

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Doctor)
*VENUE: Low MR unit
*DATE:
*ID: BS020
*INTERVIEWER: DJW

INT: FIRST OF ALL THANK YOU FOR AGREEING TO BE INTERVIEWED.
I'D LIKE TO START WITH ...

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

Doctor: Well I suppose it was set up about 1988/89, so since
then really.

INT: RIGHT, OK. AND HAVE YOU WORKED ANYWHERE ELSE AS A
CONSULTANT?

Doctor: No.

INT: THAT'S WHAT I THOUGHT, YEAH. AND THINKING ABOUT THINGS
LIKE, YOU KNOW, LIKES, DISLIKES, UNIT PHILOSOPHY, DAY TO DAY
RUNNING OF THE SERVICE, THINGS LIKE THAT, WHAT'S, TELL ME A
BIT ABOUT ...

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

Doctor: Fine, great.

INT: MM, YEAH, YOU ENJOY IT, YEAH?

Doctor: Yeah.

INT: AND IN TERMS OF THE ACTUAL STRUCTURE OF THE SERVICE, FROM
WHEN PATIENTS SORT OF COME IN, CAN YOU GIVE ME A SORT OF
THUMBNAIL SKETCH OF HOW THEY SORT OF GO THROUGH THE CLINIC,
BECAUSE YOU'VE GOT TWO ROUTES - YOU'VE GOT YOUR SCREENING AND
YOUR SYMPTOMATIC UNITS - CAN YOU JUST SORT OF TAKE ME BRIEFLY
HOW THEY GET THROUGH THE CLINIC?

Doctor: Well the screening patients will be seen at an
assessment clinic, they'll be seen by the radiologist and
clinician who may or may not be me - there are two other
doctors working with the clinic that I do. So they'll be
examined, they'll have further x-rays done, any tests that are
likely to need to be done to make a diagnosis: those that are
fine are discharged; those that have a biopsy done will, or an
arrangement is made for them to have an x-ray-guided biopsy,
they'll be seen after that's been done. So if it's done in

clinic they'll be seen the next week; if it's booked for a marker biopsy list then they'll be seen a week after that's been done. I usually see the patients coming back with results and I'll see some of them, the new ones - well 'new', just that are due to be investigated. There's no hot reporting in that clinic, so those are maybe given an inkling that there might be something more serious wrong, they won't be given a diagnosis until they come back for their results. When they come back for the results they'll be given a date - usually given a date for admission if they require surgery. At the moment times are a bit hard and there's a delay to get people in, so, so some of them won't be given a date, they're just given an idea, within three weeks, four weeks, something like that, or the week it's likely to be. The symptomatic patients come to clinic on a Friday morning, they're seen by one of three doctors usually, myself being one of them; they'll be seen first, have their x-rays done, be it ultrasounds or mammography, needle tests for cytology or core biopsy will be done in the clinic - there is hot reporting in that clinic so they usually see you after that with the result. They'll either be discharged or they'll be given a follow-up appointment if there's still some uncertainty, or they'll be again told a diagnosis of malignancy if that's the case, and again usually given a date to come in, though at the moment they're likely to be given more of an idea of a date, you know, first in May, as it were, and then sent the date through the post. There's breast care nurses in both clinics to support that ... movement really. So that's largely how it works.

INT: RIGHT, OK. AND JUST THINKING OF YOUR DAY TO DAY WORKING HERE, WHAT SORT OF THINGS DO YOU, WHAT DO YOU LIKE ABOUT WORKING HERE? WHAT DO YOU FIND ...?

Doctor: Well, I mean it's a system that we've set up that seems to work well, so we've had the ability, or not the ability, but the privilege of setting up a system which, you know, we've tailored for ourselves. It's a similar system for each of us really, though there are minor modifications that various [??] have made really for their own preferences really; but it's a system we've set up. There's good nursing support; there's good hardware in terms of the building and so on; the, you know, colleagues are good, you know, I mean, it's just a happy place to work really and all the radiological, pathological and surgical personnel get on very well really. So, you know, it's just a very pleasant place to work where you can discuss things and share any problems there may be or discuss cases or whatever really.

INT: YEAH I KIND OF PICKED UP ON THAT [???] SOME OF THE BREAST CARE NURSES FIRST AND SORT OF THEY DO SEEM TO HAVE THAT SORT OF ATMOSPHERE OVER IN THE BREAST UNIT THERE: IT WAS VERY NICE TO BE THERE.

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

Here

Doctor: Well I mean there are probably minor differences that, I mean some consultants prefer say in the symptomatic clinic to do x-rays first on arrival and then see the patients to try and save time that way: others prefer to see the patient first and book the x-rays as required. There might be slightly different attitudes in terms of what you say to the patient, what the degree of choice that you might offer, or the degree of advice that you might offer, you know, I think they're probably minor differences between people. I've not attended the clinics of my colleagues to see what they get up to, but that's the impression I get.

INT: YEAH, MM. AND MOVING ON A LITTLE BIT ... BEFORE THE CONSULTATION WHERE A DIAGNOSIS IS GOING TO BE GIVEN, AND I'D LIKE US JUST TO FOCUS JUST NOW 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?

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Doctor: Well in the screening group it's usually, the MDT will usually be before they're seen; in the symptomatic group it will be after they're seen, the difference being that the hot reporting really, you know, one clinic has hot reporting so we'll know, you know, before the results ever get to an MDT the patient's got a breast cancer, and so they'll be told in that clinic. But the screening group, you know, we don't have hot reporting and so usually they, usually you get a result through the MDT though not always, but usually that's the case.

*Q5. AND AFTER AN MDT HOW DO YOU SORT OF USUALLY FEEL AFTER THAT?

