

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Surgeon)
*VENUE: Medium MR unit
*DATE: 22/10/2003
*ID: BS003
*INTERVIEWER: DJW

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

*Q2. WHAT IS IT LIKE TO WORK AS A SPECIALIST IN THIS BREAST SERVICE?
Right. I suppose I am biased since I am the lead clinician and I am founder member of the unit if you like, because my remit was to sort of start a specialist breast unit for North Derbyshire. So I suppose it is a bit unfair in that a lot of it, it is not just me who has developed things but I have been there since the start and all the way through; so I mean overall I am fairly happy with the way things run and I think/hope we've got a good team that works well together and everybody feels part of it and although there are things we would like to do to improve the service, overall I think we are quite happy with the way things have developed and are developing.

INT: So you have been here 13 years, before that, can you compare it with anywhere else you have worked?

DOC: Well in terms of what was here before. Prior to 13 years ago, most hospitals didn't really have a specialist breast service. Breast surgery was part of general surgery, so everybody did a bit. The thing that made the difference was the breast screening programme which started about then, about 13-15 years ago so people had to focus their resource and focus their attention into a breast service and that it really when breast nurse specialists came on board and so since then we have seen screening, the development of the breast service, the breast MDT and people working in teams. I suppose we are quite proud of the fact that breast has led the way and that probably we were the first specialty to introduce team working and people getting used to working as an MDT rather than just one person making all the decisions.

INT: So in terms of structure and how things are done, you have got your consultation, then there is the time of the doctor is there any pre-ops or home visits.

DOC: We don't have home visits, I mean, our pathway is quite straightforward in that there is two streams of patients, there is symptomatic patients i.e. a lady who has gone to her GP with a breast lump, a breast problem, gets referred in. We see those in the one stop clinic and then there is screening women; women who have gone to screening who have been found to have an abnormality and we see them in the assessment clinic. Once they get to the hospital, although they can come in through two different doors if you like, once they get here, their management is exactly the same and it is the same team of people who see them.

INT: AND GENERALLY, HOW WELL DO YOU GET ON WITH YOUR COLLEAGUES?

DOC: Very well.

INT: THERE ARE FOUR OF YOU HERE I THINK, ISN'T THERE, TWO BREAST CARE NURSES AND TWO SURGEONS?

DOC: Yea, that's right yes, I mean the two surgeons, we work as a team so we, although we still have our individuality we share patients so we promote generic referrals, we try not to be away at the same times, so that there is continuity of care and we will both see each others' patients and operate on each others' patients, which we find works

well. I am fortunate in that my colleague who you will be talking to later; he actually worked with us as a registrar, so he was here as a junior first, so we knew him and he knew us which I sometimes think does have an advantage

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

DOC: Yes, I suppose they do. Again myself and my surgical colleague, I suppose we are . . .It is difficult because for most of the time we work, although we are together at MDTs, meetings and have adjacent offices and do joint ward rounds and everything, in terms of consultations with patients, we are not in with each other at the same time. Although having said that, because of this role that we previously worked as; he was here as a registrar and worked with us, I think we kind of know each other's styles and I think we are probably similar in temperament, so I think we are probably quite similar. Not that I; I don't think that that has to be a necessity for a unit to work. But I think it would cause problems if one member of the team was an aggressive psychopath and the other was not. Our oncology colleague, I suppose is a different personality from us, he is probably a bit more excitable, in the nicest possible way but you know 'viva la difference' and it is not a problem.

INT: AND THE BREAST CARE NURSES?

DOC: Yea, and again I would like to think that we all work well together and I would hope that there aren't any big barriers between, you know sometimes its an issue, consultants and nurses and whether the nurses feel that they should be more subservient to the consultants and I don't think that is the case at all. So I think both formally and informally we work well as a team.

INT: Now i would like to move on now a bit to before a consultation where a diagnosis is to be given and at this point of the interview, i would like to focus only on newly diagnosed breast cancer patients if that's ok.

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

Right, we actually have two breast MDTs a week, but the main one in terms of diagnosis is on a Tuesday lunchtime and then we see the patients in the same afternoon.

INT: AND ARE THE PATIENTS DISCUSSED PREOPERATIVE?

DOC: Yea.

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

Not particularly stressed, I mean part of the problem of course is that the MDT is squeezed into a lunchtime, so it is basically straight from the MDT to the clinic. But having said that it some ways it does have advantages, in that the MDT discussion is fresh in our minds and I have found that certainly from talking to patients it is often quite powerful because occasionally patients will say are you sure about the diagnosis and you can say well we have just had a meeting with my radiology, pathology colleagues and we have discussed your individual case and we are absolutely sure this is what it is and this is what we feel about your treatment options. So the fact that it is actually on the hoof and it is straight afterwards does have some advantages.

