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Patient and clinician factors influencing the choice of breast cancer surgery:

A Qualitative and Quantitative Study

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Chapter 9

Discussion

POTENTIAL LIMITATIONS OF THE STUDY

Selection bias

Due to ethical constraints, patients were identified and approached by their breast teams to participate in the study. It could be argued this led to the presence of selection bias of patients in the study.

The speed of recruitment of patients from the breast units was different. This was only partly explained by the breast unit case-loads. Interestingly, despite the assistance of an NCRI Clinical Trials nurse, recruitment of patients was slowest at the low MR, which was the highest turnover unit. Discussions with the recruiting clinicians confirmed the finding of the clinician interviews, that as a unit, they identified only a sub-population of patients suitable for BCT as eligible for choices; patients with smaller cancers were automatically recommended BCT rather than provided with options. Therefore their pool of patients eligible for the study was more limited than that of the medium and high MR units.

Response rate

One of the limitations of this study is the overall response rate of 51% of the patient population approached. This could be argued insufficient. However, it is similar to many published studies on DMS; where this information is available. Many existing published studies either fail to include a response rate (as denominator information is absent) or they present this information but make it impossible to meaningfully compare their response rates with that of this study, as they adopt filtering recruitment techniques which mean their actual response rates cannot be calculated; for example they recruit via preliminary surveys of patients accessed through registries.

Participants in research are a self-selected group. It is possible that certain subgroups are over or under-represented. While it may be supposed that those participating in research are more likely to represent the more active subset of decision-makers and non-responders represent a more passive group, to our knowledge no published data is currently available to support or refute this. Ethical and governance issues surrounding the conduct of research and UK laws on data protection, mean no data is available on the characteristics of study non-responders.

The response rate may affect the extent to which the findings can be extrapolated. However, it should be noted that the same limitations apply to the majority of previous published studies; so while this issue is a potential limitation, it does not negate the findings. As in all studies of this nature, the findings may be characteristic only of those patients choosing to participate in research.

Potential recall bias

The main limitation of this study (in common with many of the same type) relates to participants' retrospective recollections and the potential for recall bias or post hoc justification. The potential of recall bias is difficult if not impossible to avoid in a study reliant on the capture of information immediately after the provision of diagnosis, if it is to adhere to ethically sound practice and conducted among a subgroup of cancer patients (i.e. those not requiring a mastectomy on clinical grounds) within the UK healthcare system. As diagnosis is routinely provided within one to two weeks of initial assessment, and diagnosis and treatment options are discussed within the same consultation.

UK ethical considerations limited us to approaching patients following the completion of decision-making and surgery. Such limitations were placed due to the sensitive nature of exploring such experiences in a vulnerable group of patients, and concerns that the study itself might influence the relationship between the patient and their treating clinicians or impact the decision being studied. Ethical requirements also dictate that patients need to be permitted sufficient time to consider whether or not they wish to participate in a research study and should not feel pressurised to do so. Patients were therefore approached to participate in the study as soon as possible following their initial therapeutic surgery (the day following surgery in most instances). Consequently, there was insufficient time to recruit and conduct interviews before patients received their post-operative results.

The data was collected close to but never the less, following the decision-making experience. Completed questionnaires were received a mean 6.9 weeks following surgery and interviews were conducted a mean 6 weeks following surgery. Therefore the consequences of patients' initial therapeutic treatment were known. This raises the possibility that their recollections of their consultations and decision making experiences, and therefore our findings, might be influenced by subsequent events depending on 'favourable' or 'poor' clinical or aesthetic outcomes. For example, a patient who had undergone BCT on the advice of their clinician could perceive it as positive or negative depending on subsequent information or events. Patients might express regret and dissatisfaction regarding their original decision-making experience if they felt they were advised or recommended a treatment option without adequate information (i.e. potential need for margin re-excision) and had more extensive disease than initially anticipated or required subsequently further surgery.

Though the reported study could be considered flawed by virtue of issue of recall bias, the data was collected within a similar timeframe to many other quantitative and qualitative studies exploring treatment decision-making among cancer patients. It is therefore comparable to previous studies which suffer similar biases; including the previous UK DMS study conducted over a decade ago.(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996) The results therefore almost certainly reflect a genuine change in the DMS of the UK population. Similar trends reported in other countries(Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Lam, Fielding, Chan, Chow, & Ho 2003;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005;Mastaglia & Kristjanson 2001;Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010) add weight to this argument, as does the concordance of these results with those of a questionnaire-based decision-making study by Collins et.al., which was conducted in real-time among US breast cancer patients.(Collins, Moore, Clay, Kearing, O'Connor, Llewellyn-Thomas, Barth, Jr., & Sepucha 2009)

Much of the study is based purely on self-report findings

It could be argued that the majority of the study's findings are based purely on self-report information rather than direct observation, and that an observational approach would have been superior. Patients' recall in stressful situations is known to be suboptimal,(Butler & Hailey 1996;Fallowfield 2000) and an observational study could capture the exact words exchanged between the patients and clinicians within consultations, and analyse the various elements of communication.(Ford et al. 2000)

However, studies have demonstrated enhanced recall when it the information is specifically pertinent to patients' needs; with patients quoting their clinicians verbatim.(Fallowfield 2000)

Also, communication is complex. What is perceived from an interaction is not only the overt verbal articulation of the intended message.(Mehrabian 1972) Pure observational methods would not permit the analysis of this. Data analysis in this study was also facilitated by listening to the interview audio recordings as part of the process of analysing the verbatim transcripts. Participants' re-enactment of parts of their consultations enhanced the analysis of the verbatim transcripts.

Also, although predominantly self-report, the multi-stakeholder, multi-method nature of the study conducted permits the triangulation of data and provided a view of the extended nature of the decision making journey which starts at initial assessment and ends at arrival at a decision. The complexity, magnitude and expense of conducting a purely observational study to capture all clinician-patient consultations (from assessment to establishing consent) explored within the interviews, would probably have made it prohibitive. The study conducted also provided information on aspects of the decision making experience which are not observable. For example, clinicians' beliefs and patients' absorption, understanding, interpretation and assimilation of the information provided during consultations with their specialist clinicians, together with its incorporation into the patient's pre-existing preferences and concerns.

Relatively small number of patients undergoing mastectomy

The intention at the outset of the study was to fill half the sampling frame from each breast unit with patients choosing mastectomy and half BCT. The frame was under-filled for patients undergoing mastectomy due to difficulty recruiting this relatively small group, within the timeframe of funding for the study's interview phase (November 2003 to December 2004). Recruitment of the mastectomy group was especially difficult in the low MR breast unit, where the numbers identified as having chosen a mastectomy were particularly small. Negotiation with members of the breast unit highlighted the issue found in the clinician interviews, of different eligibility criteria for choice in this unit. We believe however, failure to fill the sampling frame did not have a detrimental effect on the findings of the study, response saturation was achieved and the findings are representative in understanding variation in unit practice.

Over the course of two patient interviews it became evident that, although identified as having been offered a treatment choice, they had instead been firmly guided toward mastectomy due to the presence of large or multifocal cancers; both were recruited from the low MR unit. We suggest this supports the study's other findings.

Minimal data on patients' prior perceptions and pre-existing decision making influences.

We present little information on patients' preconceptions, which are noted to be one of the major factors guiding patients' decisions. While some information emerged regarding these, there was insufficient data to present this as a separate theme. Much has already been written on this subject, and not wishing to duplicate previously published research, this was not an issue our study was specifically designed to investigate. Instead, our focus was on one of the other major factors demonstrated to guide patients' decisions; notably clinicians' recommendations and patients' perceptions of them.(Gort, Broekhuis, Otter, & Klazinga 2007;Johnson, Roberts, Cox, Reintgen, Levine, & Parsons 1996;Katz, Lantz, & Zemencuk 2001;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Morrow, Jagsi, Alderman, Griggs, Hawley, Hamilton, Graff, & Katz 2009;Nold, Beamer, Helmer, & McBoyle 2000;Schou, Ekeberg, Ruland, & Karesen 2002;Smitt & Heltzel 1997) These rely predominantly on the interaction and communication between patients and specialist clinicians. Relatively little is known regarding these and the impact they have over patents' decisions.

MR categorisation

The study was conducted in three breast units from a single UK region. The units recruited for the in-depth components of the study were selected to reflect the spectrum of treatment variation; demonstrating high, medium and low case-mix adjusted MRs. To optimise reflectivity of findings with units' MR categorisation, the stability of the permanent specialist team workforce over the period of the study from the onset of the audit period to commencement of the questionnaire phases of the study (April 1997 to December 2003), was also considered. The study was not conducted in the highest case-mix adjusted MR unit of the audit series (unit 10), which had consistently very high MRs even among the subgroup with cancers <15mm diameter. It was instead conducted in the second highest (unit 4). This unit had case-mix adjusted rates verging on a statistical significance; since the lower 95% confidence interval was exactly 1.0. This decision was necessitated by a substantial change in the specialist staff workforce of unit 10, between closure of the audit phase (April 2003) and the onset of the patient questionnaire and qualitative components of the study. It was felt such changes in the workforce had the potential to produce findings which were non-representative of case-mix adjusted MR categorisation.

At national level, the low MR unit studied lies within the low MR end of the spectrum and is likely to reflect outlying practice. However at national level, the high MR unit studied lay within the medium section of the MR spectrum.(Bates, Kearins, Monypenny, Lagord, & Lawrence 2009;BCCOM 2006;BCCOM Steering Group 2007) It is unlikely that the findings from the high MR unit studied represent the very high MR end of the national spectrum. Some UK units' non-case-mix adjusted MRs approach 80%. It is possible such units have similar decision-making practices to that of the low MR in our study, but with a preference or lower threshold for directing patients toward mastectomy. Our study's limitations preclude any conclusion in relation to these units. However the findings of a recently published questionnaire study regarding decision making conducted among patients of a very high MR breast screening unit in the UK, seems to support this theory.(Ballinger et al. 2008) To confirm such a supposition, it would be necessary to explore decision making among very high MR breast units outside the Trent region, utilising qualitative and qualitative methodology.

STRENGTHS OF THE STUDY

Triangulation of methodological approaches and stakeholder perspectives

The strengths of this programme of research lie in the adoption of a mixed methods, multi-perspective approach among breast units from a single region, possessing similar practice guidelines, but differ in MRs. The study utilised quantitative methodology to confirm the spectrum of practice variation was not due to cancer characteristics. Quantitative and qualitative methods were then adopted to explore the various steps involved in the process of decision-making which are enshrined in breast unit practice, from the perspectives of the various relevant interacting stakeholders. The triangulation of data from the different key stakeholder perspectives, and the qualitative exploration of the quantitative findings, facilitated the more comprehensive exploration of the multifactorial nature of decision-making and a more comprehensive answer to the research question.

DISCUSSION POINTS RAISED BY THE THESIS

Variation is not due to case-mix

Analysing a high quality externally validated database, this study demonstrates statistically significant variation in the surgical treatment of breast cancer among those suitable for BCT, is not due to case-mix. It also demonstrates the persistence of variation amongst patients with small cancers infinitely suitable for BCT or a choice of surgery (66% of the 506 cancers <20mm diameter, 87% <30mm diameter). Conclusively establishing that variables other than those included in the case-mix adjustment (cancer size, cancer site, cancer grade, patient age and year of presentation) are responsible for the observed MR variation. To our knowledge this is the first study of this type to correct data for case-mix at an individual patient level. Previous studies based their findings on aggregated data analysis, where case characteristics were amalgamated across units or hospitals.(Bates, Kearins, Monypenny, Lagord, & Lawrence 2009;BCCOM 2006;BCCOM Steering Group 2007;Farrow, Hunt, & Samet 1992;Goel, Olivotto, Hislop, Sawka, Coldman, & Holowaty 1997;Grilli, Scorpiglione, Nicolucci, Mainini, Penna, Mari, Belfiglio, & Liberati 1994;Iscoe, Goel, Wu, Fehringer, Holowaty, & Naylor 1994;Ishizaki, Imanaka, Hirose, Kuwabara, Ogawa, & Harada 2002;Mandelblatt, Hadley, Kerner, Schulman, Gold, Dunmore-Griffith, Edge, Guadagnoli, Lynch, Meropol, Weeks, & Winn 2000;Moneypenny 2004;Morris, Cohen, Schlag, & Wright 2000;Morrow, White, Moughan, Owen, Pajack, Sylvester, Wilson, & Winchester 2001;Nattinger, Gottlieb, Veum, Yahnke, & Goodwin 1992;Nattinger & Goodwin 1994;Samet, Hunt, & Farrow 1994;Sauven, Bishop, Patnick, Walton, Wheeler, & Lawrence 2003;Scorpiglione, Nicolucci, Grilli, Angiolini, Belfiglio, Carinci, Cubasso, Filardo, Labbrozzi, Mainini, & . 1995;van Nes, Seynaeve, Jones, Markopoulos, Putter, van, V, Hasenburg, Rea, Vannetzel, Dirix, Hozumi, Kerin, Kieback, Meershoek-Klein Kranenbarg, Hille, & Nortier 2010) his technique provides a potentially inaccurate representation of practice; especially among those with smaller volume workloads.

The low pseudo R^2 value of the clinicians' DCE questionnaire supports the case-mix adjustment findings that cancer characteristics routinely available pre-operatively, do not account for patterns of treatment variation observed. The five variables included in the DCE (patient age, cancer size, bra cup size, cancer site and centricity) all significantly influenced clinicians' responses. However the pseudo R^2 value of 0.29 indicates despite the statistically significant impact of these particular variables, the variables themselves only explain 29% of the clinicians' responses. Something other than these exerts the predominant influence; accounting for 71% of the responses.

Patients' information needs and the patient-specific factors influencing decisions

Consistent with previous studies among cancer patients, patients from all units exhibited high information needs(Bilodeau & Degner 1996;Blanchard, Labrecque, Ruckdeschel, & Blanchard 1988;Butow, Kazemi, Beeney, Griffin, Dunn, & Tattersall 1996;Cassileth, Zupkis, Sutton-Smith, & March 1980;Chen, Tao, Tisnado, Malin, Ko, Timmer, Adams, Ganz, & Kahn 2008;Davison, Degner, & Morgan 1995;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Fujimori & Uchitomi 2009;Galloway, Graydon, Harrison, Evans-Boyden, Palmer-Wickham, Burlein-Hall, Rich-van der Bij, West, & Blair 1997;Graydon, Galloway, Palmer-Wickham, Harrison, Rich-van der Bij, West, Burlein-Hall, & Evans-Boyden 1997;Hack, Degner, & Dyck 1994;Jenkins, Fallowfield, & Saul 2001;Jones, Pearson, McGregor, Gilmour, Atkinson, Barrett, Cawsey, & McEwen 1999;Luker, Beaver, Leinster, & Owens 1996a;Meredith, Symonds, Webster, Lamont, Pyper, Gillis, & Fallowfield 1996;Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till 1989;Vogel, Bengel, & Helmes 2008a) which did not necessarily correlate with their preferences for or achievement of, more autonomous treatment decision-making.(Blanchard, Labrecque, Ruckdeschel, & Blanchard 1988;Cassileth, Zupkis, Sutton-Smith, & March 1980;Cox, Jenkins, Catt, Langridge, & Fallowfield 2005;Davison, Degner, & Morgan 1995;Ende, Kazis, Ash, & Moskowitz 1989;Fallowfield 2008;Hack, Degner, & Dyck 1994;Strull, Lo, & Charles 1984;Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till 1989) Information needs were also largely unrelated to operative choice or unit MR. A few exceptions were noted. There were trends for active decision makers to want more information on possible side effects (p=0.051) and high MR unit patients to want examples of where surgery had been effective or not (p=0.060 and 0.066 respectively). One questionnaire item reached statistical significance. Those undergoing BCT were more likely to 'absolutely need to know' how the surgery would affect their body (p=0.049). Given the likely impact of surgery on body image, this is perhaps not surprising and would be consistent with evidence that women choosing BCT have a greater focus on body image.(Arndt, Stegmaier, Ziegler, & Brenner 2008;Carlsson & Hamrin 1994;Fallowfield, Baum, & Maguire 1986;Irwig & Bennetts 1997;Moyer 1997;Sanger & Reznikoff 1981;Schover 1994;Stefanek 1993)

Patients described the impact of known patient-specific factors over their decisions.(Carver, Pozo-Kaderman, Price, Noriega, Harris, Derhagopian, Robinson, & Moffat, Jr. 1998;Collins, Moore, Clay, Kearing, O'Connor, Llewellyn-Thomas, Barth, Jr., & Sepucha 2009;Fallowfield, Baum, & Maguire 1986;Hawley, Griggs, Hamilton, Graff, Janz, Morrow, Jagsi, Salem, & Katz 2009;Hughes 1993;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Lasry & Margolese 1992;Mandelblatt, Hadley, Kerner, Schulman, Gold, Dunmore-Griffith, Edge, Guadagnoli, Lynch, Meropol, Weeks, & Winn 2000;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Moyer 1997;Nold, Beamer, Helmer, & McBoyle 2000;Schou, Ekeberg, Ruland, & Karesen 2002;Smitt & Heltzel 1997;Wei, Sherry, Baisden, Peckel, & Lala 1995;Wilson, Hart, & Dawes 1988) For example, prior experience and expectations regarding breast cancer and its treatment, body image and a trade-off between this and fears of cancer recurrence/spread. As already outlined in the potential limitations section, this study was not designed to duplicate this previous research. However some new information regarding these patient-specific themes emerged from the interviews, which should be discussed.

Patients described their operative preferences and choices being partially innate or patient-specific. While most of these were described consistently across the breast units, there were some notable differences. For example, patients' perception of which treatment options were the least disruptive or most reassuring. Patients from all units considered BCT less disruptive as an inpatient treatment; describing a shorter hospital stay. But medium and high MR patients could describe it as a more disruptive treatment course. They spoke of the possibility of margin re-excision and commitment to several weeks of radiotherapy. Low MR unit patients tended not to voice these in the same way. They mentioned them fleetingly and in less detail.

Perceptions of which treatment provided most reassurance also varied. Low MR unit patients tended to report the options were equally 'safe'. The other unit's patients were more likely to stratify their perceptions of safety into survival (equivalent) and LRRR (higher with BCT). These impacted patients' impressions of reassurance about remaining disease-free in the long-term. Some choosing mastectomy felt they were more likely to be cured; believing minimising LRRR as far as possible must also minimise the risk of death. Some mistakenly believed mastectomy was associated with no risk of recurrence. Likewise, some (mainly low MR unit patients) expressed greater reassurance of safety from BCT. They described their awareness of mastectomy as an option, but relayed a clear impression from their consultations with clinicians, of the irrelevance of mastectomy to them; either because it was not an option presented or because clinicians heavily emphasised BCT and dismissed mastectomy. A minority extrapolated this to an increased chance of cure.

The clinician interviews reported in chapter 5 provide a potential explanation for this. The information provided, and use of emphasis and minimisation, meant many low MR unit consultations seemed filled with an excess of reassurance and recommendations, together with comparatively less factual information of the sort those undertaking more autonomous decisions described utilising. This is explored in the 'Clinicians' decision making approaches and patients' decision making considerations' section of the discussion.

The prerequisites for patient decision making

Despite the passage of time and greater dissemination of information, our findings suggest what Beaver stated in 1999 probably still holds true '*...individuals who are not presented with choices and who do not have expectations of being involved in decision making may well prefer a passive role because they are unaware of alternative roles.*'(Beaver, Bogg, & Luker 1999) Though patients largely classified themselves as preferring more autonomous roles in treatment decision making in the IDMQ, in the interviews they identified a number of barriers to more autonomous engagement in the process. At diagnosis, preconceptions of decision making paternalism were predominant and most patients expressed feeling particularly vulnerable and (in common with previous studies) experiencing difficulty in absorbing information.(Butler & Hailey 1996;Cimprich 1993;Fallowfield 2000;Hughes 1993) In the absence of pre-existing awareness of the options or strong pre-existing treatment preferences, patients' perceptions of involvement in decision making were dependent on several factors; feeling they were offered a genuine choice; understanding the rationale for a more autonomous role in the process; perceiving they possessed the necessary tools (information/knowledge and support) for informed decision making; and having a realistic timeframe to complete the process.

Of particular importance was the early possession of knowledge about why there were options and a clearly defined timeframe for making a decision. Unless specifically informed otherwise, they tended to assume decisions had to be instantaneous. In combination with the immediacy of their diagnosis and difficulty absorbing information, this could lead them to feeling overwhelmed and prompt a compulsive request for recommendations. However, if they were aware of the timescales for the decision making process and the support available at an early stage in the consultation, they described fear and concerns diminishing, the onset of information acquisition and commencement of engagement in decision-making.

In addition to these prerequisites, many described requiring time away from the clinical environment to contemplate the information provided, explore information needs and consider the options in the context of their personal preferences. In the absence of these, patients could feel insufficiently equipped or confident to engage in more autonomous decision making.

Is the shift toward more active patient DMSs over time genuine?

When many of the earlier studies into patient decision making were conducted, patients were reported to predominantly desire and adopt passive DMSs.(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996;Bilodeau & Degner 1996;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010;Wallberg, Michelson, Nystedt, Bolund, Degner, & Wilking 2000) Approximately 50% of the women with breast cancer in the previous UK study possessed a passive DMS.(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996) Our questionnaire demonstrates an apparently dramatic reversal of predominant passivity between the time-points. Less than 20% of patients in our study reported a passive PDMS or ADMS.

But do these findings represent a genuine change? To answer this we need to examine how comparable the studies were? The DMS tool utilised contained the same items as prior studies. The earlier studies adopted a card-sort application of the tool,(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996;Bilodeau & Degner 1996;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010) while we adopted a questionnaire application. This is the more commonly utilised version now.(Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Lam, Fielding, Chan, Chow, & Ho 2003;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem,

& Katz 2005;Mastaglia & Kristjanson 2001) Our study was performed at a similar(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996;Bilodeau & Degner 1996;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010) or earlier(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996;Bilodeau & Degner 1996;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010) time point from diagnosis. The main difference between the earlier studies and ours resides in the eligibility criteria. The earlier studies only excluded breast cancer patients on the basis of recurrent or metastatic disease.(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996;Bilodeau & Degner 1996;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010) Our eligibility criteria were more specific. We limited recruitment to the subgroup who were provided choices by their clinicians, as it seemed unethical to explore how patients make choices among a group who were not provided this opportunity. Other recent studies have also tended to recruit a theoretically similar subgroup of the breast cancer patient population to ours; those with stage 1 and 2 breast cancer.(Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Mastaglia & Kristjanson 2001) However, they did not differentiate between whether patients were provided options or not. The differences in methodology between the previous UK study and ours are not striking, but the differences in DMS proportions are. While our study's recruitment of the subgroup of those provided a choice may exaggerate a time-change in DMS, we feel that the dramatic nature of the shift is unlikely to be accountable to this alone. We believe the change in patients' DMS reflects a genuine alteration over time.

Why has there been a shift in patient DMS over time and the exaggeration of the active change within the high MR unit?

It has been demonstrated and is largely accepted, that over time there has been shift toward expectations of greater autonomy within the wider population.(Coulter and Jenkinson 2005) But does this account for the DMS shift among the patients of this study? If a purely cultural shift were responsible for these findings, the change in DMS should be more uniform over the units, rather than there being a statistically significant exaggeration among patients of one unit?

Patients from the high MR unit in our study, both preferred and achieved more active DMS than those from the low MR unit (p= 0.015 and p<0.001 respectively). Prior studies have demonstrated that individuals' DMS become more passive when they are diagnosed with a serious disease(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996;Butow, Maclean, Dunn, Tattersall, & Boyer 1997;Deber, Kraetschmer, & Irvine 1996;Deber, Kraetschmer, Urowitz, & Sharpe 2007;Degner & Sloan 1992;Giordano, Mattarozzi, Pucci, Leone, Casini, Collimedaglia, & Solari 2008;Levinson, Kao, Kuby, & Thisted 2005;O'Donnell & Hunskaar 2007a;O'Donnell & Hunskaar 2007b;Rothenbacher, Lutz, & Porzsolt 1997) or are asked to make a treatment decision in an unfamiliar disease context.(Deber, Kraetschmer, Urowitz, & Sharpe 2007) Our study did not include the analysis of healthy or benign diagnosis controls. But the DMS proportions identified (particularly among the high MR breast unit patients), were more akin to those previously reported among healthy populations rather than those with cancer.(Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Schou, Ekeberg, Ruland, & Karesen 2002) This prompts the question: Are patients of this unit innately more active or is there something about the high MR unit which means patients classify themselves more actively?

There are a number of possible explanations. One is that patients are not different, but are forced to assume more autonomous roles by their units. This seems unlikely. Overall concordance between PDMS and ADMS in the study was 61%, which is similar or greater than among other studies. Also, concordance did not vary by breast unit (p=0.533).

Our study also demonstrated the predominance of the active DMS among those choosing mastectomy. This is seemingly contrary to previous studies reporting proportionately more active PDMS and ADMS among those choosing BCT.(Collins, Moore, Clay, Kearing, O'Connor, Llewellyn-Thomas, Barth, Jr., & Sepucha 2009;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Mastaglia & Kristjanson 2001;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Schou, Ekeberg, Ruland, & Karesen 2002) However they are consistent with the findings of more contemporary studies.(Collins, Moore, Clay, Kearing, O'Connor, Llewellyn-Thomas, Barth, Jr., & Sepucha 2009;Davison & Degner 2002;Hack, Degner, Watson, & Sinha 2006;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Keating, Guadagnoli, Landrum, Borbas, & Weeks 2002;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Schou, Ekeberg, Ruland, & Karesen 2002) Those choosing mastectomy comprise a larger subgroup within the high MR unit. Could pushing patients to assume more active roles result in more choosing mastectomy and higher MRs? Again, this seems unlikely. Discordance in PDMS and ADMS was identified in 39%, but there was no statistically significant correlation between DMS concordance and operation type (p=0.070). If anything, there was a trend toward greater overall concordance among those choosing mastectomy (67% vs. 59%), and the achievement of more passive roles than preferred among the BCT group (11% vs. 3%).

Does post hoc justification explain the preponderance of the active DMS in the high MR unit? Do those having a more body image altering treatment like mastectomy need to assume greater ownership of their decision as a coping strategy? If so, patients choosing mastectomy who might otherwise have classified themselves in the collaborative PDMS, might classify themselves within the active category. Data from table 4.7 presenting ADMS by operation choice and breast unit MR demonstrates no patients choosing mastectomy from the medium and high MR units classified themselves with a passive DMS. This might support this explanation. However, the same table , demonstrates the passive self-allocation of 6 of the 27 (22.2%) low MR unit patients having mastectomy. This is not concordant with those having mastectomy utilising the adoption of greater decision ownership as a coping strategy.

Could patients' self-categorisation be influenced by the norms operating within the breast units' decision making culture? This might also account for the seemingly time-related shift in DMS associated with operative decisions observed in the literature. If there were a shift in clinicians' preferences over time, this might alter what is perceived and portrayed as the norm to patients. This could apply equally to clinicians' preferences for a particular treatment option or approach to decision making. For example, if there were a shift in preferences towards BCT, this option might become the norm. In this context those preferring BCT might classify themselves as collaborative decision-makers and BCT would predominate among passive patients. Likewise, those preferring mastectomy may adopt (or feel they need to adopt) a more active DMS to receive a treatment outside the perceived norm. The latter was described, but only in the context of a breast unit/decision making experience focussed on the operating norms being a combination of BCT and more paternalistic decision making. We therefore don't believe this explains the preponderance toward the active DMS described over time or within the high MR unit.

Triangulating the quantitative (IDMQ) and quantitative (clinician and patient interview) findings of this mixed methods study leads us to believe the shift in DMS over time has more to do with the decision making environment patients experience than a cultural shift toward expectations of greater autonomy. Although a statistically significant majority of patients completing the IDMQ reported a desire for more autonomous decision-making, an unexpected majority of those interviewed still anticipated a paternalistic decision making experience at diagnosis. They expected a treatment plan. They described their preconceptions as being based on prior experiences, seriousness of their diagnosis, and awareness of their deficiency of knowledge and experience. We believe the same combination of factors is responsible for both the time-related DMS shift and the exaggeration of the findings within the high MR unit. So what is different? Over time, the healthcare decision making environment patients experience has changed from a, primarily paternalistic, toward a more shared one. We suggest the key to understanding the reported DMS findings resides in whether the norm patient experience is in a shared or paternalistic decision making environment, against the background of their preconceptions of the decision making experience; that providing and normalising greater patient autonomy in decision making shifts patients' expectations (and therefore DMS) toward the more active end of the spectrum. The offer of a more autonomous role in decision making could be met with initial surprise and feeling of inadequacy. However patients' responses and preferences for involvement in decision making often altered as the encounter progressed. They described this occurring in response to three factors; their initial adjustment to diagnosis; experiences with clinicians; and acquisition of knowledge. Patients' perception of whether undertaking more autonomous roles was attractive and achievable or not, and therefore their categorisation of PDMS and ADMS, were influenced by the normalisation of either more autonomous or paternalistic decision making, and the provision or absence of the prerequisites for decision making (outlined in the earlier section). Clinicians from the medium and high MR unit described their commitment to normalising patients' participation in informed decision making and providing the prerequisite factors for this. This was particularly evident among both the doctor and BCNs consultations in the high MR unit. This is supported by the data in table 4.7. The low MR unit norm was direction. As already described, it was the only unit where any patients having mastectomy classified themselves within the passive ADMS. This may be a feature of the small numbers involved (mastectomy choice passive ADMS n=6/27, 0/29 and 0/38 patients from the low, medium and high MR units respectively), but it was also consistent with the interview findings.

Clinicians' awareness of patients' preconceptions at diagnosis and the fact they are not necessarily indicative of their PDMS is an important issue. This study suggests if preconceptions of paternalism are not countered, clinicians actively promote their particular preference or they fail to provide the other prerequisites for more autonomous decision making, patients' perceptions of passivity are reinforced or they feel too ill equipped to make their own decision. We suggest this group are more likely to categorise themselves within less active DMSs. Applying the reverse of this argument, if preconceptions of passivity was countered and patients are provided with the tools and time for decision making, a greater proportion engaged in decision making; possibly to their more naturally preferred extent; as suggested by the more active PDMS and concordance with ADMS. Evidence from patient Decision Support Instrument (DSI) studies seems consistent with this. Significantly more active PDMS were identified among women newly diagnosed with breast cancer who were in the intervention arms of the studies. Among these, shared decision making was normalised and patients were provided an independent evidence-based resource to explore options prior to consultation with their surgeon.(Belkora et al. 2008;Collins, Moore, Clay, Kearing, O'Connor, Llewellyn-Thomas, Barth, Jr., & Sepucha 2009;Davison & Degner 2002;O'Connor et al. 1999;O'Connor, Stacey, Entwistle, Llewellyn-Thomas, Rovner, Holmes-Rovner, Tait, Tetroe, Fiset, Barry, & Jones 2003b) However, unlike our study which demonstrated highest DMS concordance among those with and active PDMS 131/144 (91.0%), the DSI studies demonstrated greater levels of DMS discordance among those classifying themselves more actively.(Davison & Degner 2002)

What role do clinicians think patients want in decision making?

Clinicians' impressions of the predominant PDMS of their patients, varied by breast unit. Medium and high MR units consistently placed the majority of their patients in the collaborative group, while many low MR unit clinicians described the majority as passive. Impressions of predominant passivity were not reflected in the study's IDMQ, which demonstrated less than 20% had a passive PDMS. Clinicians recognised that reliably identifying a patient's DMS could be difficult. Most were confident detecting those with the most active DMS, but expressed less certainty discriminating between the other groups. Those seeking to engage patients in decision making and those from the medium and high MR units, prioritised the identification of DMS to tailor their consultations and support. Many low MR unit clinicians did not focus to the same extent on DMS. They viewed passive and collaborative DMS as a single category and believed those who really wanted a role in decision making would make this apparent.

Why did clinicians possess different impressions of their patients' DMS? Patients often described shock at their diagnosis and initial concerns about the adequacy of their knowledge and decision making capability. As already discussed, they also possessed predominant preconceptions of paternalism. This combination resulted in them asking for clinicians' recommendation. Clinicians described the frequency of receiving such requests and recognised that especially initially, patients could be traumatised by their diagnosis and appear passive. However, clinicians' interpretation of these reactions and requests, which formed the basis of their impressions of patients' DMS, differed depending on their particular set of beliefs and unit ethos.

The process-based clinicians viewed them as predictable responses to an acutely stressful event in an unfamiliar context. They did not necessarily conclude that they equated to a passive PDMS. They expressed concern that it was easy to incorrectly label patients as passive at this early stage, and that this might deny them a role in decision making. The outcome-focused clinicians' interpretation was different. They felt these responses confirmed patients' passivity and inability to engage in decision making. These impressions might have been exacerbated by the lack of time described for the decision making process, and the generally more directive clinician consultation styles and decision making approaches adopted.

Correctly identifying patients' PDMS is important as it should facilitate the tailoring of decision making experiences to preferences. In our study 39% of patients' failed to achieve their PDMS; presumably partly due to clinicians' inaccurate assessment of patients' DMS. As outlined earlier, the study suggests patients' PDMS are not necessarily pre-determined, obvious (even to patients) at diagnosis, or fixed. This may explain why clinicians within the study described uncertainty and difficulty in ascertaining patients PDMS (among all but the most active of DMS), and why there is clear, persistent evidence of clinicians' misallocation of patients' PDMS in this study and in the literature.(Bilodeau & Degner 1996;Bruera, Sweeney, Calder, Palmer, & Benisch-Tolley 2001;Bruera, Willey, Palmer, & Rosales 2002;Butow, Devine, Boyer, Pendlebury, Jackson, & Tattersall 2004;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Gysels & Higginson 2007;Hughes 1993;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Montgomery & Fahey 2001;O'Connor, Stacey, Entwistle, Llewellyn-Thomas, Rovner, Holmes-Rovner, Tait, Tetroe, Fiset, Barry, & Jones 2003b;Richards, Ramirez, Degner, Fallowfield, Maher, & Neuberger 1995;Rothenbacher, Lutz, & Porzsolt 1997;Strull, Lo, & Charles 1984) Further research is required to investigate how clinicians can more reliably identify and respond to the role that their patients wish to take in making treatment choices, thereby enabling patients to make decisions in healthcare and enhancing their experience of the process.