Doctor: All right. I mean there are times when, you know, you feel there have been positive decisions made to help with patient management, there'll be other times where it's been a sort of rubber-stamping exercise where, you know, it's not

been that helpful, if you like, in terms of , you know, trying to make a treatment plan, but ... so.

INT: DO YOU THINK IT VARIES AT ALL BETWEEN HEAVIER WORK, LIGHT WORKLOADS?

Doctor: So, what ...?

INT: DO YOU THINGS VARY AFTER, SAY IF YOU COME OUT OF AN MDT AND THERE'S A LOT OF NEW CANCERS OR NOT MANY NEW CANCERS TODAY ...?

Doctor: Erm, well I mean I suppose you'd notice that more at the clinics really, when you come away from the clinics, saying there's a lot of work ahead or not. The MDT ... obviously does sometimes pick up re-operations that are required, erm, for which there's a sort of a feeling of - I suppose dissatisfaction's the right word really - where you feel you thought you'd done what was appropriate and it turns out you've got to have another go because the margins are incomplete or something. So, for those, those I suppose would be fairly negative vibes at the end of an MDT if there's one or two of those cases.

INT: YOU MENTIONED EARLIER THAT SOME PATIENTS MIGHT HAVE INKLINGS OF WHAT THEIR DIAGNOSIS MAY BE ...

*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?
Here

Doctor: Well the screening patients who have got to wait the week for their result, usually they're given a bit of an idea. I mean the three people who do that clinic probably have a slightly different way of managing the patient really. One of the doctors is usually more straight with the patient who is suspected of having breast cancer, you know, they're told that this is quite possibly malignant and, or quite possibly a cancer and we're doing the test really more to confirm that - perhaps that's not, perhaps that's taking it too far, but they are given an idea that things are very suspicious. And I think the other two of us are probably a bit more vague in our, the way we put it forward, though they would be given an inkling that things are not right and that we're doing the tests and we are suspicious, but that's probably more in degree than anything else. The symptomatic patients, usually it happens fairly briskly really through the clinic, so, you know, they are seen - I mean everything happens on a Friday morning, and you will see the patient and you may have a clinical feeling

that this might be suspicious, though it's unusual to be unequivocal about it. So it's usually after the x-ray that you might realise that there's something a bit more going on here. And usually at that point, I think each of us who do that clinic will say that, you know, this is a more solid lump, we're a bit suspicious about it and we're going to do a needle test. And then obviously it's after the needle test that they'll be told what's going on. How much of that gets through to them I'm not sure really, but we try to put certainly some of it through so that it doesn't come as a, as a great shock at the end of it.

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

Doctor: Erm, I think it's variable really: some will ... they're quite suspicious themselves; I think others it will come as a, you know, a shock, [???

INT: TO SCREENING PATIENTS ESPECIALLY, YEAH.

Doctor: Well the screening patients ... I think the screening patients may be more suspicious really, I mean they've been brought up to an assessment clinic and I suspect if you took a straw poll of 20 patients coming up to an assessment clinic, 18 of them, well only 2 would get [???] of cancer perhaps and 3 would have cancer, but probably almost 17 of 18 would think they'd got cancer, you know, when they got there. So I think the patients coming up to a screening clinic, though we try and point out that this is only a second part of an assessment of their breasts, most have a feeling of doom really, and they get their anxiety that there is something serious going on, though in fact for the majority of them it isn't the case. So I think the screening patients are already anxious that they've got something going on, even though they've never felt anything and an attempt's been made to reassure them. Well, that's not true actually, is it? But, you know, we may say that this is only part of the screening process and a frequent part. The symptomatic patients I think may be a bit less suspicious: I mean some will notice they've got a lump and feel that it's the worst; others will have a lump and have been perhaps told by a GP that it's all right, you know, not much to worry about, but ...

INT: [???] YEAH.

Doctor: ... yeah, and some will have had a cyst on one side and they've now got something on the other which they're sure is a cyst. So I think, you know, some are going to be surprised by all this and others are going to feel that

they've got something nasty to start with really. So I'm not sure there's a rule really, but I don't think there's necessarily that much difference between the two populations, but for different reasons.

*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?

Doctor: Well, not really. Erm, I mean I've got a way I try and approach it but, erm, but that then tends to get a little bit patient-led as the conversation goes on really. I don't know, we are going to cover that later though what I say.

INT: YES, YES, YEAH.

Doctor: So I don't have any really pre-determined plans except to, except I will have seen the result and my aim will be to tell them the result and then try and formulate a treatment plan which I will have some influence over. I'll already have decided what I think is, probably serves them best, and that will be put into the discussion, but that's perhaps the only pre-conceived notions I have as to, you know, I try and, before I go in, I try and work out what, I know what the diagnosis is, but what treatment, you know, is likely to happen and when it's likely to happen, sort of thing. But that's all.

*Q9. PRIOR TO A CONSULTATION WHERE YOU'RE GOING TO BE GIVING A PATIENT A DIAGNOSIS, WHAT KIND OF FEELINGS DO YOU HAVE BEFORE THE CONSULTATION?

Doctor: Erm ... well I suppose most of the time you feel a little bit as a [??] of bad news really and I feel sorry for them most of the time, some more than others, because some you realise it's going to have more of an impact on some more than others, you know, the little bit of time you have seen them, there's going to be some in whom the diagnosis is either going to have a grave psychological impact or social impact or, erm ... just impact on life expectancy really. And others who, either because of the way they approach the discussion or because perhaps it's fairly low-grade disease, that it's not going to have quite such an impact really on them. But the majority are going to be knocked for six by it and so you feel a bit apprehensive and sorry about it really, I suppose.

