

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Surgeon)
*VENUE: High MR unit
*DATE: 20/10/2003
*ID: BS013
*INTERVIEWER: DJW

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

Surg: Twelve years/13 years.

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

Surg: Well I find it quite relaxed. Not too stressful but very busy. We function absolutely as a team. If anybody's on holiday then one of us will cover for them and vice versa. We cover for each other's clinics, we operate on each other's patients and we do everything we can to avoid any delays for people. But the other thing we do do is rely quite heavily on the breast, or I do, breast care nurses to pick up the pieces. So when I say I don't find it very stressful I imagine that there's a lot of upset goes on behind my back that doesn't get through to me. So, I mean, the worst part of it is the accreditation and all the targets and paperwork that comes at us from outside which we often ignore but eventually you've got to deal with some of that.

Int: Yes of course, that's right. Talking about paperwork, this project's just been through a research governance procedure and it's been a complete nightmare for us, absolutely horrendous, so I can see where you're coming from in that respect.

Surg: I think we've got a good bunch of like-minded, similar aged people so we all get on all right, there's no hierarchy.

Int: Are there about four breast care nurses here?

Surg: Well there would be five but two are away sick, so effectively three and they seem to manage alright although we're doing more cancers. I mean it makes you wonder if we need five really, and we're likely to end up, well we probably will replace them.

Int: Ahah, that's good. Do you, do nurses regularly do, sort of, home visits here?

Surg: They will do no request.

Int: On request, that's right, yeah.

Surg: ... and I think they probably do quite a lot and I'm not sure that I approve necessarily but they like doing it so they do them yeah.

Int: OK.

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

Surg: Yeah, they do. Ahem, amongst my colleagues, that are the two other surgeons, they tend probably to spend longer with their patients than I do and probably go into greater detail.

Int: Is that at initial consultation?

Surg: More, I think, when it's looking as though they will have cancer and explaining things pre-operatively and probably post-operatively. I mean, I said we're all probably much the same age group but there's probably a 15-year spread with me being the oldest and I think the way they have developed, if you like, means that they do spend more time talking to patients whereas I try and judge how the patient's taking things or accepting things, and go on as appropriately I think, with sympathy or fact, to a certain point and then I think I can go no further really and so I'll, that's when I move them on to the breast care nurses to pick up the pieces, so there are different styles certainly - I haven't observed them because obviously I'm not in there with them and I've never heard, actually, what they do say but they do spend twice as long with them as I do so I assume they're saying more.

Int: Yeah (laughter). I mean the nurses as well, what styles have you observed there?

Surg: Oh right, not at all, I have no idea because I don't actually sit in when they're doing anything either so I'm afraid I haven't observed anything.

Int: Right.

Surg: They are nurses off the wards so they come through - I think all of them have looked after breast cancer patients on the wards so they've developed in that way. We've got currently a girl seconded because of the two absentees and she have a slightly different background - it sounds like you know

Int: I've just met her actually

Surg: Oh well, she's got an entirely different background but coming from a community aspect she thought she could link things through from that point outwards if you like, so I have no idea about their styles. I mean I know a bit about the radiologists, the two, they're the people that look after the mammograms and they're, they're fairly, well the male chap is fairly dynamic and very good at biopsying anything and the lady radiologist we have is very caring and thorough and less interventional I suppose.

Int: I would like to sort of move on to what happens just before clinic begins and patients are about to hear their diagnosis and from this point of the interview I would like just to focus only on newly-diagnosed patients if we can.

Surg: Alright, yeah

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

Surg: Ahem, it's usually the day before. You see we had an MDT today which is Monday and I'll be seeing patients in the morning, on Tuesday. We have another MDT on Thursday and it's a possibility we'll be seeing patients on Friday with their diagnoses from that clinic. We have clinics, virtually, diagnostic clinics, virtually every day of the week but we concentrate them into two clinics to give the pathologists a bit of time so it's next day and so they've all been discussed in advance with the radiologist, pathologist and surgeon to make sure the diagnosis is correct.

Int: So you discuss them pre-operatively?

Surg: Yes, yes, and to determine which operation we think is most appropriate. If they are fairly advanced then we probably discuss them with the oncologist who comes to the Thursday meeting where we see mainly post-op patients but also some pre-op.

Int: The next one probably sounds a bit strange but ...

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

Surg: Ah well, pretty organised really and fairly confident. Sometimes if things have gone wrong and they do go wrong in our job, very infrequently, then you feel a bit uneasy but I mean that hasn't happened to me for two or three years so it's only when there's something untoward, something you're a bit anxious about but generally I feel, you know, right, fine, because everything's in hand and we're on top of it and so, not enthusiastic but confident.

Int: Does it vary according to if you've got a heavy or light workload or if you've got a lot of people coming through?

Surg: Workload is predictable so it's never too heavy unless, for some reason, two people have been away and there's been a Bank Holiday and all of a sudden instead of having five or ten you've got fifteen or twenty, but it would only be numbers and as it's organised at the moment that just doesn't happen so...

Int: oh right, that's good...

Surg: so, yeah, 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?

Surg: I can only speak personally yeah, and very often I will give them a little, ahem inside, you know, a bit of insight into what we're thinking...