INT: IS THERE A DIFFERENCE BETWEEN HOW YOU FEEL BETWEEN HEAVY AND LIGHT WORKLOADS? IS THERE MUCH OF A VARIATION IN THAT?

DOC: What you mean individually or from. . .

INT: WELL I MEAN YOU INDIVIDUALLY AS A PERSON COMING OUT OF THE MDT IF IT IS GOING TO BE A LOT OF DIAGNOSES.

DOC: Yea, yea it varies and I think we all accept that it is peaks and troughs and that we'll have some weeks where there won't be much breaking bad news and some weeks where you feel that you have got your black hat on and there is a lot of bad news, but that's life and I've come to terms with that and it is not a problem.

*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?

DOC: Yea, I mean I think it depends on, we always would pride ourselves that we are straight with patients. So the way the fast track clinic works, we will have seen the patient for an initial consultation. They will have had their imaging, biopsy and we then see them again for a discussion of the story so far. So in most cases a cancer is, we are pretty sure it is a cancer at the end of the first visit. So for example if on the basis of the clinical findings and the imaging it looks like its kind of 95% likely then I will discuss that with the patient and I may even say that it is 95% likely. It depends a little bit on the vibes coming back from the patient and sometimes they may want to know more, so they might say if it is cancer what is going to happen next and they want to go down the treatment line. Whereas quite often they would seem happy with, well this is what we know so far, we don't know for sure but when I come back next week we will know for sure and we'll cross that bridge when we come to it.

INT: YOU MAY HAVE ALREADY ANSWERED MY NEXT QUESTION.

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

Yea, I would think that the vast majority on the basis of what we have said and what they have picked up on what we have said know what's coming the next week. Occasionally, you'll get patients who you'll see and despite having, you know, put the same warning shots across the bough, that you do with everyone else, its as though you have never had that conversation. Again that's perfectly understandable.

INT: DO YOU THINK THEY BRING ANY KIND OF KNOWLEDGE WITH THEM ABOUT. . . I'M TALKING EXTERNAL KNOWLEDGE NOW. . . YOU TALKED INTERNALLY ABOUT PICKING UP THE VIBES AND THAT? DO THEY BRING OTHER THINGS WITH THEM?

DOC: Yea, I think so, tremendously variable and obviously there are some patients who, you know, do not appear to appreciate what's going on and it comes as a bolt out of the blue. There are others who know, because they have got a lump, because they have had a biopsy, I think many assume it is going to be cancer and anything other than cancer is a bonus.

*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?

DOC: I think the breaking bad news I think is very important and I think we try and do it as well as we can so I think, you know, environment issues, so we would do it sitting down with the patient close. The patient with a partner or somebody with them if they so choose and the surgeon with the breast care nurse. So it is done in a calm, quiet environment. Make sure that we have all the information. So we make sure that we have got the patient's notes, the information about the radiology, the information about the pathology, so get everything right. So I think in terms of setting it up, it is just important that we have all that.

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

DOC: Yea, I think it is difficult because you obviously having done it for a long time, one of the things I find difficult is that you do tend to have set speeches and set conditions and it is hard to avoid that. But I have to say I would still hope that I am sensitive to the needs of an individual patient and you appreciate that some patients you will need to spend longer and go into more detail and others, they don't want that detail and I know you will be coming onto the different types of patients and you know what people want in terms of the decision making process.

*Q10. PLEASE TALK ME THROUGH WHAT HAPPENS IN A CONSULTATION WHERE DIAGNOSIS AND TREATMENT OPTIONS ARE BEING DISCUSSED WITH A PATIENT WITH BREAST CANCER.

Right, we talked about the environment and I suppose it would be again introduction and reintroduction, so for example the partner may or may not have been there the week before and may be there then. It is kind of difficult because at the first consultation, if they haven't got somebody with them and you say to them you make sure you bring your husband with you next week, it is a bit of a give away really, so you have to do that in a kind of subtle way to make sure that they realise that they are very welcome to bring someone or not as the case may be. But then having kind of if you like broken the ice with the introductions, I think then the crucial thing is to cut the bullshit and go straight for the fact that unfortunately the needle biopsy does show that this is cancer and try and avoid euphemisms and skirting around it and then really take it from there.

INT: YOU MENTIONED EARLIER ABOUT A SORT OF SPIEL THAT YOU HAVE. DO YOU HAVE A PREFERRED STYLE OF APPROACH TO BREAKING BAD NEWS TO PATIENTS?

