

\*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Doctor)  
\*VENUE: Low MR unit  
\*DATE:  
\*ID: GPA005  
\*INTERVIEWER: DJW

INT: WELL FIRST OF ALL THANK YOU FOR AGREEING TO BE INTERVIEWED.

Doctor: That's OK.

INT: I KNOW YOU'RE VERY BUSY. SO WE'LL START WITH QUESTION ONE WHICH IS ...

\*Q1. HOW LONG HAVE YOU ACTUALLY WORKED AT THE GLENFIELD HOSPITAL BREAST UNIT?

Doctor: Two and a half years.

INT: RIGHT, OK. AND HOW MANY DAYS A WEEK DO YOU WORK THERE?

Doctor: I only do one session, so I just do literally Tuesday afternoon there and the rest of the time in general practice.

INT: RIGHT, OK. AND THINKING ABOUT THE SORT OF, THE TIME YOU PSEND THERE, YOUR LIKES, YOUR DISLIKES, THE UNIT PHILOSOPHY, THE DAY TO DAY RUNNING OF THE SERVICE THERE ...

\*Q2. WHAT IS IT LIKE TO WORK AS A SPECIALIST AT THAT BREAST SERVICE?

Doctor: It's fantastic, yeah, absolutely love it, really enjoy it, we're really well supported by sort of the breast care nurses and the auxiliary nurses and, compared with, I did have specialist interest in a couple of other areas, and compared with the set up there it's superb. It really is, yeah.

INT: OH RIGHT, YEAH. AND IS THERE ANYTHING THERE THAT YOU THINK PARTICULARLY FACILITATES YOUR WORK THERE, MAKES IT EASIER?

Doctor: Mainly the number of sort of nursing pairs of hands to, to doctor sort of ratio, that's the main thing, sort of having the breast caer nurses in there, in the consultation with me, is just fantastic because it means that, you know, if you need to spend an hour the patient I can't do that because I've got a whole cli nic full, but the breast care nurse can kind of take that on, so that really takes the pressure off me, knowing that, you know, they're gonna have that time to sit with the breast care nurse as well, so it's fantastic., And an auxiliary who's just feeding, bringing the patients in, calling them in, and just putting me into rooms all the time, keeps the throughput through. It's great.

INT: OH, [???

Doctor: Yeah.

INT: SO WHO, WHAT OTHER CONSULTANTS WORK WITH YOU IN THAT DAY?

Doctor: Just Mr Everson[?], erm, he's the main one that's in charge, and then there's both myself and Graham Praggs[?] who are the sort of hospital practitioners that work alongside him.

INT : OH RIGHT, OK. AND ON THE OTHER SIDE OF THE COIN, IS THERE ANYTHING IN PARTICULAR CONSTRAINS YOUR JOB WHILE YOU'RE THERE? ANYTHING THAT'S NOT SO EASY?

Doctor: Just the number of patients that we're trying to get through, through the system, particularly with the two-week wait.

INT: MM, THEY SEE A LOT DON'T THEY?

Doctor: They see absolutely loads, and we struggle with the radiology support to actually keep that going.

INT: MM, I THINK THAT'S EVERYWHERE, ISN'T IT REALLY.

Doctor: So, yeah.

INT: THAT'S ... I'VE BEEN TO A FEW MDTs AND STUFF WHERE IT'S ALWAYS BEEN THE SAME.

Doctor: Yeah.

INT: AND HOW DO YOU GET ON WITH THE STAFF THERE I MEAN ...

Doctor: Great.

INT: ... YEAH, YOU GET ON REALLY WELL WITH THEM?

Doctor: Great, yeah.

INT: THE CONSULTANTS AND THE NURSES AT GLENFIELD?

Doctor: It's fantastic, it's all a really approachable team, yeah. It works well, yeah.

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

Doctor: Erm, I mean, yes, we do. I mean there's a massive difference in just comparing the styles that Noel Everson and Frances Kenny, the Associate Specialist, have, compared with myself and Graham, because we've obviously got a very different general practice approach to it. I'm probably a little bit more holistic whereas they're very much into this patient's pitched up with a breast lump, we'll sort that out, whereas Graham and I probably get more stuck in with the social side of things as well, because ...