What are clinicians' preferences and motivations in breast cancer decision making

Prior to this study there was definitive evidence that doctors have treatment preferences and that these impact patients' treatment decisions,(Gort, Broekhuis, Otter, & Klazinga 2007;Johnson, Roberts, Cox, Reintgen, Levine, & Parsons 1996;Katz, Lantz, & Zemencuk 2001;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Morrow, Jagsi, Alderman, Griggs, Hawley, Hamilton, Graff, & Katz 2009;Nold, Beamer, Helmer, & McBoyle 2000;Schou, Ekeberg, Ruland, & Karesen 2002;Smitt & Heltzel 1997) but they provided little detail. There was also a lack of information about the motivations underlying clinicians' preferences and the mechanism of their influence over decisions and practice. A number of limitations were associated with the previous studies. The majority were based on vignette responses. They were predominantly conducted among surrogate clinician groups and convenience samples, rather than the pertinent specialist group whose preferences might impact on the decisions in question. Finally, all were conducted among doctors. Other relevant specialist clinicians (i.e. BCNs) were not included. This study adds to the evidence from prior studies conducted among doctors, therefore permitting a fuller description of the preferences and motivations of both occupational groups of specialist clinicians who engage with patients making breast cancer surgery decisions.

The DCE questionnaire demonstrated the existence and lack of uniformity of clinicians' preferences, along with new evidence regarding some of the intricacies of them. For example, other factors being equal, clinicians preferences for BCT, choice or mastectomy changed with cancer size ($p<0.001$). Those preferring BCT did so till cancers reached 20mm, then they moved toward patient choice, and those preferring mastectomy moved toward choice in cancers under 30mm. These different thresholds for switching preferences seem low. Rather than being absolute, the specific levels may reflect the dominant effect of another variable included such as centricity or breast size. To explore these further, ideally we should examine these preferences against their audit data. Unfortunately however, at the time of the study the level of detailed data required for confirmation of stated preferences against clinicians' practice, was only available through the NHSBSP QA process. There was an absence of similar data for symptomatic detected cancers. As a consequence, the audit phase of the study only included screen detected breast cancers; the majority of which were less than 30mm diameter (87%). Most clinicians' preferences were consistent with evidence-based guidelines for safe practice. But, the DCE also revealed that some clinicians rigidly adhered to their personal preferences despite them being contrary to evidence of safe practice and acceptable aesthetic outcome; for example, some expressed a continued preference for BCT in cancers exceeding 50mm diameter even in a small volume breast. This degree of preference adherence was uncommon.

The way patient age influenced clinicians' DCE responses varied with their preferred option. There was a positive correlation between age and preference for mastectomy, but it was less influential in patients over 80. Age should not independently influence surgery and the explanation for clinicians' purely age-based preference for mastectomy in older women is not obvious. It may indicate a conditioned impression of patient preferences, a belief that older patients are best treated with mastectomy, or it may reflect clinicians' assuming a positive correlation between increasing age and co-morbidity (despite the DCE instructions that other aspects of the cases were equal or insignificant). Age exerted less impact over those preferring BCT; only reaching statistical significance in the 70-80 year patient group.. But what might be interpreted as less 'ageism' among these clinicians, may reflect the fact that of the two operations, BCT is the more achievable under local or regional anaesthesia; which is a more important consideration among those with extensive co-morbidities.

A key finding of the DCE was that although cancer characteristics available preoperatively significantly influenced clinicians' treatment preferences ($p<0.001$), the majority (71%) of their responses were driven by other factors; as indicated by the low pseudo R^2 of 0.29. A limitation of DCE methodology is that it does not elicit of individual respondents' motives for selecting options. Selection of the equivalent preference option might reflect the view that the two treatments are exactly equal or that the provision of choices to patients is optimum. Alternatively it might be the default for those with a relative insufficiency of knowledge or experience. Future research utilising the DCE technique in similar clinical contexts should include the elicitation of respondent's motives for their responses at individual scenario level, through an addition quantitative or qualitative element to the survey.

The qualitative phase of the study permitted further exploration of clinician and breast teams' preferences and their underlying motivations. These suggest what the 'missing' influencing factors highlighted by the pseudo R^2 might be. Although treatment guidelines and cancer characteristics influenced clinicians' consideration of the options available to individual patients, they possessed beliefs about what the optimum management of their patients was. They differed in what they considered the optimum to enhance patient well-being and minimise the negative impact of the cancer diagnosis. They either primarily focussed on the optimum being a specific treatment option or it being a particular process of treatment decision making. There was variation in the strength of individual clinicians' preferences. Some declared an over-riding preference which eclipsed other considerations. Others described a more tempered preference, or balance between their preferences for BCT and shared decision making. While clinicians were happy declaring a preference for BCT, none of those interviewed declared a preference for mastectomy per se; although different levels of aversion and acceptance of mastectomy were expressed. Some believed mastectomy should be reserved as a last resort (low MR), others described it as the 'right' option for some well-informed patients (predominantly medium and high MR units). These beliefs influenced the options and level of autonomy they offered patients in treatment decision making. Those with over-riding preferences for BCT described an outcome-based approach. Those expressing patients should define the optimum treatment for themselves, described a process-based approach; providing options and shared decision making where possible.

We have demonstrated clinicians' possess preferences. But does the study confirm whether these are communicated to their patients and influence MRs? The self-report nature of study is a potential limitation in understanding this. Clinicians said what they preferred (in the DCE and interviews) or did (in the interviews). The lack of availability of the symptomatic cancer data means it is not possible to analyse clinicians' DCE responses against their individual MRs, as the number of cases for analysis is too small. However we can explore this using the example of male doctors. Their DCE responses demonstrated specific treatment preferences. The triangulation of the DCE and interview data indicates, although clinicians could state their possession of preferences for specific treatment options, their intention to relay these or allow them to influence their practice, depended on their concurrent beliefs; particularly those regarding what comprised optimum management; i.e. primacy of patient choice or the specific option.

The DCE and interviews provided a more uniform impression of BCNs preferences and motivations across the units. Their DCE responses were more consistent with the concept of patient choice and they described motivations focusing on providing their patients with psychological support, reassurance and the opportunity to consolidate information.

Breast units have different decision making cultures

Clinicians expressed their treatment preferences and motivations corporately, as well as at an individual level. A prevailing ethos was described within each breast unit, which was based on these corporately held beliefs. The patient and clinician interviews provided a generally concordant view of the decision making environments of the breast units and revealed the presence of particular decision making cultures within them. These were defined by a number of interdependent distinct and consistent differences in; some of which were overt, others more subtle. As a group, the low MR unit differed distinctly from the more comparable medium and high MR units. These differences are summarised in tables 8.1 and 8.2. The different decision making cultures provided a diverse backdrop for the experiences patients described; which either empowered more autonomous patient decision making or sustained acquiescence. In this way, although treatment guidelines and patients' cancer characteristics influenced the options available to them, these options and patients' decision making experiences were influenced by the culture of the breast unit.

The primary motivation of these decision making cultures expressed at corporate level, echoed those expressed by individual clinicians: To provide their patients optimum management. However, the primarily focus of this depended on the breast unit; a particular treatment outcome or a decision making process. The outcome-focussed clinicians believed BCT was the superior option and described providing genuine choices in a far more targeted way to a subgroup of patients whom they felt were not definitively suitable for BCT. In contrast, the process-focussed clinicians described and promoting more autonomous decision making to a much wider group. To them, any patient considered suitable for BCT was offered a choice. They referred to their belief in evidence that engagement in decision making provided patients long-lasting benefit.(Andersen, Bowen, Morea, Stein, & Baker 2009;Deadman, Leinster, Owens, Dewey, & Slade 2001;Fallowfield, Hall, Maguire, Baum, & A'Hern 1994a;Fallowfield, Hall, Maguire, & Baum 1990;Fallowfield, Hall, Maguire, Baum, & A'Hern 1994b;Hack, Degner, Watson, & Sinha 2006;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Morris & Ingham 1988;Morris & Royle 1987;Moyer 1997;Moyer & Salovey 1998;Schou, Ekeberg, Ruland, & Karesen 2002;Stewart 1995;Street, Jr. & Voigt 1997;Wilson, Hart, & Dawes 1988;Wolberg 1990)

One of the core beliefs driving breast units' cultures was the perception of the predominant DMS among patients; which varied with unit affiliation – passive in the low MR unit and collaborative in the others. These provoked different responses among clinicians. Within the process-focussed decision making culture of the medium and high MR units, the clinicians pre-empted patients' initial by specifically describing the decision making process and providing reassurance about the time, information and support available. Not wishing to deny patients a role in decision making, most targeted and purposefully deferred recommendations; to feel certain they had correctly differentiated passive patients from the other groups. The outcome-focused clinicians believed the appropriate response was the provision of the expert opinion. They pre-empted patents' reactions by providing directive information and volunteering recommendations.

Although there was a dominant decision making culture within breast units, clinicians' could vary their approaches in response to individual patients' clinical and cancer characteristics. In the medium and high MR units, there was a transition toward a more outcome-based approach when cancers were particularly small (a few mms). In this context they could describe emphasising BCT, although their approach usually remained less directed than described in the low MR units' routine practice. In the low MR unit when patients had cancers they considered borderline for BCT, there was a transition toward a more process-based approach; although most retained an element of direction. The mechanisms in place for supporting more autonomous patient decision making were less well-described at the low MR unit and the consenting process usually remained rapid. This combination may explain why this group of clinicians described the majority of patients given more autonomy struggling with it, and their impression that only those who actively sought a role seemed able to engage in the process.

Despite the wider emphasis on patient choice, and shared or informed decision-making in the NHS and by the GMC, some clinicians and clinical units seem to possess decision making cultures which are less conducive to patients engaging in more autonomous decision making, and either actively or passively promote patient acquiescence.

Differences in who gets choices/options

One of the key issues identified was clinicians' thresholds at which they believed patients should be offered treatment choices. The clinician interviews highlighted the classification of patients into different treatment groups depending on their breast unit affiliation. Clinicians from the low MR unit defined three option categories, those suitable for BCT only, a choice, or mastectomy only. The medium and high MR units utilised only the latter two; placing those suitable for BCT in the choice category. This is perhaps reflected in the different rates of identification and recruitment of eligible patients among the units. Less than 20% of the low MR unit patients having surgery for newly diagnosed breast cancer were approached to participate in the study, compared with 54% from the medium and 32% from the high MR units (see table 4.1). This is supported by interviews with patients identified as eligible for a choice of surgery, i.e. those who did not require a mastectomy on clinical grounds. Some (particularity from the low MR unit) described consultations consistent with clinicians' description of allocation of patients into the BCT only option category.

As already discussed, the DCE identified differences in clinicians preferences based on cancer size. These were reproduced in the interviews. Although as already discussed, there is insufficient data in the audit, DCE and interviews to delineate what the specific thresholds are. Nevertheless, the interviews do indicate low MR unit clinicians' greater preparedness to offer options to those with much larger sized cancers; based on the information that some only started to switch from purely offering BCT, when cancers reached 30-40mm diameter.

Is there variability among clinicians of the same unit?

As reflecting any real-life situation, the qualitative findings exposed a spectrum of beliefs, attitudes, and behaviours among individual clinicians from the same unit. However the diversity was framed within their individual unit culture. To illustrate, a minority of low MR unit doctors expressed preferences and beliefs more harmonious with the processed-based approach of the other units. They described providing additional time and consultations to afford patients more autonomy, and consenting patients at a later stage. However they still often described providing clear recommendations to their patients early in their first consultation about diagnosis and treatment; especially if they considered them clearly suitable for BCT. They did not perceive the volunteering of clear recommendations as being inconsistent with their seemingly strong stated preference for greater patient autonomy, nor their understanding that most patients followed recommendations provided. This limited level of reflexivity may correspond to a demonstration of third dimensional power described in Lukes' power theory.(Lukes 1974) The theory would suggest the units' cultures were so pervasive there were certain things clinicians from some units believed, described and accepted, which those from other breast units might question, challenge or reject.

The DCE and interviews provided a more uniform impression of BCNs' individual consultations with patients across the units. However, some variation was noted. Although some BCNs from the low MR unit articulated personal preferences consistent with a process-based approach, preferences at odds with the unit ethos were mostly suppressed. The majority described consulting within the confines of the doctors' approach. But a minority of the more experienced BCNs described sometimes engaging in a more process-based approach at patients' provocation; providing a more extensive exploration of information and the options than those included in the doctor's consultation. They also described arranging additional consultations with the doctors to expand patients' treatment options.

Do clinician gender, occupational role and age make a difference?

Clinician factors have been reported to influence their treatment preferences. The DCE demonstrated doctors were more likely to display specific treatment preferences and females were more orientated toward choices. But was being female per se associated with a greater preference for more autonomous patient decision making?

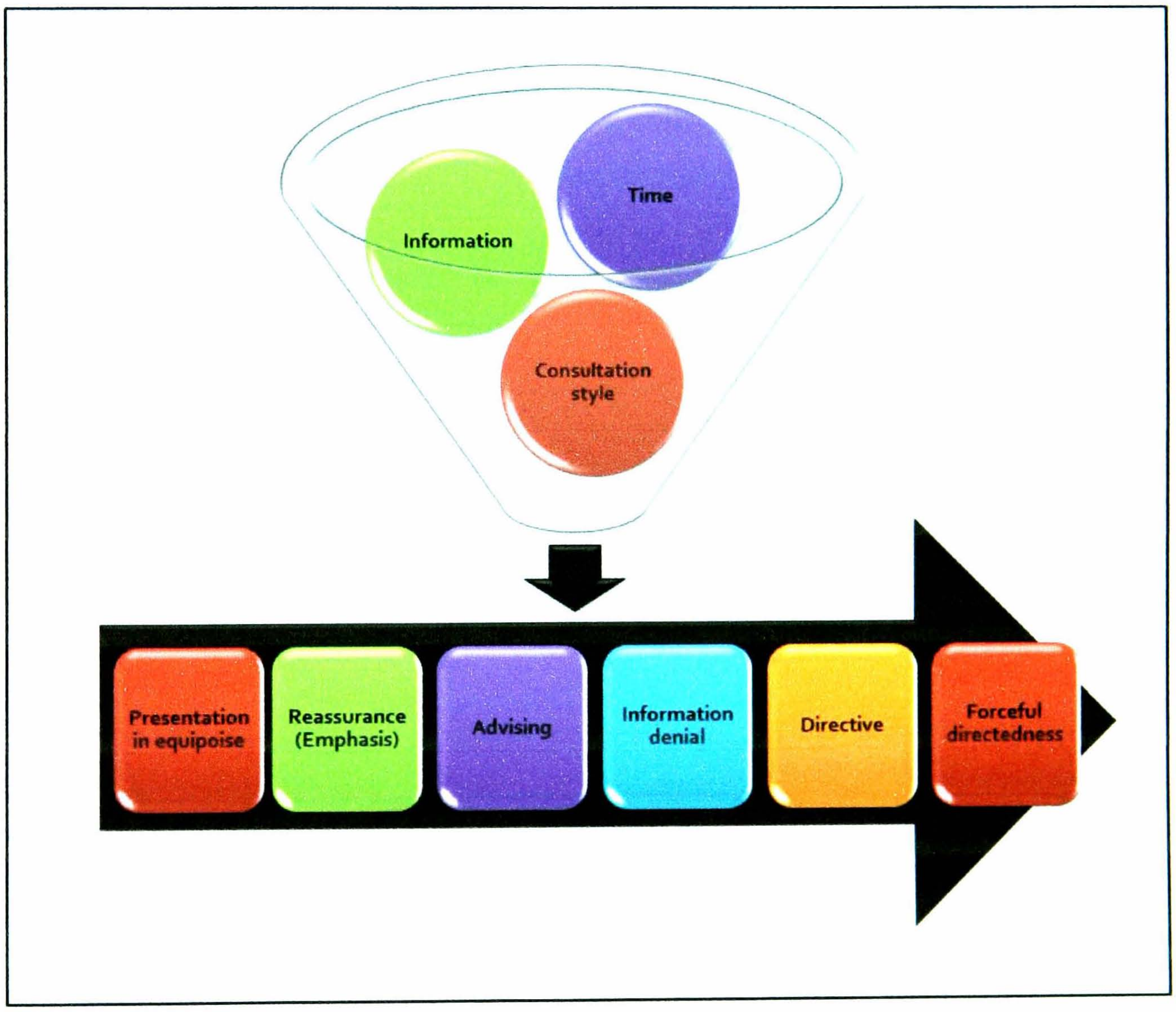
Some prior studies suggest higher BCT rates among female surgeons.(Gilligan, Neuner, Sparapani, Laud, & Nattinger 2007;Mandelblatt, Berg, Meropol, Edge, Gold, Hwang, & Hadley 2001;Schou, Ekeberg, Ruland, & Karesen 2002) Consistent with most UK breast units, all BCNs were female and the majority of consultant surgeons male. Among the DCE respondents there were 35 BCNs and 33 doctors; 10 of whom were female. The pronounced gender-role bias inherent in our study population made it difficult (if not impossible) to separate the effect of gender from occupational role over doctors' preferences, beliefs and consultation approaches. However, within these limitations, we feel it is possible that female gender among the doctor occupational subgroup is associated with a shift in preferences and decision making approach toward the less directive end of the spectrum. Of those interviewed, three of the six female doctors were consultant surgeons; two from the low and one from the high MR unit. Most consultant surgeons from the low MR unit were particularly directive, but one female consultant from this unit expressed a process-based preference. The other female non-consultant grade specialist doctors from the low MR unit were happy to present recommendations, but provided more tempered versions of the outcome-based approach described by their consultant counterparts, and were more orientated toward providing more autonomy.

The evidence from the literature is unclear about whether surgeons' years of experience(Grilli, Scorpiglione, Nicolucci, Mainini, Penna, Mari, Belfiglio, & Liberati 1994;Liberati, Patterson, Biener, & McNeil 1987;McKinlay, Burns, Durante, Feldman, Freund, Harrow, Irish, Kasten, & Moskowitz 1997) and academic affiliation have an effect over clinician preferences.(Goel, Olivotto, Hislop, Sawka, Coldman, & Holowaty 1997;Porter & McMulkin-Tait 2004) This DCE component of this study failed to demonstrate an association between preferences and clinician experience or age (for example, choice vs. mastectomy preference years of experience RRR 0.98, CI 0.95-1.00, p=0.10, choice vs. BCT preference years of experience RRR 1.00, CI 0.96-1.04, p=0.99). However, this may be a reflection of the relatively small numbers; only 10 of the DCE respondents were over 56, and only one within the 61-65 age group. The unit ethos (rather than clinician age) seemed to be a more dominant factor influencing clinicians' preferences. The interviews did however highlight a possible age/experience related difference in consultation styles among both occupational groups. Most BCNs described themselves as focusing on providing their patients with psychological support, reassurance and reiteration of the clinical consultation. As an occupational group, their personal DCE responses were more consistent with a preference for greater patient inclusion in decision making. However most described consulting within the confines of the unit ethos/culture and the doctors' consultation. A small minority of more senior and experienced BCNs from the low MR unit described stepping outside the confines of the doctors' message and holding more extensive discussions and discussing options not volunteered by the doctor. Age/experience seemed to exert an influence among the male doctor subgroup in a different way. The three older male consultant surgeons interviewed (one from the high MR and two from the low MR units) described similar doctor-centred consultation styles. Their information provision was more targeted and less extensive, and they expressed discomfort using words like 'cancer' with their patients. Their intent (treatment outcome direction or facilitation of a more autonomous process) however remained consistent with their unit ethos. Whereas the low MR clinicians' approach was more akin to their units' more directive approach, the high MR unit doctor was aware that theirs was discordant with their unit's culture and sub-optimal for their process-based intent. They and fellow clinicians from their unit described counterbalancing these 'shortcomings', which might otherwise prove barriers to more autonomous patient decision making, with a reliance on BCNs. The doctor focussed on outlining the available options and ensuring patients knew a more extensive discussion with their BCN would ensue.

Clinicians' decision making approaches and patients' decision making considerations

Patient and clinician interviews described consultation and decision making experiences consistent with those described in literature; doctor- and patient-centred consultation styles; and paternalism, shared and informed choice decision making approaches. Their descriptions provided the impression of a spectrum from facilitation of more autonomous patient decision making to treatment direction. Figure 9.1 illustrates this and the factors contributing to it.

FIGURE 9.1 The spectrum of clinicians' decision making approaches



Patients experiencing the facilitative end of the spectrum (what would be considered shared decision making), tended to describe the provision of the tools and structure for decision making.

The possession of a timeframe for the process was particularly important to patients feeling it was achievable. Both they and their clinicians also described the acquisition of information and fuller participation in treatment discussions and decision making being potentiated by a less rushed environment and the provision of support.

At the directive end of the spectrum (what would be considered paternalism), the focus was on patients being reassured and guided toward a specific decision, rather than being informed and supported for decision engagement. Direction was provided with varying strength from a more tailored less prescriptive form incorporating the encouragement of consideration of options with a gentle steer toward a specific option; through to the issue of a clear, specific non-tailored treatment plan, based on what the clinician felt was most appropriate. Sometimes to the point patients described being compelled to undergo an unwanted option.

Between these ends of the spectrum patients were presented with options, but certain aspects of treatment or cancer characteristics could be emphasised, minimised or absent. Some clinicians described their intention being to provide reassurance, others to steer patients toward the most appropriate treatment. A feature often emphasised was a small cancer size along with suitability for BCT. It is possible those clinicians who referred to cancers up to 30 and 40mm diameter as small and suitable for BCT rather than options, might adopt this type of emphasis amongst those with these larger diameter cancers.

The transition point between clinicians emphasising a treatment or aspect of the diagnosis and it becoming a recommendation, was not always obvious. The remit of the study did not include observing consultations, but triangulation of the patient and clinician interviews infers that the transition point of what is perceived by the patient as a point of emphasis or recommendation was determined by a combination of; the degree of emphasis placed on specific information components; clinicians' non-verbal communication;(Mehrabian 1972) and their use of active listening skills interacting with patients' preconceptions, knowledge and preferences. In this way, two patients hearing the same intended message or form of words might interpret reassurance or a recommendation. Clinicians also differed in their approach to the provision of overt recommendations; whether these were volunteered, provided in response to patients' requests or withheld.

There was also the impression from some patient interviews that though choices were given, clinicians failed to disclose (or patients did not absorb) crucial pieces of information which might have influenced their treatment decisions. This was consistent among some specific low MR unit clinicians' patients. The information usually related to radiotherapy being an integral component of BCT for invasive breast cancer, radiotherapy course length, the possibility of requiring a further operation for close margins, and the small but significant difference in LRRR.

A skewed power-relationship and an information/knowledge gap between patients and clinicians were evident in the interviews. These were upheld, minimised or exaggerated depending on the breast units' decision making culture and environment. These provided the impression of differences in units' conduciveness to patients' engagement in more autonomous decision making. The process-focussed clinicians and units described specifically seeking to anticipate patient needs and redress these imbalances. This is a frequently reported deficiency identified within national patient surveys(Richards and Coulter 2007) and research studies.{Stevenson, 2004 1495 /id}{Moumjid, 2009 1397 /id}{Grol, 2000 1496 /id}

The differences in clinicians'/units' approaches described was reflected in patients' decision making considerations. There was a clear tendency for patients from the medium and high MR units to describe greater complexity of decision making. They based their decisions on more comprehensive knowledge and their descriptions incorporated the extensive consideration of their preferences and concerns against the perceived pros and cons of the options. Their accounts were consistent with shared decision making and the establishing of informed consent. The low MR units sought to alleviate the discomfort of the skew in power and knowledge by providing reassurance and recommendations. The description of many of this group of patients' experiences, were consistent with a more superficial engagement in decision making. They generally described less complex, more concise considerations based on preferences but less extensive information, and a greater reliance on clinicians' reassurance and recommendations. Rather than undergoing an experience of informed consent, theirs might be more aptly defined as 'informed' compliance or compliance; a term first introduced by O'Cathain et al. from work evaluating women's maternity decision making experiences.(O'Cathain et al. 2002;Stapleton et al. 2002)

How patients and clinicians influence each other in the decision making process

The different approaches adopted by clinicians suited some patients. However, clinicians often described rigidly adhering to their usual consultation style, giving the impression of being uncomfortable and/or unwilling to adapt these to suit their patients' individual preferences. This impacted different patient groups within the units studied; those with active PDMS in the low MR unit and the passive group in the medium and high MR units.

The interviews with clinicians echo Krupat et al.'s(Krupat, Irish, Kasten, Freund, Burns, Moskowitz, & McKinlay 1999) findings, which suggest patients expressing themselves more assertively are more likely to be afforded more power in their interactions with clinicians. Patients in our study had to be either 'assertively active' to stimulate clinicians to switch to provide a more autonomous patient decision making experience and discuss options (in the low MR unit), or they had to be 'assertively passive' over the decision making process to retract (in the medium and high MR units) a more autonomous patient decision making experience and receive a treatment recommendation. Levels of assertiveness were not quantified by our study or Krupat's. But Krupat described patients only needing to display moderately assertive behaviour to elicit a response among clinicians. Our interview findings imply a much greater degree of assertion was required.

Butow et al.'s study analysing oncologists' detection and response to patients' communication clues, may help explain why such levels of assertion were required. Butow noted oncologists responded well to very explicit verbal expressions of need, and found they did not seem to detect more subtle versions; the 'hints' rather than statements.(Butow et al. 2002) If this is true, the active patients from the low MR unit would be more advantaged than the passive patients from the other units. Active patients' very obvious statements of need demanded a response from the clinicians, while passive patients' would be express their needs more subtly. In addition, the clinicians adopting a process-based approach were clear that they delayed the adoption of a more directive style to a point when they were certain their patient was passive, rather than in the early phase of shock after diagnosis. They were also concerned that once a recommendation or direction was provided, patients were likely to acquiesce to this;(Gort, Broekhuis, Otter, & Klazinga 2007;Johnson, Roberts, Cox, Reintgen, Levine, & Parsons 1996;Katz, Lantz, & Zemencuk 2001;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Morrow, Jagsi, Alderman, Griggs, Hawley, Hamilton, Graff, & Katz 2009;Nold, Beamer, Helmer, & McBoyle 2000;Schou, Ekeberg, Ruland, & Karesen

2002;Smitt & Heltzel 1997) and risk subsequent regret if they accepted it without due consideration.(Hack, Degner, Watson, & Sinha 2006;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Keating, Guadagnoli, Landrum, Borbas, & Weeks 2002;Lam, Fielding, Chan, Chow, & Ho 2003;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005) Therefore, passive patients had to amplify the expression of their PDMS and express it consistently, to elicit a response from their clinicians. The medium and high MR units BCNs provided a crucial role here. They described providing psychological and decision making support until patients' PDMS were clarified, and when identifying a particular patient need, would either address it directly or arrange an additional consultation with the doctor, if necessary.

Stakeholder contributions to decisions and patients' acquiescence to clinicians

The literature demonstrates that patient-specific factors influence patients' decisions.(Carver, Pozo-Kaderman, Price, Noriega, Harris, Derhagopian, Robinson, & Moffat, Jr. 1998;Collins, Moore, Clay, Kearing, O'Connor, Llewellyn-Thomas, Barth, Jr., & Sepucha 2009;Fallowfield, Baum, & Maguire 1986;Hawley, Griggs, Hamilton, Graff, Janz, Morrow, Jagsi, Salem, & Katz 2009;Hughes 1993;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Lasry & Margolese 1992;Mandelblatt, Hadley, Kerner, Schulman, Gold, Dunmore-Griffith, Edge, Guadagnoli, Lynch, Meropol, Weeks, & Winn 2000;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Moyer 1997;Nold, Beamer, Helmer, & McBoyle 2000;Schou, Ekeberg, Ruland, & Karesen 2002;Smitt & Heltzel 1997;Wei, Sherry, Baisden, Peckel, & Lala 1995;Wilson, Hart, & Dawes 1988) But there is also clear evidence of a pronounced impact of clinicians over patients' decisions and MRs.(Gort, Broekhuis, Otter, & Klazinga 2007;Johnson, Roberts, Cox, Reintgen, Levine, & Parsons 1996;Katz, Lantz, & Zemencuk 2001;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Morrow, Jagsi, Alderman, Griggs, Hawley, Hamilton, Graff, & Katz 2009;Nold, Beamer, Helmer, & McBoyle 2000;Schou, Ekeberg, Ruland, & Karesen 2002;Smitt & Heltzel 1997) What is not currently clear from the literature is what influences the relative contributions of the two stakeholder groups.

Stanton et al(Stanton et al. 1998) proposed patients' health-related decisions could be explained by subjective expected utility (SEU) theory. This assumes humans approach decisions rationally; assessing information logically and weigh up expected consequences against the value they place on them. Our findings and those of a small recent in-depth qualitative study,(Sinding et al. 2010) suggest the theory has merit, but alone it is too simplistic to adequately capture the process of treatment selection.

Our study provides information about the interface between clinicians and patients. The findings illustrate clinicians' were the stakeholders who possessed the majority of power to affect decision, in numerous overt, subtle, intentional and unintentional ways. They influenced how much genuine choice patients perceived they had and whether they felt this was a positive thing. When they provided options, patients' decisions were influenced by; what was communicated to them; whether they were provided direction; or sufficient time and support to engage in the process. The skewed power-relationship between patients and clinicians favoured clinicians. They were the knowledgeable expert in this situation; relied on for information, reassurance and treatment. Patients (due to the acuteness of their diagnosis) tended to be frightened, possessed comparatively little information and often displayed minimal confidence. Clinicians' control of the agenda of discussions has been reported among recent reviews of observational studies of clinician-patient consultations.{Stevenson, 2004 1495 /id}{Moumjid, 2009 1397 /id} One such review of 134 studies demonstrated clinicians failed to encourage patients to discuss their needs and concerns.{Stevenson, 2004 1495 /id} This is reflected in national patient surveys(Coulter 2011a;Richards & Coulter 2007) and the findings among some of our patients. The extensiveness of the power-relationship skew and gap in confidence and knowledge, were upheld, minimised or exaggerated, depending on the communication approaches and decision making environment clinicians generated. This affected how patients felt about engaging in the process of decision making. Also, although decisions might be based on patients' personal preferences, clinicians influenced what they perceived was safe, normal to choose and desirable. Alongside previous evidence, this study demonstrates that although patients may want to play increasingly autonomous roles in choosing their treatment, there is continued acquiescence to clinicians' preferences and recommendations.

Patients' vulnerability and lack of knowledge did not necessarily translate into patients wanting clinicians to decide their treatment. As demonstrated, 80% of patients wanted to participate in deciding their treatment. Whether and to what extent they did so depended on their decision making environments. The interviews illustrated all three dimensions of Lukes' power theory in action.(Canter 2001;Lukes 1974) Some clinicians unilaterally assumed control and failed to provide options; 1st dimension power. Clinicians controlled the consultation/decision making agenda; some directed and subjugated patients by failing to provide time and demonstrating poor listening skills; 2nd dimensional power. They also dominated patients' impressions of their decision making capability by reinforcing or overturning patients' expectations of paternalism and portrayed the norm they wished to propagate (BCT or shared decision making); 3rd dimensional power.

The dominance of clinicians in decision making illustrated by our findings have been clearly demonstrated by two quantitative studies published since the completion of this research. Morrow et. al.'s questionnaire survey among American women with breast cancer (n=1984) demonstrated that 90% given a recommendation by their surgeons followed it, and only 2% recommended BCT underwent mastectomy; while mastectomy was chosen by one third not given a recommendation for BCT.(Morrow, Jagsi, Alderman, Griggs, Hawley, Hamilton, Graff, & Katz 2009) Gort et al. used multilevel modelling to quantify the magnitude of influence of surgeons and hospitals in Netherlands had over the operative decisions of patients with early breast cancer (n= 2,929) who were suitable for BCT. Once cancer characteristics were excluded, 83.2% of treatment variability was attributable to surgeons and 16.8% to hospital factors.(Gort, Broekhuis, Otter, & Klazinga 2007) Gort did not identify what these factors were, but did exclude surgeon experience, surgeon and unit workload, teaching hospital status, and management and policy. The findings of our study identify what some of these clinician/unit level factors are; specialist teams' prevailing ethos, underlying clinician beliefs, preferences and their routine practice. They also highlight that decision making among patients is by varying degrees of informed consent or informed/uninformed compliance depending on the approach of the clinician and breast unit.