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

*Q10. COULD YOU JUST TALK ME THROUGH WHAT HAPPENS IN A CONSULTATION, JUST GENERALLY, WHERE DIAGNOSIS AND TREATMENT OPTIONS ARE BEING DISCUSSED WITH A PATIENT WITH BREAST CANCER. Here

Doctor: Erm, well I suppose I've thought [?] about this a little bit ... my ... discussion about treatment really starts from a presumption that the patient probably doesn't want a mastectomy - probably doesn't want a mastectomy - so that's how I ... so that is perhaps the only preliminary thought that I have. Anyway, so I say to the patient that, I mean, say if you're the patient, then I'd say 'You came with a lump in your breast today,' or if it's an abnormal mammogram '... with an abnormal mammogram' and 'We've been doing some tests to find out what's going on and, though initially perhaps there was some feeling that this was not serious, the x-rays have suggested that it was suspicious and we've taken a sample with a needle, and the needle tests have drawn off some abnormal cells and so it is something that isn't just an ordinary lump, it is a bit more serious and probably does mean that it's a malignant lump, a little cancer ... or a cancer. Now we need to recommend some treatment for that ...' and this is where my own views as to how you manage it then go on really, in that it'll either fall into a group where they need to have a mastectomy because it's big or it's multi-focal, or they need to have, or they can have a wide excision, yeah, that would be the preferential treatment because it's peripheral and a mastectomy would be not only over the top but more difficult to do; or it could be either, really. from its position or from its size. Now if it could be either or it's better treated by wide excision, I'd usually, you know, go along those lines and say, you know, 'We'd recommend removal of the lump and this can be done by a wide excision which we, what we mean is we remove the lump and we take a margin round it that is adequate. This will lead to some deformity but should give an adequate margin round it, and we'll also sample some glands from under the arm at the same time to assess what sort of extra treatment's likely to be necessary. There is an alternative option to that and that is removal of the whole breast, but in your case this isn't absolutely necessary but it is something you might want to consider - some ladies do but I think it would not necessarily be required and so the wide excision option would be an entirely reasonable and safe way forward.' Alternatively, if it was that of a mastectomy, then I'd be saying, you know, 'There is lump there now and because of its position and size it may be possible to remove it locally by just what we call a wide excision and get a good margin round it, but that might be difficult perhaps because of its size or its position or the fact that there are more than one area of the breast and really under those

circumstances I think you may be better served by actual removal of the whole breast rather than just removal of the lump.' So I'll, if you like, introduce that more as a concept, and usually then go on to what other treatments, you know, what else we do that day ... 'We'll do some more blood tests, the chest x-ray to look how you are generally and make sure that you are all right generally and we'll fix a date for you to come in for your surgery and you'll have a bit of time with the breast care nurse to go through what I've said.' Then I'll go through the operation and sign a consent form with you. That's about it really.

INT: AND HOW ELSE IS TYPICALLY IN THE ROOM APART FROM YOURSELF AND THE PATIENT?

Doctor: There'll be a breast care nurse and usually there's someone, whoever's come with the patient who they want to be in the room will be there, husband, or sometimes they'd rather just be on their own.

INT: AND DO YOU EVER USE ANYTHING ...

Doctor: And there's sometimes a student.

INT: ALL RIGHT. DO YOU EVER USE TOOLS SUCH AS X-RAYS, MAMMOGRAMS, DIAGRAMS, DRAWING THINGS, PICTURES?

Doctors: Yeah, well I do sometimes show them their mammogram if I'm wanting to show them that it's something that is over a wider area than they can see or feel. So if it's a small area which they either can't feel or they know is a small lump, then I don't usually show them mammograms, but if there are two areas or if there's widespread calcification then I'll often show them that really to point out to them that the disease is more extensive than can be covered by wide excision. So that's, so I'll sometimes show them pictures; I'll often do a drawing to point out, to show them the breast, to show them where it is, to show them the scar that they're likely to have. So I mostly do that in fact, most patients will get some sort of a drawing.

INT: AND DO YOU FIND PATIENTS, DO THEY FIND THIS HELPFUL?

Doctor: Well I don't know really, erm, I don't know whether they find either of those options helpful - I'd like to think that they do. I do the drawing, if I haven't done one up to that point I do it on the consent form to show them what the operation is, again really just to try and help them understand what's likely to happen to them really.

INT: AND DO YOU SPEND ANY ADDITIONAL TIME ...

Doctor: I also do, if it's carcinoma in situ I try and do a drawing for them as well: I try and explain to them what I mean carcinoma in situ, do a drawing of a duct, if it's cells and point out the cells are malignant; point out the basement membrane; point out that until the cells get out of that they can't really do much harm to them but they will eventually. So that's the other drawing that I sometimes do for carcinoma, ductal carcinoma in situ.

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

Doctor: No, I don't, I mean this is again a difference I suspect between different people in the unit, I don't routinely see people a second time, so they have their, a second time after they're told the diagnosis. They may be seen, you know, a few times up to that point to try and get the diagnosis, but once they've been told that that I've just gone through with you, I won't routinely arrange to see them again. Now there are exceptions in that, there are going to be some patients who, it plainly isn't sinking in really, and information I give will tail off at some point during that lot. I'll usually tell them the diagnosis and I'll usually tell them, you know, unless there's some uncertainty in the diagnosis, but I usually, assuming there isn't any uncertainty, I'll tell them they've got breast cancer. And I'll tell them the operation options but then I'll suggest we do the bloods and get you to come back next week and then we can go through the results with you again and go through the surgical options again. But I try and prompt them to help them make a decision about the surgical options if there are options to be considered, if there still is a choice. But they are the minority and I'm prompted to do that in patients who I can see is not taking in it or just being knocked for six by a diagnosis that they'd never even thought of before they came in, or by the breast nurse who'd picked up that, they're often quite good at picking up patients who they think probably need a bit more time to come to grips with it. But that isn't the routine in my practice, and that doesn't really depend on patients' age or, it's really how they seem as though they're taking things really. But I don't tend to try and bring them back because the clinics are busy enough, and I'm not sure they need it really, but that's just a personal inkling really. I mean some of my colleagues bring them back.