Int: an inkling, yeah ...

Surg: yes, an inkling, just to put it in their mind that they may have a problem when they come back for this result and it may be that they'll need further treatment but that generally, I would say most times I would do that and if I don't actually say it they probably pick up on it by the mannerisms and the fact that you say 'well, it looks as if there may be a problem here and we've got to do a biopsy test for you and get the result next week'. For some of them when it's outright cancer and they involve me in conversation then I'll go straight to the point with them and say 'well, yes, it does look a bit like it and we must, however, we've got to wait for this test but if you want to be thinking about it, ahem, then there are some options that you could be considering now, you know. Some of them come very, they're very worried and ask you outright, I don't think you can, "What do you think doctor?" I don't think you can lie and say 'Oh I think it's alright' or 'I don't know' - you could say 'I don't know' but I tend not to. I think honesty's best with them, or openness...

Int: I think they would appreciate that really...

Surg: It's the openness I think...

Int: It's a way of gaining trust I think...

Surg: Well that's right, yeah...

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

Surg: Is this at the first consultation?... before the diagnostic...? They aren't, to my mind they aren't, except perhaps their GP's put them into the urgent clinic.

Int: Ah right...

Surg: The two week wait. And I don't know what the GP's have said to them so I think the preparation, they have no preparation I don't think. I think it's just their own you know, feeling about it. So, there's no preparation, no.

*Q8. PRIOR TO A CONSULTATION WHERE YOU KNOW THAT A PATIENT WILL BE GIVEN A DIAGNOSIS OF BREAST CANCER, AND ASSUMING YOU HAVEN'T REALLY SAID ANYTHING BEFORE DO YOU HAVE ANY EXPECTATIONS ABOUT WHAT THAT CONSULTATION WILL BE LIKE AND WHAT ARE THEY BASED ON?

Surg: No I don't have any expectations because very often I won't have seen the patient before - they may have been seen by my colleague and it's my turn to give the result. On the other hand, if I saw them I very often can't remember them one week to the next. You know, if you tell me Mrs Smith, Mrs Jones, Mrs whatever, is coming back today for their result I may not remember that, who she was.

Int: ... once you see them.

Surg: So once I see them it may come back to me or indeed if I see them in the MDT, if I see my writing and realise it's one of mine, but of those that I do know my expectations well they're based really on what I remember of the patient and what I anticipate their outlook is and if it's DCIS then my expectations are that however the consultation starts it will actually end on a reasonably optimistic note, you know you've got a problem but we can do something about it. But as some, you know, are going to be back and then, I mean I look at it from a personal point of view, if I feel at the end of it that I've told them their problem as best I can and made a reasonably good job of it - it's the wrong way round really, then I'm reasonably happy with that consultation. It may not mean that they're particularly happy, I just sort of feel I couldn't have done it any better.

That's what, you know, that's what I aim for, just that feeling that it's bad and I'm sorry but you, and to give them the information in the nicest possible way really.

Int: You've kind of just touched on the next question really, I was going to ask you how would you describe your feelings before such a consultation when you know you're going to be breaking bad news.

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

Surg: Bad news? If it's really bad then I'm apprehensive but I'm not personally upset by it. You know, my job is not to get emotionally involved and I'm as sympathetic as I can be. You don't get too close to them or too involved and I also know, and you see we keep coming back to where I'm not the last person they see, so they don't actually leave with my comments - the last thing they remember, you know, and he said 'that Well I've only got a 50% chance of living' if that was my last comment, their last comment would be whatever the nurse says to them, so they've got a morning or an afternoon of absorbing this information and I feel I'm only the start of it so if it's really bad, you know, it's not 15 minutes and then in the car home, you know, which I think we used to do. I think the breast care nurses get much more tied up than me in the patients' emotions and probably their emotions and what I try not to do is to make any promises which you can't keep, you know, so, ahem, but there's some excitement before a consultation if you want to be truthful, because you're in possession of this knowledge that you're privileged to have, ahem, about a person because if it's good news you feel you're doing them a good service and you're quite chirpy about it. If it's really bad news then you just have to hit the right level of gravitas.

Int: Yes, it's similar to doing an interview. I mean sort of coming here today I was a little bit nervous and a little bit excited not having met you before and you not having met me.

Surg: That's right, yeah, you wouldn't know how it's going to go and what it's going to be like

Int: Yeah. So moving on now to actually during the consultation with that newly diagnosed patient. Can you please talk me through what happens in a consultation where you're giving a diagnosis and treatment options are being discussed with a patient with breast cancer. A general overview.