DOC: Well I suppose I would obviously try and be gentle, factually correct, so as I say, don't use euphemisms, so the answer is cancer and that's what people understand and then I think you really have to assess what the response is to that, and then often it will be yea, year I know that because that's what you implied last week and you said it was going to be that so we already, we've got our head around that. Where do we go from here? So you can then move on to treatment options

and I suppose my usual spiel if you like, I would try and emphasis the positives, you know, overall breast cancer has a good prognosis compared to many cancers, you know, most ladies are successfully treated and then enter into the different treatment modalities and the way that works.

INT: SO IS IT ALWAYS YOU THAT OBVIOUSLY BREAKS THE BAD NEWS.

DOC: It would always be a consultant yea, yea.

INT: AND OF COURSE IS THERE OTHERS IN THE ROOM. IS THERE ANYBODY ELSE IN THE ROOM AT THE SAME TIME.

DOC: We might have a medical student or a trainee doctor, but usually it is just the surgeon, the breast nurse and the patient.

INT: WHEN YOU ARE SORT OF DISCUSSING DIAGNOSIS WITH PATIENTS. WHO TENDS TO DO MOST OF THE TALKING AND WHO TENDS TO ASK MOST OF THE QUESTIONS.

DOC: It varies tremendously, I mean there are some patients who are so gobsmacked by the diagnosis that they can't think or ask anything and it may be the partner who is doing all the questioning or it may be that they are both gobsmacked and I think we all accept that it is a kind of gradual process and that very often you won't cover half the ground at the first visit. I think in terms of the way it would work is, they will then be able to go with the breast care nurses, the two of them to a quiet room and consolidate what has been said and they may have some subsidiary questions then, which may or may not come back to us or the breast care nurses may deal with it. And then the next step really is the pre assessment clinic, which is where they have their basic preparation for surgery but this is another opportunity to meet the surgeon and that is where we would go over in more detail and do the consent. So although in some cases we would make a definite decision about treatment at the first diagnostic consultation, very often it is not done at the first one.

INT: DO YOU USE ANY TOOLS, SUCH AS X-RAYS MAMMOGRAMS.

DOC: Yea we would usually, as I say have the mammograms and again we would usually have the histology report and actually show it to them, you know so that they can see cancer written down themselves and again we have, I mean both Dave and myself tend to do drawings and we have a file with drawings that you can draw and felt tip in to show anatomy and things like that.

INT: YEA COS SOME OF THE PHARMACEUTICAL COMPANIES ISSUE YOU WITH DIAGRAMS. UHM DO YOU SPEND ANY MORE ADDITIONAL TIME WITH THE PATIENT ONCE YOU HAVE SEEN THEM, DO YOU SPEND ANY MORE TIME WITH THEM AFTER THAT?

DOC: I think as I say there would be that consultation, then they would go off with the breast care nurse. It may well be then that on the basis of their meeting with the breast care nurse. The would want to come back to us for some particular point, which is fine. But then normally the next time we would see them would be at the pre assessment visit the next week.

INT: AND WHILE YOU ARE DISCUSSING ALL THESE ISSUES, HOW DO YOU FEEL ABOUT THESE THINGS.

DOC: Well, as I say it varies tremendously, I mean, over the years I have seen an incredible range of emotions through complete blank, anger and hysteria and so you know everyone is different, so there is no such thing as an average consultation, which is good.

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

DOC: Yea, I mean, again this varies tremendously. There are some who will clearly have asked around, talked around, spoken to their own GP and they will fire some fairly pertinent questions, like are you a proper breast surgeon. How many cases do you see a year? You know, these are the questions that people are told that they should be asking. What facilities do you have available? So that is not a problem. Some people feel threatened by that, but that doesn't bother me at all. Uhm and then we would, there would be the information that we would give them and usually the breast nurses are in the best position to do that, you know written information, but we would also encourage them to use you know Cancer Backup website, which we think is very good. We would discourage them from just surfing the net and just going to some dodgy American website, which can just end up confusing them.

INT: JUST OUT OF INTEREST, DO THEY EVER ASK ABOUT CLINICAL TRIALS?

DOC: Very rarely, very rarely.

INT: IT IS NOTHING TO DO WITH THIS!

DOC: Yea, I know but it had the other one, you know the Tony Stevens one on why do people ?????????
I mean, I think to be fair, when they get into the detail, that is one of the things, you know, how many patients do you treat a year. Are you involved in clinical trials but it is not usually up front.

INT: SO, GIVEN THAT PEOPLE HAVE VARYING DIFFERENT KNOWLEDGE AND EXPERIENCE OF CANCER. TAKING FOR INSTANCE SOMEONE WHO KNOWS A LOT ABOUT BREAST CANCER, DOES THAT MAKE IT HARDER OR EASIER TO COMMUNICATION WITH THE PATIENT.

DOC: I mean, I enjoy it if patients know a lot about it or have go a lot of questions. I enjoy that and the more difficult questions are more stimulating really.