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

Here

Doctor: Well some are quite knowledgeable: they will already have suspected what's wrong with them and they'll have looked it up a bit and they'll know, often they're a bit more knowledgeable about drugs than operations, erm, hormone drugs which are always in the news, so many are quite knowledgeable on that score and do query, you know if you say you're going to use Tamoxafen they'll say, you know, 'There is another drug, isn't there, that's a bit a new than that?' and so we'll go through that and so on. The surgery - a few will want to discuss much about the surgery, they, most of them will understand what I mean by what operations there are but if not I'll try and explain to them with drawings and things. Others will not really have gone into it at much detail at all, they may only know perhaps from a family member that's gone before them that [??] [??] but I think some will have not much idea and others will have, you know, a fair amount of knowledge really, and often the more educated ones will have a bit more knowledge, though not necessarily, some will have just tried to ignore it really.

INT: AND DO YOU THINK IT MAKES IT HARDER OR EASIER FOR A CONSULTATION WITH SOMEONE WHO'S A LOT OR A LITTLE?

Doctor: Erm ... I don't think it's necessarily, I don't intelligence necessarily makes a difference, and there's going to be some patients who are ... who are more, I mean I suppose the most difficult group of patients I would find are patients where there is some degree of delay in diagnosis, either by me or before they ever get to the clinic, and there are patients who, you know, all along we've thought are benign or we've perhaps not thought are benign but have taken some difficulty in proving that it isn't, and they're a difficult group. I mean some are remarkably forgiving in all this, erm, but you still, you know, have your own sort of guilt feelings about it. But there'll be others who, you know, are upset at, you know, this not having been picked up a bit earlier really. Some will be upset with the GP for not referring them earlier, others'll, you know, seem upset that you've not got to grips with it a bit earlier yourself really, and they're a bit more difficult to manage because, because you're already feeling that you've perhaps not done your best job for them for whatever reason. And [??] just draw a line under it and say, 'Right, OK, fine. Right, we'll just start here and try a bit harder' sort of thing, really. So I think those are perhaps the most difficult patients, I suppose. But it's more the patients, not so much their degree of intelligence, it's more their knowledge, it's that for some reason they're upset about either a delay or perhaps they're just upset at having breast

cancer and they see the messenger as being, you know, somebody to get back initially. I mean mercifully these patients are rare because I don't think anybody gains from it really, you know, the doctors become more self-conscious about how they manage them and your reasons for managing the patient change really, don't they, they no longer are the hard reasons that you do this because of this, this and this - you're doing this because you think the patients wants, you know, wants to hear this?

INT: [???] DO YOU FIND THAT A LOT OF PATIENTS COME WITH MISCONCEPTIONS ABOUT THINGS THAT THEY'VE READ OR ...?

Doctor: Well not really, I think, I mean they will come with queries, or some will come with queries as to sort of treatments that they've heard of, some of which I haven't heard of, which you then have to try and explain why you, you know, you're going along your line using drug A instead of drug B, but usually they'll accept that, you know, it's rare for them to dig their heels in and feel that their management is being compromised because of the doctor being unwilling to change their usual tack.

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

Doctor: I suppose many want to try and get it clear in their mind whether it's cancer or not and, I mean, different patients have different ideas of how they see the hieroglyphics really: some will accept that if you say tumour this is cancer, even though you are being particularly vague about it; others you can say they've got cancer and then they'll then say, 'Well, yes, but is it malignant?' So I think to try and get the message over to them that this is, and others will know that it's a cancer and that it's malignant, and still be unsure as to whether it could do them any harm or not. So I think, I think try somehow to get through all these words and make sure the patient understands that they have something which is a threat to them which does mean they need an operation or some sort of treatment to try and make things better, and even after that they may still come to harm from it, is something to try and ensure they understand, though of course many won't really be interested in that, they'll switch off somewhere along the line and just went to get on with it really. So I think the patients want to be sure that you've made the right diagnosis but I think many will assume that if you say you have you have really, and so I don't necessarily go into a lot of detail, so I'm not sure there's a lot of clarification they want from the diagnosis. Once you've told

somebody that they've got something like cancer they usually, although they may not want to believe it, but they usually accept that really whether it's, you know, the hope is you're correct really ... I suppose that's not to be a hoe, is it, but I mean, erm, I think the diagnosis isn't much of an issue really, you know, once you've been through the steps then I think the diagnosis isn't much of an issue for patients really, even though they've got to hear it.

*Q13. WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS PATIENTS NEED OR WANT TO KNOW ABOUT TREATMENT?

Doctor: Well I think they, some will want a bit more detail about the sort of operation that's on offer, some patients will just be happy to know the diagnosis, happy to know what you offer, whatever it is, and leave it at that, 'You know best, doctor, go for it' but obviously there are going to be some that will want to know a little bit more about what treatment's offered, you know, what surgical treatments are on offer and want to be part of the decision making there and what sort of other treatments are available, so I think that may be a bit more of an issue for patients to try and work what, you know, many will raise the question of radiotherapy, 'What's that? what do you mean by radiotherapy? Do you mean you lose your hair?' 'Well, no, that's chemotherapy.' 'What's chemotherapy? And so I'll go on really, so I think more time's going to have to be taken as to how you untangle their information about treatment than there is about diagnosis really.