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

Surg: Oh yes, alright, I'll talk you through. Well, I won't say 'hello' or 'hello again' and if we haven't met I'll say 'hello Mrs whatever and Mr Holiday, we haven't met but ahem the doctors who have been looking after you - I may say to them 'Have the doctors who've been looking after you said anything to you?' to find out where they stand and if they say 'No' I might say 'As you know, the radiologist was concerned about this shadow on your x-ray' or if I've been involved I might say 'As you know, we've been a bit worried about this shadow or this lump of yours and I'm sorry to say that the result has come back positive' and I will often say 'Rather as we thought it might' or 'as the x-ray doctor thought it might' and I'll often say something like 'So there it is, we can't change it, we'll have to get on and deal with it for you'. Ahem, not necessarily all in that order but anyhow that sort of thing and at some point I'm aware that I should, they'll often say 'Does that mean I've got a growth doctor?' or whatever so at some point I feel I've got to mention the word cancer so I feel I've got to get that in somewhere near the beginning so I then explain to them a little bit about cancer. If they've got DCIS I find it easier because I can say, you know, 'That's the bad news but fortunately the good news is that this is a very early growth, cancer, and tell them a bit about DCIS because I think that's a separate entity for me, pathologically, and I do, I say 'the cancer starts like this, in the ducts, and whilst it's in the ducts

you're quite safe and then I do that with my pen, you know, and I say to them 'It's only when it's got out through the duct that it can go elsewhere and it's you know, more serious but in your case it looks from the small specimen we've got as if it's contained in the duct and therefore we can get rid of it for you and so, and then I would move on to say how we might do that and likewise, for an infiltrating carcinoma I'll say 'well you've got a cancer, it'll need an operation and in your case we've got the choice of doing a wide excision which means taking away the bad bit and leaving the breast or doing a mastectomy and explain to them a little bit about why there is a choice. On the other hand if it's a bigish cancer and a smallish breast I will say to them 'Unfortunately in your case there isn't any choice about what we do' so I sort of you know 'There's a cancer and you're going to have to come in for an operation to deal with this. Unfortunately in your case there's not any choice about it. Unfortunately the only option is to do a mastectomy and explain why, you know, which is fairly easy I think. It's more difficult with the ones where you do have a choice just explaining to them why they do have a choice especially as they'll often say to you 'Well what do you think doctor?' and I'll repeat to them I'll say 'No, it isn't what I think it's what you want because you've got a choice in this, you don't have to decide now' is the other thing I'll say because I explain to them what a wide excision is and how big a piece will be removed and I generally say 'we'll take away the bad bit, perhaps the size of a couple of tangerine segments to give them some idea of the size of what's coming out and if that's alright we would follow that up with some radiotherapy rather than a mastectomy to sterilise the rest of the breast so that's more or less how I tell them it and then I would also say 'what we're also going to do is test the lymph glands under your arm and we do that regardless of what operation you have, we do that for all cancers' I say and don't spend long on that aspect but I do say 'we do that for all cancers and that will tell us whether you need any more treatment or not but the first thing is to get you in and do the surgery' and then if they say 'well what more treatment do you mean?' I'll explain 'well it could mean radiotherapy if they think they may need a wide excision, we've already mentioned that or it could mean chemotherapy if we know it's a positive and leave it at that. It depends on how much they keep questioning but I think that's as much as I can tell them that they'll absorb and understand. There's often a husband with them...

Int: I was going to ask actually...

Surg: I turn to the husband and say 'Did you understand?' I don't really look at them or acknowledge them really. I say 'hello' and then I aim, focus on the woman almost all the time unless she's too distressed and then I might turn to the husband and very often there are silences for 30 seconds or so whilst they sort of cry a little bit and the nurse gets us a tissue and so on, I don't mind that, I think...

Int: So is the breast care nurse in there at the same time?

Surg: No, it's just a nursing assistant. And then I'll say 'you don't have to decide this' or if they have decided or if there's no choice and they really have to have a mastectomy I say 'now I want you to go and see our nurse because you probably haven't taken all that in, or if they are youngish I'll say 'to get your head around it', something more modern. I say 'go and spend some time with the nurse, have a cup of tea, there's nothing worse than going off home and then saying 'oh I wish I'd asked', so spend some time with our nurse and she'll go through it again with you and help arrange your admission so I sort of suggest this is a sort of, you know we'll get the ball rolling a bit and that it will be worth seeing the nurse, and if they want to they can talk and see if it will help with admission and then ask the husband if he's there, or anybody else who's there 'did you understand that, is there anything you want to ask me now?' and emphasise that they don't have to decide now or today, you can let us know whenever and I may look and see for a date when their operation might be just to put them in the picture.

Int: So who do you think, you know looking at the day of the consultation, who do you think when you tell them the diagnosis at this stage, when you've told them the diagnosis, who does most of the talking?

Surg: Probably me, but I'm only feeding information to them and I keep saying 'Did you understand? Do you understand what I'm saying?'. Always keep checking because sometimes they're totally vacant, other times they're right with you and very honest, cheerful, not cheerful but there's a sort of excitement of getting bad news and if they're asking questions then I'll answer those but I sort of get them back on to the bit in question. They race off somewhere and I say 'look let's cross bridges one at a time, I don't know why more than you at this stage. What we need to do next is to get you in, have your operation, let's get rid of it to start with and then we'll go from there.

Int: Do you use any sort of tools such as x-rays or diagrams - you mentioned using your pen.

Surg: Yeah, that's all. Sometimes I will show them the mammogram if I think it helps, yeah, ahem, and if I say 'You remember the doctor was worried about that shadow on your x-ray?' and they say 'No, what shadow?' you see, I say well, you know, I don't always have it, or there is a shadow - so sometimes I have the x-ray, most times I don't really because most times I think they probably are aware of all that and I move them on. So I don't have any tools at all. I've often wondered, there's some drug firms producing quite nice diagrams of breast but I try and stick to, it's my own way of doing it, I mean nobody else does it. I think if you can do that you get that, it's safe because it's in the duct business but and then that, to my mind that describes as much as they need to know. Maybe it's not enough, I don't know.