The issue of satisfaction is more complex than achieving congruence in DMS

What optimises patient satisfaction and outcomes? This a particular focus among healthcare providers. The evidence suggests improved patient satisfaction and outcomes are associated with numerous factors; the adoption of an active DMS per se;(Deadman, Leinster, Owens, Dewey, & Slade 2001;Hack, Degner, Watson, & Sinha 2006;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Keating, Guadagnoli, Landrum, Borbas, & Weeks 2002;Lam, Fielding, Chan, Chow, & Ho 2003;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005) tailoring decision making to patient preferences (achieving congruence between patients' PDMS and ADMS);(Charles, Whelan, & Gafni 1999a;Keating, Guadagnoli, Landrum, Borbas, & Weeks 2002;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005) engaging in shared decision making;(Picker Institute Europe 2010) undergoing shared decision making;(Hack, Degner, Watson, & Sinha 2006;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Keating, Guadagnoli, Landrum, Borbas, & Weeks 2002;Lam, Fielding, Chan, Chow, & Ho 2003;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005) experiencing good communication;(Fallowfield 1997;Lerman, Daly, Walsh, Resch, Seay, Barsevick, Birenbaum, Heggan, & Martin 1993;Stewart 1995;Vick & Scott 1998) receiving high quality information and patient-centred care;(Degner 1998;Fallowfield 2000;Jenkins, Fallowfield, & Saul 2001;Lerman, Daly, Walsh, Resch, Seay, Barsevick, Birenbaum, Heggan, & Martin 1993;Vick & Scott 1998) and feeling safe in the care of an expert.(Lerman, Daly, Walsh, Resch, Seay, Barsevick, Birenbaum, Heggan, & Martin 1993;Sinding, Hudak, Wiernikowski, Aronson, Miller, Gould, & Fitzpatrick-Lewis 2010;Vick & Scott 1998;Wright et al. 2004)

Women's involvement in choosing their breast cancer surgery has been associated with improvements in satisfaction with the decision-making process and surgery undertaken,(Andersen, Bowen, Morea, Stein, & Baker 2009;Deadman, Leinster, Owens, Dewey, & Slade 2001;Fallowfield, Hall, Maguire, Baum, & A'Hern 1994a;Hack, Degner, Watson, & Sinha 2006;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Keating, Guadagnoli, Landrum, Borbas, & Weeks 2002;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005;Moyer 1997;Moyer & Salovey 1998;Stewart 1995;Street, Jr. & Voigt 1997) reduced regret(Fallowfield, Hall, Maguire, & Baum 1990;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Keating, Guadagnoli, Landrum, Borbas, & Weeks 2002;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Morris & Ingham 1988;Schou, Ekeberg, Ruland, & Karesen 2002) and improved psychological recovery. But how important is patients achieving their desired DMS? There is evidence that an active ADMS per se exerts a positive impact,(Bruera, Willey, Palmer, & Rosales 2002;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Hack, Degner, Watson, & Sinha 2006;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Keating, Guadagnoli, Landrum, Borbas, & Weeks 2002;Lam, Fielding, Chan, Chow, & Ho 2003;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005;Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010) in the short and long term.(Hack, Degner, Watson, & Sinha 2006) Although some demonstrate an amplification of the positive impact of active DMS when it is also the preferred role.(Charles, Whelan, & Gafni 1999a;Keating, Guadagnoli, Landrum, Borbas, & Weeks 2002;Lam, Fielding, Chan, Chow, & Ho 2003;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005) Previous studies suggest women often fail to achieve their PDMS.(Bilodeau & Degner 1996;Bruera, Sweeney, Calder, Palmer, & Benisch-Tolley 2001;Bruera, Willey, Palmer, & Rosales 2002;Butow, Devine, Boyer, Pendlebury, Jackson, & Tattersall 2004;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Gysels & Higginson 2007;Hughes 1993;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Montgomery & Fahey 2001;O'Connor, Stacey, Entwistle, Llewellyn-Thomas, Rovner, Holmes-Rovner, Tait, Tetroe, Fiset, Barry, & Jones 2003b;Richards, Ramirez, Degner, Fallowfield, Maher, & Neuberger 1995;Rothenbacher, Lutz, & Porzsolt 1997;Strull, Lo, & Charles 1984) The majority of women in our study achieved their PDMS (61% n=218/356). But it should be remembered that not all wish to assume such autonomous roles; 30% of the patients in our study undertook a more active role than preferred. Being asked to undertake a more active role than preferred has been shown to exert a negative impact on patient satisfaction.(Hack, Degner, & Dyck 1994;Hack, Degner, Watson, & Sinha 2006;Schain 1980) Lam's recent small study (n=154) conducted within 2 weeks of surgery among women with breast cancer from Hong Kong, found that assuming a more active role than preferred was associated with reduced satisfaction and less confidence in having made the right decision (p=0.005).(Lam, Fielding, Chan, Chow, & Ho 2003) But, equally negative impacts are evident among those who feel excluded from the decision process,(Bilodeau & Degner 1996;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Hack, Degner, Watson, & Sinha 2006;Lam, Fielding, Chan, Chow, & Ho 2003;Rothenbacher, Lutz, & Porzsolt 1997) and evidence from a large US study by Lantz et al. (n=1633), demonstrated that the passive DMS per se was associated with the most detrimental impact on satisfaction; even when this was the patients' PDMS.(Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005) What could be responsible for the seemingly discrepant findings of these studies? Most studies do not specifically provide contextualising information on their decision making environments, but Lam et al. do. They describe a breast unit environment dominated by clinician recommendations, and highlight substantial barriers and fewer facilitators (time and information) to more autonomous decision making among patients reporting DMS discordance.(Lam, Fielding, Chan, Chow, & Ho 2003) Lam et al.'s it is possible that the decision making environments were different. If the evidence that satisfaction increases when patients achieve either an active ADMS or DMS congruence is believed, most of our patients should be satisfied; as only 9% (n=33/356) achieved more passive roles than preferred. This contrasts with Singh's meta-analysis of North American cancer patient DMS studies (n=2742), which demonstrated identical overall concordance rates, but the predominance of passivity (57%) among the discordant group.(Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010)

But, can a quantitative tool like the Control Preferences Scale which our study and many others have utilised to identify patients' PDMS, ADMS and DMS concordance reflect patient satisfaction? A recent study by Davey et al. suggest not.{Davey, 2004 1491 /id} Based on our experience we believe the Control Preferences Scale is a useful tool to examine differences between groups and study time-trends, and that possessing information on DMS concordance can contribute to understanding patients' health care decision making experiences and satisfaction. But we suggest the crude use of this quantitative data without the addition of a qualitative exploration, can provide only limited implications of patient satisfaction. We also suggest that women's views and experiences of decision making be viewed as simplistically as many of the above studies depict; that more autonomous patient decision making equates with positive experiences and psychological impact, and less autonomous participation the reverse. Based on the evidence of our study and that of a small recently published in-depth qualitative study (n=5) by Sinding(Sinding, Hudak, Wiernikowski, Aronson, Miller, Gould, & Fitzpatrick-Lewis 2010) we suggest this view is too simplistic. The majority of patients in our study described satisfaction with their experiences. But their reasons for satisfaction were characterised differently. Satisfaction depended on not only their preferences, but their experiences with clinicians (doctors in particular).

The interviews highlight a positive correlation between patient satisfaction and their perception of receiving patient-centred care. Those given more autonomous but supported roles, tended to express satisfaction associated with their perceptions of their clinicians providing patient-centred care and decision making. Specifically they discussed satisfaction related to; being treated as partner or equal in their treatment decision making journey; the provision of clear tailored information and unrushed consultations; and having the opportunity to choose a treatment that was right for them. They also described their involvement in choosing their treatment as a positive aspect of their cancer experience; expressing it provided the opportunity to re-establish a sense of power and control they felt they deprived of at diagnosis. These were expressed among both those who found decision-making relatively uncomplicated, and those who found it more challenging. Even those who labelled themselves as passive decision-makers could view the provision of more autonomous decision making as a source of satisfaction, if it was provided in conjunction with patient-centred care and sufficient support. We agree with Deadman, that the decisional role itself can enhance patients' experiences(Deadman, Leinster, Owens, Dewey, & Slade 2001) and concur with Fallowfield, that it is difficult to separate the contributions of good communication/information provision and actual engagement in decision making, to the positive effect observed among those who participate in the process.(Fallowfield 1997) Based on our findings and the literature, we suggest there is a symbiotic effect enhancing satisfaction; the receipt of the prerequisites for decision making (including information provision at cancer diagnosis)(Degner 1998;Fallowfield 2000;Jenkins, Fallowfield, & Saul 2001) and patient-centred care. We also suggest it is possible that the increase in positive outcomes seen in the literature associated with the active DMS or achieving concordance between PDMS and ADMS, are more a reflection of these, than satisfaction resulting from the DMS per se. This is supported by the finding that patients told they could choose their treatment but not given the tools to do so (knowledge, time and support), described the concept of making a decision both unpleasant and hard or impossible.

Satisfaction was articulated in a different way by many of those describing more paternalistic experiences. Their reasons centred on being treated by a caring expert who provided reassurance and their specialist opinion. This positive view may be embedded in the finding that most women originally anticipated a paternalistic encounter. However, as evidenced by interviews among those desiring more autonomy in the process, we suggest the paternalistic approach per se is unlikely to be a source of satisfaction outside of the context where patients expect paternalism or lack of particular treatment preference. These findings highlight the complexity of what contributes to patient satisfaction and what they feel about their involvement in decision making. But why did patients express satisfaction using these different criteria in the context of often contrasting experiences? Understanding this may be assisted by examining a study by number of recently published qualitative studies. Wright et.al. found that women with breast cancer (n=39) apportioned greater value to their impressions of clinicians' traditional expert abilities and capacity to care for them, than they did regarding their communication skills or the provision of options.(Wright, Holcombe, & Salmon 2004) They also found that patients sought to maintain communication exchanges with their clinicians which would reinforce, rather than challenge these.(Wright, Holcombe, & Salmon 2004) Vick and Scott demonstrated patients' main priorities among doctors were good communication and a patient-centred style, rather than choices.(Lerman, Daly, Walsh, Resch, Seay, Barsevick, Birenbaum, Heggan, & Martin 1993) Both these studies and Lerman et.al found these were associated with improved psychological outcomes.(Lerman, Daly, Walsh, Resch, Seay, Barsevick, Birenbaum, Heggan, & Martin 1993;Vick & Scott 1998) This seems contrary to the evidence that patients now want more autonomy in medical decision making and are generally less likely to exhibit unquestioning trust in their clinicians.(Rowe and Calnan 2006) Our findings together with those above, imply patients' expressions of satisfaction are probably related to their priority need to feel safe in expert hands.(Lerman, Daly, Walsh, Resch, Seay, Barsevick, Birenbaum, Heggan, & Martin 1993;Sinding, Hudak, Wiernikowski, Aronson, Miller, Gould, & Fitzpatrick-Lewis 2010;Vick & Scott 1998;Wright, Holcombe, & Salmon 2004) Seemingly at odds with this was the marked dissatisfaction articulated by the minority, whose PDMS and/or treatment preferences were at odds with their units ethos and decision making culture. We suggest the interviews illustrate the compounding negative effects of clinicians' failure to; meet patients' expectations of the clinicians' role; provide patient-centred care; reflect published evidence of greater dissatisfaction among those with more extreme discordance in their PDMS and ADMS on the 5-point scale; and the denial of a strong preference for a specific treatment or way of making decisions. Based on this we suggest that if the trend for increasingly autonomous patient PDMS continues,(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996;Bilodeau & Degner 1996;Coulter 2011a;Coulter 2011b;Flynn et al. 2006;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Lam, Fielding, Chan, Chow, & Ho 2003;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005;Luker, Beaver, Leinster, & Owens 1996b;Mastaglia & Kristjanson 2001;Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010) those clinicians/units adopting more directive, less patient-centred, outcome-based approaches, may find their patients' satisfaction diminished.

Accurately tailoring consultations and decision making is more important than adopting a specific decision making style, to achieving a positive patient decision making experience?

The receipt of patient-centred care and tailoring were central to patients' positive experience of decision making, while negative decision making experiences were associated with the experience of clinician-centred care, the provision of insufficient information and patients' possession of inadequate knowledge. Lack of tailoring and mismatches in patient needs and preferences and clinicians' provision for these, were sources of dissatisfaction. So while clinicians should provide options, they need to be aware and responsive to the minority of patients who retain the desire for a more passive role in the selection of their treatment. It is important that the management of these patients is tailored to their preferences and that they are provided with direction at an appropriate time to meet individual patients' needs and preferences. Or they risk being more clinician/treatment-centred, than patient centred; as their approach is more closely aligned with the adoption of the clinicians' favoured treatment or decision making style, than responsive to patients' individual subjective preferences.

If they are to provide positive decision making experiences, clinicians need to be able to reliably gauge patients' preferences, concerns and needs. They also need to understand the reasons for their patients' preferences through open and tailored discussions. This ideally requires time with patients outside of the period of immediate diagnosis 'shock'. This may prove the hard to achieve. Clinicians have a relatively limited amount of time available to spend with their patients, and the majority of doctors' time is concentrated around the diagnosis consultation. Here, patients' immediate reaction to their diagnosis influences their perception of patients' preferences for involvement in decision-making. Also as already indicated, patients' feelings about participating in decision-making and their PDMS often adapt as they recover from the initial shock of their diagnosis, acquire knowledge and receive decision-making support from their clinicians. A further potential barrier to this form of optimised consultation process and decision-making support may come from the recent adoption increasingly short diagnosis to treatment targets, which have the possibility to further reduce opportunities for patients to experience multiple consultations with their clinicians if necessary.

As discussed, clinicians often make inaccurate assessments of their patients' preferences.(Bilodeau & Degner 1996;Bruera, Sweeney, Calder, Palmer, & Benisch-Tolley 2001;Bruera, Willey, Palmer, & Rosales 2002;Butow, Devine, Boyer, Pendlebury, Jackson, & Tattersall 2004;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Gysels & Higginson 2007;Hughes 1993;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Montgomery & Fahey 2001;O'Connor, Stacey, Entwistle, Llewellyn-Thomas, Rovner, Holmes-Rovner, Tait, Tetroe, Fiset, Barry, & Jones 2003b;Richards, Ramirez, Degner, Fallowfield, Maher, & Neuberger 1995;Rothenbacher, Lutz, & Porzsolt 1997;Strull, Lo, & Charles 1984) If they could accurately gauge these, the majority who want to participate in decision-making(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996;Bilodeau & Degner 1996;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Lam, Fielding, Chan, Chow, & Ho 2003;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005;Luker, Beaver, Leinster, & Owens 1996b;Mastaglia & Kristjanson 2001;Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010) could be provided with high quality comprehensible information along with sufficient time and support to make informed choices consistent with their personal preferences. While the minority who steadfastly want less autonomy in decision-making even after adjustment to their diagnosis, could be provided with carefully tailored and targeted treatment direction or a treatment plan sensitive to the individual patients' unique set of needs, concerns and preferences. These requirements and the time limitations, highlight the key role of the BCN subgroup of clinicians in the process; providing time, information and support; which is especially vital when tailoring and waiting to clarify patients' PDMS.

The role of BCNs

The provision or additional consultations with BCN varied. These were provided routinely, but formed a greater part of the support of the process to establishing consent in the medium and high MR units; and were particularly extensive in the high unit. BCNs described their role as providing their patients with support, reassurance and the reiteration/reinforcement of information provided by the doctors.

BCNs from the high MR unit appeared to undertake particularly extensive comprehensive discussions with their patients. They extensively explored patients' perceptions of their consultations, information and impression of their role in decision making. They described this being crucial for informed decision making. But the differences described between theirs and the other units might partly reflect the fact (that at the time of the study) unlike the other breast teams, BCNs described not being routinely present in the consultations where the diagnosis and treatment options were discussed between doctors and patients. The explanation given for this was a manpower-workload discrepancy. To avoid compromising the availability and length of one to one patient-BCN consultations, the unit sacrificed their presence in the diagnosis consultation for BCN time with patients immediately following the diagnosis consultation. Prior to this they had a brief discussion with the doctor to discuss the consultation, but were not privy to exactly what had been said or the patient's reactions. They therefore described questioning patients to elicit what they had understood from the consultation. Then consistent with their unit ethos of facilitating more autonomous patient decision making, they described providing information, checking understanding and exploring patients' options; even if patients perceived their doctor had a preference for a particular treatment. BCNs from the other units were routinely present in these consultations. They described checking patients' understanding. But having witnessed the consultation, it is possible they might partially base their impression of what patients had gleaned from it on their own interpretation of the encounter, rather than the patients' interpretations. Theoretically, there might be differences in how extensively BCNs explored patients' understanding.

BCNs from all units described time-pressures and high workloads limiting their time with patients. But this was especially marked among BCNs from the low MR. The differences between the units seemed to be related to the constraining influence of working within their particular team. There were differences in work-load pressures (as evidenced by the ratio of BCNs to patients illustrated in table 4.1), clinician priorities (BCN time being prioritised to consenting patients or providing additional consultation time) and time constraints imposed by when clinicians consented their patients for their treatment. Frustration with these was expressed.

Decision-making and establishing consent is a process

The units' clinicians held different perceptions regarding what decision making and establishing consent involves. Some were consistent with national guidelines, others were not.(Association of Breast Surgery at BASO 2009;Department of Health 2001a;Department of Health 2001c;Department of Health 2009;General Medical Council 2008;National Collaborating Centre for Cancer 2009;Scarth, Cantin, & Levine 2002a;Scarth, Cantin, & Levine 2002b) Medium and high MR units viewed it as a process through which a patient determined their preferred option, by exploring their preferences within the context of an attained relevant knowledge-base. Time to negotiate this process was viewed as a central requirement. In contrast, some low MR clinicians viewed it as the simple establishment of compliance to treat as considered optimal by the expert. Consistent with this, their routine process of consenting patients for treatment was swifter, and some routinely completed the process on the day of diagnosis after discussing treatment with the patient.

Based on the data of this study and existing literature, we submit that decision-making and establishing consent is a process which progresses through a number of stages requiring patient and clinician interaction. The approach adopted by clinicians (i.e. paternalistic, shared or informed choice model) dictated the extent of patient inclusion in the stages and the spacing between them. In shared and informed choice, the process commences with the acquisition of information (which can be passive, collaborative or active) through clinician disclosure and patient information seeking. The process includes discussion of treatment options, outcomes and implications. This permits patients' consideration of the options. The process culminates in the arrival at an informed tailored treatment decision; which is then confirmed by the procedure of consenting. Adoption of the paternalistic model concentrates on the two ends of the process outlined above and involved foreshortened stages with less patient inclusion in the process.

The provision of high quality correct information and skilled communication are essential to the establishment of consent and patient participation in decision making One reason decision-making and establishing consent need to be viewed as a process to be completed over a sufficient timeframe, is knowledge of the negative impact of receiving unpleasant information(Butler & Hailey 1996) or a life threatening diagnosis,(Cimprich 1993;Hughes 1993) on patients ability to recall information. The findings of this study and existing literature highlight, if patients are to understand the implications of treatments and make informed choices, information needs to be understandable, tailored(Fallowfield 2000) and provided over a period of time.(Fallowfield 1997) The one-off provision of information is not sufficient. Clinicians also need to be aware that their intended message and the words vocalised, do not necessarily equate to understanding. Therefore clinicians need to check understanding and correct inaccuracies, to ensure patients' decisions are based on correct information.

Some differences in patients' decision making descriptions were harmonious with their PDMS being active, collaborative or passive. These were evident across the units and were reflected in varying degree of their participation in the stages of the process. More autonomous patient decision making and the more participatory DMS involved greater participation in the individual stages of the process. The speed of negotiation of the process varied with DMS and strength of patient preferences. Active decision makers generally described negotiating the process more rapidly, as did those with strong (sometimes) pre-existing preferences or values. Collaborative and passive decision makers (especially the latter) described a more involved and lengthy process of knowledge acquisition and consideration, prior to feeling ready to provide informed consent to treatment. Some passive decision makers described the cessation of participation in the process, in favour of their decision being directed by their clinician. Direction was either sought or volunteered.

Clinicians' impression of a safeguard in more directive decision making

In an environment where there are increasing numbers of choices available to treat women with breast cancer, it has been argued that 'the expert' clinician should provide treatment plans rather than options. Some low MR unit doctors' expressed this within their interviews. Their rationale being that; patients were not equipped to receive and process the volume of information required to make a treatment decision; their belief that patients possessed predominantly passive PDMSs; and their belief that most patients possessed the same dislike of mastectomy as they did. Some of these consultants consented patients at the first consultation discussing diagnosis and treatment. They argued establishing consent for treatment in this way was acceptable, as patients would voice their disagreement if they did not want the proposed treatment. They felt this provided a safeguard to patients undergoing a treatment they did not want.

This safeguard impression however, was inconsistent with the same clinicians' views about patients' predominantly passive PDMS. The literature and the findings from our patient and clinician interviews suggest their argument is flawed on a number of levels: Firstly it fails to take into consideration the skewed power relationship in favour of the clinician. Secondly, clinicians are the gatekeepers of choices. They identify who receives choices and how they are provided; both of which varied greatly between the units studied. Finally, a knowledge disparity exists between patients and clinicians. Patients at diagnosis have comparatively limited knowledge; they do not necessarily know what the available treatments are, what the processes or timescales of treatment are etc. they also do not know what to ask or query. Under these circumstances it seems contradictory to presume patients (who the same clinicians feel are uniformed and passive) can be relied on to disagree with the experts' treatment plan; especially if a specific treatment is recommended or presented as a forgone conclusion. We would argue that consent cannot be assumed to be synonymous with the absence of disagreement with clinicians' plans or compliance with them. And suggest that patients requesting information on an alternative from the expert (particularly at the time of diagnosis), requires a very definite and 'active' act on behalf of the patient.

In the light of this we would suggest that if the aim is to encourage greater patient involvement in decision making, clinicians cannot merely be passively permissive of patients deciding their treatment, but actively permit and empower it; through explicit framing of the consultation and decision-making process, as one in which the patients' choice is the norm, and patients are provided understandable, comprehensive information, time and decision-making support. Without the adoption of this approach, only the most active patients are likely to get the opportunity to play a role or the role they want, in choosing their treatment.

How should breast surgery decisions be made? Getting it 'right' for patients

Based on the information from this study and evidence from the literature, we need to ask: How should treatment decisions be made where there is no definitively superior treatment option or true equipoise between treatments? As a consequence of the demonstrable benefits of patient involvement in decision making(Andersen, Bowen, Morea, Stein, & Baker 2009;Deadman, Leinster, Owens, Dewey, & Slade 2001;Fallowfield, Hall, Maguire, Baum, & A'Hern 1994a;Fallowfield, Hall, Maguire, & Baum 1990;Fallowfield, Hall, Maguire, Baum, & A'Hern 1994b;Hack, Degner, Watson, & Sinha 2006;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Keating, Guadagnoli, Landrum, Borbas, & Weeks 2002;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Lam, Fielding, Chan, Chow, & Ho 2003;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Morris & Ingham 1988;Morris & Royle 1987;Moyer 1997;Moyer & Salovey 1998;Schou, Ekeberg, Ruland, & Karesen 2002;Stewart 1995;Street, Jr. & Voigt 1997;Wilson, Hart, & Dawes 1988;Wolberg 1990) and clear evidence that patients' desire increasing involvement in decision making,(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996;Bilodeau & Degner 1996;Coulter & Jenkinson 2005;Davey et al. 2002;Davey et al. 2004;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Flynn, Smith, & Vanness 2006;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Lam, Fielding, Chan, Chow, & Ho 2003;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005;Mastaglia & Kristjanson 2001;Richards & Coulter 2007;Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010;Wallberg, Michelson, Nystedt, Bolund, Degner, & Wilking 2000) national guidelines set out by the UK's NHS, Royal Colleges and regulatory bodies such as the GMC, are unambiguous in stating that patients should undergo a process of informed consent. This necessitates the provision of tailored information along with the opportunity to ask questions and achieve understanding before consenting can take place.(Association of Breast Surgery at BASO 2009;General Medical Council 2008;National Collaborating Centre for Cancer 2009;Scarth, Cantin, & Levine 2002a;Scarth, Cantin, & Levine 2002b) It implies adoption of either a shared or informed choice model of decision making. This and other studies demonstrate that despite this, substantial barriers still exist to their patients' more autonomous participation in decisions about their breast cancer treatment.

Evidence of paternalism persists within the UK's NHS, despite the cry of 'nothing about me without me'(Coulter 2011a;Coulter 2011b;Delbanco et al. 2001) and the focus on patient engagement in healthcare decisions;(Secretary of State for Health 2011) as illustrated by this study and demonstrated consistently by national(Coulter 2011a) and international reports.(Coulter 2006;Davis et al. 2012) For example, the results of national patient surveys conducted by the Care Quality Commission suggest at least 50% of those undergoing hospital treatment, experience a more passive decision making experience than preferred, and there is no evidence of improvement in this over time(Coulter 2011a;Richards & Coulter 2007) Viewed internationally, the UK was ranked lowest amongst affluent nations in the realm of patient–centred care and patient engagement in healthcare, by the 2010 Commonwealth Fund survey.(Davis, Schoen, & Stremikis 2012) This evidence demonstrates that if we are to truly move from a paternalistic style of healthcare decision-making and clinician-centred care, to one where patients are central partners in the process, clinicians need to recognise the powerful impact they can have over patients and transform their interactions with them. They need to do more than passively permit patients' more autonomous involvement in decision-making. They also need to overcome organisational barriers to patient-centeredness(Davies and Cleary 2005) and engage in changing the culture of decision making at individual health provider and clinician level; to provide genuine choices and develop environments which are conducive to patients' comfortable participation in healthcare decisions.

However, we also need to ensure the 20% minority who have a passive PDMS also experience optimised decision making experiences; which may be more or less autonomous. There is evidence that an active DMS per se can provide a beneficial impact on patients even if it is not the preferred DMS.(Bruera, Willey, Palmer, & Rosales 2002;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Hack, Degner, Watson, & Sinha 2006;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Keating, Guadagnoli, Landrum, Borbas, & Weeks 2002;Lam, Fielding, Chan, Chow, & Ho 2003;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005;Mastaglia & Kristjanson 2001;Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010) This study also confirms positive impact of decision involvement among the majority of passive; contingent of their possession of the prerequisites decision making, experiencing a patient-centred approach and perceiving they had adequate support during the process. Many of this patient subgroup discussed their co-existing preferences for passivity in decision making and the receipt of a treatment tailored to their particular preferences. They recognised limitations in clinicians' being able to accurately tailor recommendations to their unique set of preferences, concerns and needs. Even though more autonomous decision making can be beneficial among passive patients, there is also evidence that those who undertake their preferred role in decision making receive most benefit from it(Charles, Whelan, & Gafni 1999a;Keating, Guadagnoli, Landrum, Borbas, & Weeks 2002;Lam, Fielding, Chan, Chow, & Ho 2003;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005) (Charles, Whelan, & Gafni 1999a)and that undertaking a more active role than preferred can result in a negative impact.(Lam, Fielding, Chan, Chow, & Ho 2003) And a minority of patients with a passive PDMS participating in this study, described very negative reactions to their forced autonomous involvement in decision making.

Considering all the evidence, we suggest it the most appropriate course is to tailor decision making experiences to patients' individual preferences; respecting their rights as an individual to adopt whichever role they feel most comfortable in. Ultimately, the most important consideration is that although clinicians provide treatment, it is the patient who has to live with it and their memories of the experience. Therefore optimising patients' experience of their cancer decision making and treatment is important in seeking to enhance QoL in survivorship. Especially as the physical and psycho-social impacts will have a more protracted effect as life expectancy increases; with predictions of 64% of UK women diagnosed with breast cancer at this time point living 20 years, compared with only 44% diagnosed in the early 1990s.(Blamey, Ellis, Pinder, Lee, Macmillan, Morgan, Robertson, Mitchell, Ball, Haybittle, & Elston 2007;Coleman, Babb, Damiecki, Grosclaude, Honjo, Jones, Knerer, Pitard, Quinn, Sloggett, & De Stavola 1999;Coleman, Rachet, Woods, Mitry, Riga, Cooper, Quinn, Brenner, & Esteve 2004;Hack, Degner, Watson, & Sinha 2006;Mandelblatt, Edge, Meropol, Senie, Tsangaris, Grey, Peterson, Jr., Hwang, Kerner, & Weeks 2003;Office of National Statistics 2005;Rachet, Maringe, Nur, Quaresma, Shah, Woods, Ellis, Walters, Forman, Steward, & Coleman 2009;Street, Jr. & Voigt 1997)

The findings of predominant participation in decision making in our study may reflect a move away from the traditional paternalistic model of healthcare decision-making among our group of clinicians. But, although rates of DMS concordance were higher than among previous studies and those preferring an active role had 91% (131/144) concordance, those preferring a collaborative or passive DMS were less likely to achieve their preferred role in treatment selection. It could be argued that all the approaches described within this study were equally doctor/clinician-centred and paternalistic, as they were biased toward the adoption of the clinicians' favoured management (BCT or greater patient autonomy), rather being tailored to individual patient preferences. Tailoring and optimising experiences and treatments to preferences is particularly important within situations where patients' preferences vary but no single treatment is associated with a definitively more favourable outcome; as in the treatment of breast cancers less than 50mm diameter. Two issues may hinder this; the accurate and timely identification of patients' decision making preferences and clinicians' flexibility and tailoring of their decision making approaches and consultation styles to tailor patients' experiences effectively to their individual DMS.

Reliably gauging patients' PDMS at the time this information is required remains a difficult issue, fraught with the potential for misallocation – as demonstrated by previous studies.(Bruera, Sweeney, Calder, Palmer, & Benisch-Tolley 2001;Bruera, Willey, Palmer, & Rosales 2002;Butow, Devine, Boyer, Pendlebury, Jackson, & Tattersall 2004;Gysels & Higginson 2007;Hughes 1993;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;O'Connor, Stacey, Entwistle, Llewellyn-Thomas, Rovner, Holmes-Rovner, Tait, Tetroe, Fiset, Barry, & Jones 2003b;Rothenbacher, Lutz, & Porzsolt 1997;Strull, Lo, & Charles 1984) There has been a suggestion that educating clinicians about patients' more autonomous involvement in decision making can improve their willingness to engage patients in the process and might as a consequence improve DMS identification.{Lewin, 2001 1500 /id} However, we suggest there remains a potentially substantial hindrance to effective PDMS identification demonstrated by our study; that patients' PDMS are not necessarily pre-determined, obvious (even to patients) at diagnosis, or fixed; but instead are determined by the combination of patients' preconceptions of the decision making encounter and their experiences with clinicians. It also demonstrated that their PDMS can adapt as they recover from the initial shock of their diagnosis. Making a reliable assessment in this context is perhaps additionally hampered by, clinicians trying to gauge these during consultations in time-pressured clinics while providing patients with a potentially life threatening diagnosis of cancer. We suggest providing recommendations or direction at an early stage in the decision making process should be avoided, due to difficulty in accurately identifying these PDMS and knowledge of patients acquiesce to clinicians' recommendations;(Gort, Broekhuis, Otter, & Klazinga 2007;Johnson, Roberts, Cox, Reintgen, Levine, & Parsons 1996;Katz, Lantz, & Zemencuk 2001;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Morrow, Jagsi, Alderman, Griggs, Hawley, Hamilton, Graff, & Katz 2009;Nold, Beamer, Helmer, & McBoyle 2000;Schou, Ekeberg, Ruland, & Karesen 2002;Smitt & Heltzel 1997) which can expose them to a greater risk of subsequent regret(Fallowfield, Hall, Maguire, & Baum 1990;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Schou, Ekeberg, Ruland, & Karesen 2002) dissatisfaction (Deadman, Leinster, Owens, Dewey, & Slade 2001;Fallowfield, Hall, Maguire, Baum, & A'Hern 1994a;Hack, Degner, Watson, & Sinha 2006;Moyer 1997;Moyer & Salovey 1998;Stewart 1995;Street, Jr. & Voigt 1997) and worse psychological recovery.(Andersen, Bowen, Morea, Stein, & Baker 2009;Deadman, Leinster, Owens, Dewey, & Slade 2001;Fallowfield, Hall, Maguire, & Baum 1990;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Morris & Ingham 1988;Schou, Ekeberg, Ruland, & Karesen 2002) We suggest it is appropriate to defer and careful target the provision of directive information and recommendations to the minority in whom a passive PMDS is confirmed. BCNs provide a crucial role among these patients; supporting more autonomous decision making experiences (providing reiteration of information and decision support) and providing psychological support, either until patients' treatment decision or confirmation of their passivity and provision of a treatment plan.

Based upon current evidence from the published studies and the findings of this study, we believe that including patients in appropriately supported shared decision making is the most appropriate way forward. But the concept needs to be clarified and adapted to build in flexibility. The classic description of the decision-making approaches is provided in the introduction and illustrated in figure 1.2. Shared decision making involves the two-way exchange information and incorporates decision making support. The decision making approaches have been classical described as discrete entities, but if adopted optimally, the shared approach should provide sufficient flexibility to permit its tailored application. But the key is clinicians correctly and confidently identifying patients' PDMS. If individuals' PDMS are correctly identified, clinicians should be able to appropriately guide the shared decision making approach toward a version more akin to informed choice or the paternalistic approach, dependent on patients' PDMS. This would permit the appropriate modification of decision making to the individual patient, rather than the experience being determined by clinicians' preferences, or patients' initial responses and lack of knowledge. Figure 9.2 illustrates how clinician and patient factors interact to influence decision making, and figure 9.3 outlines a proposed model of the decision making approach for the surgical treatment of breast cancer based upon the existing evidence and findings of this programme of research.

