN YOU PLEASE DESCRIBE THE FACTORS THAT WOULD LEAD YOUR TEAM TO OFFER A PATIENT ONLY A MASTECTOMY?

Doctor: Sorry? Oh, why would I offer a mastectomy without conservation treatment? That's the question?

INT: YES, JUST A MASTECTOMY, YEAH.

Doctor: Well, elderly patients that don't go, don't want to go through two operations, like if they, but that's their decision again. If I think they are suitable for breast conservation I do mention that, erm, and I say they are suitable but I do mention, if I mention there is a risk, sort of 1 in 5 that they may need a re-excision, further surgery, many of them would say that they prefer to have one operation so that's why they prefer to have the breast off, because there would be no more surgery after that. So this is one reason, where I'm not, it's not an absolute indication, but I do mention to the patient, so people who know that there is a risk of having a further operation after a wide local, they may decide that they want a one-off operation and they decide to go for a mastectomy. But again I don't present it as an absolutely indication, I don't say that 'You have to have a mastectomy because you have to have one operation, but there is the risk that you may have two,' so they decide if they want to go for it or just have the one [???]. So patients over 75-80, they usually go for a mastectomy. You know, unless the tumour is very small and there's little evidence from histology and imaging that the wide local excision would not be adequate. And then again patients that deny radiotherapy to the breast, they need to have a mastectomy, if they don't agree with having a wide local and radiotherapy then I would recommend a mastectomy because I think, er, because the risk of recurrence, local recurrence would be higher without radiotherapy. But you do get the odd patient that don't want radiotherapy and don't want mastectomy and just want the lumpectomy and they accept the high

risk, but this is very unusual, only one in 100 or 200. Other reasons, erm, well I said before, the multifocal disease which is in different quadrants. Again a tumour, I would be very careful in offering breast conservation in tumours bigger than 3, 3.5, 4 cms. I probably wouldn't unless they had a very big breast. Again it's proportional but because most people have an average breast or small breast, erm, then a tumour bigger than 30 or 35 mms would probably indicate that a mastectomy is needed.

*c. AND CAN YOU TELL ME WHAT FACTORS WOULD LEAD YOU TO OFFER A PATIENT A CHOICE BETWEEN THE TWO TYPES OF SURGERY?

Doctor: Erm, well all the rest. You know, like, I offer, I think I offer a choice in most cases when I don't offer a choice about mastectomy is when the size, because of the size of the tumour, because of the size of the primary tumour and the extent of it. And there are other indications like a patient with a lump and pathological nipple discharge, this patient needs to have a mastectomy. And then other than that I would give the option of breast conservation.

*d. AND WHAT FACTORS WOULD LEAD YOU TO OFFER ANY OTHER TREATMENTS, SUCH AS NEO-ADJUVANT TREATMENTS?

Doctor: I would, right, so, neo-adjuvant, you're talking about primary treatment, non-surgical? Like chemotherapy or hormonal?

INT: MM.

Doctor: Erm, that's, do you mean that I would exclude them from surgery because there's different categories of patients ...?

INT: NO.

Doctor: The local advanced I would probably primary chemotherapy or primary hormonal treatment, depending on their age, and then followed by surgery. Patients that we think are non- [??] not fit because of anaesthetic risk because of, you know, dementia, other factors, I may offer hormonal treatment.

INT: OK.

Doctor: But then these patients need to be followed closely and if they don't respond or if they have progressive disease, then we have to take ... so ... basically there's, I offer all the range of options depending on the right patient, so I can offer primary hormonal treatment to somebody who's not suitable for surgery; and we may offer primary, as you say neo-adjuvant treatments for somebody who has local advanced disease; and then again I may offer radiotherapy and a non-optimal treatment but the most optimal if they are high risk for surgery.

INT: OK. I'D LIKE TO MOVE ON A LITTLE BIT NOW. THE LITERATURE SUGGESTS THAT PATIENTS VARY IN THE DEGREE OF INVOLVEMENT THEY WANT WHEN MAKING DECISIONS ABOUT WHAT SURGERY TO HAVE. SOME PATIENTS WILL WANT FULL CONTROL; OTHERS WILL PREFER TO SHARE THE CONTROL; AND SOME WOULD PREFER IT IF THE PROFESSIONALS TAKE THE CONTROL.