Int: So after you've given the diagnosis and discussed the treatment do you spend any additional time with the patient after the consultation's finished? Do you see them again? Are you likely to see them again?

Surg: No, I say 'they don't need to decide now. We've usually picked a day when they can come in for their operation. I say, you know, you can tell me on the day. Go and discuss it with the breast care nurses and I sometimes leave it that they can come and see us again if they need to you know. But very rarely, most times I leave them in the hands of the nurses because I think the nurses will suss it and will say, 'come back' and say you know 'that lady would like, she can't decide. She'd like to come and see you again or whatever but that's pretty rare actually, most times the next time I see the patient will be on the morning. When I go onto the ward I may or may not know what they've decided, the day of the operation, although in truth we do.

Int: You know you mentioned earlier about your feelings before an operation. What in general are your feelings after you've been through that process of...

Surg: I don't... there are personal feelings about whether I've done it well or not or badly. Sometimes, I generally confer with the nurse assistants who, there's four or five of them, two of them have been with us for a long while and I might say to those 'Do you think she understood?' or 'Did I put my foot in it there?' or you know 'Did I get it wrong?' so I guess there are, it's just personal ego-type stuff you wonder about you know'.

Int: It's like your own feedback really.

Surg: Yeah, almost your own feedback to get the nurse assistant to say something that you wanted to hear, maybe but if I don't think it's gone well it sort of gets it off your chest to say 'I don't think I did very well with that' and they may say 'well you've done better, ah well - that's one in a hundred or one in fifty you know. But of course there's a let-out clause, if I've done badly is the breast care nurse going to do badly as well? You know, the unlucky, both of us having a bad day you know.

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

Surg: Virtually nothing, virtually nothing. Whether that's changing and some of the younger ones, the more informed ones are on the Web and so on but I would say unless they've had a relative they know virtually nothing. It amazes me that they can't say 'mastectomy' they tend to say 'massectomy' so that makes me think in my own mind that that patient doesn't know a lot about it. I find that virtually starting from scratch and I prefer to start from scratch because a lot of what they've heard is from magazines, friends, old wives' tales so they may be correct but there'll usually be some inaccuracies within it so unless they're really well informed by virtue of relatives or some type of previous experience or they are nurses I tend to start with an almost 'sweep this slate clean and not let them go off at a tangent, forget that, that's not really the case, what really happens is' or, you know.

Int: Do you think that makes it easier or harder for the consultation to go along?

Surg: If they have some? I may seem a bit unkind but I sort of nip it in the bud early on you know because I am a bit pragmatic about stuff so I do like, don't dwell on all that, just forget that for a minute and let's just listen to what I'm saying but you know, you've heard everybody else but actually I'm here with you now and my experience is that this is what we need to do'. So it is a bit "doctor knows best" but I don't think I'm quite that bad.

*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?

Surg: They need or want to know? I think where there's good news to be had you should tell them that. In other words, where the outlook's good and they would probably like to know that then make sure that thought stays with them you know, so in that situation re-emphasise that. Ahem, the important piece they need. I mean after that if you're dealing with difficult cases I don't know what they need to know. It varies from patient to patient. I think you have to try and get them to express their fears or needs as you would put it and try and answer that so it's a matter of teasing it out of them rather than me having a hit list of things that they should sort of need to know. It's nice when you can tell 'we can deal with that' and that's something I feel they need to know, the fact that we do it all the time, we're familiar with it, you know that the Unit functions well, that sort of surrounding confidence that there's a whole bunch of people and that we have plans for them and you know, accepted pathways. I wouldn't use those words but just say you know that 'we're doing this all the time and we are you know...

Int: ...and you're creating a safe environment sort of thing.

Surg: Yeah, they are now in a safe environment. But basically, when are they raised. Well I try and get them out, I try and get these things out of them in the consultation when I'm giving them the news, their anxieties so there and then. But if they're not raised then they crop up when the nurses see them and the nurses will very often I think answer those questions for them and I think that's as much as I can say about that.

Int: So when you're actually discussing diagnosis what do patients sort of understand, well, you know when you're describing that you think yeah they've picked up on that quite quickly or is there anything in particular you can think of that they pick up well about what's been talking?

Surg: No I don't think there's any one fact more than any other. No I don't think I can say that they pick up well on anything. Not in my consultation. I think if I can just go back I'm not so sure what the difference is between this question and the one before it. It's saying about treatment now.

Int: No we're just talking about diagnosis at the moment.

Surg: Say that again then, what do you think...

Int: What do you think, when you're telling patients things about, information about diagnosis and their diagnosis is there anything you think they particularly understand well or indeed understand particularly poorly, you think that they just haven't... well you mentioned the choice earlier on, you said, I mean I've been in consultation with them when they've been trying to describe choice and it was a really interesting experience because you could there was a problem there but was there anything else that you think could...