Within the process of determining patients' treatment, patients need to be provided with time. Time is a frequently sited barrier to patients' inclusion in decision making.{Gravel, 2006 1167 /id;Legare, 2008 1165 /id} This study found as others have before, that breast cancer patients have high information needs,(Bilodeau & Degner 1996;Blanchard, Labrecque, Ruckdeschel, & Blanchard 1988;Butow, Kazemi, Beeney, Griffin, Dunn, & Tattersall 1996;Cassileth, Zupkis, Sutton-Smith, & March 1980;Chen, Tao, Tisnado, Malin, Ko, Timmer, Adams, Ganz, & Kahn 2008;Davison, Degner, & Morgan 1995;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Fujimori & Uchitomi 2009;Galloway, Graydon, Harrison, Evans-Boyden, Palmer-Wickham, Burlein-Hall, Rich-van der Bij, West, & Blair 1997;Graydon, Galloway, Palmer-Wickham, Harrison, Rich-van der Bij, West, Burlein-Hall, & Evans-Boyden 1997;Hack, Degner, & Dyck 1994;Jenkins, Fallowfield, & Saul 2001;Jones, Pearson, McGregor, Gilmour, Atkinson, Barrett, Cawsey, & McEwen 1999;Luker, Beaver, Leinster, & Owens 1996a;Meredith, Symonds, Webster, Lamont, Pyper, Gillis, & Fallowfield 1996;Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till 1989;Vogel, Bengel, & Helmes 2008a) but their 'shock' at the time of diagnosis when they receive most of the information about treatment choices, hinders the absorption and processing of information. Most patients described needing time (including that away from the clinical environment) to start to adjust to their diagnosis before they were able to utilise a lot of the information and engage in decision making. Some desired further clinician consultations following this initial period, to re-explore their options and needs. Those providing and those engaging in more autonomous decision making, described the benefits of time; unrushed time for consultations; time for reiteration and exploration of information and patient needs following the immediacy of their diagnosis; time to consider the options; and to complete the decision making process and establish consent for treatment. Crucially, patients needed to be aware of the time for this, to provide confidence and a framework for their decision making journey. As well as the provision of additional time with BCNs, the incorporation of adjuncts to support patients' information exploration and decision-making (such as evidence-based communication tools{Trevena, 2006 1490 /id} and DSIs(Collins, Moore, Clay, Kearing, O'Connor, Llewellyn-Thomas, Barth, Jr., & Sepucha 2009;Molenaar et al. 2001;O'Connor, Stacey, Entwistle, Llewellyn-Thomas, Rovner, Holmes-Rovner, Tait, Tetroe, Fiset, Barry, & Jones 2003b;Waljee et al. 2007;Whelan et al. 2004)) may be of assistance in extending patients' time receiving a reiteration of information and exploring the options. The incorporation of such technologies is likely to become increasingly relevant as the number of potential options available to patients and complexity of treatments increases.

Given the current economic climate, it is reasonable to suppose that the clinician workload-manpower balance may deteriorate and time-pressures increase, as cost saving exercises promote the more efficient 'processing' of patients. If this occurs within this speciality, there may be a pressure for breast units to reduce patients' opportunity to spend the necessary time with their clinicians (possibly over multiple consultations) to explore and achieve more autonomous decisions. This may risk clinicians being pushed towards adopting the more time and manpower-efficient directive or paternalistic consultation approach, which requires less time and clinician support. The practice of establishing consent at a very early stage (as seen in the low MR unit) would seem to deny patients a meaningful role in decision making. Decisions made within such a short timeframe are in most, are more likely to reflect more than clinicians' preferences; as exemplified by some patients who tried to subsequently retract their consent. To minimise the negative impact of patients experiencing time-pressure, a balance needs to be achieved between shortening timelines to treatment associated with achieving hospital targets, and providing patients with sufficient time to negotiate the decision making process.

FIGURE 9.2 How clinician and patient factors influence decision making

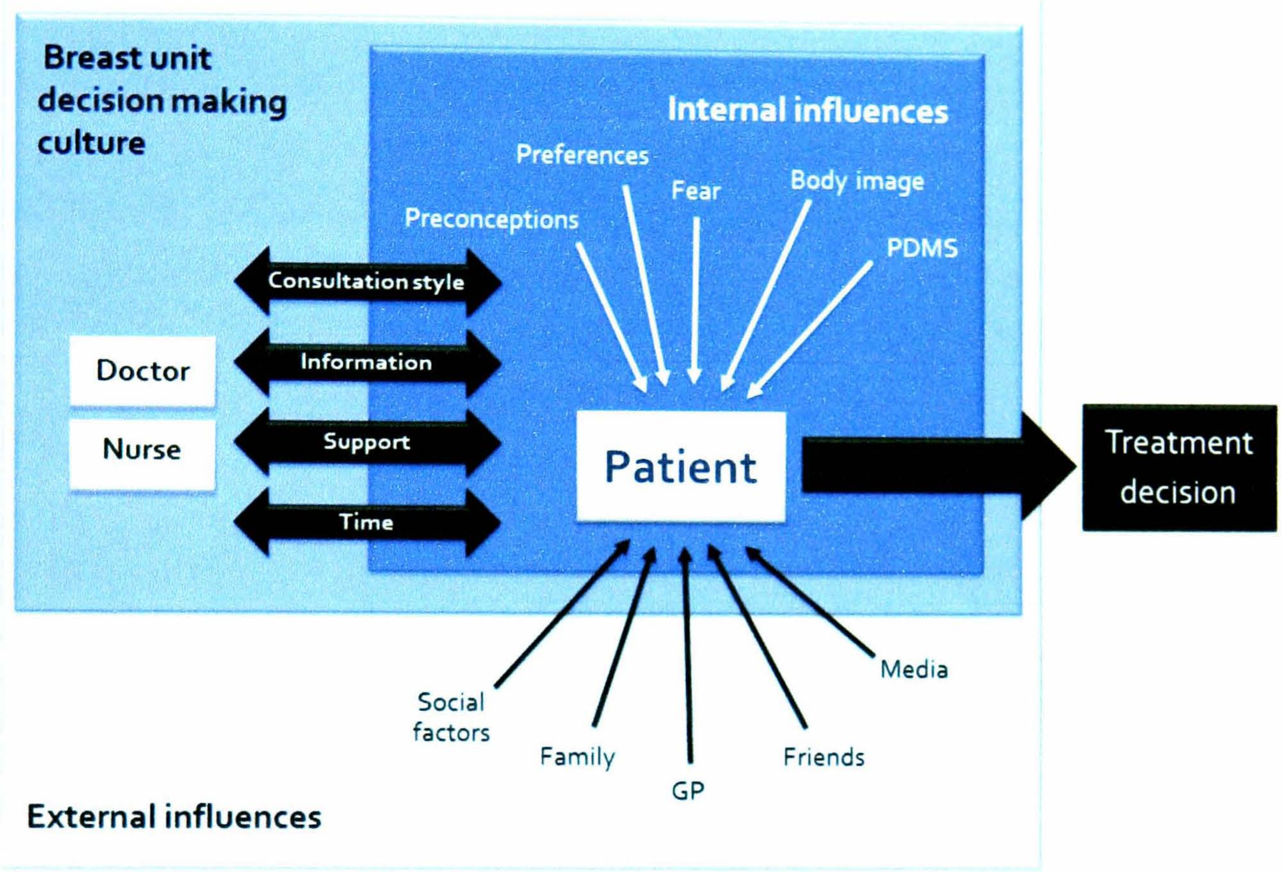
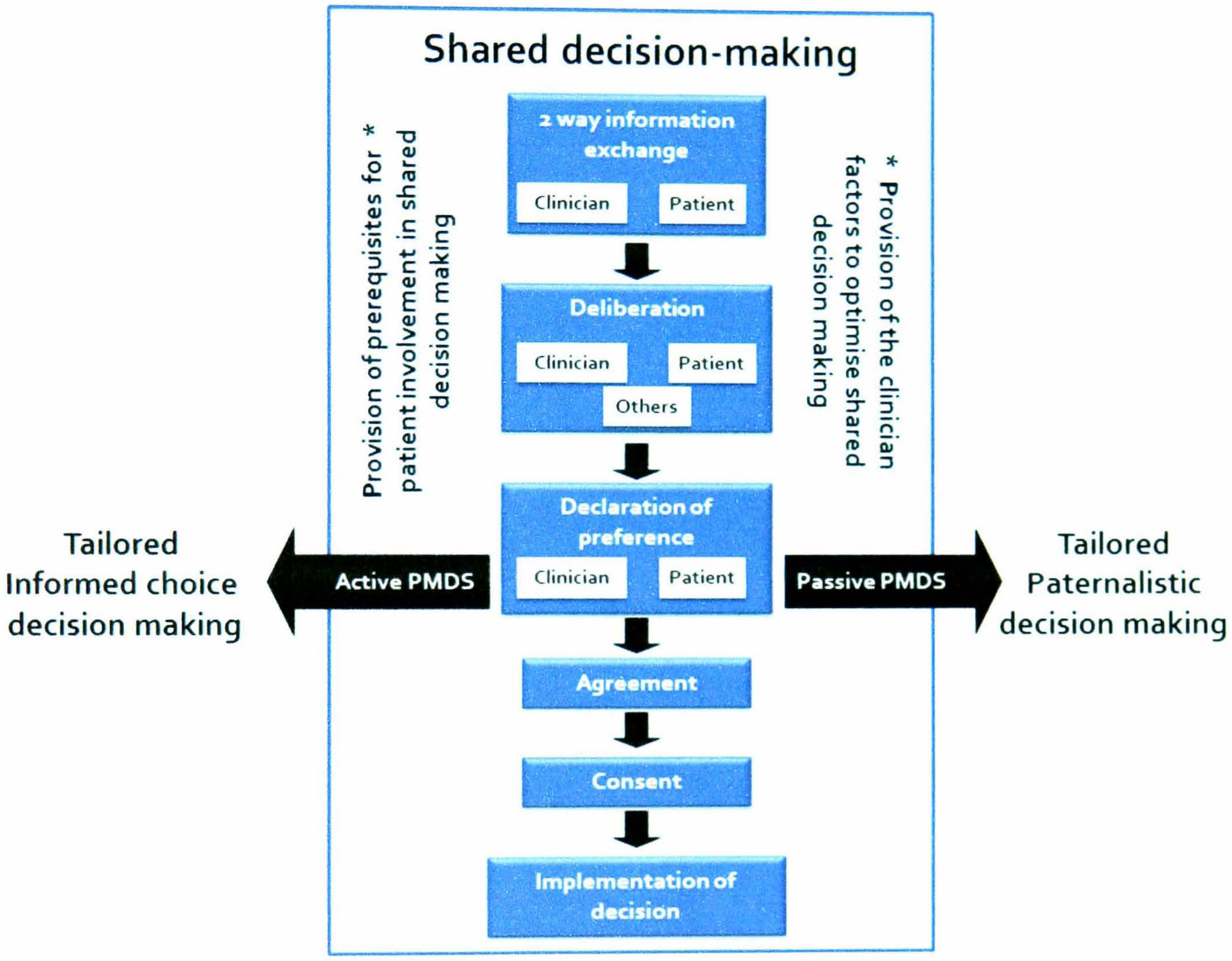


FIGURE 9.3 Proposed model the decision making approach for the surgical treatment of breast cancer



*see tables 9.1 and 9.2

TABLE 9.1 Summary of the prerequisites for patient involvement in shared decision making

Awareness of the availability of patient involvement in decision making & the options	
Perceive provided a genuine choice	
Understand why there is a choice	• Rationale for a more autonomous role in the process
Possess tools for informed decision making	• Information/knowledge • Time • Support
Decision making & psychological support	• Clinicians, especially BCNs
Time	• Realistic timeframe for decision making • Unrushed consultations & accessibility • Time away from the clinical environment
Safety	• Of the options • Of the decision making environment • What will happen if unable make decision
Confidence	• For decision making in a supported environment

TABLE 9.2 Summary clinician factors to optimise shared decision making

Minimise skewed power-relationship	
Provide prerequisites for patient decision making	
Communication skills	• Good communication skills; active listening etc. • Patient-centred approach • Tailor communication & information
Portray	• Caring • Traditional expert abilities
Accurately identify PDMS	• Differentiate between initial reactions & passive PDMS
Information	• Clear • Plain English • Non-biased full information • Reiterate (within & over consultations)
Check understanding	
Provide tools to reiterate pertinent points of tailored information	
Defer direction/recommendations till later in the decision making process	

Chapter 10

Implications

Suggestions in response to the study findings

Practice and policy issues

The evidence from the published literature and this study cause us to question how we should respond. Some of the issues relate to practice and policy.

- Should we accept and define a 'correct' MR or an acceptable range?

The UK Department of Health previously proposed adopting BCT: MR ratios as performance indicators of breast unit practice to discourage treatment variation.(Department of Health 2001b) These have not been adopted so far in the UK; possibly due to the potential difficulty in defining a 'correct' MR or acceptable range. The ideal MR could only be established having when we know what ideal practice is; more autonomous or more paternalistic decision making. The ideal MR or range could then be calculated from units confirmed to provide the ideal practice. This might prove a difficult.

Perhaps the more fundamental issue to consider is that, this is probably too simplistic a solution. Focussing on achieving a specific numeric target would be unlikely to promote best practice or a more patient-centred tailored approach to consultations and decision making. Target achievement usually becomes the focus to the exclusion of other factors. We would suggest this focus might force breast team practice away from a more tailored patient-centred approach; especially if units are penalised for failing to achieve the target.

- Should patients only have mastectomy if breast conservation is contraindicated?

Some (like many of the low MR unit clinicians) would argue that the expert clinician should recommend treatment plans, as patients are not equipped to receive and process the volume of complex information required to come to a genuinely informed decision. Some clinicians are also likely to feel strongly that patients should only have a mastectomy if breast conservation is contraindicated We would suggest such approaches contradict current evidence demonstrating that patients want more control over their treatment decisions and prefer a patient-centred approach. Based on this we would suggest clinicians need to be informed this data demonstrating individuals benefit from undergoing their preferred treatment; with improved satisfaction, aids psychologically adjustment and reduces regret.

The way forward

The current evidence from published research and this study suggest that when there is equivalence in many aspects of BCT and mastectomy, patients should have the opportunity to participate in supported, but genuine decision making, as this improves psychosocial functioning in both patient and their partners.

Previous studies have demonstrated that clinicians are often unsuccessful at gauging their patients' preferences,(Bilodeau & Degner 1996;Bruera, Sweeney, Calder, Palmer, & Benisch-Tolley 2001;Bruera, Willey, Palmer, & Rosales 2002;Butow, Devine, Boyer, Pendlebury, Jackson, & Tattersall 2004;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Gysels & Higginson 2007;Hughes 1993;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Montgomery & Fahey 2001;O'Connor, Stacey, Entwistle, Llewellyn-Thomas, Rovner, Holmes-Rovner, Tait, Tetroe, Fiset, Barry, & Jones 2003b;Richards, Ramirez, Degner, Fallowfield, Maher, & Neuberger 1995;Rothenbacher, Lutz, & Porzsolt 1997;Strull, Lo, & Charles 1984) and the involvement and empowering patients of patients in decision making, requires a reciprocal change in clinicians.(Hack, Degner, Watson, & Sinha 2006;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Kaner et al. 2007;Keating, Guadagnoli, Landrum, Borbas, & Weeks 2002;Lam, Fielding, Chan, Chow, & Ho 2003;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005;Street, Jr. & Voigt 1997) This may include the education of clinicians and teams regarding patients' preferences for involvement in decision-making and in some breast units the adopting a new ethos. It will also require a change in consultation styles for some clinicians, from a more prescriptive less open approach, to a more tailored flexible discussion style which encourages and supports patients' more autonomous decision-making. Many patients require time to acquire knowledge, explore their preferences and make a decision. The findings also suggests the adoption of a patient-centred approach with the implementation of shared decision making in a flexible way, is the most appropriate route of decision making. Clinicians would provide reassurance and non-directive information, along with a structure, time and suitable clinician support to facilitate patient decision making. They would additionally utilise active listening skills to tailor information and decision making experiences to patients' preferences. They would defer and carefully target the provision of directive information and recommendations, to the minority who definitely do not want a role in choosing their treatment. This approach should enable clinicians to more reliably provide recommendations based on patients' preferences rather than their own. It should also prevent the disempowering of the majority who can benefit from participating in deciding their treatment.(Andersen, Bowen, Morea, Stein, & Baker 2009;Deadman, Leinster, Owens, Dewey, & Slade 2001;Fallowfield, Hall, Maguire, Baum, & A'Hern 1994a;Fallowfield, Hall, Maguire, & Baum 1990;Fallowfield, Hall, Maguire, Baum, & A'Hern 1994b;Hack, Degner, Watson, & Sinha 2006;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Morris & Ingham 1988;Morris & Royle 1987;Moyer 1997;Moyer & Salovey 1998;Schou, Ekeberg, Ruland, & Karesen 2002;Stewart 1995;Street, Jr. & Voigt 1997;Wilson, Hart, & Dawes 1988;Wolberg 1990) The evidence from this study and others refs also suggests if informed consent is to be achieved, consent for treatment should only be established after an appropriate interim period of consideration. Otherwise consent is more likely to represent (informed) compliance.

Where there is no superior treatment, implementation of the above necessitates clinicians becoming more aware of patient decision-making styles. It may require clinicians to undergo specific advanced communication skills training, with a focus on the provision of reassurance while synchronously providing unbiased equipoise options with full information, incorporating active listening skills and empowering techniques. Clear, robust, flexible support mechanisms need to be in place to routinely assist patients undergoing decision making. Some are also likely to need more time with both their breast teams and social support networks to work through the process of decision-making. In some breast units the structure of the decision making process may need adapting. For example, to provide additional routine consultations between diagnosis and the establishing of consent, and routinely delaying consent to ensure maximal consideration.

There is evidence to suggest that the use of a Decision Support Instrument (DSI) can prove a useful adjunct to the information and support for decision making provided by clinical teams in consultations; assisting knowledge consolidation and option consideration.(Whelan, Levine, Willan, Gafni, Sanders, Mirsky, Chambers, O'Brien, Reid, & Dubois 2004) The routine incorporation of these into clinical practice might provide some of the additional support patients require for genuine involvement in decision making and improve communication within consultations; patient satisfaction with the process and outcome of the decision-making journey; and concordance between PDMS and ADMS for future patients. In a progressively target driven, time pressurised, economically challenged healthcare system, those balancing budgets will seek to implement cost efficient ways to support patients.

However, the implementation of methods to increase patient participation in decision making through instruments like DSIs requires a concurrent change in clinicians to avoid worsening discordance between patients' PDMS and ADMS; as this would risk increasing dissatisfaction and regret. Raising clinicians' awareness of patient DMS through education from the dissemination of information is important. Clinicians need to be made aware of the current status of patient PDMS and their attitudes to decision making, together with how these can impact patients' short and long term satisfaction, regret and adjustment. They also need to be aware of how their consultation approaches and provision of supportive measures can aid patient decision making and achieving a positive outcome from it.

Adopting these changes to practice uniformly should reduce the range and degree of practice variation currently recognised.

Decision making in a changing NHS

If patients are to the come to genuinely informed decisions, rather than merely comply with their expert clinicians, they need to be equipped and supported to receive and process large volumes of complex information. Cancer treatment is constantly evolving. In a speciality like breast cancer, there are an increasing variety of options available to women as new treatments and extended treatment options are introduced; For example neo-adjuvant chemotherapy & reconstructive/oncoplastic techniques including therapeutic mammoplasty, mini-flaps etc. An increase in the number of options makes patient decision making more complicated; as the details about each need to be considered. This strengthens the argument for identifying, defining and adopting best practice.

Wider implications

Although the study was focussed on the surgical management of breast cancer in the context where there is equipoise between the options in question, the findings may prove useful in explaining why treatment variation exists optimise healthcare experiences in other aspects of breast cancer treatment such as immediate and delayed breast reconstruction and in other clinical contexts where practice variation and patients involved in healthcare decision making co-exist; such as caesarean section rates,(Paranjothy et al. 2005) de-functioning ileostomy and reversal rates in colorectal cancer(Koperna 2003) and the management of localised prostate cancer.(Zeliadt et al. 2006) The reported findings could prove beneficial if applied to optimise healthcare experiences in other clinical contexts where patients are asked to be involved in healthcare decision-making.

Chapter 11

Conclusions

Research Questions

To what extent does inter-unit variation in the surgical treatment of breast cancer persist after correction for case-mix?

Statistical significant variation in practice remains following case-mix correction; which was more pronounced among the smallest cancers.

Do clinician preferences influence patients' decision making in breast cancer?

Clinicians' preferences influence patient decision making in breast cancer. Clinicians in this study possessed different perceptions of when patients should be involved in choosing their treatment. They displayed a preference for a specific outcome of decision making (BCT) or a decision making process (more autonomous patient decision making). This dictated the subgroup of patients clinicians provided greater decision making autonomy; influencing the options provided to patients, how information was portrayed, the time and process of patients' decision making experiences.

Although most patients offered the opportunity to engage in deciding their treatment wished to do so, an unexpected minority anticipated this role. Many also described needing time to acquire knowledge and confidence make a decision. As gatekeepers of information and time, clinicians were able to narrow the knowledge and power disparity between themselves and patients to facilitate more autonomous patient decision making or reinforce paternalistic expectations. Patients undergoing more autonomous decision making described **a** more complex informed **process,** with consideration of their preferences in the context of information about the options. These differences were associated with variation in MRs between the breast units.

How do clinicians influence patients' decision making in the light of treatment guidelines?

The majority of clinicians operated within their units' treatment guidelines. However, guidelines were flexible and the different units' clinicians interpreted them differently; specifically, when mastectomy was not indicated on clinical grounds most low MR unit clinicians offered only BCT, whereas the other units provided a choice of BCT or mastectomy.

The triangulated findings of the qualitative and quantitative findings of the study suggest although treatment guidelines and patients' cancer characteristics influenced clinicians' consideration of the options available to individual patients, the options presented to them and their decision making experiences, were influenced by breast units' decision making culture with its central ethos, underlying belief system, (including what the optimum management comprised) and its reinforcing processes; including the process for establishing consent for treatment.

The decision making environment generated by the clinician/unit either reinforced or counteracted patients' preconceptions of passivity and paternalism, and influenced the extent of control of clinicians had over their decisions.

How is patient satisfaction with the decision making experience influenced by the above?

Satisfaction was expressed by most patients, but their reasons varied by unit. Low MR unit patients often expressed satisfaction related to receiving the reassurance of an expert's care; which included recommendation or direction to the 'most appropriate' or 'best' treatment. The other units' patients expressed satisfaction related to the tailored, patient-centred approach of their clinicians. Many patients found the ability to select their preferred treatment a source of satisfaction.

However a small minority who felt 'forced' to undertake a more autonomous or more passive role than desired, voiced marked dissatisfaction. This was exacerbated among active decision makers who in addition did not undergo their preferred treatment.

Primary End Point

To identify the patient and clinician factors influencing choice of surgery in women with breast cancer in Trent.

MR variation is genuine; not an artefact of case-mix and caseload. It is largely due to clinicians' beliefs and preferences which combine to produce a unit ethos and define a decision making culture within breast units. These determine which groups of patients clinicians provide genuine treatment options to, and the form of decision making provided; facilitative to more autonomous patient decision making or directed/paternalistic; sustaining patients' continuing acquiescence.

Closing statement

The shift in modern healthcare provision and decision-making from a paternalistic to a shared model is based on reported evidence of improved psychological outcomes and satisfaction among patients.(Hack, Degner, Watson, & Sinha 2006;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Keating, Guadagnoli, Landrum, Borbas, & Weeks 2002;Lam, Fielding, Chan, Chow, & Ho 2003;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005) Therefore, in clinical contexts where the available options offer no definitive superior clinical benefit, patient preferences are prioritised. This is enshrined in guidelines (Association of Breast Surgery at BASO 2009;General Medical Council 2008;Kaufmann, Morrow, von, & Harris 2010;National Collaborating Centre for Cancer 2009;Scarth, Cantin, & Levine 2002b) and legislation.(Department of Health 2009;Nattinger, Hoffman, Shapiro, Gottlieb, & Goodwin 1996;Nayfield, Bongiovanni, Alciati, Fischer, & Bergner 1994) Women diagnosed with early invasive breast cancer are typical of this group and can be offered the choice between BCT or mastectomy as their primary surgical treatment.

This study was set against the backdrop of persistent widespread variation in MRs, despite the call for patients to be offered treatment options where possible, with no clear explanation for this practice pattern. Employing an inductive process and a mixed methodology, multi-perspective approach, the study investigated variation in hospital breast unit MRs from the key stakeholder perspectives (patient, specialist doctor and BCN) in a single UK region. The study design and findings reflect the complexity of communication and decision making in healthcare. The study reports new findings of the interface between patients and clinicians engaging in treatment discussions and decision making and offers potential explanations for variation in practice. It adds to the existing evidence and provides further information, permitting a fuller description of the prelude to and interface between, patients and specialist clinicians in situations where patients are given choices and treatment varies.

In the region studied, informed consent and (informed) compliance were associated with treatment variation. Lower MRs were associated with the provision of genuine decision making opportunities to a narrower subgroup, and the uptake of BCT reduced with shared informed decision-making. These findings defy the conventional assumption that higher BCT rates arise from a more fully informed group of patients being permitted to choose their own treatment. In this region, Breast clinicians as individuals and as a speciality need to be challenged about what the standard of care or optimum management is for this group of patients; and having considering the evidence, decide whether patients benefit most from being involved in selecting their treatment in the majority of cases, or whether clinicians are the most appropriate stakeholders to make these decisions. Other studies demonstrate the lack of conclusive evidence of the superiority of a specific operation(Fisher, Anderson, Bryant, Margolese, Deutsch, Fisher, Jeong, & Wolmark 2002;Pockaj et al. 2009;van Dongen, Voogd, Fentiman, Legrand, Sylvester, Tong, van der, Helle, van Zijl, & Bartelink 2000;Veronesi, Cascinelli, Mariani, Greco, Saccozzi, Luini, Aguilar, & Marubini 2002) but distinct differences between the two options,(Arndt, Stegmaier, Ziegler, & Brenner 2008;Clarke, Collins, Darby, Davies, Elphinstone, Evans, Godwin, Gray, Hicks, James, MacKinnon, McGale, McHugh, Peto, Taylor, & Wang 2005;Early Breast Cancer Trialists' Collaborative Group 2002;Irwig & Bennetts 1997;Jatoi & Proschan 2005;Moyer 1997;Pockaj, Degnim, Boughey, Gray, McLaughlin, Dueck, Perez, Halyard, Frost, Cheville, & Sloan 2009;van Dongen, Voogd, Fentiman, Legrand, Sylvester, Tong, van der, Helle, van Zijl, & Bartelink 2000) differences in patients' preferences, and convincing evidence of the benefit of involving patients in treatment decision making. In the light of this study's findings and existing evidence, we suggest MRs per se cannot be considered accurate reflections of quality in patient care, and that the rates of specific surgical procedures should not be the focus for improvements in healthcare service delivery and disease management in breast cancer. We suggest the focus should remain on the provision of choice to patients; even though this may result in some units' MRs increasing. Echoing wider societal changes, patients' expectations for decision control in medical care and their views of experts, are likely to change over time. Increasing accessibility of information through the internet and social networking is likely to mean that patients diagnosed with breast cancer in the future, arrive at their diagnosis expecting to choose their treatment, and possessing more information to do so. If this happens clinicians adopting more directive or paternalistic consultations and decision making approaches may find their patients less satisfied with their care; where currently, due to patients' low or non-existing expectations of decision control, most feel satisfied and reassured by their experts deciding what is 'best' for them.

Chapter 12

Future research

The findings of this study contributed to the development of BresDex, an interactive web-based Decision Support Instrument for women with breast cancer; providing patients given a choice of surgery with a supplementary and independent tool to aid the assimilation of information and guide those to explore their preferences and options. This research study was funded by Cancer Research UK and developed by The BresDex group; comprising; Professor Malcolm Reed and Lisa Caldon from the Academic Unit of Surgical Oncology, University of Sheffield; Professor Glyn Elwyn, Professor Adrian Edwards and Dr Rhodri Evans from the Centre for Health Sciences Research at Cardiff University; Dr Joan Austoker and Dr Alison Clements from the Department of Primary Health Care, the University of Oxford; and Mrs Julietta Patnick from NHS Cancer Screening Programmes. The Decision Support Instrument will shortly be available through NHS direct.

Expanding the observational audit performed in this study to examine individual breast unit practice at a national level, incorporating both screening and symptomatic data collected by the newly/imminently changing National Cancer Registries. Performing case-mix adjustment similar to that adopted in this study, with the addition of screening vs. symptomatic route of detection. This would permit the understanding of how much real variation in practice there is in the UK nationally; how much is attributable to chance (in units with low volume practice), cancer characteristics and route of detection. The analysis could incorporate other unit factors such as type of unit (screening unit vs symptomatic vs. mixed, teaching hospital vs. district general hospital), workload, patient-clinician ratio; geographic area/mean deprivation scores etc. provided such data is available.

Expansion of the DCE to breast clinicians on a national level would permit the further elucidation of clinician beliefs and preferences; which this study has demonstrated are associated with clinicians' approach to consultations and decision making. One of the limitations of the study presented here is the relative deficiency of female doctors of all occupational subgroups and the non-consultant grade specialist clinicians as a whole. Including greater numbers of these would assist further understanding of the influence of gender and occupational role on clinician preferences. Such issues are particularly important; as the female consultant group should increase over time consistent with changes in medical school applications women entering surgical specialities; and the non-consultant grade workforce may also increase in the future.

If breast clinician belief and preference data can be linked with their units' breast cancer outcome data, then the data provided by these two studies would permit the analysis of consultants' case-mix adjusted practice styles against their preferences. If possible, the data would be analysed at individual consultant level as well as clinical team level by aggregating clinician preference data at each unit and exploring how this is associated with patients' outcome/surgery choice. For example with three clinicians at a breast unit we would have to aggregate their three individual DMS into a single style and use this in our analysis. By using multilevel modelling on groups of consultants with similar practice patterns and preference demonstrations the study should achieve sufficient power to examine these relationships.

One of the limitations of this study is that though there was demonstrable variation in practice in the region and the units studied represented high, medium and low MR at a regional level, although our low MR unit represents outlying low MR unit practice nationally, the Trent region did contain a unit representative of very high MR rate practice nationally. Conducting a similar study to the one performed but among breast units representing the very high end of the national MRs spectrum (following adjustment of raw MR data for the specific units' case-mix) would permit the exploration of the clinicians' and units' ethos, beliefs, preferences and routine processes which might differentiate the very high MR unit practice from medium and low practice.

It is recognised that the described programme of research relied on predominantly self-reported findings. The remit of the study did not include observation of the actual consultations between patients and clinicians. Therefore no information is provided on the subtleties of verbal versus non-verbal communication or intended versus perceived consultation messages in this context. Understanding decision making where there are options would benefit from further mixed methods research into what it is about communication which determines treatment decisions through the exploration of the subtleties of verbal versus non-verbal communication and intended versus perceived meaning of consultation messages. One way to achieve this would be to conduct a study involving a combination of direct observation of such consultations, together with interviews with both clinicians and patients participating in the consultation. This could be achieved utilising content analysis and the analysis of body language within video recorded interviews utilising tools such as the Medical Interaction Process System (MIPS),(Ford, Hall, Ratcliffe, & Fallowfield 2000) in combination with interviews stimulating reflexivity; incorporating the consultation participants viewing specific elements of their consultation as prompts to facilitate exploration of the content of communication and interpretation of meaning. A longitudinal study adopting the combination approach (including immediately prior and post to diagnosis/initial treatment discussion, during and following treatment decision-making prior to receiving the results of surgery and following the completion of treatment) would provide information on the evolution of decision making and an understanding of how patients' feelings alter based on their experiences.

A current gap in the literature is knowledge of the longitudinal effects of more autonomous patient decision making and directed decision making on patients. With improvements in breast cancer survival rates information on this would be beneficial in confirming whether a particular approach is superior in terms of medium and long patient outcomes; and the others factors influencing these.