INT: WELL YOU'LL SEE THEM ON A DAY TO DAY, YOU KNOW, WEEK TO WEEK BASIS ANYHOW, WON'T YOU, I MEAN?

Doctor: Yeah, yeah. Although you have to remember that when we're at the breast clinic that is, it tends to be a one-off contact, but I think because we've got that ...

INT: BREAST CANCER PATIENTS IN THE COMMUNITY [???

Doctor: Yeah we have, but they're, obviously not all of them will come into contact with us at Glenfield because there are quite a lot of symptomatic clinics going on and they may get referred up to another consultant. But I probably because we do look after them in the community, we probably put a slightly different emphasis on our consultation skills and would probably take a slightly different history and ask different questions to someone who was a surgeon whose role is, if it's cancer or not, if it is let's get on and do some surgery. So ... yeah, so we have got the slightly different consultation styles really.

INT: YOU'LL PROBABLY BE, YOU'LL PROBABLY HAVE LIKE A [???] A LONGER-TERM VIEW OF THE PATIENT, DO YOU? BECAUSE I MEAN ...

Doctor: Yeah.

INT: YEAH, BECAUSE THEY'LL TEND TO SEE THEIR GP ONCE THEY'VE BEEN THROUGH SURGERY ...

Doctor: Absolutely

INT: [???] THEY'LL COME AND SEE THEIR GP FOR ...

Doctor: Yeah, absolutely ...

INT: ... THINGS LIKE [???]

Doctor: I mean certainly, you know, I know from looking after patients at the Glenfield that Graham and I won't hesitate to actually pick up the phone and speak to a GP if we've got, you know, a very young patient or somebody who's taken information badly, because we know what it's like with the boot on the other foot, with them coming in your door, and if you've not got the information from the hospital to communicate that to you, leaves you wide open and in a very difficult position, whereas I wouldn't have thought for a second that a consultant surgeon would bother.

INT: MM YEAH, [???]

Doctor: No, no.

INT: YEAH, I'D LIKE TO MOVE ON TO A LITTLE BIT, BEFORE A CONSULTATION WHERE A DIAGNOSIS IS TO BE GIVEN AND I'D LIKE US NOW JUST TO CONCENTRATE ON NEWLY DIAGNOSED BREAST CANCER PATIENTS, OK.

Doctor: Right.

INT: DO YOU, THEY HAVE A BREAST MDT EVERY WEEK HERE, I THINK IT'S MONDAY, IS THAT RIGHT?

Doctor: It is Monday, yes.

INT: DO YOU EVER GO TO THAT MDT?

Doctor: No, no, because Monday I'm at my practice.

INT: RIGHT, OK. WELL I CAN'T ASK YOU HOW YOU FEEL ABOUT THAT AFTERWARDS, THEN, CAN I? [chuckles]

\*Q4. WHEN IS YOUR REGULAR BREAST MDT MEETING HELD IN RELATION TO THE CLINIC WHERE PATIENTS ARE GIVEN A DIAGNOSIS OF BREAST CANCER? [not asked]

\*Q5. HOW DO YOU USUALLY FEEL AFTER AN MDT MEETING? [not asked]

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

Doctor: I mean certainly, erm, we try, erm, and do a one-stop clinic where possible. So patients would expect on the whole to go out with a diagnosis at the end of that session. Erm, it is very, very occasional that we ever wait for an MDT discussion before letting the patient know the diagnosis, and certainly

having seen and clinically assessed the patient and then have had imaging done, erm, if I was, you know, suspecting breast cancer but was waiting for a result of a core biopsy or something, then my sort of fears would be conveyed to the patient at that time. I would never let them go thinking that this might turn out to be OK if it's pretty much bound[?] or obvious that this is a malignancy you're dealing with and you're just waiting for your final core biopsy result to sort of pull all that together again. Erm, so most of the patients that I see, if I am suspicious about malignancy, would be told of that when I see them.

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

Doctor: It's a variety of different factors. It depends upon sort of the age of, the age of the patient, erm, sort of intellectually what kind of capacity they have as a patient and their sort of prior experiences; and you can, when you're actually breaking bad news to them, you can never judge quite exactly how they're going to react.