*Q15. FIRSTLY DO YOU THINK THAT PATIENTS ARE GETTING THE DEGREE OF CHOICE THEY WANT?

Doctor: From me, yes. I give them all the choices, so I go with what they want ... unless I think there's an absolute indication for something, but again, you

know, I don't try and change their mind. I just give them the options and then they have to make up, you know, decide for themselves.

INT: DO YOU FIND AT ALL THAT WHEN YOU OFFER THE PATIENTS CHOICE OF TWO TYPES OF SURGERY, DO YOU FIND THAT THEY'RE SURPRISED [???

Doctor: Do I find that they're surprised?

INT: THAT THEY'RE SURPRISED THEY HAVE A CHOICE?

Doctor: No, they're not surprised, most of them I think probably expect it, but they ask you if the two treatments are equal, that's their concern.

INT: RIGHT, YEAH. THAT THEY'RE NOT GETTING A LESSER TREATMENT, YEAH?

Doctor: Yes.

INT: WE'RE ON QUESTION 16, HAVE YOU GOT YOUR ... SO I DON'T HAVE TO GET THE CARDS OUT AT ALL.

Doctor: OK.

*Q16. THERE'S FIVE CHOICES THERE, BULLET POINTS. THINKING ABOUT YOUR EXPERIENCES WITH THE PATIENTS WOULD YOU PLEASE LOOK AT THE RESPONSES BELOW AND TELL ME, DURING CONSULTATIONS, WHO GENERALLY MAKES THE FINAL DECISION ABOUT WHAT SURGICAL TREATMENT TO HAVE?

Doctor: OK. The patient tends to make the final ... oh, er, ... well again it depends on the type of patient, doesn't it, but I think it's probably 2, they make the final decision after they consider what I recommend. Yeah, I mean I don't share the responsibility, I just give them the option. But when they ask me to decide then I decide, so I cannot say that they make the final decision. They actually, they do make the final decision but their final decision may be that they want me to decide. That's what I'm saying, so I think it's 2. They do make the final decision after seriously considering my opinion.

INT: AT THIS POINT I'D LIKE US TO TALK ABOUT YOUR EXPERIENCES IN 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 INTO ONE OF THREE DIFFERENT DECISION MAKING STYLES OR CATEGORIES, THAT'S THE ACTIVE, COLLABORATIVE AND PASSIVE DECISION MAKERS, AND I'M PROBABLY AWARE NOW FROM DOING SO MANY INTERVIEWS THAT YOU MIGHT NOT EVEN THINK ABOUT THEM IN TERMS OF ACTIVE AND PASSIVE AND COLLABORATIVE DECISION MAKERS, BUT JUST FOR THE PURPOSES OF THIS STUDY, IN THIS FINAL SECTION OF THE INTERVIEW I'D LIKE TO ASK YOU A FEW QUESTIONS ABOUT HOW YOU FIND COMMUNICATING WITH THESE TYPES OF PATIENT DURING THE CONSULTATION PROCESS THAT LEADS TO A FINAL TREATMENT DECISION. I'D LIKE US TO START WITH SITUATIONS WITH ACTIVE DECISION MAKERS. FOR THE PURPOSES OF THIS STUDY WE DEFINE ACTIVE DECISION MAKERS AS PATIENTS WHO TEND TO MAKE THEIR OWN FINAL TREATMENT DECISIONS EITHER WITH OR WITHOUT SERIOUSLY CONSIDERING THEIR SPECIALIST'S OPINION.

*Q17. FIRSTLY, I'D LIKE YOU TO TRY AND THINK ABOUT A SITUATION YOU HAVE HAD WITH A PATIENT WHO WAS ACTIVE AS ACCORDING TO THAT DEFINITION. WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, PLEASE TELL ME ABOUT YOUR EXPERIENCE WITH THAT PERSON UP TO THE POINT WHEN THEY MADE A TREATMENT DECISION. DO YOU THINK THAT ...