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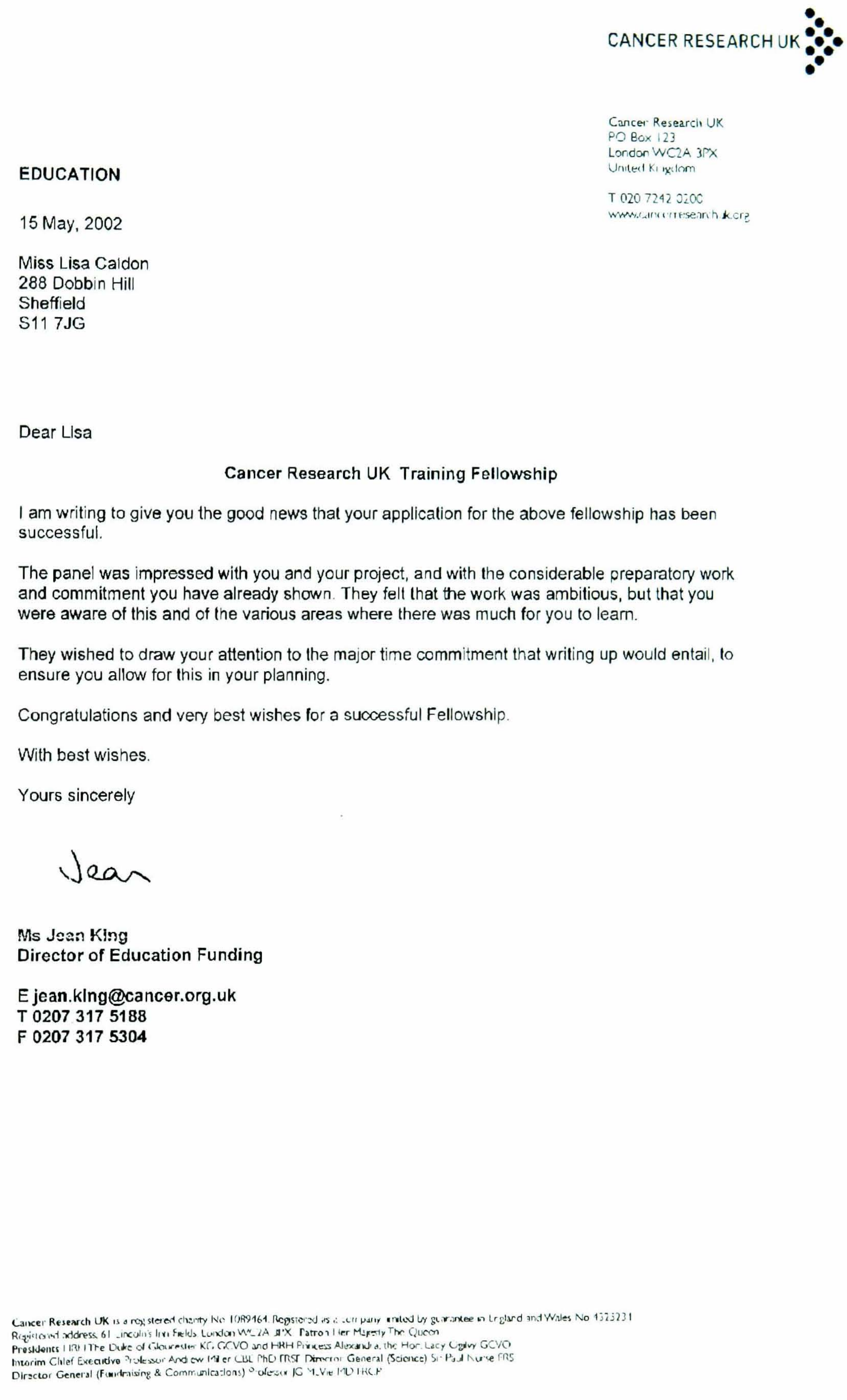
Appendix 1

Funding, Insurance, NCRN trial acceptance

APPENDIX 1.1 Funding: Cancer Research UK and Royal College of Surgeons of England



CANCER RESEARCH UK

Cancer Research UK
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United Kingdom

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www.cancerresearchuk.org

EDUCATION

15 May, 2002

Miss Lisa Caldon
288 Dobbin Hill
Sheffield
S11 7JG

Dear Lisa

Cancer Research UK Training Fellowship

I am writing to give you the good news that your application for the above fellowship has been successful.

The panel was impressed with you and your project, and with the considerable preparatory work and commitment you have already shown. They felt that the work was ambitious, but that you were aware of this and of the various areas where there was much for you to learn.

They wished to draw your attention to the major time commitment that writing up would entail, to ensure you allow for this in your planning.

Congratulations and very best wishes for a successful Fellowship.

With best wishes.

Yours sincerely

Jean

Ms Jean King
Director of Education Funding

E jean.king@cancer.org.uk
T 0207 317 5188
F 0207 317 5304

The Royal College *of* Surgeons *of* England
35-43 Lincoln's Inn Fields, London WC2A 3PE
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Research Board
Chairman: Professor Peter Bell FRCS
Secretary: Martyn Coomer
tel 0207 869 6612
fax 0207 869 6644
e-mail: mcoomer@rcseng.ac.uk

13 June 2002

Miss Lisa Caldon
288 Dobbin Hill
Sheffield
S11 7JG

Dear Miss Caldon,

The Royal College of Surgeons of England Research Fellowship

Project title: *Health care professional factors influencing choice of surgery in breast cancer*

I am delighted to inform you that your application has been successful for a College Surgical Research Fellowship. We received 143 applications and have made 21 awards; you and your colleagues have done very well to achieve this grant amongst some very strong competition. Would you please complete the enclosed form indicating your wish to accept the Research Fellowship, the title of your project and your start date, which should be no later than 1 August 2002. We will let you know the full title of your Research Fellowship i.e. the name of the donor, in the forthcoming weeks.

As you may know, your application has been reviewed by three external referees. Please ring me on 0207 869 6612 for feedback which I am sure you will appreciate.

The terms and conditions of your award were outlined to you at the time of application and have been accepted by yourself and the host institution. However, we enclose a document for your information that we hope will clarify any queries you may have. Your salary and costs will be administered by the host centre and invoiced quarterly in arrears to the College. You will need to liaise with Dr J Pursglove in the finance department of your host institution to ensure that the department is also fully aware of your start date and salary scale. Please let me know if you need any assistance with this. There is also a Research Training Support Grant of up to £3000 – you and your supervisor should complete and sign the enclosed form. The costs should then be included with the salary in arrears invoice.

We also enclose two leaflets for your information. One is an outline of what to expect from your supervisor and the other offers information on our library services.

It is a condition of acceptance of the Research Fellowship that you produce a final report for the College and we will contact you nearer the time with regard to this.

Advancing Surgical Standards
Registered Charity No. 212808

To assist in advertising the Research Fellowship Scheme it would be much appreciated if you would kindly show the enclosed slide at any presentation you may give relating to this award and please also acknowledge the College on any posters you may be producing from the work. If you would prefer the slide sent to you via email in a Powerpoint format please ring Bumbi Singh, Research, on 0207 869 6611 or email research@rcseng.ac.uk.

✓ 21/6/02 .

We are keen to maintain and enhance the profile of the Research Fellowship Scheme throughout the U.K. and abroad; as part of this exercise we need to arrange for you to be photographed by the College photographer, John Carr. Please arrange to see John within the next few months as it is very important that these photographs are taken before the autumn for fundraising purposes– he can be contacted on 020 7869 6188.

Finally, as part of the Research Fellowship we offer you the opportunity to take part in a three-day Research Methods Course; the course is held twice a year, in October and March usually at a site external to the College and we will be in touch with you over the summer with the dates. In addition, we will invite you to be presented with your diploma at a Diplomates Ceremony held in January or July each year.

Again, many congratulations on gaining the Research Fellowship. Please let me know if I can be of any further help.

Every good wish.

Yours sincerely

Martyn Coomer

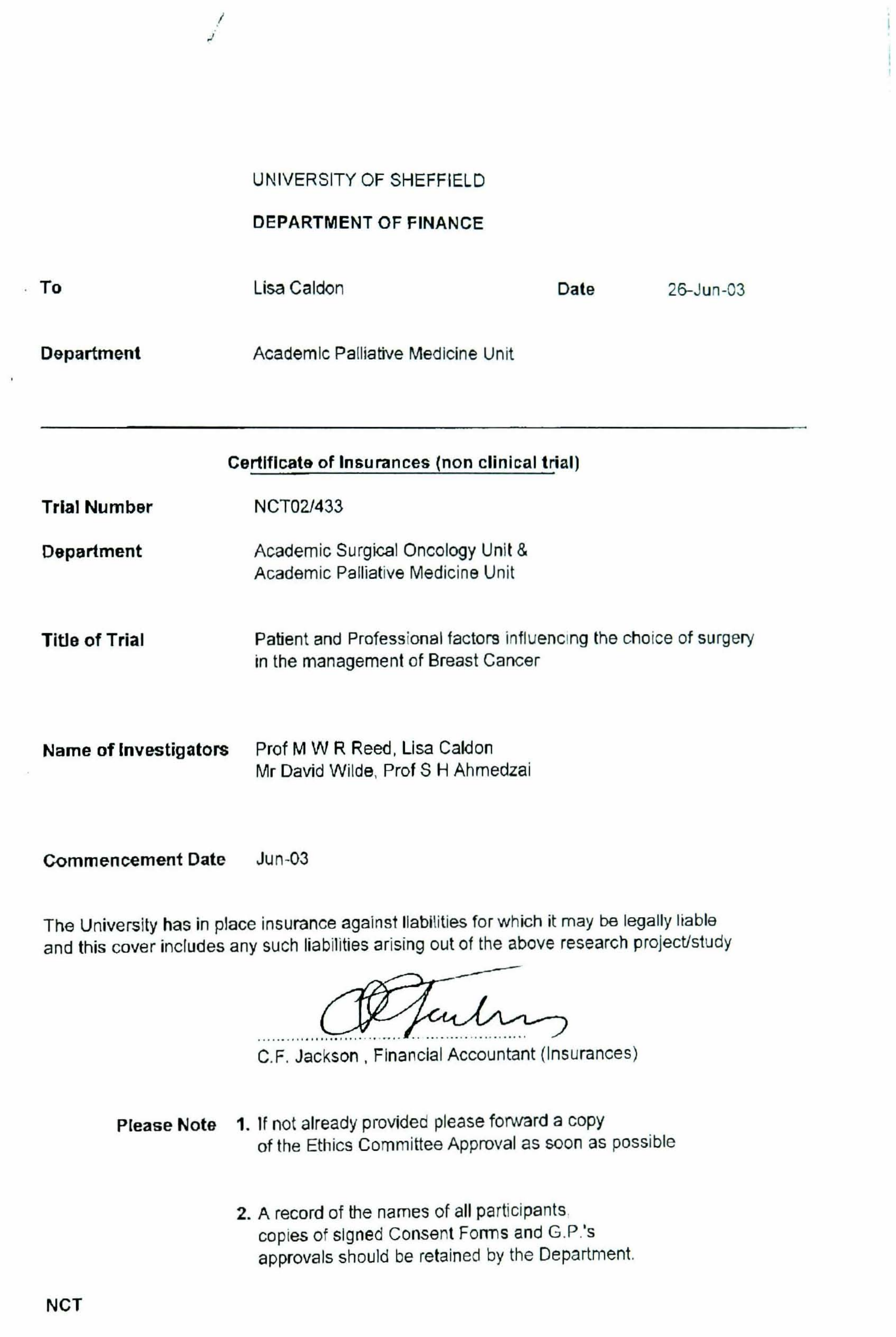
Martyn Coomer
Secretary
Research Board

Enc. – Form, Supervisor information, library services, terms and conditions and slide.

Copy to:
Mr M Reed
Dr J Pursglove
Mr P Mason, Finance Department, RCS
John Carr, RCS, Photographic Department

V

APPENDIX 1.2 Certificate of insurance



UNIVERSITY OF SHEFFIELD

DEPARTMENT OF FINANCE

To	Lisa Caldon	**Date**	26-Jun-03
Department	Academic Palliative Medicine Unit		

Certificate of Insurances (non clinical trial)

Trial Number	NCT02/433
Department	Academic Surgical Oncology Unit & Academic Palliative Medicine Unit
Title of Trial	Patient and Professional factors influencing the choice of surgery in the management of Breast Cancer
Name of Investigators	Prof M W R Reed, Lisa Caldon Mr David Wilde, Prof S H Ahmedzai
Commencement Date	Jun-03

The University has in place insurance against liabilities for which it may be legally liable and this cover includes any such liabilities arising out of the above research project/study

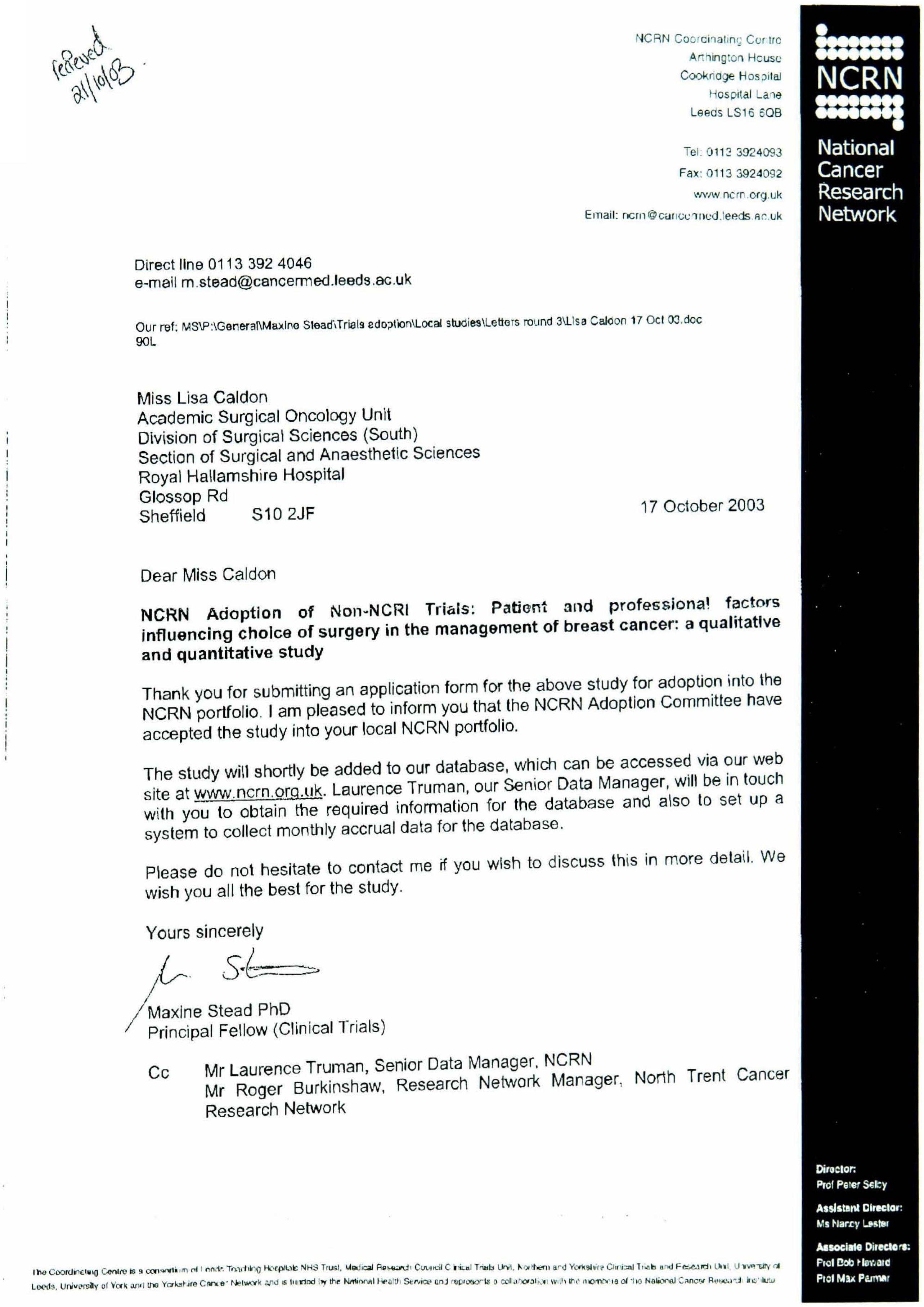
C.F. Jackson , Financial Accountant (Insurances)

Please Note

1. If not already provided please forward a copy of the Ethics Committee Approval as soon as possible
2. A record of the names of all participants copies of signed Consent Forms and G.P.'s approvals should be retained by the Department.

NCT

APPENDIX 1.3 Non-NCTI Clinical Trial registration acceptance



recieved
21/10/03

NCRN Coordinating Centre
Arthington House
Cookridge Hospital
Hospital Lane
Leeds LS16 6QB

Tel: 0113 3924093
Fax: 0113 3924092
www.ncrn.org.uk
Email: ncrn@cancermed.leeds.ac.uk

NCRN
National
Cancer
Research
Network

Direct line 0113 392 4046
e-mail m.stead@cancermed.leeds.ac.uk

Our ref: MS\P:\General\Maxine Stead\Trials adoption\Local studies\Letters round 3\Lisa Caldon 17 Oct 03.doc
90L

Miss Lisa Caldon
Academic Surgical Oncology Unit
Division of Surgical Sciences (South)
Section of Surgical and Anaesthetic Sciences
Royal Hallamshire Hospital
Glossop Rd
Sheffield S10 2JF

17 October 2003

Dear Miss Caldon

NCRN Adoption of Non-NCRI Trials: Patient and professional factors influencing choice of surgery in the management of breast cancer: a qualitative and quantitative study

Thank you for submitting an application form for the above study for adoption into the NCRN portfolio. I am pleased to inform you that the NCRN Adoption Committee have accepted the study into your local NCRN portfolio.

The study will shortly be added to our database, which can be accessed via our web site at www.ncrn.org.uk. Laurence Truman, our Senior Data Manager, will be in touch with you to obtain the required information for the database and also to set up a system to collect monthly accrual data for the database.

Please do not hesitate to contact me if you wish to discuss this in more detail. We wish you all the best for the study.

Yours sincerely

Maxine Stead PhD
Principal Fellow (Clinical Trials)

Cc Mr Laurence Truman, Senior Data Manager, NCRN
Mr Roger Burkinshaw, Research Network Manager, North Trent Cancer Research Network

Director:
Prof Peter Selby

Assistant Director:
Ms Nancy Lester

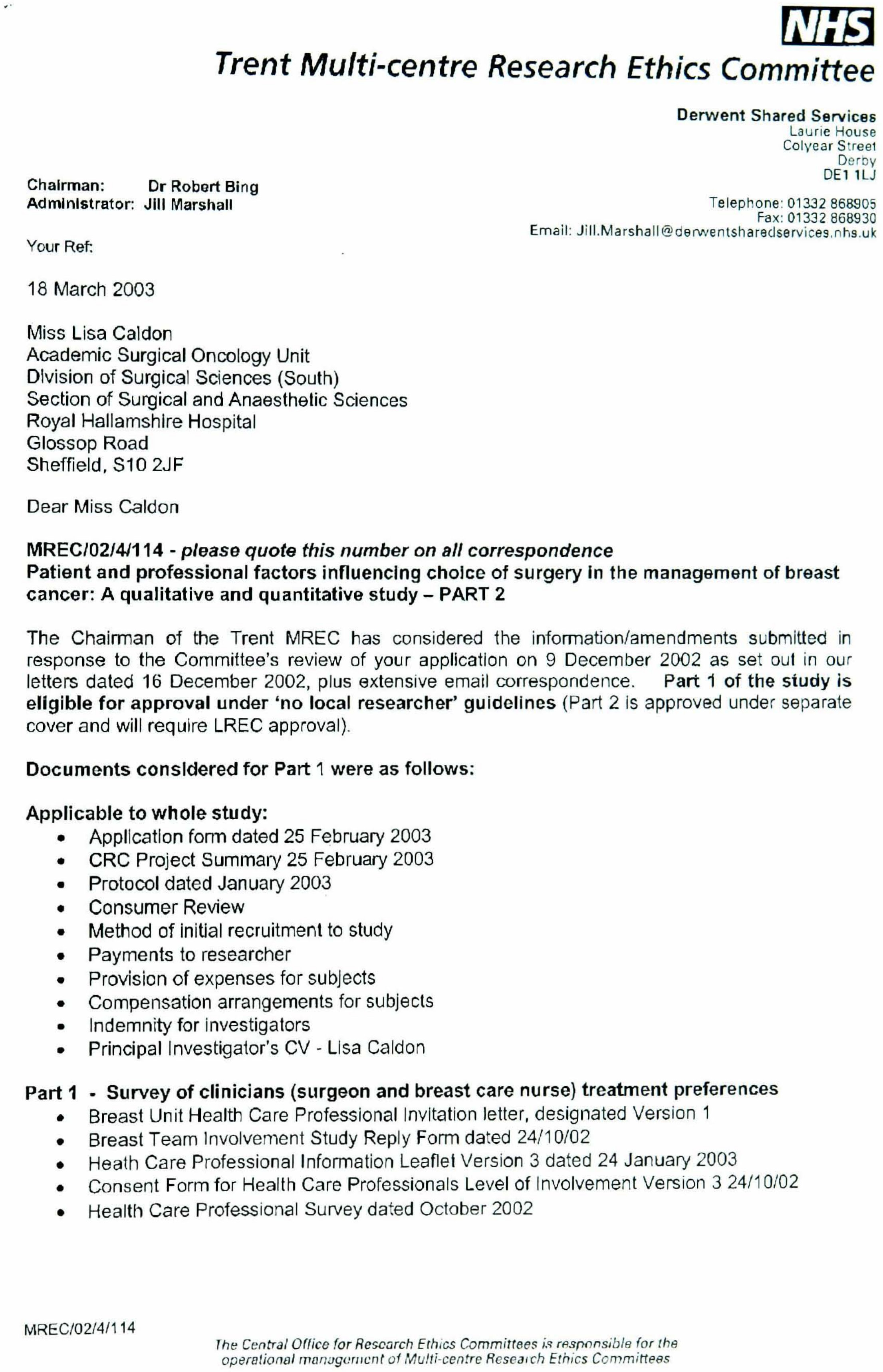
Associate Directors:
Prof Bob Haward
Prof Max Parmar

The Coordinating Centre is a consortium of Leeds Teaching Hospitals NHS Trust, Medical Research Council Clinical Trials Unit, Northern and Yorkshire Clinical Trials and Research Unit, University of Leeds, University of York and the Yorkshire Cancer Network and is funded by the National Health Service and represents a collaboration with the members of the National Cancer Research Institute

Appendix 2

Ethics and governance documents

APPENDIX 2.1 Multi-Centre Research Ethics approval letters



NHS

Trent Multi-centre Research Ethics Committee

Derwent Shared Services
Laurie House
Colyear Street
Derby
DE1 1LJ

Telephone: 01332 868905
Fax: 01332 868930
Email: Jill.Marshall@derwentsharedservices.nhs.uk

Chairman: **Dr Robert Bing**
Administrator: **Jill Marshall**

Your Ref:

18 March 2003

Miss Lisa Caldon
Academic Surgical Oncology Unit
Division of Surgical Sciences (South)
Section of Surgical and Anaesthetic Sciences
Royal Hallamshire Hospital
Glossop Road
Sheffield, S10 2JF

Dear Miss Caldon

MREC/02/4/114 - *please quote this number on all correspondence*
Patient and professional factors influencing choice of surgery in the management of breast cancer: A qualitative and quantitative study – PART 2

The Chairman of the Trent MREC has considered the information/amendments submitted in response to the Committee's review of your application on 9 December 2002 as set out in our letters dated 16 December 2002, plus extensive email correspondence. **Part 1 of the study is eligible for approval under 'no local researcher' guidelines** (Part 2 is approved under separate cover and will require LREC approval).

Documents considered for Part 1 were as follows:

Applicable to whole study:

- Application form dated 25 February 2003
- CRC Project Summary 25 February 2003
- Protocol dated January 2003
- Consumer Review
- Method of initial recruitment to study
- Payments to researcher
- Provision of expenses for subjects
- Compensation arrangements for subjects
- Indemnity for investigators
- Principal Investigator's CV - Lisa Caldon

Part 1 - Survey of clinicians (surgeon and breast care nurse) treatment preferences

- Breast Unit Health Care Professional Invitation letter, designated Version 1
- Breast Team Involvement Study Reply Form dated 24/10/02
- Heath Care Professional Information Leaflet Version 3 dated 24 January 2003
- Consent Form for Health Care Professionals Level of Involvement Version 3 24/10/02
- Health Care Professional Survey dated October 2002

The members of the MREC present agreed that there is no objection on ethical grounds to the proposed study. I am, therefore, happy to give you our **approval under Section C of the DoH "No local researcher" guidelines (November 2000 version 2) for Part 1 only,** on the understanding that you will follow the conditions of approval set down below. The project must be started within three years of the date on which MREC approval is given.

While undertaking the review of your application the MREC noted the research involves the establishment of a new disease or patient database for research purposes with no patient contact. **For this reason you are not required to notify any LRECs when undertaking Part 1 of the study.**

MREC Conditions of Approval

- The protocol approved by the MREC is followed and any changes to the protocol are undertaken only after MREC approval.
- The MREC would expect to see a copy of any finalised questionnaires before they are used.
- You must complete and return to the MREC the annual review form that will be sent to you once a year, and the final report form when your research is completed.

Legal and Regulatory Requirements

It remains your responsibility to ensure in the subsequent collection, storage or use of data or research sample you are not contravening the legal or regulatory requirements of any part of the UK in which the research material is collected, stored or used. If data is transferred outside the UK you should be aware of the requirements of the Data Protection Act 1998.

ICH GCP Compliance

The MRECs are fully compliant with the International Conference on Harmonisation/Good Clinical Practice (ICH GCP) Guidelines for the Conduct of Trials Involving the Participation of Human Subjects as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997. The Standing Orders and a Statement of Compliance are available on the Internet at www.corec.org.uk.

Yours sincerely

Jill Marshall

Jill Marshall
Trent MREC Administrator
on behalf of Dr Robert Bing, Chairman

NHS
Trent Multi-centre Research Ethics Committee

Derwent Shared Services
Laurie House
Colyear Street
Derby
DE1 1LJ

Chairman: Dr Robert Bing
Administrator: Jill Marshall

Telephone: 01332 868905
Fax: 01332 868930
Email: Jill.Marshall@derwentsharedservices.nhs.uk

Your Ref:

28 May 2003

Miss Lisa Caldon
Academic Surgical Oncology Unit
Division of Surgical Sciences (South)
Section of Surgical and Anaesthetic Sciences
Royal Hallamshire Hospital
Glossop Road
Sheffield, S10 2JF

Dear Ms Caldon

MREC/02/4/114 – *please quote this number on all correspondence*
Patient and professional factors influencing choice of surgery in the management of breast cancer: A qualitative and quantitative study – Part 1

The Trent MREC has reviewed the proposed amendment to the above application.

The members of the Committee present agreed that there is no ethical objection to the proposed amendment to the study. I am, therefore, happy to give you our approval on the understanding that you will follow the protocol and conditions of approval, as agreed.

Documents approved for this amendment:

- **Specialist Breast Health Care Professional Questionnaire Version 4 dated 28.4.03**
- **Specialist Breast Health Care Professional Questionnaire Consent Form Version 1 dated 22.4.03**
- **Breast Unit Study Reply Form (Audit and Survey) Version 1 dated 3.3.03**

Since this study was approved under the Supplementary Operational Guidelines for NHS Research Ethics Committees "Multi-centre Research in the NHS - the process of ethical review when there is no local researcher", November 2000, there is no requirement for you to inform LRECs of this amendment.

Yours sincerely

Jill Marshall
Trent MREC Administrator

NHS
Trent Multi-centre Research Ethics Committee

Derwent Shared Services
Laurie House
Colyear Street
Derby
DE1 1LJ

Chairman: **Dr Robert Bing**
Administrator: **Jill Marshall**

Telephone: 01332 868905
Fax: 01332 868930
Email: Jill.Marshall@derwentsharedservices.nhs.uk

18 March 2003

Miss Lisa Caldon
Academic Surgical Oncology Unit
Division of Surgical Sciences (South)
Section of Surgical and Anaesthetic Sciences
Royal Hallamshire Hospital
Glossop Road
Sheffield, S10 2JF

Dear Miss Caldon

MREC/02/4/114 - ***please quote this number on all correspondence***
Patient and professional factors influencing choice of surgery in the management of breast cancer: A qualitative and quantitative study – PART 2

The Chairman of the Trent MREC has considered the information/amendments submitted in response to the Committee's review of your application on 5 December 2002 as set out in our letter dated 16 December 2002 plus extensive email correspondence. **Part 1 of the study (survey of clinician's treatment preferences) is approved under a separate letter under Section C of 'No Local Researcher Guidelines' and does not require LREC approval.**

The documents considered for Part 2 were as follows:

Applicable to whole study:

- Application form dated 25 February 2003
- CRC Project Summary 25 February 2003
- Protocol dated January 2003
- Consumer Review
- Method of initial recruitment to study
- Payments to researcher
- Provision of expenses for subjects
- Compensation arrangements for subjects
- Indemnity for investigators
- Principal Investigator's CV - Lisa Caldon

Part 2 Impact of clinicians' consultation skills on patient decision making and satisfaction

- GP letter Version 1 dated 22 January 2003

2a Discussion Groups

- Patient Introduction Letter - Version 2 dated 17 January 2003
- Patient Information Leaflet - Discussion group Version 4 dated 23 January 2003
- Patient Reply letter - Discussion Group Version 1 9/9/02
- Patient Consent Form - Discussion Group, Version 4 dated 24 January 2003
- Discussion Group Schedule Version 1 dated 19/7/01

2b Postal questionnaire of patients

- Patient's Introduction letter to questionnaire Version 2 dated 17 January 2003
- Patient's Study Reply Form Version 1 dated 3/11/02
- Patient Information Sheet Re: Questionnaire and Interview Version 3 dated 23 January 2003
- Patient Consent for Questionnaire Version 2 dated 24 January 2003
- Patient Postal Decision Making Choices Questionnaire Version 1 dated 14/8/02

2c Semi-structured interviews with patients, specialist breast care nurses and doctors

- Cover Sheet (Prompt Sheet) for Interview Version 2 dated 28/1/02
- Patient Interview Schedule Version 4 dated 27/1/02
- Surgeon Interview Schedule Version 4 dated 27/1/02
- Specialist Nurse Interview Schedule Version 4 dated 27/1/02
- Patient Consent Form for semi-structured interview Version 3 dated 24 January 2003
- Letter to Patient not being interviewed Version 2 dated17 January 2003
- Sampling Frame for Interview Recruitment

The Chairman, acting under delegated authority, is satisfied that these accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. I am, therefore, happy to give you our approval on the understanding that you will follow the Conditions of Approval set out below. A full record of the review undertaken by the MREC is contained in the attached MREC Response Form. The project must be started within three years of the date on which MREC approval is given.

Conditions of Approval

- No research subject is to be admitted into the trial until agreement has been obtained from the appropriate local research ethics committees.

- You must follow the protocol agreed and any changes to the protocol will require prior MREC approval.

- The MREC would expect to see a copy of any finalised questionnaires before they are used.

- You must promptly inform the MREC and appropriate LRECs of :
  - (i) deviations from or changes to the protocol which are made to eliminate immediate hazards to the research subjects;
  - (ii) any changes that increase the risk to subjects and/or affect significantly the conduct of the research;
  - (iii) all adverse drug reactions that are both serious and unexpected;
  - (iv) new information that may affect adversely the safety of the subjects or the conduct of the trial.

- You must complete and return the standard progress report form to the MREC one year from the date on this letter and thereafter on an annual basis. This form should also be used to notify the MREC when your research is completed.

Whilst the MREC has given approval for the study on ethical grounds, it is still necessary for you to obtain management approval from the relevant Clinical Directors and/or Chief Executive of the Trusts (or Health Boards/DHAs) in which the work will be done.

Local Submissions

It is your responsibility to ensure that any local researcher seeks the approval of the relevant LREC before starting their research. To do this you should submit the appropriate number of copies of the following to the relevant LRECs:

- this letter
- the MREC Application Form (including copies of any questionnaires)
- the attached MREC Response Form
- Annex D of the Application Form
- **one** copy of the protocol
- the final approved version of the Patient Information Sheet and Consent Form

It is important to check with the respective LRECs the precise numbers of copies required as this will vary and failure to supply sufficient copies could lead to a delay. In addition, you should submit to LRECs only the revised paperwork reflecting the requirements of the MREC, as referenced in the Response Form

Local Sites

Whilst the MREC would like as much information as possible about local sites at the time you apply for ethical approval, it is understood that this is not always possible. You are asked, however, to send details of local sites as soon as a researcher has been recruited. This is essential to enable the MREC to monitor the research it approves.

ICH GCP Compliance

The MRECs are fully compliant with "the International Committee on Harmonisation/Good Clinical Practice (ICH/GCP) Guidelines for the Conduct of Trials Involving the Participation of Human Subjects" as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end, it undertakes to adhere as far as is consistent with its Constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice adopted by the Commission of the European Union on 17 January 1997. The Standing Orders and a Statement of Compliance, together with the guidelines and application form are available on the internet at www.corec.org.uk

Yours sincerely

Jill Marshall

Jill Marshall
Trent MREC Administrator
on behalf of Dr Robert Bing, Chairman

Enc: MREC Response Form

NHS
Trent Multi-centre Research Ethics Committee

Derwent Shared Services
Laurie House
Colyear Street
Derby
DE1 1LJ

Chairman: **Dr Robert Bing**
Administrator: **Jill Marshall**

Telephone: 01332 868905
Fax: 01332 868930
Email: Jill.Marshall@derwentsharedservices.nhs.uk

Your Ref:

28 May 2003

Miss Lisa Caldon
Academic Surgical Oncology Unit
Division of Surgical Sciences (South)
Section of Surgical and Anaesthetic Sciences
Royal Hallamshire Hospital
Glossop Road
Sheffield, S10 2JF

Dear Ms Caldon

MREC/02/4/114 – ***please quote this number on all correspondence***
Patient and professional factors influencing choice of surgery in the management of breast cancer: A qualitative and quantitative study – Part 1

The Trent MREC has reviewed the proposed amendment to the above application.

The members of the Committee present agreed that there is no ethical objection to the proposed amendment to the study. I am, therefore, happy to give you our approval on the understanding that you will follow the protocol and conditions of approval, as agreed.

Documents approved for this amendment:

- **Specialist Breast Health Care Professional Questionnaire Version 4 dated 28.4.03**
- **Specialist Breast Health Care Professional Questionnaire Consent Form Version 1 dated 22.4.03**
- **Breast Unit Study Reply Form (Audit and Survey) Version 1 dated 3.3.03**

Since this study was approved under the Supplementary Operational Guidelines for NHS Research Ethics Committees "Multi-centre Research in the NHS - the process of ethical review when there is no local researcher", November 2000, there is no requirement for you to inform LRECs of this amendment.

Yours sincerely

Jill Marshall

Jill Marshall
Trent MREC Administrator

NHS
Trent Multi-centre Research Ethics Committee

Derwent Shared Services
Laurie House
Colyear Street
Derby
DE1 1LJ

Chairman: **Dr Robert Bing**
Administrator: **Jill Marshall**

Telephone: 01332 868905
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Email: Jill.Marshall@derwentsharedservices.nhs.uk

28 May 2003

Miss Lisa Caldon
Academic Surgical Oncology Unit
Division of Surgical Sciences (South)
Section of Surgical and Anaesthetic Sciences
Royal Hallamshire Hospital
Glossop Road
Sheffield, S10 2JF

Dear Ms Caldon

MREC/02/4/114 – *please quote this number on all correspondence*
Patient and professional factors influencing choice of surgery in the management of breast cancer: A qualitative and quantitative study – Part 2

The Trent MREC has reviewed the proposed amendment to the above application.