INT: AND WHEN YOU'RE CONSULTING WITH PATIENTS ABOUT DIAGNOSIS AND TREATMENT DO YOU THINK THERE'S ANYTHING GENERALLY THAT'S NOT UNDERSTOOD VERY WELL?

Doctor: Yes, well, I mean, I suppose, many don't understand the difference between radiotherapy and chemotherapy. Many may not realise the sort of deformity you get from just a simple wide excision, you know, you sell that as being operation which preserved the breast and, though you point out there may be some deformity, they may not have the real impression, you know, they may not what deformity might ensue as a result. They have a breast, sure, which is mostly there but the bit that isn't will be terribly obvious. Erm ... and the sort, I suppose the drug treatments they may not know much about really, they may need a fair amount of information on, so [??] that's a given for all these, I suppose, to explain all the treatments we have to try and give them something to look at afterwards.

INT: DO THEY EVER GET SURPRISED THAT THEY'VE GOT A CHOICE OF TREATMENTS, THE ONES THAT DO?

Doctor: Erm ... well some are a bit confused by choice, some of them; some would prefer not to have a choice or just send it back to you really.

INT: WHY AREN'T YOU TELLING ME [???

Doctor: Well, yes, you tell, you know, 'What do you think?' you know, which is I suppose why I try and pre-empt that a little bit by giving them a bit of an inkling to start with what, you know, what would be easy to choose, and then back off if they say, 'Well actually, I want a mastectomy actually.'

INT: I'D LIKE TO MOVE ON NOW TO WHAT A PATIENT'S ACTUALLY OFFERED.

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

*a. ONLY BREAST CONSERVATION SURGERY

Doctor: Well it would need to be either cancer or pre-cancer localised to one area of breast tissue, so at least, to at the most one quadrant, to an area perhaps not so much on centimetres in terms of, you know, less than so many centimetres, but more in relationship to the size of the rest of the breast really. So one cancer as opposed to more than one; over, not extending beyond a quadrant, if you like; and over an area ...

[knock at door - Break in recording]

INT: THE NEXT ONE, YEAH, WITHIN THE CONTEXT OF THE UNIT'S GUIDELINES AND PUBLISHED RESEARCH AGAIN ...

Doctor: Who would get breast conservation?

INT: YEAH, THAT'S RIGHT.

Doctor: So, smallish tumours with regard to the size of the breast: now this might include a tumour perhaps as big as 3 cms or even 4 cms, if the patient wants a breast conservation and if it was a big enough breast to absorb that, you know, a sort of big breast. But usually tumours around less than 2 or 3 cms, one quadrant, not multi-focal.

*b. AND WHAT ABOUT FACTORS THAT WOULD LEAD THE TEAM ONLY TO OFFER A ONLY A MASTECTOMY?

Doctor: Well ...

[Break in recording]

Doctor ... more than one tumour, diagnosable pre-operatively, areas of carcinoma in situ or micro-calcification over a wider area than a quadrant, or even taking up the whole of a quadrant, would push me towards that. Lobular carcinomas that seem to be moderately large even though they might not be as large as the others, you know, because of the margins are often more vague, so those might push me a little bit more towards a mastectomy; central tumours usually, though not necessarily, again, if it's a small central tumour in a big breast I'd treat it by just wide excision plus nipple rather than a mastectomy, but if it's a larger central tumour then a mastectomy. So does that answer your questions?

INT: YEAH, THAT'S FINE. THE LITERATURE SUGGESTS THAT PATIENTS VARY IN THE DEGREE OF INVOLVEMENT THEY ACTUALLY WANT IN MAKING DECISIONS ABOUT WHAT SURGERY TO HAVE: SOME WANT FULL CONTROL, SOME PREFER TO SHARE THE CONTROL AND SOME PREFER IT IF THEIR PROFESSIONALS TAKE FULL CONTROL.

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

Doctor: Yes, I think so.

INT: AND, YOU HAVEN'T GOT THE INTERVIEW SCHEDULE ...

Doctor: Is that just for my practice or for the practice here generally or for the practice nationally?

INT: WELL FOR THE PRACTICE GENERALLY.

Doctor: Yeah, I mean, I think patients in Leicestershire are getting the choice they want, and I think my patients are probably getting the choice they want as well.

*Q16. AND THINKING ABOUT YOUR EXPERIENCES WITH PATIENTS, CAN YOU PLEASE LOOK AT THE RESPONSES ON THIS CARD AND TELL ME, DURING CONSULTATIONS, WHO GENERALLY MAKES THE FINAL DECISION ABOUT WHAT SURGICAL TREATMENT TO HAVE? WHICH OF THOSE FIVE DO YOU THINK?

Doctor: ... I think it's sort of somewhere between 2 and 3 really, I mean there is some input from me but I wouldn't say

it was necessarily completely equal. I would never over-ride their wishes, erm, so it's probably somewhere between 2 and 3. I mean the patients do tend to make a final decision, or at least they're happy with the decision that's made shall we say, which I suppose means something similar though not quite the same. Whether they've seriously considered my opinion I don't know really, of course, because only they can answer that, but my opinion if you like will have been at least put over in some sort of way, either consciously or subconsciously, so it has to be sort of towards that, but I would like to think at the end of it that we have shared the responsibility.

Comment [MSOffice1]: ? put in thesis
- edited down

INT: RIGHT, OK. SO SOMEWHERE BETWEEN ...

Doctor: Yeah, so sort of those two really rather than ...