INT: MM, YEAH, SURE.

Doctor: You get patients that pitch up with a benign breast lump that have been on the internet, decided they've got cancer and they haven't. You'll equally say get patients that pitch up with a, you know, a clinically very obvious malignancy and, because the GP's not given them any hint of what they think it is, then they think it's benign. Erm, and so they've got absolutely no mental preparation for anything other than the fact that this is a benign lump and they're just coming to get it checked it out and they'll be going home OK at the end of it.

INT: YEAH, SURE.

Doctor: Erm, so you get a whole spectrum of how well prepared they are for it. And you'll also get patients who have seen friends or relatives go through it, so they've got their own sort of agenda on what this is and how it should be dealt with. Erm, so that's quite difficult to sort of, you know, go through that with them.

\*Q8. RIGHT, OK. AND PRIOR TO A CONSULTATION WHERE YOU KNOW THAT A PATIENT WILL BE GIVEN A DIAGNOSIS OF BREAST CANCER BY YOURSELF, DO YOU HAVE ANY EXPECTATIONS ABOUT HOW THAT CONSULTATION'S GONNA GO AND WHAT WOULD THEY BE BASED ON IF YOU DO?

Doctor: We all have our own personal expectations and I think from a personal perspective I like to feel as though, you know, sort of, they're going to be dealt with honestly and openly, erm, and have sufficient time for them to be able to address their sort of concerns and expectations. And also give them enough information that you can sort of get them to first base so that they can go home and they've got information to mull over, that it will answer their main concerns and expectations, because I think if that hasn't been addressed with the patient then you're on a hiding to nothing and your consultation's failed if you've not established that with them.

\*Q9. HOW WOULD YOU DESCRIBE YOUR FEELINGS BEFORE SUCH A CONSULTATION WHEE YOU KNOW YOU'RE GOING TO BE BREAKING BAD NEWS?

Doctor: Quite stressful.

INT: YEAH?

Doctor: Yeah, quite stressful, quite anxiety-provoking. Erm, easier in a more elderly patient, erm, because you know that the chances are it's not going to be the thing that kills them, but, you know, you get a younger woman in there, 30 to 50, they've got young children, you know, you can see a very similar social set-up to yourself and that's immensely stressful. And you never know quite how a patient's going to take it.

INT: NO, OF COURSE.

Doctor: Some of them take it brilliantly well, others of them will, you know, leave the building and you're then running round the car park after them to try and get them back again. So it is quite stressful knowing quite which way they're gonna go. And I think, you know, the breast care nurses find that equally stressful. You never get used to breaking bad news to people: it's a horrible thing to do.

INT: I KNOW FROM INTERVIEWING DIFFERENT PATIENTS AND YOU GO INTO, YOU GO INTO THEIR HOMES AND SOMETIMES EVEN THE MOST, THE INNOCUOUS QUESTION, YOU OBVIOUSLY GET SOME QUESTIONS YOU THINK, 'WELL I'VE GOT TO BE CAREFUL HOW I ASK THIS QUESTION BECAUSE THIS IS THE ONE WE'VE IDENTIFIED COULD BE A BIT DISTRESSING,' AND IT'S USUALLY SOMETHING WHICH IS LIKE A LITTLE PROMPT OR A QUESTION OR SOMETHING WHICH YOU THINK IS NOT GONNA [???] AND IT JUST SETS THEM AWAY AND YOU THINK, 'WELL I WASN'T EXPECTING THAT AT ALL.' JUST REALLY, PEOPLE TAKING IT SO DIFFERENTLY.

Doctor: Yeah, absolutely. And because, you know, we haven't been able to, I mean you build up a little bit of a relationship but it's not the sort of relationship I have with my patients in general practice where, you know, I kind of, I know what makes them tick and I understand them more, and breaking bad news to those sort of people is easy because you can gauge more how to do it, and you've got more of an understanding of the sort of level of information that they're gonna want to hear, whereas in the breast care setting I might have seen them for five minutes, sent them off for imaging and they come back and I have to say, 'I'm sorry, I've got bad news for you.' Very different ... very, very different. And there's a good chance that they're probably never gonna see me again as well.