Surg: No choice can be a problem especially if they are of that old-fashioned frame of mind that says, you know, that they're not used to having a choice about what this is and they can't make that choice so I think choice about treatment is a real problem. Very few of them actually doubt their diagnosis but I do always emphasise there it is and it's there and you excise, so there it is and there's nothing you can do about it. We can't dwell enough, on the 'if onlys' you know 'if I'd come sooner' or whatever, that sort of thing so let's look forward and get on and deal with it but I don't think I say anything more that I can tell about diagnosis.

Int: Well I've got a similar sort of question namely about...

*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?

Surg: Well, they may not be raised, for some folk they'll be raised right at the diagnosis, what's the treatment, they won't have any problems, they move straight on to that. Some of them I suspect will only raise these questions with the nurses after they've seen me. I think those that have to have a mastectomy, that's not a problem. It may take a while to repeat and reinforce why they should have a mastectomy but at the end of the day that's usually, it is sort of the gold standard and so I don't think there's anything wrong with doing a mastectomy and you try and emphasise to them that that is the best thing for them and you then lay emphasis on the fact that you've got to make sure we get rid of this thing properly and it doesn't come back. Of course with those that you're doing wide excisions for treatment you have actually told them all about how they have a choice, wide excision is just as good as a mastectomy or we wouldn't give them the choice and they say 'which would you have?' and I'll say 'well, either you know, we wouldn't be giving you the choice if we didn't think one was as good as the other'. You then have to backtrack with the wide excision and say if it reappears in the breast then that, there is a chance that it can reappear in the breast, you know, it's a very small chance but if so we can still deal with it you see and that's a tricky one because you're sort of saying well you can have a wide excision but it might not work so we have to get round that one and then of course the fact that you give radiotherapy and try and sell it that the radiotherapy sterilises the rest of the breast but even so I think you're obliged to give them that important piece of information that that can happen, albeit it fairly, and that it won't affect their longevity. Again, otherwise we wouldn't offer you the choice.

Int: Is there anything they particularly understand poorly about treatment?

Surg: Me or they?

Int: They

Surg: No, I would hope at the end of it they, I don't think necessarily that first consultation they will have any idea much about what their operation will look like. I might say you'll look flat chested if I feel you were having difficulty with a mastectomy or the breast will be much the same shape because we'll try and reshape it if you're having a wide excision but it will be a bit smaller and it may be indented so to get, I don't think they're able to picture it in their mind terribly well.

Int: Cosmetics...

Surg: ...what they may look like and the result of it. But again I would hope that they will pick that up with the nurse.

Int: I'd like to move on now to what the patient is offered in terms of treatment.

*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

Surg: Only?

Int: Only yes.

Surg: Well we would never do that actually. We would always mention that they could have mastectomy alternatively in case they were of a very anxious disposition and just wanted to remove it doctor. You know. I don't, you know this breast is no good so I wouldn't ever offer, I wouldn't tell them to have a wide excision without ever mentioning a mastectomy. If on the other hand, however, we thought it was perfectly reasonable to have a wide excision the factors that determine that - is that what we were talking about? -

Int: Yes

Surg: ? yes

Int: Yes, they would be within the context of the Unit's guidelines published research etc.

Surg: OK. Well there'd be the signs of the tumour, it's proximity to the nipple, whether it's central in the breast or not and its size relative to the size of the breasts. A small tumour and a big breast or a big tumour and a small breast you know. So those are the main things. Age comes into it to a certain extent but it doesn't actually exclude you from having a wide excision although the young ones, you may have to warn more if you like that there's a chance that that would have to be converted depending if the results of the histology were against them you know, if it was a rapidly growing tumour but it's basically just those things. We've not talked about reconstruction in this, we're not, this isn't part of it is it really?

*b. ONLY A MASTECTOMY

Int: No - and a similar sort of idea about mastectomy.

Surg: All right. Well, a central tumour might lead us to recommend a mastectomy. Multiple tumours, multifocal disease would, which I forgot to mention, it would have to be a single tumour for wide local excision and the appearance on the x-ray, the extent of the disease on the x-ray, the mammogram and that would be it really. Whatever would get us an acceptable clearance of margins with a reasonable cosmetic result.

*c. A CHOICE BETWEEN MASTECTOMY & BREAST CONSERVATION SURGERY

Int: And what would lead the team to offer a patient a choice between mastectomy and breast conservation?

Surg: You'd get a choice if you were suitable for wide local excision because if you were suitable for wide local excision you can have it done. If that, if you, I often use 'if you prefer to keep your shape' but as I say, if they had that choice they would also have the choice of a mastectomy. We might say you know, this is perfectly, it's perfectly reasonable to treat this with a wide local excision which means you don't have to lose your breast and so we might talk no more about mastectomy if they don't sort of bring that topic up as it were at that time but anybody who can have a wide local can have a mastectomy.

*d. OTHER TREATMENTS

Int: And what factors would lead the team to offer a patient other treatments, which is chemo, radiotherapy that sort of thing.