Doctor: I think what tends to [???] active decision makers if they come ready to ask specific questions and I'm preparing to answer their questions, and at the

end, you know, so that I can enable them to make their mind up. So that's my role with the active decision makers.

INT: CAN YOU THINK OF ANYBODY IN PARTICULAR THAT YOU MIGHT HAVE CONSULTED WITH RECENTLY OR THAT WAS LIKE THAT?

Doctor: Er ... yes, I can think of one, not very recently yes.

INT: AND WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, COULD YOU JUST TELL ME ABOUT HOW THE CONSULTATION WENT WITH THEM?

Doctor: I think they particularly came to see me because I think, two cases: one came to see me because they didn't like the surgeon that they met before so they came to have a second opinion, and at the same time they, not that the surgeon was from this hospital, I'm not suggesting that, you know, the previous surgeon they saw. And at the same time they wanted to, they wanted to discuss the option of having a sentinel [?] node done so there were interested to hear about options that will reduce their axillary or complications from the arm risk. And they were glad that I could offer them axillary sample rather than axillary clearance. And, I can remember another one who doubted the previous decision made that they would need a mastectomy so they came to me for a second opinion and the truth is that by viewing the x-rays and re-examining the patient I couldn't decide that they had a big cancer that had, that would require a mastectomy, it was actually a recurrence but it was a screening detected sort of type of recurrence, so I accepted that a wide local excision would be a possibility. However this lady had widespread DCIS around the recurring cancer and so she eventually needed a mastectomy and that was a widespread DCIS so it was rightly assessed on imaging as a, you know, a recurrence, though it wasn't very big. And it wasn't very big but she did have a lot non-invasive cancer in the rest of the breast and she did require a mastectomy eventually. I think she was happier because she could have, at that time, have the option of having breast reconstruction whereas if she had on the first place she wouldn't have it because we would have assumed that this was, you know, more progressed and she may have required radiotherapy, whereas afterwards we knew that she didn't need radiotherapy post-mastectomy and so she had the mastectomy with immediate reconstruction so she would have it.

INT: AND THINKING ABOUT THOSE TWO PATIENTS, HOW DID YOU GET ON WITH THEM DURING THE CONSULTATION?

Doctor: Well I got along with them fine because, as long as you avoid making comments about other clinicians that have seen the patient before, then you get on fine because if they're happy with the consultation they received from me, then they go away happy.

INT: THAT'S THEIR MOST RECENT EXPERIENCE, YEAH.

Doctor: But if they had a bad experience from me then, then again they would want to have a second consultation with somebody else. The cases where I have difficult consultations is with patients that have denial, but again, you know, that's usually the first time, it's unusual to get somebody who sees the second or third or fourth. We do get a few of those and so we try to do our best. Or I think I would have difficulty if the first consultation wasn't very good or, erm, you have doubts or ... or they receive information that is not very clear to them, not necessarily because of me but because of that the information cannot be clearer and they need repeat biopsy or something like that. Then it's difficult: it's difficult when the information that they initially received is changing and they hear different [???] And I also find it difficult when I'm not there and when they have to be seen by another clinician and then they lose confidence because nobody can know somebody as well as I do, that I have see

them before, and I have treated them, and so, you know, the second clinician that will assess the same problem, needs very careful assessment of the notes and patient when they talk to them, because it's very easy to get something not right if somebody has been followed, a surgeon [???] and they have seen me three times and another clinician another three times, and suddenly they get a third one, you have to very carefully review what's going on before, otherwise if you don't get all the details they would lose confidence if you go in there and tell them something else that they haven't had before.

INT: AND THINKING ABOUT THOSE TWO PATIENTS, WHAT OTHER INFLUENCES DO YOU THINK WERE APPARENT IN THEIR DECISION MAKING?

Doctor: Their partners, erm, and the information that they had received or they sought.

INT: AND LOOKING BACK NOW, HOW SATISFIED WERE YOU WITH THE EXPERIENCE CONSULTING WITH THESE TWO PEOPLE?