INT: MY NEXT QUESTION, YEAH, IS LIKE HOW MUCH, HOW MUCH CONTACT ARE YOU GOING TO HAVE WITH THAT PATIENT AFTERWARDS?

Doctor: Yeah. I might not see them again because the next time that they come back to the breast clinic they'll be seeing Mr Everson, erm, then they may get involved in the oncologists and, although we do see patients for follow-up, the role that Graham and I have as hospital practitioners is to see the urgent suspected cancer, two-week wait patients, not to be looking after the, you know, five-, six-, seven-year follow-up patients ...

INT: YEAH, OF COURSE, YEAH.

Doctor: ... so there's a good chance they won't ever see me again so from a personal perspective you like to get it right ...

INT: YEAH, OBVIOUSLY ...

Doctor: ... as often as you can.

\*Q10. YEAH. [CHUCKLES] ERM, PLEASE TELL ME WHAT HAPPENS IN A, GENERALLY IN A CONSULTATION WHERE YOU KNOW YOU'RE GOING TO BE GIVING A DIAGNOSIS OF BREAST CANCER AND TALK ABOUT TREATMENT OPTIONS? FROM LIKE WHEN THE PATIENT WALKS THROUGH THE DOOR, WHAT'S THE SORT OF TYPICAL SORT OF THING THAT HAPPENS?

Doctor: They tend to have a two-stage consultation, so at the beginning of the clinic I will bring them into the consulting room, have a look at what the GP has written in the letter, go in, clinically examine them and then decided what investigations I want them to have done. If at that point, even on the clinical examination, if I'm suspicious that I've, you know, we've got a potential cancer here, then I will say to them something along the lines of, 'I am quite worried about what I find on examining you, so we need to send you off for some imaging,' so, you know, I do start to sow the seeds if clinically I'm worried. Then obviously they go off and they'll have, you know, a mammogram, maybe an ultrasound - maybe have some needle tests under ultrasound guidance, or they may come back through to me to have a fine needle aspirate done, and then have to go off again and wait for 45 minutes until we finally get the result back together again. So it can be a bit bitty, just assimilating all the information that you need. And then we, finally when we've got a diagnosis, erm, then a breast care nurse will come in with me and the sort of thing I'll say is, you know, along the lines of, 'Well it's been really useful to get the mammograms and the ultrasound scan. We've now got the result of the needle test and I'm sorry that this has confirmed that this is a malignancy, a cancer.' I tend not to use the word malignancy because they don't understand what that means, but 'This is a breast cancer.' Erm, and then just sort of leave them for a minute or two, and it's not unusual for me to, you know, particularly if they're there with a relative, to actually come out of the room and leave them for ten minutes just with that initial piece of sort of shocking information, and then go back in when the initial shock has settled. And then go in there and then just spend some time with them and start to talk through, you know, the diagnosis and give them as much information as they want - they often want more than we can tell them - because they always want to know, you know, 'Well how far has it gone? Is it aggressive?' You know, 'Am I going to die from this?' and, you know, you obviously can't give them that sort of information, but at least try and point out some of the relevant bits and pieces that might help them. Like, you know, 'I can't feel any glands under your armpits so I don't think there's any sign this has gone to the nodes, but we don't know until we've done the surgery,' sort of thing.

INT: NO, OF COURSE, MM.

Doctor: So you just sort of build them through it. Erm, and then after they've had the opportunity to sort of go through the questions then we obviously sort out some staging investigations and then they'll go off and time with the breast care nurse and get some leaflets and that sort of thing. Quite often, erm, ...

[Interruption in recording]

INT: YEAH, SO YEAH ...

Doctor: Where had we got to? Erm, yeah, quite often, it depends on the, it depends on the patient because some of them at the time will have actually been seen by Mr Everson as well, he'll stick his head round and give them a date for surgery. Sometimes patients are too distressed to sort of take in all the information that you've given them and, although we'll send them away with a date, I'll actually bring them back to clinic the next week and say to them, you know, 'Look, go home, write a load of questions down on a piece of paper and bring it back next week. I don't care if you've got three side of A4, we'll just go through them systematically and answer all of your concerns.' And some patients want to do that, other patients, 'No, you've told me as much as I need to know, I understand what's going to happen,' and they're quite happy to go away knowing they've got the breast care nurses to call if they've got any concerns.