INT: I'LL PUT THAT THERE [???] PUT THAT TO ONE SIDE. I'D LIKE TO MOVE ON NOW TO SORT OF COMMUNICATING WITH PATIENTS WHO HAVE BREAST CANCER. AT THIS POINT I'D LIKE US JUST TO TALK ABOUT YOUR EXPERIENCES COMMUNICATING WITH PATIENTS AND IN PARTICULAR I'D LIKE US TO FOCUS ON THE PATIENTS IN WHOM, FOR CLINICAL REASONS, MASTECTOMY IS NOT THE ONLY OPTION, OK? RESEARCH HAS IDENTIFIED THAT PATIENTS WITH BREAST CANCER FALL INTO ONE OF THREE DECISION MAKING STYLES: ACTIVE DECISION MAKERS, 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 PATIENTS DURING THE CONSULTATION PROCESS THAT LEADS TO A FINAL TREATMENT DECISION. I'D LIKE TO START WITH SITUATIONS WITH ACTIVE DECISION MAKERS AND, FOR THE PURPOSES OF THIS STUDY, WE DEFINE AN ACTIVE DECISION MAKER AS A PATIENT WHO MAKES THEIR OWN FINAL TREATMENT DECISION EITHER WITH OR WITHOUT SERIOUSLY CONSIDERING THEIR SPECIALIST'S OPINIONS.

*Q17. I'D LIKE YOU TO THINK ABOUT THE SITUATION YOU'VE HAD WITH AN ACTIVE PATIENT MAKING DECISIONS AND, WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, PLEASE TELL ME ABOUT YOUR EXPERIENCE WITH THEM UP TO THE POINT WHEN THE TREATMENT DECISION WAS MADE. SO DO YOU HAVE AN IDEA OF SOMEBODY YOU THOUGHT WAS FAIRLY ACTIVE IN THEIR DECISION MAKING?

Doctor: Yes, I mean, we, erm, I suppose there was somebody this week where she, you know, it was a tumour that could have been treated locally by wide excision, I put forward that as being, you know, the sort of thing that we'd recommend, 'You need an operation to have the lump removed, you could have it done by just removing the lump together with a good margin,' erm, I didn't even have time to get on to another option really, which I'd eventually have got round to, erm, to which

she said, 'Well, how about having the whole lot off?' So I said, 'Well that's another option to consider, it may not be necessary,' and then I went through the advantages and disadvantages of, you know, the wide excision will leave a breast, she'll still need radiotherapy, there's a slightly higher local occurrence rate than if she had a mastectomy; mastectomy's a bigger operation and will lead to a flat chest afterwards, erm, but may not need radiotherapy. And she said, 'Well, I'll have that.' You know, so I mean, I would say she's an active decision maker, I suppose, or at least she decided what she wanted.

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

Doctor: All right because, I mean, I'm quite happy, and the only patients that I would have some difficulty with would be if they wanted something that I felt really wasn't really right for them, you know, so let's say that the patient had something that really was best treated by mastectomy and they were pretty determined to avoid a mastectomy, and then you're really left with probably compromising your surgery, but then I would do that, you know, I would say, 'Fine, OK, we'll remove what we can, you will get a lot of deformity getting round it, but then we'll see what the margins are like, and if the margins are fine, you know, you've had your operation, we won't need to do any more - if they're not, and they may well not be, then we may need to suggest you have a further operation.' And I mean some women are happier to accept a mastectomy under those rules and have it as two stages, if you like, than as one. But those are the ones that, if you like, I'd try a bit harder with them to avoid a second operation but in fact sometimes they're right, of course, you do what you think is not quite the right operation but it turns to be all right for them. But it's usually that way round, it's not the patient who [???] about wide excision who then wants a mastectomy, that's normally fairly straightforward really. I mean you might try and dissuade them, [???] you know, it just seems an over-the-top operation but it's the patient who wants a wide excision and you think they should have a mastectomy because you feel a wide excision going to be incomplete or inadequate, and sometimes you've got to do that as two stages.

INT: AND IN THE CASE OF THIS LADY, HOW DID YOU THINK THINGS WENT FROM THE CONSULTATION [???] ?

Doctor: Yeah, I mean she was happy enough because I suppose I was, you know, I just backed off, didn't want to push for something that she didn't seem to want, which, you know, either would do, one was perhaps slightly more appropriate

than the other, but either would do so it didn't matter, that was fine. So she was happy with that.

INT: WHEN YOU WERE TALKING [???] WAS THERE ANY SORT OF INFLUENCE APPARENT AS TO WHY SHE WAS MAKING THAT SORT OF CHOICE?

Doctor: I think she didn't want the risk of it happening again and she didn't want the possibility of a second operation to get better margins, and she didn't to feel that she was going to be left with something that might cause her harm in the future, even though the risks of that were perhaps small, she didn't want that risk.

INT: AND LOOKING BACK HOW SATISFIED DO YOU FEEL WITH THE EXPERIENCE OF CONSULTATING WITH THAT LADY?

Doctor: Well I think it was all right really because she ... she's got what, as it were, she wanted, for want of a better word: she, it was discussed so it wasn't felt that she was given no informa-, that there was no, she went away thinking that, I mean I think towards the end she did say, 'Well, do you think I'm making the right decision?' and again we were able to just go through that with her really, so I think, not only did she get the operation which she felt happiest with, but at least she felt that she hadn't, erm, made a decision which was, which couldn't be justified on medical grounds. So I think everybody was all right really.

INT: AT WHAT POINT WHEN YOU'RE DOING YOUR CONSULTATIONS DO YOU THINK YOU THINK, 'AH, I'M TALKING TO AN ACTIVE DECISION MAKER?' I MEAN YOU MIGHT NOT ACTUALLY THINK ABOUT THAT [???]