The members of the Committee present agreed that there is no ethical objection to the proposed amendment to the study. I am, therefore, happy to give you our approval on the understanding that you will follow the protocol and conditions of approval, as agreed.

Documents approved for this amendment:

- **Study reply form – discussion groups Version 2 dated 3.3.03**
- **Consent form – discussion group Version 5 dated 3.3.03**
- **Study reply form – questionnaire and/or interview – Version 2 dated 3.3.03**
- **Consent form – questionnaire Version 4 dated 9.4.03**
- **Patient information needs and decision making preferences questionnaire (IDMQ) Version 2 dated 9.4.03**
- **Specialist health professional semi-structure interview consent form version 1 dated 22.4.03**
- **Consent form – patient interview Version 4 dated 3.3.03**
- **D & NP Notes Version 5 dated 9.4.03**

A copy of this amendment should be sent to all the LRECs involved in the review of this study for information. If the issues contained in the amendment are local issues as defined in the DoH Guidelines, then the LRECs' approval is required.

Yours sincerely

Jill Marshall
Trent MREC Administrator
on behalf of Dr Robert Bing, Chairman

NHS

Trent Multi-centre Research Ethics Committee

Derwent Shared Services
Laurie House
Colyear Street
Derby
DE1 1LJ

Telephone: 01332 868905
Fax: 01332 868930
Email: Jill.Marshall@derwentsharedservices.nhs.uk

Chairman: **Dr Robert Bing**
Administrator: **Jill Marshall**

Your Ref:

8 September 2003

received 11/9/03

Miss Lisa Caldon
Academic Surgical Oncology Unit
Division of Surgical Sciences (South)
Section of Surgical and Anaesthetic Sciences
Royal Hallamshire Hospital
Glossop Road
Sheffield, S10 2JF

Dear Ms Caldon

MREC/02/4/114 – ***please quote this number on all correspondence***
Patient and professional factors influencing choice of surgery in the management of breast cancer: A qualitative and quantitative study – Part 2

Part 2 - Amendments to health professionals' semi-structured interview process

The Trent MREC has reviewed the proposed amendment to the above application.

The members of the Committee present agreed that there is no ethical objection to the proposed amendment to the study. I am, therefore, happy to give you our approval on the understanding that you will follow the protocol and conditions of approval, as agreed.

Documents approved for this amendment:

Revised application form dated 11 August 2003
Project proposal dated August 2003
CV – Dr Karen Collins, Academic Palliative Care Unit (new co-researcher, replacing Dr Tony Stevens)

2a – Discussion groups:

- Patient introduction letter – Discussion Group (post-OP) Version 3 dated 13 August 2003
- Patient introduction letter – Discussion group (pre-OP) Version 3 dated 13 August 2003
- Patient Information Leaflet – Discussion Group Version 6 dated 13 August 2003
- Discussion Group schedule Version 4 dated 14 August 2003

2b Postal Questionnaire of Patients:

- Patient's introduction letter – Questionnaire and interview (post-OP) Version 3 dated 13 August 2003
- Patient's introduction letter – Questionnaire and interview (pre-OP) Version 3 dated 13 August 2003
- Patient information sheet – Questionnaire & Interviews Version 5 dated 13 August 2003

2c Semi-structured interviews with patients, specialist breast care nurses and doctors

- Patient interview schedule Version 5 dated 14 August 2003
- Specialist nurse interview schedule Version 5 dated 14 August 2003
- Surgeon interview schedule Version 6 dated 14 August 2003

A copy of this amendment should be sent to all the LRECs involved in the review of this study for information. If the issues contained in the amendment are local issues as defined in the DoH Guidelines, then the LRECs' approval is required.

Yours sincerely

Jill Marshall
Trent MREC Administrator
on behalf of Dr Robert Bing, Chairman

NHS

Trent Multi-centre Research Ethics Committee

Chairman: Dr Robert Bing
Administrator: Jill Marshall

Derwent Shared Services
Laurie House
Colyear Street
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DE1 1LJ

Telephone: 01332 868905
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Email: Jill.Marshall@derwentsharedservices.nhs.uk

Your Ref:

1 October 2004

Miss Lisa Caldon
Academic Surgical Oncology Unit
Division of Surgical Sciences (South)
Section of Surgical and Anaesthetic Sciences
Royal Hallamshire Hospital
Glossop Road
Sheffield, S10 2JF

Dear Lisa

MREC/02/4/114 – *please quote this number on all correspondence*
Patient and professional factors influencing choice of surgery in the management of breast cancer: A qualitative and quantitative study – Part 2

Thank you for your letter of 28 September 2004. It is usual for the duration of the study for which MREC approval is given to apply to all the sites where the study is taking place, and for that duration to be quoted on the old Annex D or new Part C.

If it was just an error that a lesser period was quoted on the Annex D for the former North and Southern Derbyshire LRECs, then perhaps the (now) Derbyshire LREC would accept it as such, and note the change, without the need for a Part C. However if they or their R & D Department feel that extending it for a further 12 months might have local implications, then I think you would need to complete a Part C if they request it.

As far as Trent MREC is concerned, the study is approved for the 36 months quoted in the application form, with effect from 18 March 2003 when it was given final approval. I cannot see the need for an amendment being submitted to Trent MREC because there is no change to the duration of the study approved by them.

I hope this is helpful to you.

Yours sincerely

Jill Marshall
Trent MREC Administrator
on behalf of Dr Robert Bing, Chairman

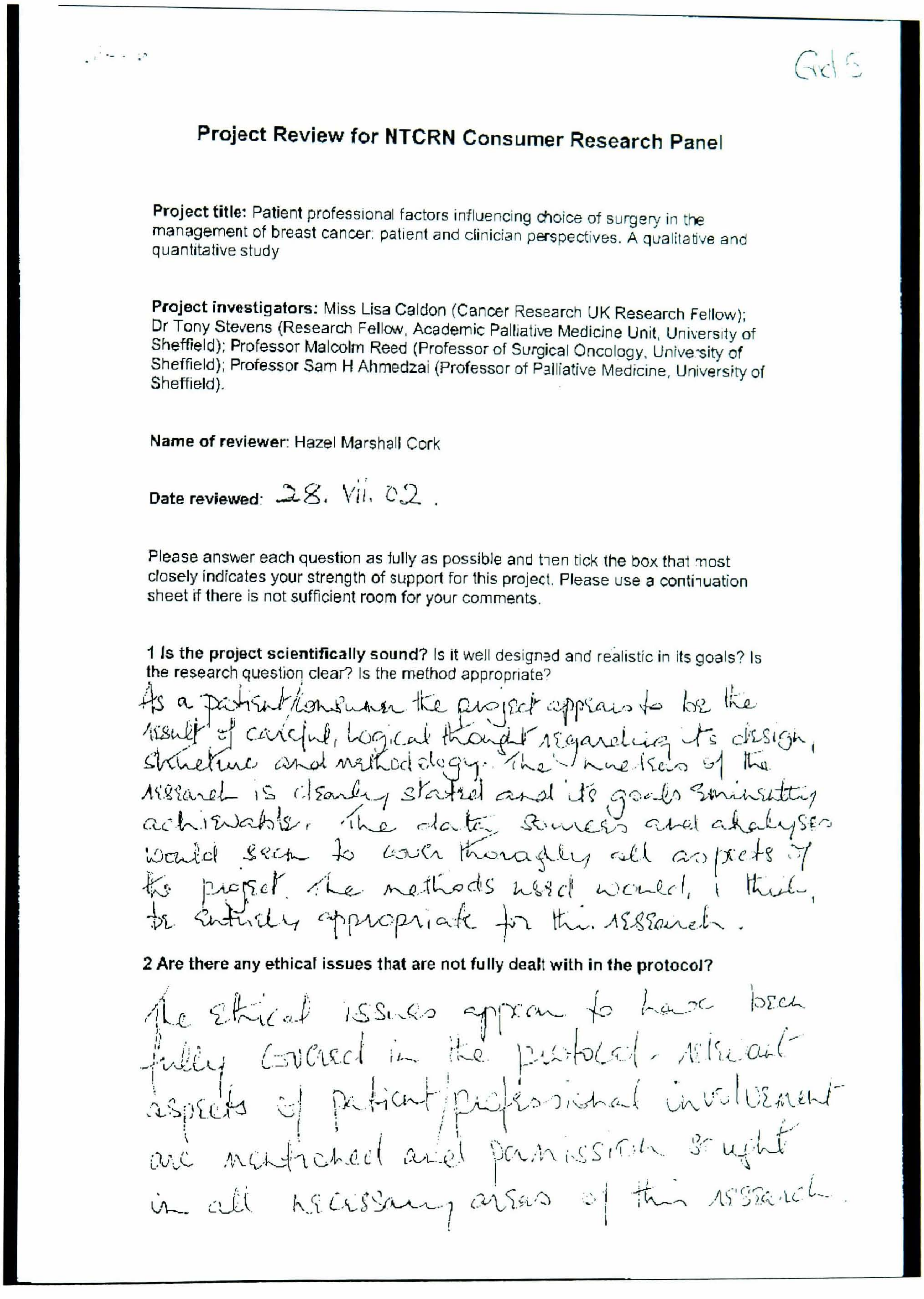
cc Jenny Hancock, Administrator, Derbyshire LREC

APPENDIX 2.2 LREC & Research governance reference numbers and approval dates

Breast unit	LREC ref no.	Date passed	RG ref no.	Date passed
1	*	24/6/03	*	2/6/03
2 & 7	03/1/031	11/9/03	*	12/8/03
3	0308/694(N&S)	13/8/03	0307/694	1/8/03
4	SDAH/2003/076	8/9/03	SDAH/2003/076	19/8/03
5	03/72	9/9/03	433/203/Surg/RH	22/9/03
6	7143M	4/10/04	UHL/9024	16/10/03
8	*	4/8/03	*	13/8/03
9	C1110313	9/12/03	(N)030N32	28/11/03
10	RLREC/NLR/11/03	2/6/03	RD/03/06/01	2/6/03
11	03/258	23/9/03	STH03/258	23/9/03
*Approval granted, no number provided				

Appendix 3

Consumer reviews



Gd 5

Project Review for NTCRN Consumer Research Panel

Project title: Patient professional factors influencing choice of surgery in the management of breast cancer: patient and clinician perspectives. A qualitative and quantitative study

Project investigators: Miss Lisa Caldon (Cancer Research UK Research Fellow); Dr Tony Stevens (Research Fellow, Academic Palliative Medicine Unit, University of Sheffield); Professor Malcolm Reed (Professor of Surgical Oncology, University of Sheffield); Professor Sam H Ahmedzai (Professor of Palliative Medicine, University of Sheffield).

Name of reviewer: Hazel Marshall Cork

Date reviewed: 28. vii. 02.

Please answer each question as fully as possible and then tick the box that most closely indicates your strength of support for this project. Please use a continuation sheet if there is not sufficient room for your comments.

1 Is the project scientifically sound? Is it well designed and realistic in its goals? Is the research question clear? Is the method appropriate?

As a patient/consumer the project appears to be the result of careful, logical thought regarding it's design, structure and methodology. The nucleus of the research is clearly stated and it's goals eminently achievable. The data sources and analyses would seem to cover thoroughly all aspects of the project. The methods used would, I think, be entirely appropriate for this research.

2 Are there any ethical issues that are not fully dealt with in the protocol?

The ethical issues appear to have been fully covered in the protocol. Relevant aspects of patient/professional involvement are mentioned and permission sought in all necessary areas of this research.

3 Does the project duplicate or conflict with any other work that you are aware is being done or has been done in the past?

I have not found any other research into why women choose mastectomy or lumpectomy.

4 Does the project address important issues eg will the project enhance the care and treatment of patients with cancer?

I feel sure that this project will raise awareness, and thereby enhance care and treatment, into what issues women face when diagnosed with breast cancer and looking at treatment options.

5 Are the timescales for the project realistic?

Yes.

6 Does the project represent value for money?

Yes.

7 Any other comments about this project.

I am very interested in this project and look forward to following its progress and analysing the results. I was surprised by the widely differing rates of mastectomy V lumpectomy in Trent and will be interested to see if health professionals are what makes the difference!

Please tick the box that most closely indicates your strength of support for this project

☑ Strongly support this project

☐ Support this project with reservations

☐ Need more information

☐ Reject

Project Review for NTCRN Consumer Research Panel

Project title: Patient professional factors influencing choice of surgery in the management of breast cancer: patient and clinician perspectives. A qualitative and quantitative study

Project Investigators: Miss Lisa Caldon (Cancer Research UK Research Fellow); Dr Tony Stevens (Research Fellow, Academic Palliative Medicine Unit, University of Sheffield); Professor Malcolm Reed (Professor of Surgical Oncology, University of Sheffield); Professor Sam H Ahmedzai (Professor of Palliative Medicine, University of Sheffield).

Name of reviewer: Gillian Speed

Date reviewed: 26 September 2002.

Please answer each question as fully as possible and then tick the box that most closely indicates your strength of support for this project. Please use a continuation sheet if there is not sufficient room for your comments.

1 Is the project scientifically sound? Is it well designed and realistic in its goals? Is the research question clear? Is the method appropriate?

As far as I am aware, the project is well designed and realistic in its goals. I feel sure the methods used will find an answer to the question of whether health professionals actually do influence women's decisions or not.

2 Are there any ethical issues that are not fully dealt with in the protocol?

Again, as far as I am aware, all ethical issues have been carefully and thoughtfully dealt with.

3 Does the project duplicate or conflict with any other work that you are aware is being done or has been done in the past?

To my knowledge this project does not conflict with / or duplicate, present or previous studies.

4 Does the project address important issues eg will the project enhance the care and treatment of patients with cancer?

This project will, in my opinion, greatly benefit patients with cancer and enable their care & treatment to be analysed and improvements effected, following the results of the research.

5 Are the timescales for the project realistic?

The timescales seem adequate and realisable.

6 Does the project represent value for money?

Given the validity and worth of the project it would seem to be excellent value.

7 Any other comments about this project.

From the patient/consumer perspective I have found reading this proposal to be both stimulating and thought provoking. The research into treatment preferences/counselling skills of the medical personnel & their resulting effects on surgical decisions/choices made by women attending B.C. units will be of great importance for future patients, surgeons and nurses. There is... (cont. over)

Please tick the box that most closely indicates your strength of support for this project

☑ Strongly support this project

☐ Support this project with reservations

☐ Need more information

☐ Reject

Appendix 4

Clinician Survey 14 Breast Units

APPENDIX 4.1 Clinician information leaflet

Surgical Management Preferences and Choices in Breast Cancer

Health Care Professional Information Leaflet

Please read this carefully

You are invited to take part in this research study. Funding for the project has been provided by Cancer Research UK, and the Royal College of Surgeons of England is contributing toward the audit and health care professional survey elements of the study. Before you decide whether or not you wish to take part it is important for you to understand why the study is being done and what it will involve if you agree to take part. Please read the following information carefully and feel free to question us if there is anything you don't understand or would like more information about. To aid this process we are happy to visit your department and talk to your multidisciplinary team about this study. You will be given as much time as you wish to make a decision about whether to be involved in the study.

Please turn over

Why is this study being conducted?

We are familiar with the presentation of data describing the observation of differences in mastectomy and breast conservation surgery rates in the management of breast cancer. The annual publication of the audit of screen detected breast cancers highlights these differences at both the unit level in regional reports and regional level within national reports. These observations are not unique to the Trent or the UK, similar patterns of variance being observed internationally.

Published literature suggests that primary tumor characteristics fail to account for the observed variations, and points to a number of potential factors influencing the pattern of variance observed; ranging from patient factors (body image, conflicting fears, prior knowledge and experience, perception of chance of cure etc.), to professional factors (decision making, professional's recommendation and communication styles) and the interaction of the patient and professional (patients' perception of a recommendation). In the context of patients for whom there is a choice of surgical treatments, the decision making process is complex and likely results from a combination of the afore-mentioned factors.

The aim of this research study is to clarify the extent of treatment variation within Trent over time, and identify the factors associated with it; investigating the decision making and consultation process from the perspective of specialist breast professionals (surgeons and nurses) and patients from Trent.

Why have I been approached?

We are approaching all specialist breast surgeons and nurses within the Trent Region. As with all studies, the larger the number of participants the more representative the findings; we therefore hope to recruit as many as possible breast units from the region to the study, and ideally need the involvement of all individuals from the units, in order to provide representative results.

Who is organising the study?

This study is being funded by Cancer Research UK and sponsored by the University of Sheffield. The principle investigator of the project team is Professor Malcolm Reed from the Academic Surgical Oncology Unit of the University of Sheffield. Professor Sam H. Ahmedzai from the Academic Palliative Medicine Unit will also be supervising the study. Working on the project will be Miss Lisa Caldon, lead investigator, and Mr. David Wilde, Research Associate.

The funders of the study will pay the researchers Lisa Caldon and David Wilde an annual salary to undertake the project. They will not receive any additional payments. No one else will be paid as a result of your participation in this study.

What does the study involve?

The project brings together a combination of qualitative and quantitative methodologies, to examine variation in mastectomy rates at both the macro and micro level: Macro level investigation entails the statistical analysis of extensive audit datasets pertaining to the surgical management of women with breast cancer. Micro level investigation comprises exploration of the treatment decision-making process from both the specialist breast professionals' (surgeons and nurses) and their patients' perspective.

There are two main stages of the study.

The first stage will be conducted across all participating breast units in Trent, evaluating individual teams' management of breast cancer, and is sub-divided into 2 parts:

1. Adjusting mastectomy rates audit data for case-mix and identification of associated variables.
2. Multi-professional team member decision analysis: Survey of specialist surgeon and breast care nurse management of individual case scenarios with respect to key primary tumour characturistics.

The second stage, investigates the diagnosis and treatment decision-making process from both the patient and clinician's standpoint, to identify the key factors associated with the decision making process. For pragmatic reasons this stage of the project will be limited to three Trent breast units. The three units representing the spectrum of treatment rates observed (a high, medium and low mastectomy rate unit). Three methods will be employed within this stage.

1. Patient discussion/focus groups
   Total 24 patients: 8 patients per group, 3 groups over 3 units
   To inform the study and assist in refining the design of semi-structured interview schedules.

2. Patient postal questionnaire
   Total 300 completed responses: 100 per unit.
   600 to be distributed, assuming a 50% response rate

A simple 2-page questionnaire to identify patient's decision making style preferences (active, passive or collaborative) and recruit to further sub-stages of the study.

3. Semi-structured interviews with patients, specialist Breast Care Nurses and surgeons

   Total 180 interviews over the 3 units

   Semi-structured interviews will be centred on the management of twenty cases from each unit; 10 mastectomy and 10 breast conservation surgery, in which there was a choice of surgical treatment options according to treatment guidelines. For each patient responder interviewed, their surgeon and specialist breast care nurse will also be interviewed, to achieve triangulation of impression of the process of information transfer and decision-making in individual cases.

If we decide to be involved, what level of input would be required?

That will depend on the level to which your unit wishes to be involved in the study. There are 3 levels of possible involvement.

1. Audit only
2. Audit and Professionals' survey
3. Audit, Professionals' survey and patient-involvement stage.

Why are you doing an audit?

We believe that good quality audit is a vital first stage of our project. By adjusting for the characteristics of the cases managed by the individual units we will be able to confirm whether the pattern observed at aggregate level is simply due to differences in the units' case-mix or not.

What would involvement in the audit involve?

Involvement in this stage of the study requires providing us with your unit and surgeon identifier numbers for the Breast Screening program and Trent Cancer Registry. We are not asking your team to request or search through notes, we will only be using information you have already provided. Information will be covered by a signed confidentiality agreement, and provided to us in individualised format but devoid of patient identifiers. This data will be stored in password-protected databases and remain strictly confidential. The main researcher (Lisa Caldon) and Stephen Walters, a lecturer in statistics at the Sheffield School of Health and Related research (ScHARR) will analyse the data.

What would involvement in the Professionals' survey involve?

Involvement in the professionals' survey would involve completing a questionnaire comprising 2 sections; the first involving choosing between treatment options in 25 case scenarios where key primary tumour variables are altered; the second answering a series of questions about yourself. To ensure that the study's results are representative it is important that all members of the unit take part in this sub-stage. The questionnaires will be posted to you and will take about one hour to complete. You will be provided with a freepost envelope to return it to us. We need to be able to identify who you are for the purposes of data analysis, but all responses will remain strictly confidential and any results anonymised.

What would involvement in the patient-involvement stage of the study involve?

This is the most involved stage of the project, the in-depth study of the consultation and decision making process of the surgical management of breast cancer in three units in Trent; one each to represent a unit with a high, a medium and a low mastectomy rate. We will be using the case-mix adjusted rates, and are interested in units with consistent practice over time.

This stage of the study is divided into 3 parts, a patient questionnaire, patient focus groups and semi-structured interviews. The first two parts of this section involve the recruitment of patients only. As a professional, you will only be asked to take part in the third part of this stage, but will be asked as a team, to help recruit patients. Interviews will be conducted within 3 months of your patient's surgical treatment, by an experienced researcher using a schedule consisting of open questions. We are aware of the busy nature of breast unit work, and have designed a single page A4 prompt sheet that we feel will assist you in the recall of the diagnosis provision and treatment discussion consultation(s). We would ask the involved individual nurse and surgeon to complete the prompt sheet for all patients undergoing surgery during the time of recruitment to the study.

Interviews regarding patients are expected to take between 15 and 20 minutes each. In each participating unit, interviews will be conducted around 20 patient episodes. This equates to a total of between 5 hours and 6hours 40 minutes of breast care nurse time and surgeon time over a period of 8 months. Interviews will be arranged to suit you.

Interviews with health professionals will be assisted by the presence of case notes and the prompt sheet filled in by the individual professional following the consultation. By exploring and triangulating the process of decision making from the patient and professionals standpoint, we hope to identify the most powerful factors influencing the process from all three perspectives.

How will patients be recruited?

We aim to recruit patients following their initial treatment surgery. To do this we will be asking the units breast care nurses to provide patients fulfilling the inclusion criteria of the study, with an information pack prior to their discharge from hospital. The information pack includes an introductory letter, information leaflet and a freepost study reply card that the patient will return to us indicating whether they would be interested in participating in the study or not, and to what level. On receipt of the study reply form indicating interest, we will send them further information and a consent form. The information pack contains contact telephone numbers that patients can use, should they require more information about the study.

Patients recruited will provide us with consent to view their notes, to confirm the nature of their treatment and aid the interview process.

What will happen to me if I take part?

Whether you decide to take part or not, we would ask you to please complete the Study Reply Form and return it in the FREEPOST envelope provided. If you decide not to take part, please tick the box beside "No, I do not wish to take part in this study" and return the form to us after filling in your name. You do not need to fill in any other details on the form.

If you wish to take part in the study, then please tick the box beside "Yes, I would like to take part in this study" and indicate the level to which you would like to be involved by ticking the relevant box below the main statement. Then fill in the contact details section and return the form to us. Once we receive your form, a member of our research team will contact you.

Feel free to call us with any queries you may have and/or talk the study over with anyone else.

The interviews may be audiotape recorded with your consent. Any information you provide during the discussion will only be available to the research staff working on this study. Tapes will be labeled with an identifier number, but will not be stored with any record of your identity. Tapes will be stored in a locked room at the Royal Hallamshire Hospital, Sheffield, which is only accessible to the research staff. The tapes, electronic transcript data and paper records collected over the course of the study will be kept until the end of the study and then destroyed. Tapes will be transcribed by a professional agency.

Access to any data stored on the project will be restricted to researchers working on this study. Data stored on computer will be password protected. The same research team that collected the data will also perform the analysis of the information.

The information collected will remain confidential and prior to publication all results will be anonymised.

Do I have to take part?

No. Your taking part in this study is entirely voluntary. If you would prefer not to take part, you do not have to give a reason. You may also withdraw from the study at any time.

What are the possible risks of taking part?

There are no specific risks associated with taking part in this study.

What are the possible benefits of taking part?

The results of this study will provide us with a better understanding of how treatment decisions are made, and increase our understanding of the possible reasons behind the variation in mastectomy and breast conservation surgery rates we observe in Trent. Following data analysis, we will be offering individualised feedback on an individual professional and unit basis to those participating in the study. Again, confidentiality is assured for this process.

How will this information be used?

Anything you say will be treated in the strictest confidence. Any information gathered during this study will be made available only to researchers working on the study. No names will be mentioned in any reports of the study and care will be taken to ensure that you cannot be identified.

What if I am harmed?

As there are no specific risks associated with this study it is highly unlikely that you will be harmed. If you have any complaints or concerns please contact the Principal Investigator, Professor Malcolm Reed, in the first instance - telephone 0114 271 3326, or the Director of the Division of Clinical Sciences(South), Professor HF Woods - telephone 0114 371 2475

Will anyone else be told about my participation in this study?

No. We will not inform anyone outside of the research team of your participation in the study.

Who can I contact for more information?

Miss Lisa Caldon, the Research Coordinator - telephone 0114 271 2225.

What if I have other concerns?

If after reading this information sheet you decide not to take part in the study, but feel you need to discuss any of the issues we have raised, or you have other questions about this study, please contact either the Principal Investigator, Professor Malcolm Reed - telephone 0114 271 3326, or Miss Lisa Caldon, the Lead Investigator - telephone 0114 271 2225, or write to them at the Academic Surgical Oncology Unit, K Floor, Royal Hallamshire

Hospital, Sheffield S10 2JF.

If you have any complaints about the way the investigators have carried out the study, you may contact *(insert local name, address, and telephone number of appropriate complaints department for each clinic site).* A list of potentially useful contacts appears on page 10.

Please keep this information leaflet for future reference

Useful contacts

If you want to know more about the project		
Lead investigator	Miss Lisa Caldon	0114 271 2225
Research Associate	Mr. David Wilde	0114 271 1707
If you have a complaint about the project		
Principal Investigator	Professor MWR Reed	0114 271 3326
Director of the Division of Clinical Sciences (South)	Professor HF Woods	0114 371 2475
Local Complaints Department	*<insert local information>*	

Surgical Management Preferences and Choices in Breast Cancer

Breast Unit STUDY REPLY FORM

Please tick the appropriate boxes below

☐ **NO**, as a Breast Unit we do not wish to take part in this study
☐ **YES**, as a Breast Unit we would like to take part in this study

If **YES**, please indicate the level to which you are willing to be involved in the study

☐ **YES**, to the audit section of this study
☐ **YES**, to the audit and survey sections of this study
☐ **YES**, to the audit, survey, and if approached, the patient-focused sections of this study

If you wish to be involved, please provide us with the contact details of a member of the team with whom we can liaise **(IN BLOCK CAPITAL LETTERS PLEASE)**

Name ______________________________________

Contact address ______________________________________
____
____

Telephone No ______________________________________

Email address ______________________________________

To be signed by the LEAD CLINICIAN of the breast unit please

____________________ ____________________

Signature Name Date

Please return the completed slip in the enclosed FREEPOST envelope.

Thank you

«title» «fname» «lname»
«address»
«postcode»

Dear «fname»,

Re **'Patient and professional factors influencing choice of surgery in the management of breast cancer: A qualitative and quantitative study'**

Some time ago we wrote inviting your unit to participate in part one of the above study, involving specialist breast team members completing a postal questionnaire. You replied indicating you were happy for your unit to be involved.

Having received approval to proceed from your local Research Governance process and Research Ethics Committee, we are now distributing questionnaires to the members of your team. I enclose a copy of the questionnaire for you to complete. A consent form is located on page 4. On completion please return it to us in the freepost envelope provided.

Any information provided will be treated confidentially: No one outside the research team will have access to your personal responses (including other members of your team). At the conclusion of this stage of the study we will provide you with feedback: The unit's data in the context of Trent-wide data, and if requested will provide feedback on your responses as an individual. In due course, when the full study is analysed, anonymised feedback will be provided to all participating units.

Participation is voluntary; however you will understand to optimise the chance of accurately understanding this issue, we need to involve as many professionals from the team as possible. We therefore ask you encourage the involvement of your team members. If anyone has questions regarding the project we are happy to answer them. All those approached have been sent an information leaflet, the questionnaire and freepost SAE. If we have neglected to send this information to any permanent members of the team who are involved in talking to patients about the diagnosis and treatment of breast cancer, please contact us with their details and we will send them a questionnaire pack.

We would like to take this opportunity to thank you for your involvement in this project, and look forward to hearing from you.

Yours sincerely

APPENDIX 4.4 Clinician DCE questionnaire

Unit/HCP Identifier
☐☐☐☐☐/☐☐☐☐☐

Information Needs and Decision Making PreferencesSpecialist Breast Health Care Professional Questionnaire

Thank you for taking part in this study.

Please complete this questionnaire in your own time. The questions are easy to complete and for the most part only require you to tick a box. So to complete all the questions here will probably take you about 10 25 minutes. All the questions are important so we do need you to complete all of them.

All information that you will provide will remain strictly confidential.

When you have finished please post the questionnaire back in the **FREEPOST** envelope provided – **you do not need a stamp**.

If you have any queries about this questionnaire or the study, please contact

Lisa Caldon on 0114 271 2225 or David Wilde on 0114 271 1707

Academic Surgical Oncology Unit, Division of Clinical Sciences (CSUHT),

About this Questionnaire

This questionnaire is divided into two sections.

Section one

This section comprises a series of 25 clinical scenarios on which you are asked to make a treatment decision. A worked example is also provided for you at the beginning of the section.

Section two

section is made up of six questions, five of which are a series of psychological measurement scales. These scales are included as it is recognised that decision styles can be associated with psychological response patterns.

At the end of each section there is a blank page provided for you to write any comments you wish to make (please use additional sheets if necessary).

What will the results be used for?

The results of this questionnaire will be used entirely for the purposes of research. We need to be able to identify who you are, however your responses will be kept confidential. No one outside the research team, including your own breast team, will be informed of your responses as an individual.

The signed consent form will be detached upon receipt of the completed questionnaire and will be stored separately from your responses.

Any results of this questionnaire and the broader study, of which this is a part, will be anonymised for the purposes of publication and presentation.

At the end of the study individualised feedback will be available upon request.

If you have any queries regarding the study or the questionnaire please contact either:

Lisa Caldon Office: 0114 271 2225/3326

Thank you for completing this questionnaire and taking part in the study.

If you have any queries about this questionnaire or the study, please contact

Lisa Caldon on 0114 271 2225 or David Wilde on 0114 271 1707

Academic Surgical Oncology Unit, Division of Clinical Sciences (CSUHT),

1. **READ THE ACCOMPANYING HEALTH CARE PROFESSIONAL INFORMATION SHEET**

2. **SIGN AND DATE THE CONSENT FORM (PAGE 4)**

3. **HAVE SOMEONE WITNESS THE CONSENT FORM**

IT IS VERY IMPORTANT YOU COMPLETE THE POINTS ABOVE, OTHERWISE WE CANNOT USE THE INFORMATION YOU PROVIDE IN YOUR QUESTIONNAIRE.

Study Number: MREC/02/4/114

Unit/staff ID number: _ _ _ _ _ / _ _ _ _ _

The University of Sheffield
Section of Surgical and Anaesthetic Sciences
Academic Surgical Oncology Unit
& Academic Palliative Medicine Unit
K Floor Royal Hallamshire Hospital
Sheffield S10 2JF
UK

Professor MWR Reed MBChB, BMed.Sci, MD, FRCS (Eng)	Tel: +44 (0)114 271 3326
Professor SH Ahmedzai BSc, MB ChB, FRCP	Tel: +44 (0)114 271 3792
Miss Lisa Caldon MB ChB, FRCS (Eng)	Tel: +44 (0)114 271 2225
Mr David Wilde BSc, MSc	Tel: +44 (0)114 271 1707

SPECIALIST HEALTH PROFESSIONAL QUESTIONNAIRE CONSENT FORM

(Version 1: 22/04/03)

Surgical Management Preferences and Choices in Breast Cancer: A qualitative and quantitative study.

If you wish to take part in the study, please read the statements below, and initial the boxes to the right if y agree with the statement.

To confirm agreement Please initial the b

1. I confirm that I have read and understand the information sheet dated 22nd January 2003 (Version 3) for the above study. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I agree to take part in the health professional questionnaire part of the study. ☐

____________________	____________	____________________
Name of respondent *((Print in BLOCK CAPITALS)*	Date	Signature
____________________	____________	____________________
Witnessed by *(Print in BLOCK CAPITALS)*	Date	Signature

Breast Unit name ____
(Print in BLOCK CAPITALS)

Please turn over to Section One

Before commencing the questionnaire we would like to know a little bit about your professional background

Please tell us...

Your age

21 - 25	☐1	**46 - 50**	☐6
26 - 30	☐2	**51 - 55**	☐7
31 - 35	☐3	**56 - 60**	☐8
36 - 40	☐4	**61 - 65**	☐9
41 - 45	☐5	**66 - 70**	☐10

Your sex

Male	☐1	***Female***	☐2

Your profession

Nurse	☐1	***Staff Grade***	☐4
Consultant Surgeon	☐2	***GP Clinical Assistant***	☐5
Associate Specialist	☐3	***Trust Doctor***	☐6

What year did you qualify as a nurse/doctor
(Please write in your answer)

☐

What year did you commence as a specialist nurse/doctor in the breast cancer field
(Please write in your answer)

☐

In your experience what does Breast Conservation Surgery mean to you?
(Please mark more than one box if appropriate)

Wide local excision ☐1

Segmentectomy ☐2

Quadrantectomy ☐3

Other (please state below) ☐4

Please turn over to Section One

Section One

The scenarios are concerned with the importance that **you, as an individual specialist** (rather than as a member of your breast team) place on various factors determining the surgical management of breast cancer.