INT: MM. SO DO YOU, DO YOU TALK ABOUT TREATMENT OPTIONS, YEAH?

Doctor: Yeah, definitely. And they'd, again, depending upon how much they're able to take in at that consultation, they'll definitely know, go away knowing what type of surgery they need, whether it's wide local or mastectomy, and I will have had a discussion with them about chemo, radiotherapy, and explained what sort of things influence what sort of adjuvant treatment they're going to need.

INT: AND WHEN, WHEN YOU'RE IN A CONSULTATION, THERE'S YOURSELF, YOU SAID THE BREAST CARE NURSE ...

Doctor: Yeah.

INT: THERE'S THE PATIENT, IS ANYBODY ELSE IN THERE WITH THEM AT THE TIME?

Doctor: No ... a relative if they've got them, got them with them.

INT: OK. AND WHEN YOU'RE TALKING ABOUT TREATMENT OPTIONS THEMSELVES, DO YOU HAVE A PREFERRED STYLE OR APPROACH TO ACTUALLY TALKING ABOUT THOSE THINGS?

Doctor: Again, I try and pick up a little bit on what the patients are feeding back to me, and quite a lot of them have got some sort of pre-conceived ideas about breast surgery and sort of they've probably known people who have had, you know, very gruesome mastectomies kind of 20 years ago, and that really shapes how they're feeling about it.

INT: MM, WELL, THEY WERE VERY RADICAL THEN, WEREN'T THEY?

Doctor: Yeah, they really were, really disfiguring, and, you know, I kind of always sort of lay it open, say, 'Well you have two choices on the surgery that you can have ...' that's provided that that's gonna be acceptable, obviously you get the odd case where they don't actually have a surgical option, and you're gonna have to sort of point out that there are two ... [break in recording] ... available but, because of the site, the size of their cancer, then a wide local is unlikely to sort of serve them in the best way possible. But if they've got, if they've clearly got, you know, a small cancer in the upper outer quadrant and that's gonna be amenable to wide local, then I will explain that they have got the two options and go through the pros and cons of mastectomy versus wide local. Erm, so that they do have that opportunity to choose, but young women by, you know, a long way now, they do tend to choose wide local [???].

INT: RIGHT, OK. WHERE ARE WE UP TO? I'VE LOST WHERE WE'RE UP NOW. [CHUCKLES] WHEN YOU'RE TALKING ABOUT OPERATIONS, DO YOU USE ANY VISUAL AIDS SUCH AS X-RAYS, DIAGRAMS, PHOTOGRAPHS, ANY WRITTEN INFORMATION, ANYTHING LIKE THAT?

Doctor: We use written information, erm, we've got some sort of pre-printed leaflets that we give out that talk about mastectomy versus wide local excision and chemotherapy and radiotherapy, and we often give those that patients sort of go away with. We're quite happy with patients are, feel they're not in a position to make a decision on that day. They still get their theatre slot and we'll bring them back the next week when they've had more chance to assimilate that information. Sometimes I will show them their mammograms, or their ultrasound scan and, again, it depends on the patient, but some people find a visual aid is quite useful to helping them make a decision. Erm, but not often, it has to be said, especially with the elderly ladies, they're not interested in seeing their scans as a general rule but, you know, certainly for, if a patient ever asks of course we show them to them. And for some people who are having difficulty choosing between the two then I will show their pictures so that they can appreciate what size we're talking about and that sort of thing.

INT: DO YOU EVER DRAW ANY DIAGRAMS FOR THE PATIENT OR ANYTHING LIKE THAT?

Doctor: Erm, I am someone who does, who does routinely draw a lot for patients but I tend not, I haven't done much at the breast clinic.

INT: RIGHT, OK.

Doctor: Yeah.

INT: AND THESE SORT OF VISUAL AIDS, DO ANY OF THE PATIENTS FIND THESE PARTICULARLY HELPFUL?