INT: AND WHAT ABOUT PATIENTS WHO HAVE NO SORT OF KNOWLEDGE?

DOC: Well, I think that is very difficult then, because I think you have to avoid being kind of patronising about it but sometimes you do get the impression that clearly they don't seem to have any insight either, because they are so stunned or they just don't have any insight or don't want to have any insight and you know we still see patients who just want you to do what you think is best and don't want to be involved really in it at all.

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

DOC: I think they need a clear, you know it is cancer, or it is pre cancer so no bullshit, this is the fact. Then they need to understand the different modalities so, surgery, radiotherapy, drug treatment and sometimes it is quite difficult to. . . , they think it is either one or the other, so getting across that it is a multi modality treatment, and again I think the positive bit that overall breast cancer is relatively good prognosis. So it is not all doom and gloom, that there is light at the end of the tunnel. Because I think the initial visit all they can see is the funeral and the order of hymns and they can't see anything beyond that and it is important to try and steer them through that.

INT: WHEN YOU'RE DISCUSSING DIAGNOSIS WITH PATIENTS IS THERE ANYTHING YOU THINK THEY PARTICULARLY UNDERSTAND VERY WELL WHEN YOU SPEAK TO THEM AND THINK 'YEAH, DON'T HAVE TO GO THORUGH IT AGAIN, IT'S KIND OF TAKEN STRAIGHT IN?

Doc: I think you know, people they appreciate you know breast cancer is common and they appreciate the importance of spread of breast cancer, lymph glands things like that so I think most people understand that.

INT: AND IS THERE ANYTHING YOU THINK IS UNDERSTOOD POORLY ABOUT DIAGNOSIS?

Doc: I think as I say it's the fact that treatment is complicated and involves different modalities which all work in a slightly different way so the fact that it's not one or the other, it's often combinations.

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

INT: AND TALKING ABOUT TREATMENT OPTIONS, A SIMILAR SORT OF IDEA, WHAT DO YOU THINK ARE THE MOST IMPORTANT PIECES OF INFORMATION PATIENTS NEED OR WANT TO KNOW ABOUT TREATMENT OPTIONS AND WHEN DO THEY TEND TO GET RAISED?

Doc: Well they need to know the diagnosis and then immediately sort of into the options and the fact that you know for instance, normally surgery would be the first treatment modality and that then there are these two broad options between mastectomy and breast conservation and then you know, get into the pros and cons of those and then the fact that the systemic treatment is a kind of add on on top of that and can occur with either.

INT: IS THERE ANYTHING ABOUT TREATMENT OPTIONS THEY UNDERSTAND PARTICULARLY WELL?

Doc: Well I think, you know, women know what a mastectomy is and they know what a lumpectomy is, so I think they know that, they seem to have that prior knowledge.

INT: AND IS THERE ANYTHING THEY FIND DIFFICULT TO UNDERSTAND?

Doc: As I say, I think it's the fact that different treatment modalities work in slightly different ways so for example, radiotherapy

is a local treatment to reduce local recurrence whereas drug treatment has a systemic so, you know, reduces risk of distant disease.

INT: DO THEY EVER HAVE A PROBLEM WITH CHOICE, YOU KNOW DESCRIBING WHEN YOU GIVE A CHOICE TO PATIENTS, DO YOU HAVE A PROBLEM WITH THAT?

Doc: Yeah, I mean it is, so for example let's say if a woman has premalignant change but it's widespread throughout the breast the fact that the surgeon may advise mastectomy, mastectomy is, I think, often perceived as bad so they think mastectomy means it must be really bad whereas their prognosis will be excellent but you know, as I say, I think that's very common that women perceive that if it's, if the doctor's recommending a mastectomy things must be really bad which isn't necessarily the case.

INT: I'M GOING TO MOVE ON A LITTLE BIT NOW TO WHAT A PATIENT'S ACTUALLY OFFERED IN TERMS OF TREATMENT. THIS IS A LOVELY QUESTION..

*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

Doc: Right. We would never offer only breast conservation surgery.

*b. ONLY A MASTECTOMY

INT: AND WHAT ABOUT OFFERING ONLY A MASTECTOMY, WHAT WOULD BE THE FACTORS THAT YOU NEED FOR THAT?

Doc: We'd never, and again, I hope that we would try and be as objective as possible and give them the facts and clearly there would be a list of things that would be relative indicators for mastectomy you know, large tumour size, multifocality etc. but we would never paint it as a 'you must have this' or 'you must have that' and personally it's not a problem to me if a woman says 'I won't have a mastectomy' I will explain to her the reasons why we think she should have it but would never make her feel that, you know, somehow she was being a silly girl and we wouldn't treat her or something if she chose to kind of go against what, you know, the treatment that we were steering her towards.