Doctor: Well of course there are patients who almost at the start of the, you know, when you go and take and examine them, you start thinking, you know, this is perhaps somebody who's gonna want to take a more active part, so I suppose you might pick it up at that point. Others you find just towards the end really, once you start putting forward an idea for what you should do, almost towards the end of the meeting really, I suppose, they'll become a bit more positive really. I think you probably can't make a decision to say that they're not active almost until you've finished really. Some quite late on will make a decision one way or the other. But some you can feel early on might be more active than others, but they may not and it may just be that they're ... they may not be assertive as ... as the information filters through, you know, they may back off really, may just become more withdrawn.

INT: AND DO YOU THINK THAT SORT OF THAT KIND OF, ONCE YOU'VE REALISED, THAT REALISATION COMES TO YOU, DO YOU THINK IT CHANGES OR SHAPES THE WAY YOU APPROACH THAT PATIENT FROM THEN ON?

Doctor: Well I think it does if, I think what they're like to start with influences you a bit, doesn't it? I mean I think, I think if they are withdrawn and anxious to start with you may go a bit more carefully with what you say to them and do to them, and if they're particularly articulate you might go into more detail as to what you're doing and why you're doing it ... erm ... so I think you probably, I think I'm influenced by how they seem to me, you know, the patients who don't seem to be particularly worried or concerned might not get quite to much ...

[Break in recording]

*Q18. THE NEXT SITUATION I'D LIKE YOU TO THINK ABOUT IS WITH COLLABORATIVE DECISION MAKERS AND FOR THE PURPOSES OF THE STUDY WE DEFINE COLLABORATIVE DECISION MAKERS AS PATIENTS WHO TEND TO SHARE FINAL TREATMENT DECISION RESPONSIBILITIES WITH THEIR SPECIALISTS. SO WHAT WE'VE JUST DONE WITH THE ACTIVES, I'D LIKE YOU TO THINK ABOUT A COLLABORATIVE PATIENT, IT MIGHT BE HARDER THIS TIME, I FIND THEY'RE A HARDER GROUP, BUT, AND AGAIN WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, PLEASE TELL ME ABOUT AN EXPERIENCE WITH THEM UP TO A POINT WHEN THE TREATMENT DECISION WAS MADE?

Doctor: ... Erm ... yes, I mean it's difficult to separate the collaborative from the final group really because the final group, the passive ones, isn't it, because they, because is a collaborative patient just a passive patient who has listened to what you're saying and ...

INT: IT'S OFTEN A DIFFICULT [???] EVERY PROFESSIONAL I'VE INTERVIEWED SO FAR HAS HAD A PROBLEM WITH THIS.

Doctor: Yes, but, yes, I can imagine patients who may well fit into this group, yes.

INT: MM, YEAH? IF YOU COULD TELL ME ABOUT JUST ONE OF THEM, IF THERE'S ANYBODY YOU'VE HAD A CONSULTATION WITH, WITHOUT REVEALING ANY CONFIDENTIAL DETAILS OBVIOUSLY, JUST TELL ME ABOUT THE STORY ...

Doctor: Perhaps if you could just stop that for a second ...

[Break in recording]

Doctor: Yes, I mean, there's, I mean a patient who you go through the various options, well, and, sorry, we're concentrating on patients having conserving surgery, is that right?

INT: NO, JUST PEOPLE WHO'VE HAD A CHOICE.

Doctor: That's right, OK. So you've gone through the two options that are available and then I can remember such a patient who has then wanted more detail really about what's what, you know, 'What do you mean by that? What are the benefits of that?' I think they form quite a small group, this, because [??] obviously they are going to have to ask for more information about what a mastectomy is, what the benefits are, what the disadvantages are, and the side with the wide excision and the radiotherapy and things. So I think, I think they do form quite a small group if they are truly collaborative, and they want then really to try and work out, and it's perhaps this group who are going to be sent away to think about it really, and who want more thought - not necessarily more information really, they may have what they need - but more time to think about it and then come back and discuss it as a second thing really. I think the other two groups you can deal with very quickly really, either because they accept what you want to do or they, you accept what they want you to do. But this group may have some more difficulty trying to work out two of the two options are available, not necessarily, so they may require two visits and they require more [??] [??] what's what and what they mean really.

*Q19. OK. I'LL MOVE ON NOW TO THE THIRD GROUP, THE PASSIVE PATIENTS. FOR THIS STUDY WE'VE GOT A DEFINITION AND IT'S PATIENTS WHO TEND TO WANT TO LEAVE THE FINAL TREATMENT DECISION EITHER TO THE SPECIALIST, EITHER WITH OR WITHOUT THE SPECIALIST SERIOUSLY CONSIDERING THEIR OWN OPINIONS. HAVE YOU GOT A PARTICULAR PATIENT IN MIND WHO YOU THOUGHT WAS PARTICULARLY PASSIVE?

Doctor: Yes, well, I mean, I mean perhaps it's because I, perhaps you could say I'm not particularly observant really, but I mean I would have thought that quite a lot of patients will fit into this group: they'll either sort of positively fit into this group by saying, you know, 'What do you think?' and I suspect I'd fit into that group in terms of, you know, if I was given a load of options by somebody who I considered as knowledgeable in the field, erm, I mean if there was an obvious one I'd go for then I might, but I'd have to say, ask them what they thought really, what they thought was the best option. So I think there's ... so I suspect there's a large

number of patients who will either say, 'Well, you're the doctor, you decide,' or will just not really be part of the discussion really, you know, they'll just sit there and soak up the information and really not take much part in it, possibly because they, they're a bit shell-shocked in what's going on. Now it could be that they should be seen again to make sure that they aren't a more active person anaesthetised at the time by the information that they've been given, but, erm, but I suppose I tend to rely on them coming back to me for more information at some point, you know, which they're all given an option to do, even if they've not got another date planned before their admission, another visit. But I think there's quite a lot of patients who will either not take part much in the conversation and so you are left really saying, you know, making your offers as to ... and I wouldn't ... I'm not sure if I thought they were this group of patients I would give them the offer really. I mean, you know, I probably would not try to get to the position to say, 'We could do this and this ...' you know, '... the choice is yours,' I'd perhaps try and give them a clue. I'd try and lead the patients who I thought were a bit more assertive, were a bit more corroborative [?], the choices more for them to do it. I think if I got the feeling they were being passive, I would try and point out, you know, what seemed to be the most obvious, appropriate procedure really, whichever it happened to be.