Doctor: You mean my satisfaction or their satisfaction?

INT: YOURS TO START WITH, YEAH.

Doctor: Er, well I didn't have a problem, because as I said I was their second opinion and I think in all, not just in surgery, but in all aspects of medicine, the second opinion is always better for many reasons, you know. If it's an acute pain then the second doctor can easily diagnose more because there are more symptoms and there are more signs than the first one has seen, so the second doctor is always perceived to be better than the first one. The same thing in surgery, the first one gives an opinion, if the patient is not happy then you know that they wouldn't be happy with that, so you are prepared to leave it up to them and discuss, you know, all the options they want. Not that I don't discuss them before but, you know, I usually go straight to the point to discuss which is the optimal option when I see somebody, but if I know somebody has had trouble accepting things then I even more ... well ... try to be more helpful with giving them options and helping them decide.

INT: MM. AND HOW SATISFIED DO YOU THINK THEY WERE WITH THE EXPERIENCE?

Doctor: I think they were very satisfied.

INT: DO YOU THINK THEY GOT THE TREATMENT ...

Doctor: And they were grateful.

INT: AH YEAH.

Doctor: That's what they told me, so I think ...

INT: AND, YEAH, YOU MENTIONED EARLIER, YOU SAID THAT YOU KNOW, YOU SEEMED TO KNOW QUITE SOON WHEN YOU'RE DEALING WITH SOMEONE WHO SEEMS TO BE QUITE AN ACTIVE DECISION MAKER, IS THAT RIGHT?

Doctor: Well either from the breast care nurse or from, you know, as soon as I, they discuss the first couple of things.

INT: AND DOES THAT SORT OF AWARENESS, IF YOU LIKE, INFLUENCE OR CHANGE HOW YOU GO IN TO CONSULT WITH THAT PERSON IN ANY WAY?

Doctor: Well it does, yes.

INT: IN WHAT WAY DO YOU THINK?

Doctor: It does because, erm, I tend to listen to what they say more when I know they, you know, try to listen and understand what they want to get out of the consultation, whereas if I know they're not active I try to give them the information and let them understand what's happening, and then I let them make the questions at the end.

INT: I'D LIKE TO MOVE ON NOW TO SITUATIONS WITH COLLABORATIVE DECISION MAKERS AND FOR THE PURPOSES OF THIS STUDY WE DEFINE COLLABORATIVE DECISION MAKERS AS PATIENTS WHO TEND TO SHARE FINAL TREATMENT DECISIONS AND RESPONSIBILITIES WITH THEIR SPECIALISTS.

*Q18. I'D LIKE YOU, JUST AS WE'VE DONE NOW, TO TRY AND THINK OF A PATIENT WHO YOU THOUGHT WAS PARTICULARLY COLLABORATIVE ABOUT MAKING DECISIONS, AND, WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, TELL ME ABOUT YOUR EXPERIENCE WITH THEM UP TO THE POINT WHEN THEY MADE A DECISION. THIS IS QUITE OFTEN THE HARDEST ONE.

Doctor: Well I think the way the consultation goes is always the same. It starts by trying to understand what they want and at the same time trying not to miss the main points that need to come across regarding their treatment.

INT: IS THERE ANYBODY IN PARTICULAR YOU CAN THINK OF WHO YOU THOUGHT WAS PARTICULARLY COLLABORATIVE YOU COULD TALK ABOUT?

Doctor: ... Erm, well, I don't know ... I think most patients would be in the collaborative or the passive, so that means all the rest apart from the active.

INT: AND HOW DO YOU FIND CONSULTING WITH PEOPLE WHO ARE PARTICULARLY COLLABORATIVE ABOUT THINGS?

Doctor: Well I find it easy. With the passive decision makers it's a bit difficult because I sort of have to make the decision for them so I have to, I have to, er, fish out all the details that would enable them to decide and would help them, influence them decide, something about them, and make the decision for them knowing how they would feel on certain aspects of their life or what is important to them.