In your responses to this section we would like you to imagine that for reasons unconnected with patient choice, that there are **only 2** surgical options available; **mastectomy** and **breast conservation surgery** (i.e. any surgery more conservative than mastectomy), and that primary chemotherapy and breast reconstruction surgery are **not** available.

In this questionnaire we are only interested in surgery to the breast. We are not asking you to state your opinion regarding axillary surgery; our assumption being that the axillary surgery you would perform would be the standard type for your practice.

The 25 scenarios in this section are presented in a tabulated form, each in its own box, and differ according to the following five aspects:

Patient age (years) Divided into the following age bands:

(<40) (40 - <60) (60 - <70) (70 - <80) (≥80)

Total tumour size (mm) Divided into the following size bands:

(<20) (20 - <30) (30 - <40) (40 - <50) (≥50)

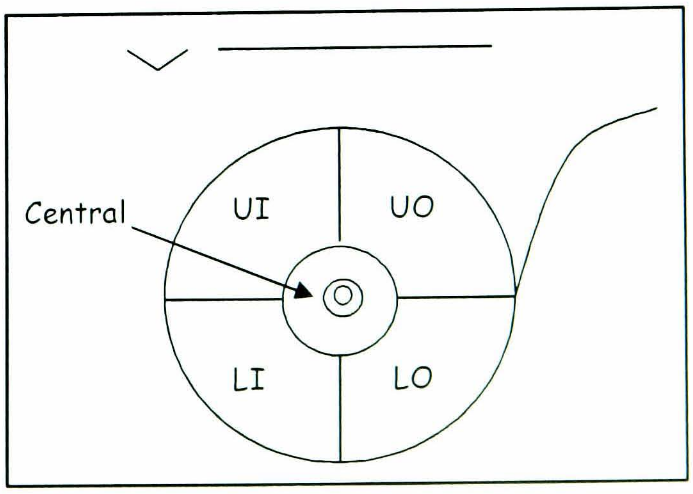
NOTE: In multi-focal tumours, the figure represents the sum of all the individual areas of tumour present.

Bra Cup size Divided into the following bra cup sizes:

A, B, C and ≥D

In this questionnaire the tumour site is designated as being within the:

Upper outer quadrant (UO), upper inner quadrant (UI), lower outer quadrant (LO), lower inner quadrant (LI) or central area of the breast – see diagram below.



Tumour focality	Designated as being either: ***Unifocal*** *- a single area of tumour* ***Multi-focal, single-quadrant*** *- greater than one area of tumour, lying , within a single quadrant of the breast.* **NOTE:** For the purposes of this study, the central site is also to be treated as a 'quadrant'.

Please assume that other aspects of the scenarios are equal or not significant.

Based on the information provided in each of the 25 scenarios, you are asked to indicate **your** preferred choice of breast surgery by placing a tick in the relevant box below the scenario description. If you prefer both options equally, please tick both boxes.

Please turn over to see an example of what we would like you to do

Example of Clinical Scenario

This is how each scenario will be presented:

Scenario X

Patient Age (years)	**60 - <70**
Total tumour size (mm)	**<20**
Cup size	**C**
Site	**LI**
Focality	**Unifocal**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy	**Breast Conservation Surgery**
☐1	☐2

the above scenario (X), the patient is aged between 60 and 69 years old, they have a tumour of less than 20mm diameter in total, within their C cup breast. The tumour is situated within the lower inner quadrant and is unifocal.

If, after reading this information, your preferred treatment option was **Breast Conservation Surgery**, then your response would be to tick the Breast Conservation Surgery box.

	✓
Mastectomy	**Breast Conservation Surgery**
☐1	☐2

Please turn over to commence the scenarios

Scenario 1

Patient Age (years)	**<40**
Total tumour size (mm)	**40 - <50**
Cup size	**≥D**
Site	**LI**
Focality	**Unifocal**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy ☐1 **Breast Conservation Surgery** ☐2

Scenario 2

Patient Age (years)	**60 - <70**
Total tumour size (mm)	**≥50**
Cup size	**B**
Site	**LI**
Focality	**Multi-focal, single quadrant**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy ☐1 **Breast Conservation Surgery** ☐2

Scenario 3

Patient Age (years)	**≥80**
Total tumour size (mm)	**≥50**
Cup size	**≥D**
Site	**LO**
Focality	**Unifocal**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy ☐1

Breast Conservation Surgery ☐2

Scenario 4

Patient Age (years)	**≥80**
Total tumour size (mm)	**40 - <50**
Cup size	**C**
Site	**UI**
Focality	**Multi-focal, single quadrant**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy ☐1

Breast Conservation Surgery ☐2

Scenario 5

Patient Age (years)	**70 - <80**
Total tumour size (mm)	**40 - <50**
Cup size	**B**
Site	**Central**
Focality	**Unifocal**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy	**Breast Conservation Surgery**
☐1	☐2

Scenario 6

Patient Age (years)	**40 - <60**
Total tumour size (mm)	**20 - <30**
Cup size	**C**
Site	**LI**
Focality	**Unifocal**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy	**Breast Conservation Surgery**
☐1	☐2

Scenario 7

Patient Age (years)	**40 - <60**
Total tumour size (mm)	**<20**
Cup size	**B**
Site	**LO**
Focality	**Multi-focal, single quadrant**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy ☐1 **Breast Conservation Surgery** ☐2

Scenario 8

Patient Age (years)	**<40**
Total tumour size (mm)	**20 - <30**
Cup size	**B**
Site	**UI**
Focality	**Unifocal**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy ☐1 **Breast Conservation Surgery** ☐2

Scenario 9

Patient Age (years)	**40 - <60**
Total tumour size (mm)	**40 - <50**
Cup size	**A**
Site	**UO**
Focality	**Multi-focal, single quadrant**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy	**Breast Conservation Surgery**
☐1	☐2

Scenario 10

Patient Age (years)	**60 - <70**
Total tumour size (mm)	**20 - <30**
Cup size	**≥D**
Site	**UO**
Focality	**Multi-focal, single quadrant**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy	**Breast Conservation Surgery**
☐1	☐2

Scenario 11

Patient Age (years)	**40 - <60**
Total tumour size (mm)	**≥50**
Cup size	**A**
Site	**UI**
Focality	**Unifocal**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy	**Breast Conservation Surgery**
☐1	☐2

Scenario 12

Patient Age (years)	**40 - <60**
Total tumour size (mm)	**30 - <40**
Cup size	**≥D**
Site	**Central**
Focality	**Unifocal**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy	**Breast Conservation Surgery**
☐1	☐2

Scenario 13

Patient Age (years)	**70 - <80**
Total tumour size (mm)	**≥50**
Cup size	**C**
Site	**UO**
Focality	**Unifocal**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy ☐1 **Breast Conservation Surgery** ☐2

Scenario 14

Patient Age (years)	**70 - <80**
Total tumour size (mm)	**30 - <40**
Cup size	**A**
Site	**LI**
Focality	**Multi-focal, single quadrant**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy ☐1 **Breast Conservation Surgery** ☐2

Scenario 15

Patient Age (years)	**<40**
Total tumour size (mm)	**<20**
Cup size	**A**
Site	**UO**
Focality	**Unifocal**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy	**Breast Conservation Surgery**
☐1	☐2

Scenario 16

Patient Age (years)	**<40**
Total tumour size (mm)	**30 - <40**
Cup size	**C**
Site	**LO**
Focality	**Multi-focal, single quadrant**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy	**Breast Conservation Surgery**
☐1	☐2

Scenario 17

Patient Age (years)	**60 - <70**
Total tumour size (mm)	**40 - <50**
Cup size	**A**
Site	**LO**
Focality	**Unifocal**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy ☐1 **Breast Conservation Surgery** ☐2

Scenario 18

Patient Age (years)	**≥80**
Total tumour size (mm)	**20 - <30**
Cup size	**A**
Site	**Central**
Focality	**Multi-focal, single quadrant**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy ☐1 **Breast Conservation Surgery** ☐2

Scenario 19

Patient Age (years)	**≥80**
Total tumour size (mm)	**30 - <40**
Cup size	**B**
Site	**UO**
Focality	**Unifocal**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy	**Breast Conservation Surgery**
☐1	☐2

Scenario 20

Patient Age (years)	**60 - <70**
Total tumour size (mm)	**<20**
Cup size	**C**
Site	**Central**
Focality	**Unifocal**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy	**Breast Conservation Surgery**
☐1	☐2

Scenario 21

Patient Age (years)	**70 - <80**
Total tumour size (mm)	**<20**
Cup size	**≥D**
Site	**UI**
Focality	**Multi-focal, single quadrant**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy ☐1 **Breast Conservation Surgery** ☐2

Scenario 22

Patient Age (years)	**≥80**
Total tumour size (mm)	**<20**
Cup size	**A**
Site	**LI**
Focality	**Unifocal**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy ☐1 **Breast Conservation Surgery** ☐2

Scenario 23

Patient Age (years)	**70 - <80**
Total tumour size (mm)	**20 - <30**
Cup size	**A**
Site	**LO**
Focality	**Unifocal**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy	**Breast Conservation Surgery**
☐1	☐2

Scenario 24

Patient Age (years)	**60 - <70**
Total tumour size (mm)	**30 - <40**
Cup size	**A**
Site	**UI**
Focality	**Unifocal**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy	**Breast Conservation Surgery**
☐1	☐2

Scenario 25

Patient Age (years)	**<40**
Total tumour size (mm)	**≥50**
Cup size	**A**
Site	**Central**
Focality	**Multi-focal, single quadrant**

Please indicate your preferred choice of surgery in this case by ticking the relevant box below. If you prefer both equally, please tick both boxes.

Mastectomy	**Breast Conservation Surgery**
☐1	☐2

Thank you for completing **Section One**. If you have any comments you wish to make, please write them on this page. Use additional sheets if necessary. Ensure any additional sheets used are clearly marked with the section they refer to.

Please turn over to commence Section Two

Section Two

In this section we ask you to respond to a series of questions/statements about yourself. The section is divided into 6 parts.

Part One

The table below contains factors that may be available when discussing a diagnosis of breast cancer and its surgical management.

As an individual specialist, rather than as a member of your breast team, how important do you think the influence of each of these factors is in the decision making process with respect to surgery in primary breast cancer?

For each individual factor tick the box that best describes how important you think that factor is.

Factor	Very important	Important	Some importance	Not important	No opinion
Tumour size	☐1	☐2	☐3	☐4	☐5
Tumour: breast size ratio	☐1	☐2	☐3	☐4	☐5
Tumour site	☐1	☐2	☐3	☐4	☐5
Tumour type	☐1	☐2	☐3	☐4	☐5
Past medical history	☐1	☐2	☐3	☐4	☐5
Avoidance of radiotherapy	☐1	☐2	☐3	☐4	☐5
Patient's method of transportation	☐1	☐2	☐3	☐4	☐5
Patient's treatment preference	☐1	☐2	☐3	☐4	☐5
Patient's age	☐1	☐2	☐3	☐4	☐5
Patient's socio-economic circumstances	☐1	☐2	☐3	☐4	☐5
Menopausal /pre-menopausal status	☐1	☐2	☐3	☐4	☐5
Other *(please specify below)*	☐1	☐2	☐3	☐4	☐5
Other *(please specify below)*	☐1	☐2	☐3	☐4	☐5
Other *(please specify below)*	☐1	☐2	☐3	☐4	☐5

Part Two

scale in the table below is composed of a pair of phrases separated by a series of boxes. Each pair represents two types of contrasting behaviour. Each of us belongs somewhere between the two extremes.

For each pair of phrases, please mark a box between the phrases, which best describes you.

	+++	++	+	-	+	++	+++	
Not at all independent	☐1	☐2	☐3	☐4	☐5	☐6	☐7	**Very independent**
Not at all emotional	☐1	☐2	☐3	☐4	☐5	☐6	☐7	**Very emotional**
Very rough	☐1	☐2	☐3	☐4	☐5	☐6	☐7	**Very gentle**
Not at all competitive	☐1	☐2	☐3	☐4	☐5	☐6	☐7	**Very competitive**
Not at all kind	☐1	☐2	☐3	☐4	☐5	☐6	☐7	**Very kind**
Not at all aware of the feelings of others	☐1	☐2	☐3	☐4	☐5	☐6	☐7	**Very aware of the feelings of others**
Gives up easily	☐1	☐2	☐3	☐4	☐5	☐6	☐7	**Never gives up easily**
Not at all self confident	☐1	☐2	☐3	☐4	☐5	☐6	☐7	**Very self confident**

Part Three

For each statement in the table below please indicate the extent to which you agree or disagree **with the statement, by placing a tick within the relevant box.**

Statement	**Disagree Strongly**	**Disagree Somewhat**	**Agree Somewhat**	**Agree Strongly**
An expert who does not come up with a definite answer probably doesn't know much.	☐1	☐2	☐3	☐4
There is no such thing as a problem that cannot be solved.	☐1	☐2	☐3	☐4
A good job is one where, what is to be done and how it is to be done are always clear.	☐1	☐2	☐3	☐4
In the long run, it is possible to get more done by tackling small, simple problems rather than large and complicated ones.	☐1	☐2	☐3	☐4
What we are used to is always preferable to what is unfamiliar.	☐1	☐2	☐3	☐4
A person who leads a well organised, routine life, in which few surprises or unexpected happenings arise, really has a lot to be grateful for.	☐1	☐2	☐3	☐4
I like parties where I know most of the people more than the ones where all or most of the people are complete strangers.	☐1	☐2	☐3	☐4
The sooner we all acquire similar values or ideas, the better.	☐1	☐2	☐3	☐4
I would like to live in a foreign country for a while.	☐1	☐2	☐3	☐4
People who fit their lives into a schedule probably miss most of the joy of living.	☐1	☐2	☐3	☐4
It is more fun to tackle a complicated problem, than to solve a simple one.	☐1	☐2	☐3	☐4
Often the most interesting and stimulating people are those who don't mind being different or original.	☐1	☐2	☐3	☐4
People who insist upon a yes or no answer just don't know how complicated things really are.	☐1	☐2	☐3	☐4
Most of our most important decisions are based upon insufficient information.	☐1	☐2	☐3	☐4
Teachers or supervisors who hand out vague assignments give opportunities for individuals to show initiative and originality.	☐1	☐2	☐3	☐4
A good teacher is one who makes you wonder about your way of looking at things.	☐1	☐2	☐3	☐4

Part Four

The questions in the table below relate to your health over the past few weeks.

Please indicate your response to each statement by placing a mark within the relevant box.

Have you recently...	Better than usual	Same as usual	Less than usual	Much less than usual
Been able to concentrate on whatever you're doing?	☐1	☐2	☐3	☐4
Lost much sleep over worry?	☐1	☐2	☐3	☐4
Felt that you were playing a useful part in things?	☐1	☐2	☐3	☐4
Felt capable of making decisions about things?	☐1	☐2	☐3	☐4
Felt constantly under strain?	☐1	☐2	☐3	☐4
Felt that you couldn't overcome your difficulties?	☐1	☐2	☐3	☐4
Been able to enjoy your normal day-to-day activities?	☐1	☐2	☐3	☐4
Been able to face up to your problems?	☐1	☐2	☐3	☐4
Been feeling unhappy and depressed?	☐1	☐2	☐3	☐4
Been losing confidence in yourself?	☐1	☐2	☐3	☐4
Been thinking of yourself as a worthless person?	☐1	☐2	☐3	☐4
Been feeling reasonably happy, all things considered?	☐1	☐2	☐3	☐4

Part Five

The statements in the table below relate to your feelings about working **as a specialist**.

Please indicate your response to each statement by placing a mark within the relevant box.

Statement	Every day	A few times a week	Once a week	A few times a month	Once a month or less	A few times a year	Never
I deal very effectively with the problems of my patients.	☐1	☐2	☐3	☐4	☐5	☐6	☐7
I feel emotionally drained from my work.	☐1	☐2	☐3	☐4	☐5	☐6	☐7
I feel I treat patients as if they were impersonal objects.	☐1	☐2	☐3	☐4	☐5	☐6	☐7
I feel fatigued when I get up in the morning and have to face another day.	☐1	☐2	☐3	☐4	☐5	☐6	☐7
I feel that at times I am callous towards people.	☐1	☐2	☐3	☐4	☐5	☐6	☐7
I feel I am positively influencing other people's lives through my work.	☐1	☐2	☐3	☐4	☐5	☐6	☐7
Working with people all day is a real strain for me.	☐1	☐2	☐3	☐4	☐5	☐6	☐7
I don't really care what happens to some patients.	☐1	☐2	☐3	☐4	☐5	☐6	☐7
I feel exhilarated after working closely with my patients.	☐1	☐2	☐3	☐4	☐5	☐6	☐7

Part Six

The statements in the table below relate to how you feel about the uncertainties sometimes involved in your work **as a specialist**.

Please indicate your response to each statement by placing a mark within the relevant box.

Statement	Strongly agree	Moderately agree	Slightly agree	Slightly disagree	Moderately disagree	Strongly disagree
The uncertainty of patient care often troubles me.	☐1	☐2	☐3	☐4	☐5	☐6
Not being sure of what is best for a patient is one of the most stressful parts of being a specialist.	☐1	☐2	☐3	☐4	☐5	☐6
I am tolerant of the uncertainties present in patient care.	☐1	☐2	☐3	☐4	☐5	☐6
I find the uncertainty involved in patient care disconcerting.	☐1	☐2	☐3	☐4	☐5	☐6
I usually feel anxious when a diagnosis is uncertain.	☐1	☐2	☐3	☐4	☐5	☐6
When a diagnosis I uncertain, I imagine all sorts of bad scenarios – patient dies, sues, etc…	☐1	☐2	☐3	☐4	☐5	☐6
I am frustrated when a patient's diagnosis is unknown.	☐1	☐2	☐3	☐4	☐5	☐6
I fear being held accountable for the limits of my knowledge.	☐1	☐2	☐3	☐4	☐5	☐6
Uncertainty in patient care makes me uneasy.	☐1	☐2	☐3	☐4	☐5	☐6
I worry about malpractice when a patient's diagnosis is not known.	☐1	☐2	☐3	☐4	☐5	☐6
The vastness of the information specialists are expected to know overwhelms me.	☐1	☐2	☐3	☐4	☐5	☐6
I frequently wish I had gone into a speciality or subspecialty that would minimise the uncertainties of patient care.	☐1	☐2	☐3	☐4	☐5	☐6
I am quite comfortable with the uncertainty in patient care.	☐1	☐2	☐3	☐4	☐5	☐6
The hardest thing to say to patients or their families is, "I don't know."	☐1	☐2	☐3	☐4	☐5	☐6
When specialists are uncertain of a diagnosis, they should share this information with their patients.	☐1	☐2	☐3	☐4	☐5	☐6
If I share my uncertainties with patients, I will increase the likelihood of being sued.	☐1	☐2	☐3	☐4	☐5	☐6
I almost never tell other specialists about the diagnoses I have missed.	☐1	☐2	☐3	☐4	☐5	☐6
If I shared all of my uncertainties with my patients, they would lose confidence in me.	☐1	☐2	☐3	☐4	☐5	☐6
I am afraid other specialists would doubt my ability if they knew about my mistakes.	☐1	☐2	☐3	☐4	☐5	☐6
If I do not make a diagnosis, I worry others will stop referring patients to me.	☐1	☐2	☐3	☐4	☐5	☐6
I never tell other specialists about patient care mistakes that I have made.	☐1	☐2	☐3	☐4	☐5	☐6
I always share my uncertainty with my patients.	☐1	☐2	☐3	☐4	☐5	☐6

Thank you for completing **Section Two**. If you have any comments you wish to make, please write them on this page. Use additional sheets if necessary. Ensure any additional sheets used are clearly marked with the section they refer to.

Please continue on a separate sheet if necessary

Please turn over to find out what to do with the completed questionnaire

Thank you for completing this questionnaire and taking part in the study.

Before returning the questionnaire, please ensure that...

- You have completed and signed the consent form on page 4
- You have had the consent form witnessed by someone
- If you have used any additional sheets of paper to write comments on, make sure that each sheet is clearly marked with the section the comments refer to
- Securely attach any additional sheets to the questionnaire with a paper clip

You can now return the completed questionnaire in the FREEPOST envelope provided to:

Miss Lisa Caldon MBChB, FRCS (Eng)
Clinical Research Lecturer
THE UNIVERSITY OF SHEFFIELD
Academic Surgical Oncology Unit
Division of Surgical Sciences (South)
Floor K
Royal Hallamshire Hospital
Sheffield
S10 JEF

THANK YOU AGAIN FOR YOUR HELP AND CO-OPERATION

Thank you for completing **Section Two**. If you have any comments you wish to make, please write them on this page. Use additional sheets if necessary. Ensure any additional sheets used are clearly marked with the section they refer to.

Please turn over to find out what to do with the completed questionnaire

Thank you for completing this questionnaire and taking part in the study.

Before returning the questionnaire, please ensure that...

- You have completed and signed the consent form on page 4
- You have had the consent form witnessed by someone
- If you have used any additional sheets of paper to write comments on, make sure that each sheet is clearly marked with the section the comments refer to
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Floor K
Royal Hallamshire Hospital
Sheffield
S10 JEF

THANK YOU AGAIN FOR YOUR HELP AND CO-OPERATION

APPENDIX 4.5 Clinician questionnaire covering letter

Dear

Re **'Patient and professional factors influencing choice of surgery in the management of breast cancer: A qualitative and quantitative study'**

Having received approval to undertake the above study by your local Research Governance process and Research Ethics Committee, we are now distributing questionnaires to individual members of your team. I therefore enclose a copy of the questionnaire for you to complete. A consent form is located on page 4. On completion please return it to us in the FREEPOST envelope provided. Piloting confirms the questionnaire takes a maximum of 25 minutes to complete.

Any information you provide will be treated confidentially: No one outside the research team will have access to your personal responses (including other members of your team). At the conclusion of the study we will provide you with feedback: The unit's data in the context of Trent-wide data, and if requested will provide feedback on your responses as an individual. This would be available only to you, no one else.

If you have questions regarding the questionnaire or the project we are happy to answer them either over the phone or through email.

We would like to take this opportunity to thank you for your involvement in this project. We look forward to hearing from you and to working with you on the rest of the project.

Yours sincerely

Appendix 5

Clinician correspondence and Interviews

(3 Breast units)

APPENDIX 5.1 Clinician interview consent form

Study Number: MREC/02/4/114

Unit/staff ID number: _ _ _ _ _ / _ _ _ _ _ _

The University of Sheffield
Section of Surgical and Anaesthetic Sciences
Academic Surgical Oncology Unit
& Academic Palliative Medicine Unit
K Floor Royal Hallamshire Hospital
Sheffield S10 2JF
UK

Mr David Wilde BSc, MSc

Tel: +44 (0)114 271 1707

SPECIALIST HEALTH PROFESSIONAL SEMI-STRUCTURED INTERVIEW CONSENT FORM

Surgical Management Preferences and Choices in Breast Cancer:
A qualitative and quantitative study.

If you wish to take part in the study, please read the statements below, and initial the boxes to the right if you agree with the statement.

Please initial the box

3. I confirm that I have read and understand the information sheet dated 22nd January 2003 (Version 3) for the above study. ☐
4. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I agree to take part in the semi-structured interview section of the study. ☐
4. I agree to the discussion session being audio recorded. ☐

Name of respondent (CAPITAL LETTERS PLEASE)	Date	Signature
Witnessed by (CAPITAL LETTERS PLEASE)	Date	Signature

Breast Unit name ________________________________

APPENDIX 5.2 *Clinician interview schedule clinician version (no prompts)*

Unit/Surgeon Identifier

☐☐☐☐☐/☐☐☐☐☐

Surgical Decision Making:
Doctor's Interview

Thank you for taking part in this study.

The aim of this study is to find out how patients arrived at the decisions they made, in relation to their options for surgery for their illness. If at any time, you do not understand any of the questions, or you wish to stop the interview, please feel free to say so.

All information that you will provide will remain strictly confidential.

Academic Surgical Oncology Unit, Division of Clinical Sciences (CSUHT),

Section of Surgical and Anaesthetic Sciences, K Floor, Royal Hallamshire

Checklist (Pre-Interview)

Has the participant read the ***Information Sheet****?*	
Has the participant read through the ***Interview Schedule****?*	
Does the participant have any ***questions*** *at this stage?* ***(if YES, write down what they are)***	
Talk the participant through *the project and what will happen during the interview*	
Take the participant through the ***Consent Form*** *and have them* ***sign it***	

About you and the unit you work in

To begin with I would like to ask you a few questions about how you find working in the Breast Service here at ***<Name of unit here>****.*

1. *How long have you worked in this breast unit?*

2. *What is it like to work as a specialist in this breast service?*

3. *Do you feel that professionals have different styles and different ways of working, if so, what styles have you observed?*

Before a consultation where a diagnosis is to be given

I would now like to talk about what happens just before a clinic begins where patients are to hear about their diagnosis. From this point in the interview I would like us to focus only on ***newly diagnosed breast cancer patients****.*

4. *When is your regular breast MDT meeting held in relation to the clinic where patients are given a diagnosis of breast cancer?*

5. *How do you usually feel after an MDT meeting?*

6. *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?*

7. *What way, if any, are patients themselves prepared for the news that they have breast cancer?*

8. *Prior to a consultation where you know that a patient will be given a diagnosis of breast cancer, do you have any expectations about what the consultation will be like and what are they based on?*

9. *How would you describe your feelings before such a consultation?*

During a consultation with a newly diagnosed patient

10. *Please talk me through what happens in a consultation where diagnosis and treatment options are being discussed with a patient with breast cancer.*

About patients' information needs

11. *In your experience, what do patients tend to know about breast cancer and its treatment options before they come to see you?*

12. *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****?*

13. *What do you think are the most important pieces of information patients need or want to know about **treatment** and **when are they raised**?*

What a patient is offered

14. *Within the context of your Unit's Guidelines and published research, please describe the factors that would lead your team to offer a patient...*

Interviewer Note:

Read out text in quotation marks

"The literature suggests that patients vary in the degree of involvement they want when making decisions about what surgery to have. Some patients will want full control over the decision making process, some prefer to share that control, and others will prefer it if their professionals take full control."

15. *Do you think patients are getting the degree of choice they want?*

16. *Thinking about your experiences with the patients you see* ***[SHOW CARD 1]*** *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?*

- ***The patient tends to make the final decision regarding the treatment they will have***
- ***The patient tends to make the final decision about which treatment will they will have after seriously considering my opinion***
- ***The patient and I generally share the responsibility for making final decisions regarding which treatment is best***
- ***I tend to make the final decision about which treatment the patient has after seriously considering the patient's opinion***
- ***I tend to make the final decision about which treatment the patient has***

Communicating with patients who have breast cancer

At this point I would like us to talk about your experiences communicating with patients. ***In particular****, I would like us to focus on* ***patients in whom, for clinical reasons, mastectomy is not the only option****.*

Interviewer Note:

Read out text in quotation marks

"Research has identified that patients with breast cancer tend to fall within 1 of 3 different decision making styles. These are:

Active *decision makers*

Collaborative *decision makers*

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 each of these types of patient during the consultation process that leads to a final treatment decision. I would like to start with situations with ***ACTIVE*** *decision makers.* ***[SHOW CARD 2]*** *For the purposes of this study we define active decision makers as..."*

"Patients who tend to make their own final treatment decisions, either with or without seriously considering their specialist's opinion."

Definition adapted from:

Beaver K, Luker KA, Owens RG, Leinster SJ, Degner LF, Sloan JA. Treatment decision making in women newly diagnosed with breast cancer. Cancer Nurs. 1996;19:8-19

17. *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.*

Interviewer Note:

Read out text in quotation marks

*"I would now like you to think about situations with **COLLABORATIVE** decision makers. **[SHOW CARD 3]** For the purposes of this study we define collaborative decision makers as..."*

"Patients who tend to share final treatment decision responsibilities with their specialist."

Definition adapted from:

Beaver K, Luker KA, Owens RG, Leinster SJ, Degner LF, Sloan JA. Treatment decision making in women newly diagnosed with breast cancer. Cancer Nurs. 1996;19:8-19

18. *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.*

Interviewer Note:

Read out text in quotation marks as a lead in to Question 20

"I would now like you to think about situations with ***PASSIVE*** *decision makers.* ***[SHOW CARD 4]*** *For the purposes of this study we define passive decision makers as…"*

"Patients who tend to want to leave final treatment decisions to their specialist, either with or without their specialist seriously considering their opinion."

Definition adapted from:

Beaver K, Luker KA, Owens RG, Leinster SJ, Degner LF, Sloan JA. Treatment decision making in women newly diagnosed with breast cancer. Cancer Nurs. 1996;19:8-19

19. *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.*

Interviewer Note:

Read out text in quotation marks

"The literature tells us that there are a variety of influences on patients making decisions about surgical treatment..."

20. *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?*

21. *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?*

22. *Is there anything else you would like to add to what we have been talking about today?*

Checklist (Post-Interview)

Does the participant have any ***questions*** *at this stage?* ***(if YES, write down what they are)***	
Talk the respondent through what happens next regarding…	
The involvement of the participant	
What kind of feedback they can expect to receive and when	
Briefly what will happen with the rest of the study	
Leave contact details with the participant and thank them for their help	
Write up any notes from the interview	

APPENDIX 5.3 *Clinician interview schedule interviewer version (with prompts)*

For office use only

☐ ☐ ☐ ☐ ☐

Unit/Surgeon Identifier

☐ ☐ ☐ ☐ ☐ / ☐ ☐ ☐ ☐ ☐

Surgical Decision Making: Doctor's Interview

Recorder Interview ID Code

Thank you for taking part in this study.

The aim of this study is to find out how patients arrived at the decisions they made, in relation to their options for surgery for their illness. If at any time, you do not understand any of the questions, or you wish to stop the interview, please feel free to say so.

All information that you will provide will remain strictly confidential.

Checklist (Pre-Interview)

Does the participant have any **questions** at this stage? (if YES, write down what they are)	
Talk the participant through the project and what will happen during the interview	
Take the participant through the **Consent Form** and have them **sign it**	

Interviewer:	**Venue:**	**Date: / /2003**

About you and the unit you work in

*To begin with I would like to ask you a few questions about how you find working in the Breast Service here at **<Name of unit here>**.*

1. How long have you worked in this breast unit?

2. What is it like to work as a specialist in this breast service?

    Prompts

    Likes & dislikes

    What is the unit philosophy?

    Day to day running of the service

    Structure of the service, time after doctor, pre-op and/or home visits

    Constraints / facilitations

    What is this place to work in compared to others?

    How well do you get on with your colleagues?

    Examples of these

3. Do you feel that professionals have different styles and different ways of working, if so, what styles have you observed?

   Prompts

   Impact on how consultations go and patient decision making / satisfaction

Before a consultation where a diagnosis is to be given

I would now like to talk about what happens just before a clinic begins where patients are to hear about their diagnosis. From this point in the interview I would like us to focus only on ***newly diagnosed breast cancer patients****.*

4. When is your regular breast MDT meeting held in relation to the clinic where patients are given a diagnosis of breast cancer?

   Prompts

   Are patients discussed pre-op at this MDT **(if NO, go to Q6)**

5. How do you usually feel after an MDT meeting?

   Prompts

   Heavy / light workloads

   Bearing upon following consultations

6. 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?

   Prompts

   Inklings

   Bring a relative or friend

7. What way, if any, are patients themselves prepared for the news that they have breast cancer?

8. Prior to a consultation where you know that a patient will be given a diagnosis of breast cancer, do you have any expectations about what the consultation will be like and what are they based on?

9. How would you describe your feelings before such a consultation?

Prompts

Look for continuity / links from **Q5**

During a consultation with a newly diagnosed patient

10. Please talk me through what happens in a consultation where diagnosis and treatment options are being discussed with a patient with breast cancer.

Prompts

Person who breaks the news

Others in the room

Do you have a preferred style or approach to breaking bad news to patients?

If yes, please describe it?

How do previously discussed work styles manifest in consultations?

Examples of this...

Who does most of the talking / questions and when asked

What tools used? X-rays, diagrams, photographs, written information?

Which of these do patients find the most helpful and why?

Do you spend any additional time with the patient after the consultation?

What are the specialist's feelings about discussing these issues?

About patients' information needs

11. In your experience, what do patients tend to know about breast cancer and its treatment options befor they come to see you?

Prompts

Harder / easier consultation process

Examples of this

Look for continuity / links from **Q7**

12. 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**?

Prompts

Confirmation of cancer

Stage of disease

Prognosis

Survival

Types of treatment

Physical and psychological aspects of cancer

Family risk of disease

When discussing diagnosis, what do patients understand <u>well</u> about what is told to them?

...And what information is understood <u>poorly</u>?

13. What do you think are the most important pieces of information patients need or want to know about **treatment** and **when are they raised**?

Prompts

Likelihood of recurrence

Likelihood of cure

Stage of disease

Prognosis

Survival

Types of treatment

How to spot a potential recurrence

Family risk of disease

Coping with cancer

When discussing treatment options, what do patients understand <u>well</u> about what is tol to them?

...And what information is understood <u>poorly</u>?

What a patient is offered

14. Within the context of your Unit's Guidelines and published research, please describe the factors that would lead your team to offer a patient...