INT: AND HOW SATISFIED ARE YOU WITH CONSULTING WITH THE DIFFERENT TYPES OF, THE ACTIVE DECISION MAKERS, THE COLLABORATIVE DECISION MAKERS AND THE PASSIVES?

Doctor: Well I mean the people you're least sure you've done the right job for are the latter group, aren't they? Because they're a group who, you've made the decisions for them, and it really only may turn out afterwards that that might not be the decision that they would have made or ideally would have preferred in other circumstances, if they'd been given time or the ability or the fact that they, erm, were somehow able to, you know, in retrospect it may prove not to be the right decision for them, the patient who, you know, you feel has to have a mastectomy and you put forward a mastectomy, and they're totally shocked as a result of being told they've got a mastectomy, have to have a ... that they've got cancer and they now need a mastectomy, they appear passive and yet when eventually they've had their mastectomy they, it may be that, though it was the right surgical option, in terms of the psychology of it they, you've done them some harm really. Erm ... so I suspect it's the group that are the passive people, you only find out in retrospect whether the right psychological decision was made. I mean you can justify the

surgical decision, I suppose, just on size of tumour and size of breast and things, but whether it was right, whether it was right for them you might only find out later and you might find out that it might not have been. Whereas the patients who tell you what they want, even though it might not be what you want to offer, but they tell you what they want, and as long as you're prepared to go down that line, and those that discuss it a bit with you, say, 'Well, you know, I think I'd rather have this,' they're the easy ones because you do know that at least you're doing a procedure that, OK, they'd rather not have to go through but at least it's their preferred option. So I think you feel a bit more comfortable, or a little bit more certain that you're doing the right operation for that person as opposed to for that cancer with the first two groups.

INT: LAST COUPLE OF QUESTIONS. THINKING, SORRY, THE LITERATURE TELLS US THERE ARE A VARIETY OF INFLUENCES ON PATIENTS MAKING DECISIONS ABOUT SURGICAL TREATMENT.

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

Doctor: Well I mean I suppose the doctor who sees them in the clinic probably has the, one of the greatest influences. Erm ... but it depends a little bit on who that doctor is and how the patient sees that doctor, I suppose, as being ... you know, someone who they could, if you like, trust with the decision making. I think the breast care nurses have an influence as well, because it's the breast care nurses that often go through what we've meant by the options and reiterated things probably at the time when they've had a bit more time to think about it. But it's unusual for the breast care nurse to come back and say, 'Well, you know, having talked to the patient I think, you know, you should see them again and go through it with them again because I think they actually need something else,' though that does happen, though whether that was the influence of the breast care nurse I don't know, I mean, it's just talking through what was said, so I suppose has the doctor has the most influence I suppose.

*Q21. AND WHAT KIND OF EXTERNAL INFLUENCES DO YOU TEND TO SEE WITH YOUR PATIENTS, SORT OF, I MEAN, FOR INSTANCE, LIKE THE FAMILY, FRIENDS, THAT KIND OF THING?

Doctor: Erm, well you do some women that, some will be a bit influenced by a husband who either wants or doesn't want them to have certain procedures. I mean some will be a bit against a mastectomy, some would be a bit for them having a

mastectomy, you know, just anything to keep them from coming to harm in the future really and they just feel that the patient might be choosing to avoid a mastectomy for them, they would ... just in the fear that the loss of the breast would put the sort of husband off, that the husband may [???] [???] so many will have some influence from that. Some will have influence from people who have gone before them with breast cancer, you know, mother, perhaps a sister, have had a procedure that either has worked or hasn't worked, and so they, that influences them - we do see that from time to time.

YY

INT: AND IF YOU HAD THE - A COLLEAGUE SUGGESTED THIS QUESTION - IF YOU HAD THE POWER AND MONEY TO CHANGE ONE THING ABOUT THE SYSTEM HERE, WHAT DO YOU THINK IT WOULD BE?

Doctor: Erm, well I think, I mean I suppose the only thing that I would like to see changed would be to have less patients per doctor, as it were, to give you a bit more time to ... to discuss, you know, more time with your patient really, so you don't ... and so what would be required would be presumably more staff / facilities - that's not necessarily more surgical staff, more, but more staff of whatever specialities are required to mean that I'd see less patients in my clinic than I do at the moment, and then I could spend a bit more time with them really. And similarly on the ward, a bit more time with them on the ward, I suppose, so that's the only thing I'd want really is, you know, a reduction in the workload I suppose. Because you do whisk round, ward rounds tend to be whisked round a bit, and the best time almost is at the end of the day when there's, you can just go and talk to the patients - some of them may or may not have their relatives with them and you just sit on the end of the bed and chat to them a bit. You're not, you know, there isn't another doctor with you, you know, with other jobs to do, and so ... so that's it really I suppose. More hours in the day or more people to take part in those hours, I suppose.

*Q22. FINAL QUESTION, IS THERE ANYTHING ELSE YOU'D LIKE TO ADD TO WHAT WE'VE BEEN TALKING ABOUT, ANYTHING YOU THINK WE'VE MISSED OR ANYTHING LIKE THAT?

Doctor: I can't really say really. Query

INT: OK, THANK YOU VERY MUCH.

[End of interview]

*Q23. THE REST OF THE TAPE HERE...
Here