Surg: Ah right, inoperable tumours are automatically sent for new adjuvant chemotherapy. I mean the only other group that you wouldn't consider surgery on are the old folk where they're not fit for surgery but they're not fit for either sort of surgery really but inoperable tumours which are the big, more than 5cm inflammatory tumours, not just the inflammatory or inflammatory tumours but where there's a lot of skin change and then, so if it's surgically irresectable then we would advocate going for new adjuvant and you'd point out that we're going to do things in a different order. they're going to have the chemotherapy to shrink it all down and then the surgery later and just point out the two different ways of treating them but in their case we're going to go backwards.

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

Int: The literature suggests that patients vary in degree of involvement that they want when making decisions about what surgery to have. Some patients will want full control over the decision, some prefer to share the control and others prefer the professionals to take full control. The first question is 'Do you think the patients are getting the degree of choice that they want?

Surg: I think so but I'm probably biased and I haven't looked into it to know but I would like to think that we're offering them choice where appropriate. I mean at the end of the day we are making a team decision about the surgery so it's not just my opinion it's the opinion of my two surgical colleagues, the radiologist and even the oncologist or pathologist to a certain extent so I feel that takes the personal dogmatic approach or whatever, pragmatic or biased approach, I might have as an individual out of it. So I think we are offering them choice where it's appropriate, which I would hope corresponds to the degree of choice they want. They can't have a choice where there isn't a choice, sadly or at least if they wanted that choice you would have to point out, ok we can do that but I have to tell you that in fact it may not work and so they could reverse our decision. I have had that where somebody says 'under no circumstances am I going to have a mastectomy'. I've talked to them and said 'well, ok, we'll try for you but you have to give us, there is the proviso that if it's not good enough then it's not good enough. I don't - and I think that's probably been acceptable to them. So if they've got really strong minded, or a phobia, or something else that says 'I'm not going to have that whatever you say' which would usually be a mastectomy, then you just have to... I would go with them really. I'm never going to operate on anybody, I'm never going to do a mastectomy to anybody who flatly refuses to have one. Well they wouldn't would they? But I wouldn't try to persuade them too hard either. I would go with them because they've got to take responsibility for their decisions and as long as they understand what risks they run then that's a reasonable way of going on I think.

Int: I was going to show you this card but you've got the interview schedule in front of you. There's five little choices there, bullet points.

*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?

Surg: Well the patient makes the final decision.

Int: That's number one, the top one.

Surg: I mean after seriously considering my opinion, well I would hope, well it's 1 or 2 really but it's their decision and I give them my opinion and advice, so does that make it 2 really?

Int: I can't tell you.

Surg: I would think...

Int: This really is your decision!

Surg: Well I hope they've seriously considered my opinion so I would say it's the second one so if you don't mind me changing tack there.

Int: That's fine.

Surg: I mean it's a bit difficult because we generally share the responsibility but now then... well, they make the final decision I would hope and it's done with information I've offered them. Yes, ok I'll settle for the second one.

Int: This is about communicating with patients who have breast cancer. At this point I would like us to talk about your experiences of communicating with patients in particular, I would like us to focus on patients in whom for clinical reasons mastectomy is not the only option.

Surg: All right.

Int: Research has identified that patients with breast cancer tend to fall into one of three different decision making styles - active, collaborative 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 types of patients during the consultation process that leads to a final treatment decision. To start with I'd like to deal with the situation of the active decision makers. So we define active decision makers as such, it's on there anyway, but it's just bigger text to read really.

*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.

Surg: If they don't seriously consider my opinion? I have had patients like this and if having discussed it with them, given them my opinion, or my advice and they make their own decision contrary to that then I'll accept it, I'll go with it. If it's impossible for me to do what they ask, in other words, if say they have a tumour that's inoperable then it's going to be difficult and I wouldn't be able to do that but if they say to me 'I'm not going to have treatment at all I'm going to go and eat mistletoe' or whatever, then that's their decision and they are at liberty to do that. If they want another opinion from elsewhere I'm perfectly happy for them to do that, that's up to them. If they are adamant they won't have an operation when I would suggest that it's appropriate then I would try and help them to choose an alternative. It might be reasonable to have radiotherapy even if you won't have a mastectomy, it would be reasonable to go onto Tamoxifen say if we knew the ER status, it would be reasonable to have chemotherapy. They may not want any of those, of course, in which case I can't help them. So active people have decided to make their own decisions and I'll go with them.

Int: Can you think of a specific example of a patient you've actually met where you could tell me a bit about when you met them ...

Surg: Well yes, there is one in particular who refused to have a mastectomy and went off and had the herbal therapies at Bristol or wherever else and she came back to see us at intervals. We agreed to monitor her. She's had mammograms. She keeps coming back and I haven't heard from her for a long time actually, to ask us to test her and see if the cancer's gone away and so on and we've been happy to do that so I don't have any problem with

that. If there's anything they want me to do that's reasonable that is their way of dealing with their illness then I'll do that. So that's the main one that I can remember. I haven't had any refuse mastectomies and persuade me to do something else that I didn't, no, no. I wouldn't ever attempt to do something that I couldn't condone. I wouldn't want to do anything that they wanted me to do that would make them worse. Very few, very few have done that.

Int: That patient you spoke about did they get on well with yourself and the nurse?