Doctor: I personally haven't had much feedback actually.

INT: OH RIGHT.

Doctor: I haven't had people saying, 'Oh that leaflet was excellent, it answered a lot of questions,' so I don't really feel able to sort of comment on that. Erm, I think the breast care nurses would probably be in a better position to, you know, give that sort of feedback on the information we're giving them.

INT: RIGHT. AFTER THE CONSULTATION'S SORT OF FINISHED, DO YOU HAVE ANY ADDITIONAL TIME WITH THE PATIENT AFTER THAT?

Doctor: Erm, my, my consultation tends to go on as long as it needs to. I don't have sort of a set 10 minutes with that patient and away they go, and in an ideal world, we like to be not in with the patient more than 15/20 minutes because with the best will in the world we've got another 20 patients sitting outside to come through. Erm, but if a patient has clearly taken it badly and obviously need some of my time, then so be it, and if I'm in the room for three-quarters of an hour, an hour, then that's the way the cookie crumbles. Erm, and I like to, I like to think that when they then sort of move on and go with the breast care nurse, that all the breast care nurse is doing is simply reiterating everything that we've already discussed.

INT: RIGHT, YEAH.

Doctor: What I don't like them to have to do is feel as though they're having to cover a load of ground that I've not even touched on, purely because we've been constrained by time. So ...

INT: DOES, WHEN YOU'RE TALKING ABOUT TREATMENT OPTIONS, DO, ARE PATIENTS AT ALL SURPRISED THAT, OR SHOCKED THAT THEY'VE GOT A CHOICE?

Doctor: Yeah, yeah. And I think, erm, historically it was very much the feeling that, you know, 'Well, you're the doctor, you tell me what to do,' and you do still sometimes get people who say that and say, 'Well I don't know, don't make me choose, you tell me what's best for me.' But, sort of the younger patients are I think quite pleased to actually be involved in part of their treatment, rather than just being blanket told, 'This is what we need to do.'

INT: RIGHT. AND WHEN YOU'RE ACTUALLY TALKING ABOUT THESE ISSUES, DIAGNOSIS, TREATMENT OPTIONS, WHAT ARE YOUR FEELINGS ABOUT HAVING TO TALK ABOUT THESE THINGS?

Doctor: Erm, I feel quite comfortable about talking about it. I don't have any concern that I'm not gonna be able to answer anything that's kind of coming back from me. Erm ... mm ... yeah, no, I feel, I feel, I don't want to actually, the apprehension of going in and breaking bad news to somebody is the worst bit,

erm, but once you've actually gone in there and realised that the patient is still in the room, and not run to the car park, then the rest of it is absolutely fine, and it's just a question of trying to gauge the pace at which you give the information, rather than, you know, flying in 'You've got cancer, the breast care nurse will tell you what's going on. See you later.'

INT: YEAH. I'D LIKE TO TALK A LITTLE BIT ABOUT PATIENTS INFORMATION NEEDS.

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

Doctor: Again, it depends on their, their ideas about what they're actually pitching up with. You will have well-educated patients who have got, you know, have been on the internet, they've come and they've got absolutely reams and reams of stuff off it, and they will have a fairly clear idea as to where they think they're going with it. You'll have other patients who actually want to know nothing about it, and are quite happy for you to just, erm, talk them through the surgery that they need, but they actually don't want to know anything more. So very, very variable about what people know and understand. I think the people who have the most pre-conceived ideas about it are those that have friends or family members that have been through it and had sort of an adverse outcome.

INT: RIGHT, YEAH.

Doctor: You tend to not get many people coming back and saying, 'Oh yes, my friend had that and she's still here and it's all worked out OK.' If someone's had a fairly stormy course then that really does shape what they feel about it, and we've had women who, in that situation, have elected for mastectomy purely because they can't face going through what they've seen their relatives go through.

INT: RIGHT, OK. AND DO YOU THINK THAT PATIENTS' SORT OF LEVEL OF KNOWLEDGE AND WHAT THEY KNOW ABOUT BREAST CANCER AND ITS TREATMENTS, DOES IT MAKE FOR A HARDER OR AN EASIER CONSULTATION PROCESS IF THEY KNOW A LOT OR A LITTLE, WHAT DO YOU THINK?