*Q19. FINALLY IN THIS SECTION, I WOULD LIKE YOU TO THINK ABOUT A SITUATION YOU HAVE WITH A PATIENT WHO WAS PASSIVE ABOUT MAKING DECISIONS. AGAIN, WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, PLEASE TELL ME ABOUT YOUR EXPERIENCE WITH THEM UP TO THE POINT WHEN A TREATMENT DECISION WAS MADE. [Not asked]

INT: SO YOU SORT OF, WITH THE PASSIVE YOU ...

Doctor: So, yeah, the fact that they're saying, 'You can make the decision for me,' doesn't necessarily mean that they will be happy with it. So it's me that I have to make sure that they're going to be happy with the decision that has been made.

INT: MM. AND WHEN YOU'RE DOING THAT, DID YOU SAY, YOU SAID THAT YOU FISHED OUT THE DETAILS, DO YOU FEED THAT BACK TO THEM AND TRY TO GET THEM TO GET A REACTION BACK TO SAY, WELL, YES, THIS PERSON'S HAPPY OR THEY'RE NODDING OR WHATEVER?

Doctor: Yes, I am trying to, yes, yes.

INT: AND WHEN YOU'RE DEALING WITH PASSIVE DECISION MAKERS, THESE TYPES OF DECISION MAKER - ACTIVE, COLLABORATIVE, PASSIVE - IS THERE ANY ONE PARTICULAR TYPE ARE HARDER MORE DIFFICULT OR EASIER TO WORK WITH?

Doctor: ... from the passive decision makers?

INT: FROM EITHER, YEAH.

Doctor: All categories.

INT: ALL THE CATEGORIES, YEAH.

Doctor: Erm, OK, that's the question again, sorry.

INT: YEAH, IS THERE ANY PARTICULAR CATEGORY OF DECISION MAKER YOU FIND EASIER OR HARDER TO CONSULT WITH, TO WORK WITH?

Doctor: Erm ... well I think the active ones are harder to work with because they are the more, you know, they will be the more criticising at the end.

INT: RIGHT, OK. AND THINKING ABOUT ALL PATIENTS NOW, JUST IN GENERAL, FROM THE MOMENT WHEN A PATIENT SORT OF HEARS THEIR DIAGNOSIS THAT THEY'VE GOT, YOU KNOW, A BREAST CANCER TO THE POINT WHEN THEY MAKE A DECISION, HOW LONG DO YOU THINK IT TAKES THEM, JUST ON AVERAGE, TO MAKE A DECISION?

Doctor: From diagnosis to make a decision what treatment they want to have?

INT: YEAH, MM, JUST ON AVERAGE.

Doctor: Probably some need one or two days and some, there may be some that need weeks, with repeat of the consultations, but the average would probably need days.

INT: MM, A FEW DAYS, YEAH. I'D LIKE TO FINISH OFF WITH A COUPLE OF QUESTIONS NOW. THE LITERATURE TELLS US THERE'S A VARIETY OF INFLUENCES ON PATIENTS MAKING DECISIONS ABOUT SURGICAL TREATMENT.

*Q20. THINKING ALL, THINKING FIRST OF ALL, SORRY, IN A WIDER SENSE, BEYOND THE UNIT, THE BREAST UNIT, WHO OR WHAT DO YOU THINK HAS THE GREATEST INFLUENCE ON PATIENTS' DECISIONS ABOUT WHAT SURGICAL TREATMENT TO HAVE?

Doctor: Erm, sorry I don't understand the question.

INT: YEAH, SO, THERE'S A VARIETY OF INFLUENCES ON PATIENTS' DECISION MAKING ...

Doctor: By clinicians?

INT: NO, NO. THINKING FIRST OF ALL OUTSIDE OF THE UNIT, NOT ANYTHING TO DO WITH THE UNIT, IN [???] ...

Doctor: Yes, OK, OK.

INT: OUTSIDE OF THE UNIT WHO DO YOU THINK HAS THE, OR WHO OR WHAT HAS THE GREATEST INFLUENCE ON PATIENTS' DECISION MAKING?