*c. A CHOICE BETWEEN MASTECTOMY & BREAST CONSERVATION SURGERY

INT: SO I MEAN THE NEXT RESULT, PLEASE DESCRIBE THE FACTORS THAT WOULD LEAD YOUR TEAM TO OFFER A PATIENT A CHOICE BETWEEN MASTECTOMY AND BREAST CONSERVATION

Doc: Yes, so we would always offer a choice but if you know, let's say if it was a large multifocal tumour we would try and get across to them that breast conservation wouldn't be a particularly good choice.

INT: NO, RIGHT, YES. AND WHAT ABOUT OTHER TREATMENTS? WHAT FACTORS WOULD LEAD YOU TO OFFER OTHER TREATMENTS?

*d. OTHER TREATMENTS

Doc: I think, you know, we would always talk about you know, 'cos women would say 'well, I don't want surgery' and obviously you know there would be conventional other treatments so for example primary systemic treatment and then surgery at a later date or primary systemic treatment or occasionally you have patients who don't want any treatment or they want to go and have some you know, mistletoe therapy

or some odd herbal treatment or something and again, we would try and give them our evidence to show why we're offering what we're offering but again, wouldn't if that's what they wanted we wouldn't, you know, lock the room and not let them out.

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

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

Doc: I think so, but I would say that wouldn't I so I mean that's one of the reasons why I think these studies are important because of course what patients perceive isn't necessarily what we think we're telling them so that's why it needs to be done. INT: I'VE GOT A CARD FOR YOU TO LOOK AT. THERE'S FIVE CHOICES ON THERE AND I'D LIKE YOU TO CHOOSE ONE.

*Q16. THINKING ABOUT YOUR EXPERIENCES WITH THE PATIENTS YOU SEE PLEASE LOOK AT THE RESPONSES ON THE CARD AND TELL ME, DURING CONSULTATIONS, WHO GENERALLY MAKES THE FINAL DECISION ABOUT WHAT SURGICAL TREATMENT TO HAVE? Doc: Right. (Quite a long pause) I would hope that it would be option 3 so that the patient and I had to share the responsibility.

INT: SO THE NEXT SECTION IS COMMUNICATING WITH PATIENTS WHO HAVE A BREAST CANCER. AT THIS POINT I WOULD LIKE US TO TALK ABOUT YOUR EXPERIENCES COMMUNICATING WITH PATIENTS IN PARTICULAR I WOULD LIKE US TO FOCUS ON PATIENTS IN WHOM, FOR CLINICAL REASONS, MASTECTOMY IS NOT THE ONLY OPTION. RESEARCHERS HAVE IDENTIFIED THAT PATIENTS WITH BREAST CANCER TEND TO FALL INTO ONE OF THREE DECISION-MAKING STYLES. ACTIVE DECISION-MAKERS, COLLABORATIVE DECISION-MAKERS AND PASSIVE DECISION-MAKERS. IN THIS FINAL SECTION OF THE INTERVIEW I WOULD LIKE TO ASK YOU A FEW QUESTIONS ABOUT HOW YOU FIND COMMUNICATING WITH THESE PATIENTS DURING THE CONSULTATION PROCESS THAT LEADS YOU TO A FINAL TREATMENT DECISION. TO START WITH I'D LIKE TO DEAL WITH SITUATIONS WHERE YOU HAVE ACTION DECISION-MAKERS AND FOR THAT I WANT YOU TO USE THIS DEFINITION WE HAVE OF ACTIVE DECISION-MAKERS. PATIENTS WHO TEND TO MAKE THEIR OWN FINAL TREATMENT DECISION EITHER WITH OR WITHOUT SERIOUSLY CONSIDERING THEIR SPECIALIST'S OPINION.

*Q17. FIRSTLY, I WOULD LIKE YOU TO THINK ABOUT A SITUATION YOU HAVE HAD WITH A PATIENT WHO WAS ACTIVE ABOUT MAKING DECISIONS. WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, PLEASE TELL ME ABOUT YOUR EXPERIENCE WITH THEM UP TO THE POINT WHEN A TREATMENT DECISION WAS MADE.

Doc: Yeah, I mean I've pencilled in actually because I've thought about patients that we'd had in the last couple of weeks so, I mean an active decision-maker we had recently and it was a lady in fact, with a very small screen detected cancer who would have been eminently suitable for breast conservation it kind of helped in that I already knew the lady because I'd done surgery for a thyroid cancer 10 years before so we kind of knew each other quite well and so we kind of had a good rapport so that kind of made life easier but it was interesting that as, with a small screen-detected cancer, I was starting to launch into my speech about this would be suitable for breast conservation treatment and she just basically told me to shut up and she'd decided she was going to have a mastectomy and that was the end of it.