Doctor: Again, erm, it depends upon the type of patient and where they're, you know, there are a lot of people who use the internet and think that every source of information on the internet is the gospel truth, and sometimes actually tackling that and trying to point out that these are just a range of opinions, can be quite difficult, and so if you've got a patient that is totally fixed on, 'Well, you know, this is what I've got, I was a bilateral mastectomy, I'm not having chemotherapy, radiotherapy, I'm gonna pop off to India and get a herbal combination treatment,' that's very, very challenging. It's part of why I enjoy the job, to be honest with you, but equally so you will get people who have sort of been on the internet, looked at two or three sites and have thought, 'Oh, I can't take any of this in, I don't understand a word of it, so I'm not going to look any further.'

INT: MM, YEAH.

Doctor: Erm, so, there's a spectrum of people and how they react.

INT: YEAH, HOW THEY REACT AND EVERYTHING.

Doctor: Yeah.

\*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 GENERALLY RAISED?  
Doctor: They want to know, erm, Why now? Why me? What are you going to do about it? Why has it happened? You know, what have I done to cause this to come on? Is it my smoking over the last 30 years? This sort of thing. Erm, and, you know, when are you gonna do something about it? And they always want it tomorrow. And those are the questions they want to, want to be answered. And, and moving on from that, some people then want to know, you know, well, how long has it been there for? How aggressive it? Am I going to need chemotherapy? Am I going to need radiotherapy? Erm, but I think the most important ones are the Why now? Why me? What have I don't to cause it? and When are you going to get rid of it?

INT: MM, YEAH. WHEN YOU'RE TALKING ABOUT DIAGNOSIS, DO YOU THINK THERE'S ANY INFORMATION THAT'S UNDERSTOOD POORLY, NOT VERY WELL?

Doctor: I think, depending upon the kind of phrases that the doctor might choose to use, then yes, things can be very much misinterpreted, because patients as a general blanket rule can get quite confused with sort of benign and malignant, and they don't understand the difference between the two, so that does come down to sort of using simple phrases that the patient can actually understand and not complicating it with jargon. And certainly, having seen people talk about a malignancy and then, then as soon as we go out the room and the patient says, 'So, have I got cancer then?' You know, they just don't understand that. So I think that would be, it's our own way that we phrase the questions that is the biggest source for misinterpretation.

\*Q13. AND A SIMILAR SORT OF QUESTIONS IS WHAT DO YOU THINK ARE THE MOST IMPORTANT PIECES OF INFORMATION PATIENTS NEED OR WANT TO KNOW ABOUT THEIR TREATMENT OPTIONS?

Doctor: I think as a general rule you don't get many patients who are, probably only sort of 10 per cent we see are absolutely adamant that they want mastectomy or wide local excision, and that isn't really part of their bigger agenda. It's more a question of when, that's what they want to know, when am I having this surgery? And a lot of patients, in terms of their treatment options, they are not so bothered about the radiotherapy but if they can avoid chemo, because chemo is historically sort of associated with 'I'm gonna be poorly, I'm gonna lose my hair, I'm gonna be sick,' then they will actively pursue a treatment option that avoids chemotherapy.

INT: RIGHT, OK. YEAH, [???] A LOT OF PATIENTS, EVEN THE WORD, THEY DON'T REALLY LIKE THE WORD CHEMOTHERAPY ...

Doctor: Yeah, yeah.

INT: IT BRINGS [???]

Doctor: It just conjures up horror, horror images for them. Even if they've not actually had any sort of close involvement with anybody that's been through, it's just that sort of, the media hype on it. It just conjures up all the wrong images. It really does.

INT: MM. AND THE FACT THAT THAT'S WHEN YOU'RE GONNA LOSE YOUR HAIR IF ANYTHING ...

Doctor: Yeah.

INT: I THINK THAT'S A BIG THING FOR A LOT OF THEM ...

Doctor: A big thing, yeah.

INT: AGAIN, IS THERE ANY INFORMATION ABOUT TREATMENT OPTIONS YOU THINK IS NOT PARTICULARLY WELL UNDERSTOOD?