Doctor: The way they see their body and their life, so it's them, the patient, their patient, their family, partner or family

[Interruption in recording]

INT: YEAH, SO YOU SAID THE PATIENT'S FAMILY ...

Doctor: Who else will influence them? I think the main influences are from the most immediate environment which is usually the family, people who don't have a

family their closest friend, so it is their environment, their closest environment. So first family and then friends. And then it is information that you get from the street, so any information good or bad, newspapers, leaflets, anything ... internet ...

INT: WHEN YOU SAY CLOSE FAMILY IS THAT FAMILY WHO'VE HAD PREVIOUS EXPERIENCE OF BREAST CANCER OR ...?

Doctor: No, no, no.

INT: SO JUST FAMILY.

Doctor: It does influence them.

INT: AND NOW THINKING WITHIN THE ...

Doctor: Because their lifestyle is depending on the family. Because my lifestyle is not particularly, is not independent from the family that I live in, and if I don't have a family, you know, the best friend that I go out with, we have similar lifestyles. And their decisions affect mine and my decisions will affect how the family will, erm, I don't know, I think it's because we, on some occasions we take decisions for ourselves but we also try to put that in the context of our nearest environment.

INT: YES, MM.

Doctor: So we are influenced by the influence we will have with the decisions and their perception of what we should be having. We are influenced by others, either we want it or not, either we say it or not. It is an unconscious, you know, function. Erm ... I don't know how to say this ... erm, anyway ...

*Q21. AND, I WAS GOING TO SAY NEXT OF ALL, 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 SURGERY TO HAVE?

Doctor: About what surgery to have?

INT: YEAH, ABOUT WHAT THEIR DECISIONS ABOUT [???] ...

Doctor: [???] which person you mean?

INT: NO, THE TREATMENT THEY'RE GOING TO HAVE, WHAT SURGERY, WHAT SURGICAL TREATMENT THEY'VE GOING TO HAVE.

Doctor: OK ... what is the question? The question is who ...?

INT: YEAH, WHO OR WHAT WITHIN THE BREAST TEAM ...

Doctor: Oh, who or what?

INT: YEAH, WOULD HAVE THE GREATEST INFLUENCE ON PATIENTS' CHOICE OF WHAT SURGERY THEY'RE GONNA HAVE?

Doctor: Well, the assessment, the evaluation of their disease basically, now am I clear or is that not clear?

INT: YES, YES.

Doctor: The assessment of what type of disease they have. Erm ... and their general health.

INT: OK. ERM, IF YOU HAD THE POWER AND THE MONEY TO CHANGE ONE THING ABOUT THE SYSTEM HERE WHAT DO YOU THINK IT WOULD BE?

Doctor: Erm, introduce systems to assist, erm ... one-stop definitive diagnosis.

INT: AH ONE-STOP CLINICS, YEAH, MM.

Doctor: We do have one-stop clinics but, you know, first of all ... at the minute this seems to be the problem, perhaps that's why it's in my mind. It's not that we don't have a one-stop clinic but it's just the fact that some people may need to come for a repeat biopsy for some reason if the first one was [???] it's another [???] you know, [???] you know, I would hope that we had the system to do, to complete our assessment and results in one clinic, without having to ask them to return to the second clinic to get more biopsies or re-do it.

*Q22. FINALLY, IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD TO WHAT WE HAVE BEEN TALKING ABOUT TODAY? ANYTHING YOU THINK WE'VE FORGOTTEN OR YOU THINK IT'S IMPORTANT THAT WE HAVEN'T MENTIONED YET?

Doctor: Mm, well we've said a lot.

INT: WE HAVE, YEAH, BEEN TALKING NEARLY AN HOUR I THINK. THERE'S A LOT TO GET THROUGH. ANYTHING ... NO?

Doctor: Yes, there is, yes. A long one. [?]

INT: OK? RIGHT. IF THERE ISN'T ANYTHING ELSE I'LL STOP THE INTERVIEW. THAT'S IT.

Doctor: Oh, that's the end, is it? OK.

INT: YES.

[End of interview]