Surg: Yes, I think we did. I mean I think we had a... it's a few years ago... we had a rather prolonged discussion because I wanted her to be sure that she knew what she was doing and that whilst I didn't, I had no proof this stuff didn't work, I couldn't be sure that it wouldn't work so I said, that's your decision you know and I'll be interested to know how you get on so I really wanted her to be sure she was prepared to take responsibility for it and I think I documented that fact and off she went.

Int: How did she hear of it then this treatment?

Surg: Well there are lots of people who are into organic food and she'd got it through women's magazines but she actually had a very long and complicated name for this and she hadn't got that from them. In about ten minutes I could think of it. It's some sort of 'ology'. Don't worry, it's a sort of treatment. It comes from Europe I suspect but anyhow they've given it her...

Int: Did she kind of know what she wanted when she came in?

Surg: Oh I think so yeah. She declared up front that she wasn't going to have any, that if this test was positive she wasn't going to, she knew what she wanted to do. So away she went. It would be interesting to know if she's still alive, it's quite a few years.

Int: So looking back now at that sort of actual experience how satisfied were you at the end of it all?

Surg: Oh I was quite content if you like. I was not dissatisfied. It's not my job I don't think to force people, certainly in surgery, you can't make people have operations good heavens. It's like assault isn't it? So it was an easy decision. I didn't have any problem with it.

Int: Do you think she was satisfied with it?

Surg: Yes I think so, 'cos we had, we were able to tell her what was wrong and what we would recommend and she could consider that and she made her own choice which was different and we talked about it for a while and she didn't begin to doubt about what she wanted to do. She wasn't asking me to persuade her otherwise so that's fine.

Int: So from when you first met her at what point did you realise this person's quite an active sort of, not perhaps using that terminology, but you know if she's quite a headstrong person who's going to make her own decisions.

Surg: Oh virtually in the first minute I think she declared her belief if you like.

Int: When you realise that that happens does it ever change your approach to how the consultation's going?

Surg: To her consultation? Oh yeah. I mean I then see it as my duty to make sure she understands the seriousness of her illness, as far as, as much as we know, in that we know that she's got breast cancer and that there is no, well conventionalism, well there's no evidence that any treatment works any better than what we do without being arrogant about it and that all these other remedies are not substantiated so she knows what she's letting herself in for and if she understands that and accepts that, then I feel it's her positive attitude about what she was going to do, 'cos I don't understand what the immune system does, I felt it might give her a chance, you know, that there may be a mind over matter thing that we know nothing about. Of course everybody that goes off to beat cancer never does, Steve McQueen and, you know, Mrs McCartney that was, all these people go off to beat it and never do but that still doesn't quite give you carte blanche to

assume nothing will work and then of course, we have got the Bristol Centre which gets into the press for its' care of people with advanced cancer and so on which seems to have some benefit they would say, so I would never be 100% against anything or 100% for what we do.

*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 would like you to think now about situations with collaborative decision-makers using the definition that's under, just before question 18, patients who end to share final treatment issues and responsibility with their specialist. I would like you to think about a situation that you've had with a patient who was collaborative about making decisions and again, without revealing any confidential details, please tell me about your experience with the person up to the point when you made the decision what treatment they were going to have.

Surg: Ok, these are more straightforward. I think the most important thing about the collaborative person is to make them aware of both sides of the story if you like, the pros and cons for the choice they have in as much as, they've got to have all the information they need basically and they've got to have the information about where things may go wrong or at least where their choice could lead to further surgery if you like. If they have a mastectomy they're not going to get some of the sequelae you get after conservation so they've got to know that side of things and that possibility and understand whereas, of course, the mastectomy people have got to know that a mastectomy is irreversible and once you've done it you've done it. Now, of course, there's a let out with a mastectomy in that they may have reconstruction at a later date, so if I think people are uneasy then I've got to make sure they understand both sides of the argument, both coins if you like and if I think they're edging towards having a mastectomy then I suppose essentially I might encourage them by mentioning reconstruction and if they're heading for a wide excision then they have definitely got to know that they'll be under surveillance thereafter and it could mean another operation, so as long as they've got all the facts including the negative ones then I feel...

Int: Is there a particular patient that springs to mind where you had that kind of experience?

Surg: No, not a lot to be honest because it's almost so routine now that nobody stands out as being, what's the word? - a dilemma that's gone wrong, no. The biggest problem I suppose is those who have a wide excision and have a re-excision and it's still there because you've gone quite a way from the collaborative stage then and then you have to move into more dogmatic decisions you know, but if they're collaborating they just need to know all the facts.

Int: And the final one is I would now like you to think about situations with passive decision makers and there's a definition there which you can read yourself.

*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.

Surg: 'Patients who tend to want to leave their final treatment to their specialists either with or without their specialists seriously considering their options'. Well...

Int: Can you think of any particular patients you've had?