Doctor: ... I don't think so. No, I'd say those'd be the ... no, I don't think so. It seems to be ... yeah.

INT: I'D LIKE TO MOVE ON TO A LITTLE BIT ABOUT WHAT A PATIENT IS ACTUALLY OFFERED.

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

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

Doctor: Erm, it would be dependent upon the site and the size of the cancer, whether we thought there was any locally advanced disease at presentation, and if we've got any indication on a core biopsy that, of the histological diagnosis, whether it was a highly aggressive, invasive one or, you know, they don't always give you that information, can't always use that. But certainly if it was, you know, a focus of DCIS as opposed to infiltrating ductal carcinoma, then that might swing us more one way or the other. But those are the sort of factors that we'd be ... and obviously age of the patient as well.

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

Doctor: So, if you've got a large, central cancer, then more than likely you're gonna end up with a mastectomy. If they've got a relatively small cancer but in a small-breasted lady so that it occupies a fairly significant volume of the breast, erm, then that might enter into it. Obviously if they've got multi-focal they'll end up with a mastectomy. Erm, and if they've got a sort of inflammatory cancer with no nodes, but usually inflammatories have got advanced disease at presentations, but that might indicate it. Same as if they were pitching up with Pagett's, you know, the indication for, of treatment of Pagett's is mastectomy, and you'd be a fool to offer them wide locals. So, there are certain set criteria that would [???] a mastectomy. And patient choice.

\*c. YEAH. AND WHAT FACTORS WOULD LEAD THE TEAM TO OFFER A PATIENT A CHOICE BETWEEN MASTECTOMY & BREAST CONSERVATION?

Doctor: So, erm, it tends to be those patients that satisfy the criteria for mastectomy would probably have a less flexible amount of counselling from us in terms of giving them a choice, and certainly I think if I felt that their, the way their cancer presented, they're going to be best served with a mastectomy then I would tell them that. They would be aware that there's a choice of surgical options but I would really sort of be guiding in the direction of mastectomy. If, however, they've got a cancer that's amenable to wide local excision, then, you know, I would, they'd be sort of counselled fairly evenly in that this is something that we could remove locally and, you know, sort of talk through the pros and cons of mastectomy versus wide local, make them aware that, if we don't think the excision margins are good enough, then run a small risk of further surgery, and, you know, give them a much more open, more flexible, sort of choice element to it.

INT: RIGHT.

Doctor: Yeah.

\*d. AND WHAT FACTORS WOULD LEAD THE TEAM TO OFFER A PATIENT ANY OTHER TREATMENTS?

Doctor: Erm, in terms of, well if you think it's sort of neo-adjuvant treatment, sort of chemotherapy, radiotherapy, before any surgery is proposed, or may not be proposed anyway. Obviously if they've got locally advanced disease at the time of presentation then they're gonna need an oncology opinion first. If you've got a very elderly lady who's pitched up with a breast cancer, then it may be that you don't offer them any surgical treatment, and they get Tamoxafen as a first-line ...

INT: RIGHT.

Doctor: And review that way.

INT: THE ONCOLOGY DEPARTMENT, IT'S NOT THAT [???] IS IT AT GLENFIELD?

Doctor: No, it's at the Royal.

INT: OH, THE ROYAL, YEAH, THAT'S RIGHT. ERM, THE LITERATURE SUGGESTS THAT PATIENTS VARY IN THE DEGREE OF INVOLVEMENT THEY WANT WHEN MAKING DECISIONS ABOUT WHAT SURGERY TO HAVE: SOME PREFER FULL CONTROL, SOME PREFER TO SHARE THE CONTROL; OTHERS WANT TO LEAVE IT TO THE PROFESSIONALS TO TAKE CONTROL.

\*Q15. DO YOU THINK THAT THE PATIENTS YOU SEE IN GLENFIELD ARE GETTING THE DEGREE OF CHOICE THEY WANT?

Doctor:

\*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?  
Here

\*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.  
Here

\*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.  
Here

\*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.  
Here

\*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?  
Here

\*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?

Here

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

Here

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

Here