INT: RIGHT, OK. AND HOW DID YOU GET ON WITH THAT PATIENT?

Doc: Well fine. As I say, I suppose it was slightly odd in that I already knew her well professionally so I already knew that she was a woman who would speak her mind and so that was kind of easy but again, I think we do sometimes see people who appear to be, make, jump to a decision and then may change it so even in that situation we would always, we wouldn't make the final decision until they'd seen the breast nurse and then we'd seen them in the pre-assessment clinic and done the consent but generally if someone like that goes straight to one treatment choice they're probably not going to change their mind.

INT: DID THE PATIENT GET ON WELL WITH THE NURSE WHO WAS DEALING WITH HER?

Doc: Yes.

INT: SO HOW ARE YOUR FEELINGS ABOUT HOW THE ACTUAL CONSULTATION WENT?

Doc: I mean as I say, it was fine and it was very straightforward and pretty painless and, so that was an easy one.

INT: DID SHE END UP ACTUALLY HAVING THE MASTECTOMY?

Doc: Yes

INT: SHE FOLLOWED THROUGH THE DECISION? YES, OF COURSE, YES. WERE THERE ANY OTHER INFLUENCES APPARENT AS TO WHY?...

Doc: Hers was, she'd already had one cancer and done well from that and felt that she was kind of cured and she, I mean in her words, she didn't want to bugger about having little operations, radiotherapy, the worry that it was going to come back again and more intensive follow up and she'd rather just get rid of it and have a mastectomy and as I say, she'd already thought all that through before she came back so this was a case where she'd picked up all the warning shots at the first consultation so when we told her it was cancer 'yes of course, I knew that was what you were going to say because that's what you said you thought it was'.

INT: LOOKING BACK, HOW SATISFIED ARE YOU WITH THE EXPERIENCE OF THAT PATIENT?

Doc: I mean, I was satisfied and I would hope that she was and I don't think either of us would regret that she, you know, we both felt she'd made the right decision for her.

INT: THIS IS KIND OF A STRANGE QUESTION. AT WHAT POINT ARE YOU AWARE WHEN YOU'RE TALKING TO A PATIENT THAT THIS PERSON IS QUITE ACTIVE IN THE DECISION-MAKING>

Doc: I think it's usually quite early on in that it would tend to be people who are more vocal and they're talking more and they're clearly, you know, their thought processes are working in terms of what they want so, I think, you know, often it's a personality thing rather than just specifically the situation they're in.

INT: AND HOW DOES THAT AWARENESS CHANGE YOUR APPROACH TO THAT PERSON IN TERMS OF, BECAUSE YOU SAID YOU'VE GOT TO GET A CERTAIN WAY OF BREAKING NEWS.

Doc: Yes, yes. I don't think that it would particularly change that but I would be aware that I might have to, you know, engage in more

discussion with them and, but as I say I think it's their personality rather than the issue that they're faced with at that moment.

INT: RIGHT, OK.

*Q18. THIS TIME I WOULD LIKE YOU TO THINK ABOUT A SITUATION YOU HAVE HAD WITH A PATIENT WHO WAS COLLABORATIVE 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.

INT: I'D LIKE YOU NOW TO THINK ABOUT SITUATIONS WITH COLLABORATIVE PATIENTS, DECISION-MAKERS. FOR THE PURPOSES OF TH STUDY WE DEFINE COLLABORATIVE DECISION-MAKERS AS PATIENTS WHO TEND TO SHARE FINAL TREATMENT DECISIONS AND RESPONSIBILITIES WITH THEIR SPECIALISTS. THIS TIME I WOULD LIKE YOU TO THINK ABOUT THE SITUATION, VERY SIMILAR TO WHAT WE'VE JUST DONE, WITH THE PATIENT WHO YOU THINK WAS COLLABORATIVE ABOUT MAKING DECISIONS. AGAIN WITHOUT REVEALING ANY CONFIDENTIAL DETAILS, PLEASE TELL ME ABOUT THE EXPERIENCE WITH THAT PATIENT UP TO THE POINT WHEN THEY MADE A TREATMENT DECISION.

Doc: Right. I mean I think this, I suppose in general terms, these consultations take longer and they can be more complicated an again the case that I thought of for this was one whose treatment options she had a huge range of treatment options, it's a lady with the breast cancer gene who'd had one breast cancer, which was a small breast cancer and then has got a recurrence in the same breast so really she had a huge range of options from having breast conservation to mastectomy to bilateral mastectomy because of her family history risk to all of those options with or without breast reconstruction done at the same time or at a later date, so a big range of options and she's very keen to consider all of the options so she's going to see the plastic surgeons and so her decision is going to take some time to resolve.