Surg: No, there must be them and I am trying to think how I would feel about them now. If they leave the final decision totally to me then again I've just got to be sure they understand what we're doing. If we're doing a mastectomy I think it's very important, if we decided the easiest or best

easiest, that's a bad word isn't it? The best way forward for them is a mastectomy because it's simplest and it's done with and it's finished and I somehow sense that maybe for older folk that's what they would really like, I try and sense what they would like, so for a mastectomy if I feel that's most appropriate for the patient, I've got to be sure they know what they'll look like afterwards and once you've done it you've done it and you can't come back from that... the wide excision ones it's much the same you know, they've got to understand that a wide excision's fine but if it comes back you may have to have a second operation so, my experience of it is if I can get the decision the right then the patients are quite happy about it. I would try to involve anybody else who's with them in it if I can. I don't like it. I don't like it where there's a choice that I make the decision. It is sometimes, I'm going to use this word 'easy' again, it is sometimes easier to do the simple thing where the patient allows you carte blanche, the simplest thing being the simplest operation with the least follow-up and the least extra treatment and so on and the least risk of it going wrong, which is a mastectomy of course, so as I've probably said I try and sense whether the patient is somebody who basically would just like it done and dusted you know, but where they have a genuine choice then I do try to get them to collaborate. I try and move them from passive to collaborative and most will I think, that's why I'm having difficulty thinking of anybody. I think most will join in and accept some responsibility and I suspect at the end of the day I convert them into collaboratives rather than make the decision for them.

Int: You say you didn't like that kind of decision with passive people. What really don't you like about it?

Surg: Well where there's a choice, of course, it becomes my choice and I may well decide to do what's easiest for me but not what's not necessarily going to suit them best. I think my opinion of this is influenced by age and if I think we can do a wide excision in a young person rather than a mastectomy I will or a younger person. I don't like doing mastectomies in young people because, when I've made the decision, because of what it does to them you know. On the other hand, I do know that the risk of recurrence is highest in young women if we do the wide excisions so I don't like making that decision for them because it hangs over me then. If a few years later they say 'I wish I hadn't had a mastectomy' then I've done that, if a few years later it reappears then, you know, I've made that decision for them as well so I much prefer that they take some responsibility for it but I would, just thinking about it now, suggests that age is an important part of how I feel which of course makes me ageist, but there we are, maybe I am.

*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: I've got a last couple of questions here. Literature tells us that there are a variety of influences on patients making decisions about surgical treatment. I would like you to think of, first of all, in a wider sense, who or what do you think is the greatest influence on patients' decisions about which surgical treatment to have?

Surg: Who or what? Well patients differ. I mean, those that have had family with this disease who've succeeded with a certain treatment will probably accept that treatment. Those who've seen treatment go wrong would probably opt to have a different sort of treatment so I mean, their previous experience would influence their decision so that's partly to do with where they come from to start with. After that who has the greatest influence is I guess, the surgeon backed up by the breast care nurse but I guess we do really, surgeons.

Int: Yes, but the next questions are within the context of the breast team.

*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?

Surg: Well in my, the patients I talk to, it's me followed very closely by the breast care nurses and I mean, sometimes the patients will leave me not having, most times not having made a decision and I, the decision comes back to me so I think it's shared pretty equally actually between me and the breast care nurses, so they're bias, if there is one, could be tipping the balance.

Int: How long do you think, you know when you've actually given a diagnosis and you've talked her through the options, how long do you think it roughly is between the patient sort of getting information to making the actual decision. How long do you think it takes them to do that?

Surg: Are these some people where there's a choice? I would hope it's two or three hours minimum and I would hope that they maybe go home and think about it. How long it actually is I know from experience that a lot of them do decide that morning and the nurses come back and tell me in that same session 'she's decided to have' yes, and generally I'll say 'oh yeah, that's fine' or 'yeah, I thought she might' or you know, so by and large there are very few I suppose, well the nurses might tell you better, who actually go away undecided so they decide I think within two or three hours.

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

Surg: No I don't think so. We seem to have been pretty thorough.

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

Int: I do have one little question right at the end which is a bit of a strange question. If you had the money and power to change one thing about the system what do you think it would be?

Surg: If I had the power to change one thing? To do with patient choice do you mean?

Int: Just the system here.

Surg: Just the system here? Well, we'd have brand new customised clinics with plenty of time really. That would be all. I mean we lack a bit of time with the patients and we are in a rather higgledy-piggledy clinic across the corridor but I suspect that, I don't know, there's a slight quaintness about it that I quite like but I mean we are obviously going to be in a customised clinic in about five years' time but this one has grown and evolved and it actually works very well. Now of course I'm only in a part of it, I'm not so sure what it's like for the patient having to come into this room and go into that room. I suspect it would be a, I mean I think the way, a bit more time. Maybe the luxury of having a nurse in with me during the consultation.

Int: This is a breast care nurse?

Surg: Yes, and a posher clinic but having had the breast care nurse in there I mean I think if there were two of us sat there then the patient wouldn't get that second opportunity in a different environment with somebody who talks to them on a different level because I'm not, but I'm probably talking down to them in a lot of patients' eyes. They're listening to the doctor so I'm talking down, whereas off with the nurse it's pretty level conversation I would hope and they, the patient may express themselves more, ask more, be more decisive or objective or less condescending or whatever, but they've also had that time gap that we were just talking about, you know 'when should they make this decision?' and I think just the fact that they're in the hospital here for two or three hours rather than twenty minutes or half an hour with just be and the nurse in one room probably helps them. So in a roundabout way it works for them I think.

Int: Okey-doke, I think that's it.