INT: AND HOW DO YOU FEEL ABOUT HOW THE CONSULTATIONS GO WITH THIS LADY?

Doc: I mean fine but I think, you know, it's obviously much harder, much harder emotionally because there's all the issues, there's not only the breast cancer and her concern about that but there's the family history hang-ups as well and then there's the body image thing so, you know, the whole package is much more complicated.

INT: AND WHAT SORT OF INFLUENCE IS THERE APPARENT IN THIS SITUATION?

Doc: I mean, there's what we're saying, what her husband's saying, what the rest of her family are saying, so I think, you know, she's got a lot of pressures and again, I mean I suppose it's difficult for this in that she hasn't yet made her final decision but I think we regard it as an evolutionary thing. We've already seen her two or three times and then she's going to go and see the plastic surgeons and so we accept that it'll probably take a while for her to make the decision.

INT: HOW SATISFIED ARE YOU WITH THIS KIND OF EXPERIENCE, DEALING WITH THIS TYPE OF DECISION-MAKER?

Doc: Yeah, I'm pleased in that I think we've kind of, we've encouraged her to make decisions and make the right decisions for her and take her time rather than rush her into, try and bully her into one decision or another.

INT: AND SO WHEN YOU KNOW YOU'VE GOT THIS KIND OF DECISION-MAKER, HOW AGAIN, DOES THAT CHANGE YOUR APPROACH IN ANY SORT OF WAY?

Doc: I mean I suppose you just need to be absolutely sure that they have as much information they need at the level they need and from all the agencies that they need to hear it from and I think we would have a pretty low threshold now for getting another opinion, so for instance if they're not sure and they're unhappy about, you know, the information they're getting from us we would say, you know, if you want to go and talk about it to your own GP or if you want to go and see another breast surgeon and see what they've got to say about it, then we would encourage that.

INT: THIS MIGHT SEEM LIKE A STRANGE QUESTION, BUT AT WHAT POINT ARE YOU AWARE THAT YOU'RE DEALING WITH A COLLABORATIVE DECISION-MAKER?

Doc: Well I suppose it's when they want us to say a lot and when they've got a lot to say themselves.

*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.

INT: THE LAST QUESTION IN THIS SECTION IS TO DO WITH PASSIVE DECISION-MAKERS AND, I'M NOT GOING TO READ IT ALL OUT BUT ESSENTIALLY WE'RE GOING TO DO THE SAME THING AGAIN. THAT'S THE DEFINITION FOR A PASSIVE DECISION-MAKER, PATIENTS WHO TEND TO WANT TO LEAVE THE FINAL TREATMENT DECISION TO THE SPECIALIST EITHER WITH OR WITHOUT THE SPECIALIST SERIOUSLY CONSIDERING THEIR OPINION. IN THIS FINAL BIT OF THE SECTION I WOULD LIKE YOU TO THINK OF A SITUATION WITH A PATIENT WHO YOU THOUGHT WAS PASSIVE ABOUT MAKING DECISIONS AND JUST AGAIN TELL US, WITHOUT ANY CONFIDENTIAL DETAILS, YOU KNOW, HOW YOU FOUND THE EXPERIENCE IN COMMUNICATING WITH THAT PATIENT.

Doc: Yeah, I mean I suppose from an intellectual point of view they're not as challenging because they, if you like, they kind of roll over and one of the difficulties of course is they always say 'well, what would you recommend?' and you say 'well there are these options and it's not really for me to recommend one thing or the other 'cos there is this clear choice' and then of course they would then say 'well, what would your wife have?' which I always find a difficult one because I either tell them the truth which is that my wife would say she would have a mastectomy because we've discussed it or I lie and say you I know, 'you can't ask me that question' or we'd face each, so it's kind of a bit difficult that.

INT: DO YOU HAVE A PARTICULAR PATIENT IN MIND?

Doc: Yeah, again, when I was reading through this we, we get I think quite a lot of those patients who I think would say well, you know, we'll have whatever you recommend so again, the consultation I suppose tends to be the shorter one and then we would basically go, I suppose, on the basis of the MDT discussion so let's say if there was anything at all that would make us veer towards a mastectomy on oncological grounds, you know a relatively large tumour, relatively near the centre of the breast, possibility of it being multi-focal in this sort of case

we'd say, well you'd probably be best having a mastectomy.

INT: So, THE PATIENT YOU HAD IN MIND, HAVE THEY ACTUALLY MADE A DECISION.

Doc: Yes, I mean they went straight for mastectomy.

INT: AND WHAT KIND OF INFLUENCES WERE APPARENT WITH THIS PERSON?

Doc: I suppose they again, I'm sure it's a personality thing, they would tend to be passive-type people anyway and may be the vanishingly small number of people who would think that doctor knows best but they might be influenced by the fact that they would think that, you know, they've had a good experience from the Unit and you know, people say they seem to know what they're talking about and so if they recommend that then that's what I'll have.

INT: AND HOW SOON DID YOU REALISE THAT YOU WERE ACTUALLY DEALING WITH A PASSIVE DECISION-MAKER.

Doc: Again, pretty quickly really.

INT: AND AGAIN, DOES THAT CHANGE YOUR APPROACH TO HOW YOU'RE GOING TO DEAL WITH THAT PATIENT AND IN WHAT WAY?

Doc: I suppose for better or for worse we would tend to reinforce that they've made the right decision. So to try and you know, encourage them that yeah, you know, we respect that they've made that decision taking our recommendation and I'm sure that that's the right decision for them.

INT: AND HOW SATISFIED ARE YOU WITH THE EXPERIENCE OF DEALING WITH THAT PARTICULAR PATIENT?

Doc: Again, fine.

INT: AND WHAT ABOUT THE PATIENT THEMSELVES? DO YOU THINK THEY WERE SATISFIED WITH THE CONSULTATION EXPERIENCE?

Doc: Yeah, yeah, yeah.

INT: RIGHT, LAST COUPLE OF QUESTIONS. THE LITERATURE TELLS US THAT THERE ARE A WIDE VARIETY OF INFLUENCES NO PATIENTS MAKING DECISIONS ABOUT SURGICAL TREATMENTS, SOMETHING WHICH WE'VE TOUCHED ON ALREADY.

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

INT: BEYOND THE UNIT SORT OF THING.

Doc: So not, influences outside the Unit?

INT: OUTSIDE THE UNIT, YES.

Doc: I suppose the media. You know, family experiences, friends, relatives who've had one treatment or another, that tends to be very important so if they know they've got someone in the family whose had a mastectomy and has done well then often they will go for a mastectomy

because they think that it was the mastectomy that made them do well, which of course may well not be the case, but I think that's a pretty hard one to shift and similarly if someone's had a lumpectomy and done badly, they tend to think lumpectomy is a bad thing to have so I think that's important and then the media, you know, so if Koo Stark and I don't even know what treatment she had but you know, everyone seems to know about it so that would kind of influence people as well.

*Q21. AND THINKING WITHIN THE CONTEXT OF THE BREAST TEAM HERE, WHO OR WHAT DO YOU THINK HAS THE GREATEST INFLUENCE ON PATIENTS' DECISIONS ABOUT WHICH SURGICAL TREATMENT TO HAVE?

Doc: I fear that the surgeon will probably be the most influential.

INT: AND WHY DO YOU THINK THAT?

Doc: I think it's just a kind of role-play thing that people, so you know, a surgeon must know what he's talking about. Not necessarily the case but I think that they probably, that's my perception, that the surgeon is the most influential although I would like to be wrong.

*Q22. IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD TO WHAT WE HAVE BEEN TALKING ABOUT TODAY?

Doc: No, as I say, it's difficult because I think it's very hard when you're kind of in the thick of it to kind of sit back and look objectively at the kind of information that's being given and how it's put and that's why as I say I think this is important. I mean it does kind of concern me that smaller cancers that are picked up on screening I think there is a tendency to subtly steer those patients towards breast conservation rather than a, you know, a symptomatic lump cancer where we may not push them so much towards conservation but hopefully this will all be flushed out with this.

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

INT: I'VE GOT ONE QUESTION TO ASK YOU. IT WAS A COLLEAGUE OF MINE WHO SUGGESTED THIS THING SO I THREW IT IN RIGHT AT THE END BECAUSE I THOUGHT IT WAS A GOOD QUESTION. IF YOU HAD THE POWER AND MONEY TO CHANGE ONE THING ABOUT THE SYSTEM HERE, WHAT WOULD IT BE?

Doc: Yes, that is a good question isn't it? I think we would want to be able to provide breast reconstruction locally. At the moment breast reconstruction patients have to go Sheffield's Northern General so it means that in terms of offering options, so for example, rather than lumpectomy, mastectomy another option would be mastectomy plus primary reconstruction. Now although that it is an option it's a very difficult option because it means they have to go to a strange place, meet a different team of people, have a longer delay before they have the surgery so it's not really a viable option and we think that that's unfair.

INT: I DON'T THINK THERE'S ANYTHING ELSE. DO YOU HAVE ANY QUESTIONS?

Doc: No, no. I was interested to read the stuff about collaborative and everything because Sam Lenster who was the kind of driver of that paper, I was in Liverpool when he was there and I know they did a lot of work with the psychologists there looking at decision-making, so.