    Prompts

    Only Breast Conservation Surgery

    Only a Mastectomy

    A choice between Mastectomy & Breast Conservation Surgery

    Other treatments - please state which

Interviewer Note:

Read out text in quotation marks

"The literature suggests that patients vary in the degree of involvement they want when making decisions about what surgery to have. Some patients will want full control over the decision making process, some prefer to share that control, and others will prefer it if their professionals take full control."

15. Do you think patients are getting the degree of choice they want?

16. Thinking about your experiences with the patients you see **[SHOW CARD 1]** 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?

- **The patient tends to make the final decision regarding the treatment they will have**
- **The patient tends to make the final decision about which treatment will they will have after seriously considering my opinion**
- **The patient and I generally share the responsibility for making final decisions regarding which treatment is best**
- **I tend to make the final decision about which treatment the patient has after seriously considering the patient's opinion**
- **I tend to make the final decision about which treatment the patient has**

Own description:

Communicating with patients who have breast cancer

At this point I would like us to talk about your experiences communicating with patients. ***In particular****, I would like us to focus on* **patients in whom, for clinical reasons, mastectomy is not the only option***.*

Interviewer Note:

Read out text in quotation marks

"Research has identified that patients with breast cancer tend to fall within 1 of 3 different decision making styles. These are:

Active *decision makers*

Collaborative *decision makers*

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 each of these types of patient during the consultation process that leads to a final treatment decision. I would like to start with situations with ***ACTIVE*** *decision makers.* ***[SHOW CARD 2]*** *For the purposes of this study we define active decision makers as…"*

"Patients who tend to make their own final treatment decisions, either with or without seriously considering their specialist's opinion."

Definition adapted from:

Beaver K, Luker KA, Owens RG, Leinster SJ, Degner LF, Sloan JA. Treatment decision making in women newly diagnosed with breast cancer. Cancer Nurs. 1996;19:8-19

17. 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.

Prompts

What happened – the story

How did you get on with the patient and nurse?

How did the nurse get on with the patient?

Specialist's feelings about how things went

How was the decision arrived at?

What influences were apparent?

Looking back, how satisfied were you with the experience?

...and how satisfied do you think the patient was with the experience?

At what point were you aware that you were talking to an ACTIVE decision maker?

Did this awareness change your approach to this person?

Interviewer Note:

Read out text in quotation marks

*"I would now like you to think about situations with **COLLABORATIVE** decision makers. **[SHOW CARD 3]** For the purposes of this study we define collaborative decision makers as..."*

"Patients who tend to share final treatment decision responsibilities with their specialist."

Definition adapted from:

Beaver K, Luker KA, Owens RG, Leinster SJ, Degner LF, Sloan JA. Treatment decision making in women newly diagnosed with breast cancer. Cancer Nurs. 1996;19:8-19

18. 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.

Prompts

What happened – the story

How did you get on with the patient and nurse?

How did the nurse get on with the patient?

Specialist's feelings about how things went

How was the decision arrived at?

What influences were apparent?

Looking back, how satisfied were you with the experience?

...and how satisfied do you think the patient was with the experience?

At what point were you aware that you were talking to a COLLABORATIVE decision maker?

Did this awareness change your approach to this person?

Interviewer Note:

Read out text in quotation marks as a lead in to Question 20

"I would now like you to think about situations with ***PASSIVE*** *decision makers.* ***[SHOW CARD 4]*** *For the purposes of this study we define passive decision makers as..."*

"Patients who tend to want to leave final treatment decisions to their specialist, either with or without their specialist seriously considering their opinion."

Definition adapted from:

Beaver K, Luker KA, Owens RG, Leinster SJ, Degner LF, Sloan JA. Treatment decision making in women newly diagnosed with breast cancer. Cancer Nurs. 1996;19:8-19

19. 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.

Prompts

What happened – the story

How did you get on with the patient and nurse?

How did the nurse get on with the patient?

Specialist's feelings about how things went

How was the decision arrived at?

What influences were apparent?

Looking back, how satisfied were you with the experience?

...and how satisfied do you think the patient was with the experience?

At what point were you aware that you were talking to an PASSIVE decision maker?

Did this awareness change your approach to this person?

Re-cap over last two prompts for any of the decision makers you may have missed out.

Interviewer Note:

Read out text in quotation marks

"The literature tells us that there are a variety of influences on patients making decisions about surgical treatment..."

20. 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?

21. 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?

22. Is there anything else you would like to add to what we have been talking about today?

Prompts

If you had the money and power to change one thing about the system here, what would that be?

Checklist (Post-Interview)

The involvement of the participant	
What kind of feedback they can expect to receive and when	
Briefly what will happen with the rest of the study	
Leave contact details with the participant and thank them for their help	
Write up any notes from the interview	

APPENDIX 5.4 *Clinician post interview letter*

<<insert professional's name and title>>
<<insert address>>

Dear *<<insert professional's name>>*

We would like to take this opportunity to thank you for participating in the study 'Patient and professional factors influencing choice of surgery in the management of breast cancer: A qualitative and quantitative study'. As David mentioned during the debrief session after your interview, your involvement as a participant in the study is now over.

Healthcare Professional Survey
We have been pleased with response rate to this part of the study. All those approached from the unit have kindly completed and returned their surveys. The data has been entered and awaits analysis.

Interviews
All interviews within the unit have now been conducted. It was evident that all staff taking part had taken the time to read through the schedule as advised and prepare themselves thoroughly. The recordings of these interviews are currently being transcribed. With the completion of transcription, we look forward to starting data analysis.

Feedback
As described in the Healthcare Professional Information Sheet you received, feedback of results will be offered to the unit and the individual (upon request). We will let you know more about this with time.

We have been delighted with the professional approach, attitude, courtesy and help shown to us by all staff in the unit. We look forward to working with you all during the patient recruitment phase over the next few months. If you experience any problems associated with the project don't hesitate to contact us.

Once again thank you for your participation.

Yours sincerely

APPENDIX 5.5 *Clinician finalising patient recruitment information*

FINALIZING LETTER RE IN DEPTH STUDY 3 UNITS PATIENT RECRUITMENT PHASE

Dear,

Re **'Patient and professional factors influencing choice of surgery in the management of breast cancer: A qualitative and quantitative study'**

As you are aware we have now received all the necessary permissions to commence the study, and are ready to commence recruitment of patients to it. I wanted to write to you at this stage to confirm a few practical details and invite you to ask any questions.

To confirm:

- Inclusion criteria are: All women newly diagnosed with breast cancer who were/are eligible for a choice of surgical treatments (breast conservation surgery or mastectomy).
- The only exclusion criteria are: Women who were only eligible for mastectomy, and those with current diagnosed acute psychiatric illness, liable in the opinion of the patient's doctor to affect their ability to give fully informed consent.
- Information packs regarding the study should ideally be given to all eligible patients, as identified at the MDT, and recorded in the MDT notes by the data co-ordinator or clerk. We would like to be sent a list of those eligible for inclusion in the study and who has received a pack etc. This way we will be able to keep track of recruitment.

  Please see the attached fax form which could be used for this purpose. The form could either be faxed to us or emailed, depending on your preference.
- The first phase of patient recruitment is to the discussion groups. We need to recruit 8 patients in total, ideally 4 who chose mastectomy and 4 who chose conservation surgery.
- When the required number of women have been recruited to this phase, we will provide you with the information packs for recruitment to the questionnaire/interview phase.
- The process of recruitment will be the same for both phases; only the patient information leaflets in the information packs will be different.
- We anticipate that there will be more expressions of interest in the study in those receiving information about the discussion groups, than we are able to include in the groups themselves. We anticipate this occurring due to the proportions of those undergoing the different surgical options at any point in time. These 'excess' individuals will be invited by us to participate in an interview instead of the discussion group, that way they can still be included in the study.
- If it becomes evident over the course of an interview that a patient has become distressed, David (with the patient's permission) will contact the appropriate unit team member to inform them of the event.
- Following an interview David will contact the participating patient to thank them for their involvement and ask whether they have any questions or comments. Would you like him to inform you as to who was interviewed and when?

If you have questions please either ring or email, and if you would like to meet up to discuss any of this in person, please me know and we will arrange to come and see you.

While I am on leave David Wilde will be conducting the majority of the patient elements of the field work, and we have clerical assistance to run the office. David will be available to liaise with you in the event of any queries and problems, so please do not hesitate to contact him (Mobile 07810 656 075, office 0114 271 1707). As David will be spending a proportion of his time out of the office interviewing he may not always be immediately available. If you have any urgent inquires Dr Karen Collins, a senior Research Associate in the Academic Palliative Medicine Unit who is well versed in the project will be acting as David's immediate supervisor and will be available to speak to you (Office 0114 271 ....). Malcolm Reed will also be available through his secretary Ann Duffes.

We are looking forward to working with you on the rest of the project.

As always, all the best.

Yours sincerely

Patient and professional factors influencing choice of surgery in the management of breast cancer: A qualitative and quantitative study

Eligibility for approach for the study

- Patients eligible for inclusion are all women newly diagnosed with breast cancer that were eligible for a choice of surgical treatments (breast conservation surgery or mastectomy).
- **Exclusion criteria** are:
    - Women who were only eligible for mastectomy.
    - or women with current diagnosed acute psychiatric illness, liable in the opinion of the patient's doctor to affect their ability to give fully informed consent.

Recruitment procedure

- Eligible patients to be identified by the patient's senior doctor at diagnosis and confirmation of local disease extent.
- These patients' details are transferred to the fax form provided, to identify those to receive an information pack about the study.
- All eligible women are therefore given with a unique identifier number (from the fax form) which should correspond to the number on the information pack they are given. This will help in the event of illegible patient writing on study reply forms they return to us.
- Please email or fax the form to David Wilde weekly to enable us to keep track of recruitment rates.
- Study information packs should ideally be given to **<u>all</u> eligible patients** identified by the team, on the ward post operatively. (There is space on their pack letter to write their name and the date on.)
- The first phase of patient recruitment is to discussion groups. When the required number of women has been recruited to the discussion group phase, we will provide you with the information packs for recruitment to the questionnaire/interview phase.
- If this process works for the first phase we will use it for the second.
- **Please contact us early if you are experiencing problems with recruitment or any other aspect of the study, and we will try and resolve them with your help.**

Thanks. Lisa and Dave

Patient and professional factors influencing choice of surgery in the

Appendix 6

Patient Information needs and decision making Questionnaire

(3 Breast units)

APPENDIX 6.1 *Patient approach letter*

Treating breast unit letter head

/ / 2005

Dear

As a woman who has recently undergone surgery for breast cancer, we are writing to you and other women in a similar situation from across the Trent region, to see if you would be interested in taking part in a new research study. The study is being funded by Cancer Research UK and being carried out by the University of Sheffield.

The study is called "Surgical management preferences and choices in breast cancer". You can find out more by reading the information sheet that comes with this letter.

Reports published by the NHS show that in the treatment of breast cancer there are differences in the numbers of women having mastectomy and those having surgery that does not involve the removal of the whole breast. We would like to understand more about how women make their decision about what operation to have for breast cancer and how they feel about it. The study will investigate these reasons from both the woman's and professionals' point of view.

Please read the information sheet and think about whether you wish to take part. Taking part or not is entirely up to you. Whatever you decide, you will still continue to receive the same care from your breast team.

If you decide you would like to take part, tick the "Yes" box on the Reply Form provided. Fill in the rest of the form (as described in the information sheet) and post the form in the FREEPOST envelope provided. You don't need a stamp. When your form has been received, you will be contacted by the research team.

If you decide not to take part, tick the "No" box on the reply form. Then post the form in the FREEPOST envelope and you will not contacted about this study again.

If you would like to find out more about the study, the project secretary Mrs. Margaret Jane will be able to answer most inquiries, or put you through to Miss Lisa Caldon, the Lead Investigator. Margaret is based at the Trent Palliative Care Centre on 0114 262 0174. Alternatively you can email Lisa at l.caldon@sheffield.ac.uk.

Thank you for your help.

Yours sincerely

Surgical Management Preferences and Choices in Breast Cancer

Please read this carefully

You are invited to take part in a research study. Before you decide whether or not you wish to take part it is important for you to understand why the study is being done and what it will involve if you agree to take part. Please read the following information carefully. Discuss it with your friends and relatives if you wish. Please ask us if there is anything you don't understand or if you would like more information. You will be given as much time as you need to make a decision.

Please turn over

Why is this study being conducted?

The study has arisen from questions generated by reports published by the NHS, showing that in the treatment of breast cancer there are differences in the numbers of women having mastectomy and those having surgery that does not involve the removal of the whole breast. This finding occurs throughout the UK and internationally. Earlier research suggests that there are no significant differences between the two treatments in terms of the length of time that people live after surgery. The differences in treatment are not related to the size of the tumour, the place in which it develops or to the spread of the disease in the body.

The aim of this research study is to understand how patients make decisions about the treatment of breast cancer and why differences exist in the types of surgery women with breast cancer have. There are many potential reasons for this. Our study as a whole will investigate these reasons from both the patients' and professionals' point of view.

Why have I been approached?

This study is composed of several parts. This information leaflet tells you about two of them; a questionnaire and interview. We aim to recruit women from 3 breast units across the Trent region who have undergone surgery as part of their treatment for their illness. The purpose of the project is to help us understand more about how women arrive at their decision about what type of surgical treatment to have for breast cancer, and how they subsequently feel about the decision they have made.

We are asking all patients in this part of the study to complete a short, confidential questionnaire. Later on, if you indicated on the Study Reply Form that you would be happy to take part in the interview phase of the study as well, we will contact you and ask if you would be willing to be interviewed by a researcher.

Who is organising the study?

This study is being funded by Cancer Research UK and sponsored by the University of Sheffield. The principle investigator of the project team is Professor Malcolm Reed from the Academic Surgical Oncology Unit of the University of Sheffield. Professor Sam H. Ahmedzai from the Academic Palliative Medicine Unit will also be supervising the study. Working on the project will be Miss Lisa Caldon, lead investigator, and Mr. David Wilde, Research Associate.

The funders of the study will pay the researchers Lisa Caldon and David Wilde an annual salary to undertake the project. They will not receive any additional payments. No one else will be paid as a result of your participation in this study.

What will happen to me if I decide to take part?

Whether you decide to take part or not, please complete the Study Reply Form and return it in the FREEPOST envelope provided. You do not need a stamp. If you decide not to take part, please tick the box beside "No, I do not wish to take part in this study" and return the form to us. You do not need to fill in any other details on the form.

If you do wish to take part in the study, please tick the box beside "Yes, I would like to take part in this study" and indicate in the section below, which parts of the study you would like to be involved in. You will then need to fill in the contact details section and return the form to us in the FREEPOST envelope. You do not need a stamp.

If, on the form you agree to take part in the questionnaire, we will post you:

- A covering letter
- A Consent Form
- A short questionnaire
- A FREEPOST envelope to return both the Consent Form and questionnaire.

We would ask you to complete the Consent Form and fill in the questionnaire and return them to us. An envelope will be provided; you do not need a stamp.

It is important that the Consent Form is filled in, signed and returned along with the questionnaire; otherwise we cannot use the information you provide.

We will also be asking a certain number of patients who complete the questionnaire if they are willing to be interviewed.

The interviews may be audiotape recorded with your consent. Any information you provide during the discussion will only be available to the research staff working on this study. Tapes will not be stored with any record of your identity. Tapes will be stored in a locked room at the Royal Hallamshire Hospital, Sheffield, which is only accessible to the research staff. The tapes, electronic transcript data and paper records of discussions will be kept until the end of the study and then destroyed. Tapes will be transcribed by a member of the research team. Access to any data stored on computer will be restricted to researchers working on this study and will be password protected. The same research team that collected the data will perform the analysis of the information.

Do I have to take part?

No. Your taking part in this study is entirely voluntary. If you would prefer not to take part, you do not have to give a reason. If you decide to take part, but later feel you do not want to continue, you are free to withdraw from the study at any time, and do not need to give a reason. Your consultant will not be upset and your treatment will not be affected. Your treatment and follow up will not be affected by your decision to take part in the study or not.

What are the possible risks of taking part?

There are no specific risks associated with taking part in this study. If you decide to take part in the study we ask you to complete and sign the consent form, indicating whether you want to just be involved in the questionnaire part or whether you would also consider taking part in the interview stage as well. The questionnaire part of the project, will be posted to you and should take no more than 10 minutes to complete.

If you take part in an interview, it will take about an hour to complete. For your convenience, the interview would usually take place in your home, but could be conducted elsewhere depending on your preference. If during the course of the interview, it is observed that you require further support we would refer you to your breast care nurse.

What are the possible benefits of taking part?

The information we get from this study will provide us with a better understanding of the consultation and decision making process in breast cancer. At the end of the study a report will be written which will feed the results back into the breast service in Trent, and to you if you request it. No names will be mentioned in any reports of the study and care will be taken to ensure that you cannot be identified.

How will this information be used?

Anything you say will be treated in the strictest confidence. Any information gathered during this study will be made available only to researchers working on the study.

What if I am harmed?

As there are no specific risks associated with this study it is highly unlikely that you would be harmed. If you have any complaints or concerns please inform either the principal investigator of the project, Professor Malcolm Reed, your breast care nurse or a senior member of your breast team. If you are still not satisfied after discussing the matter you should ask to see a member of the Hospital Management or write to the Mrs Julie Acred (OBE), Chief Executive, Southern Derbyshire Acute Hospitals NHS Trust, Derby City General Hospital, Uttoxeter Road, Derby, DE22 3NE. A list of potential useful contacts appears on page 10.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanism is available to you in respect of your health care treatment. Your access to this is not compromised in any way if you take part in a research study.

Will anyone else be told about my participation in this study?

What you tell the researchers will remain confidential between you and them. If you decide to take part in the study, it is advisable that your General Practitioner is made aware of this. We will only do this with your permission. If you are happy for us to inform your General Practitioner of your involvement in the study please initial the box on your consent form, "I agree to my General Practitioner to knowing I am taking part in this study".

In order to obtain a full picture of the consultation and decision making process, your surgeon and breast care nurse will also be interviewed. They will not be made aware of what you have said to the researchers.

Who can I contact for more information?

The project secretary, Mrs. Margaret Jane will be able to answer most inquiries, or put you through to Miss Lisa Caldon, the Lead Investigator or Mr. David Wilde, the Research Associate. Margaret is based at the Trent Palliative Care Centre on 0114 262 0174 (extension 26). Alternatively you can email us at l.caldon@sheffield.ac.uk or d.wilde@sheffield.ac.uk.

What do I need to do now?

Whether or not you wish to take part in this study, please return the reply form you have been given. There is a FREEPOST envelope included so you don't need a stamp.

If you indicate that you are not interested in the study, we will not contact you further.

If you indicate that you are interested in the study, we will send you a Consent Form, the questionnaire and a FREEPOST envelope. **Please sign the consent form if you decide if you would like to take part in the study and return it to us**. We also ask that you keep this Information Sheet for future reference.

Feel free to call us with any queries you may have and/or talk the study over with anyone else.

What if I have other concerns?

If after reading this information sheet you decide not to take part in the study, but feel you need to discuss any of the issues we have raised, or you have other questions about this study, please contact either Miss Lisa Caldon, the Lead Investigator or Mr David Wilde, the Research Associate, through Mrs.

Margaret Jane on 0114 262 0174 (extension 26), or write to them at the Academic Surgical Oncology Unit, K Floor, Royal Hallamshire Hospital, Sheffield S10 2JF.

If you have any complaints about the way the investigators have carried out the study, you may write to: Mrs Julie Acred (OBE), Chief Executive, Southern Derbyshire Acute Hospitals NHS Trust, Derby City General Hospital, Uttoxeter Road, Derby, DE22 3NE. A list of potentially useful contacts appears on page 10.

Useful contacts

If you want to know more about the project		
Lead investigator	Miss Lisa Caldon	**0114 262 0174 (extension 26)**
Research Associate	Mr. David Wilde	**0114 262 0174 (extension 26)**
If you have a complaint about the project		

Local Complaints Department	All local complaints are directed to the Patient Advocacy Liaison Service (PALS)	**0800 783 7691** or **01332 340 131** ext. 5156 or ext. 6960
Derby Independent Complaints Advocacy Service	Various advocates covering different areas	**0845 650 0088**
Your own breast care nurse		

Please keep this information leaflet for future reference

APPENDIX 6.3 *Patient study reply form*

Surgical Management Preferences and Choices in Breast Cancer

STUDY REPLY FORM
Questionnaire and/or interview

Please tick the appropriate box

☐ **NO**, I do not wish to take part in this study

☐ **YES**, I would like to take part in this study

If **YES**, please indicate the level to which you are willing to be involved in the study. **You may tick more than one box.**

☐ **YES**, to the short questionnaire part of this study

☐ **YES**, if approached, to the interview part of this study

If **YES**, please provide us with your contact details **(IN BLOCK CAPITAL LETTERS PLEASE)**

Name ______________________________

Contact address ______________________________

____

____

Telephone No ______________________________

Email address ______________________________

Date ______________________________

Please return this completed slip to us in the enclosed FREEPOST envelope. You don't need a stamp.

Thank you

APPENDIX 6.4 *Patient Information Needs and Decision Making Preferences Questionnaire*

Unit/Patient Identifier

☐☐☐☐☐/☐☐☐☐☐

For office use only ☐

Information Needs and Decision Making Preferences Questionnaire

Thank you for taking part in this study.

Please complete this questionnaire in your own time. The questions are easy to complete and only require you to tick a box. So to complete all the questions here will probably take you about 10 minutes. All the questions are important so we do need you to complete all of them.

All information that you will provide will remain strictly confidential.

If you have any queries about this questionnaire or the study, please contact

Lisa Caldon on 0114 271 2225 or David Wilde on 0114 271 1707

Academic Surgical Oncology Unit, Division of Clinical Sciences (CSUHT),

Section of Surgical and Anaesthetic Sciences, K Floor, Royal Hallamshire

Unit/Patient ID number: __ __ __ _

CONSENT FORM (questionnaire) - **Version 4: 09/04/03**

Surgical Management Preferences and Choices in Breast Cancer: A qualitative and quantitative study

If you wish to take part in the study, please read the statements below, and initial the boxes to the right if you agree with the statement.

Please initial box

5. I confirm that I have read and understand the information sheet dated 23rd January 2003 (Version 3) for the above study. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason ☐

6. I understand that it will be necessary for research staff attached to the study to access my medical records. I give permission for these individuals to have access to this data. ☐

7. I understand that sections of the research materials may be looked at by responsible individuals from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to this data. ☐

8. I agree to my General Practitioner to knowing I am taking part in this study. ☐

5. I would like to know the results of the questionnaires once all the data has been analysed. ☐

6. I agree to take part in the above study. ☐

____________________ ______________ ______________________

Name of respondent
*(Print in **BLOCK CAPITALS**)*

Date

Signature

For office use only

____________________ ______________ ______________________

BEFORE YOU CONTINUE WITH THIS QUESTIONNAIRE, HAVE YOU...

4. READ AND UNDERSTOOD THE SURGICAL MANAGEMENT PREFERENCES AND CHOICES IN BREAST CANCER, PATIENT INFORMATION LEAFLET, QUESTIONNAIRE AND INTERVIEWS
5. COMPLETED THE CONSENT FORM ON PAGE 2?
6. SIGNED AND DATED THE CONSENT FORM?

IT IS VERY IMPORTANT YOU COMPLETE POINTS 1 & 2 ABOVE, OTHERWISE WE CANNOT USE THE INFORMATION YOU PROVIDE IN YOUR QUESTIONNAIRE.

IF YOU HAVE COMPLETED THE CONSENT FORM, PLEASE GO ONTO THE QUESTIONNAIRE ON THE NEXT PAGE.

Please note that in the interests of confidentiality, once we have received your questionnaire, the consent form will be detached and stored separately from your questionnaire

Your Information Needs

In this questionnaire, we would like to find out what information you would want to know when making decisions about your illness and the treatment you receive for it.

A number of statements are given below that describe the information someone may want to know about their illness and surgical options. **Please tick the box to the right of each statement** that best describes how you feel at this time.

Information about...	**I absolutely need this information**	**I would like to have this information**	**I do not want this information**
What all the possible side effects are.	☐1	☐2	☐3
What the surgery will accomplish.	☐1	☐2	☐3
Whether or not it is cancer.	☐1	☐2	☐3
What the likelihood of cure is.	☐1	☐2	☐3
Which parts of the body will be involved?	☐1	☐2	☐3
Exactly how the surgery will affect my body.	☐1	☐2	☐3
What the daily (or weekly) progress is.	☐1	☐2	☐3
What the specific medical name of the illness is.	☐1	☐2	☐3
Whether it is inherited.	☐1	☐2	☐3
How effective the surgery has been for other patients	☐1	☐2	☐3
Examples of cases where the surgery has been effective.	☐1	☐2	☐3
Examples of cases where the surgery has not been effective.	☐1	☐2	☐3

Please turn over

Your Decision Making Choices

After they have all the information they need about their illness and possible surgical options, some patients prefer to leave these decisions up to their doctor. Some prefer to share these decisions, whilst others prefer to make their own decisions about what surgery they receive.

Please tick the box next to the statement that best describes the situation that you believe would be **IDEAL.**

I prefer to make the final selection about which treatment I will have.	☐ 1
I prefer to make the final selection of my treatment after seriously considering my doctor's opinion.	☐ 2
I prefer that my doctor and I share responsibility for deciding which treatment is best for me.	☐ 3
I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion.	☐ 4
I prefer to leave all decisions regarding my treatment to my doctor.	☐ 5

Please tick the box next to the statement that best describes the situation that **ACTUALLY HAPPENED** during your consultation(s).

I made the final selection about which treatment I had.	☐ 1
I made the final selection of my treatment after I had seriously considered my doctor's opinion.	☐ 2
My doctor and I shared the responsibility for deciding which treatment was best for me.	☐ 3
My doctor made the final decision about which treatment was used, but seriously considered my opinion.	☐ 4
My doctor made all the decisions regarding my treatment.	☐ 5

Please turn over

Which doctor did you see during your consultation **regarding your surgical options**?

Consultant ☐ 1
Associate Specialist ☐ 2
Staff Grade ☐ 3
Specialist Registrar ☐ 4
Basic Surgical Trainee ☐ 5
Other *(please state)* ☐ 6

If you can remember, please write in the name of the doctor you saw

Please write in BLOCK CAPITALS

What operation did you have for your breast cancer?

None ☐ 1
Mastectomy ☐ 2
Mastectomy + Breast Reconstruction ☐ 3
Wide Local Excision / Breast Conservation Surgery ☐ 4
Other *(please state)* ☐ 5

Feedback of results

If you would like to know the results of this study, please tick the box below.

Please let me know the results of this study when it has finished ☐

Please note: This study is scheduled to run for 18 months, therefore it may be a while before the data is analysed and the results are available.

That is the end of the questionnaire
Thank you for your cooperation

Appendix 7

Patient correspondence and Interviews

(3 Breast units)

APPENDIX 7.1 Patient Pre Interview Letter

Interview: ……….. at …………am

Dear

Further to our conversation on the telephone, please find enclosed a copy of the interview schedule for the above date.

Please do not fill this in, this is just for you to have a look at before I visit you so you have an idea of what we will be talking about during the interview.

If you have any queries in the meantime, please don't hesitate to telephone on 0114 271 2225.

Thank you again for your interest in this study and I look forward to meeting you.

Yours sincerely

David Wilde

Research Associate

DS. Wilde

APPENDIX 7.2 Patient Interview Schedule Patient Version - No Prompts

Patient Satisfaction with Surgical Decision Making Interview

Thank you for taking part in this study.

The aim of this study is to find out the views of patients about the choices they had, and the decisions they made, in relation to their options for surgery for their illness. If at any time, you do not understand any of the questions, or you wish to stop the interview, please feel free to say so.

All information that you will provide will remain strictly confidential.

Checklist (Pre-Interview)

Has the participant read through the **Interview Schedule**?	
Does the participant have any **questions** at this stage? (if YES, write down what they are)	
Talk the participant through the project and what will happen during the interview	
Take the participant through the **Consent Form** and have them **sign it**	

1. Can you tell me a bit about what you knew or understood about breast cancer before you realised something was wrong with your breast?

2. Please tell me about the time from when you first realised there was something wrong with your breast to the time you went to hear about your results.

3. And what happened when you went to the clinic and were told you had breast cancer?

4. What were you told about your diagnosis?

5. How much did you understand about what you were told about the cancer?

6. Did you spend any time alone with the BCN after seeing the doctor?

7. And what happened while you were talking about what operation you could have?

8. Can you tell me more about the times you were talking with the **DOCTOR**?

9. Can you tell me more about the times you were talking with the **NURSE**?

10. Did the breast team give you any cancer / treatment / support information?

11. So, please tell me what operation(s) you had for your breast cancer?

12. Looking back, from when you were first diagnosed until now, what do you feel about the care you have received?

13. Now that you have been through this experience, what do you think are the most important things someone with breast cancer needs to know...

14. ...About diagnosis?
15. ...About the operation(s) they can have?

16. Is there anything else you would like to add to what we have been talking about today?

APPENDIX 7.3 Patient Interview Schedule Interviewer Version - With Prompts

Patient Identifier

☐☐☐☐☐/☐☐☐☐☐

Recorder Interview ID Code

Patient Satisfaction with Surgical Decision Making Interview

Thank you for taking part in this study.

The aim of this study is to find out the views of patients about the choices they had, and the decisions they made, in relation to their options for surgery for their illness. If at any time, you do not understand any of the questions, or you wish to stop the interview, please feel free to say so.

All information that you will provide will remain strictly confidential.

Checklist (Pre-Interview)

Has the participant read the **Information Sheet**?	
Has the participant read through the **Interview Schedule**?	
Does the participant have any **questions** at this stage? (if YES, write down what they are)	
Talk the participant through the project and what will happen during the interview	
Take the participant through the **Consent Form** and have them **sign it**	

Interviewer:	**Venue:**	**Date: / /2003**

1. Can you tell me a bit about what you knew or understood about breast cancer before you realised something was wrong with your breast?

   Prompts:

   Patient's own medical history

   Patient's family's history of breast cancer

   Previous knowledge of breast cancer diagnosis and treatment – Family / friends / media / GP

   What was going through your mind?

2. Please tell me about the time from when you first realised there was something wrong with your breast to the time you went to hear about your results.

   Prompts:

   Timeline from start to clinic

   What was going through your mind?

Feelings / fears / anxieties

Did you talk about your initial thoughts to anyone – partner / family / friends?

Did any of the doctors / nurses give a clue or hint about what the diagnosis might be?

If YES, who was that?

Talking to a male doctor / change of doctor?

Had you thought that it might be breast cancer?

Any thoughts about what you might do about it?

3. And what happened when you went to the clinic and were told you had breast cancer?

Prompts:

Anyone else went with you?

Feelings immediately before clinic

Expectations about what you might be told / happen next?

4. What were you told about your diagnosis?

Prompts:

How was the news broken to you – who told – any aids or tools

Hearing about the results / diagnosis

Was the patient in normal clothes or a gown?

Was there anything about the doctors / nurse in the clinic?

Was there anyone else in the room at time?

During this time, how did you get on with the doctor / nurse?

What were your feelings knowing you had breast cancer?

5. How much did you understand about what you were told about the cancer?

Prompts:

What did you understand about what was said to you?

Was there anything you found difficult to understand or take in?

If you didn't understand some things, do you think the doctors and nurses picked up on that?

If YES, did they help you to understand? Who did?

Did you have any thoughts about what treatment you might want at that stage?

Did you get the impression that there might be one treatment better than another?

6. Did you spend any time alone with the BCN after seeing the doctor?

Prompts:

What did you talk about?

Did you have any further contact with the BCN? When? Where? Any other times?

7. And what happened while you were talking about what operation you could have?

Prompts:

Who talked to you about what operation(s) you could have?

What aids / tools were used?

What did you know about breast cancer operations before this?

Throughout the consultation, who asked most of the questions?

Who did most of the talking?

8. Can you tell me more about the times you were talking with the **DOCTOR**...

Prompts:

When talking about what operation you would have, do you feel the doctor listened to you?

Do you feel the doctor understood your needs?

Do you feel the doctor understood your concerns?

Did the doctor seem to have a particular treatment in mind?

9. Can you tell me more about the times you were talking with the **NURSE**...

Prompts:

When talking about what operation you would have, do you feel the nurse listened to you?

Do you feel the nurse understood your needs?

Do you feel the nurse understood your concerns?

Did the nurse seem to have a particular treatment in mind?

10. Did the breast team give you any cancer / treatment / support information?

Prompts:

Who gave it you and when? Did they go through it with you?

Could you take this information home with you to look at? How useful was it?

Only ask these if it has been established that the patient understood that they had a choice of treatment options.

- Were you told when your options might be?
- Were you told you could change your mind?
- Did you ask if it would be possible to change your mind after opting for one or another treatment option?
- How long did it take you to make up your mind about what surgery you might have?

11. So, please tell me what operation(s) you had for your breast cancer?

Prompts:

Influence of doctor / nurse / family member / friend on the decision made

Was there someone to speak to from the team in between talking about your treatment and having your operation?

Were you given or did you look for, find or were given any other information about breast cancer and its treatment?

GP

Relatives

Friends / Neighbours

Support groups

Books

Magazines

Video(s)

Internet

Telephone help line

Only ask these if it has been established that the patient understood that they had a choice of treatment options.

- How was that decision made?
- Time to make a decision?
- Do you feel you had the amount of choice you wanted?
- What was the most important thing you were told that helped you make your

ASK BEFORE CONTINUING INTERVIEW ABOUT ANY FURTHER OPERATIONS / TREATMENTS

12. Looking back, from when you were first diagnosed until now, what do you feel about the care you have received?

Prompts

Has it met your expectations?

In what way did it not meet your expectations?

If you were told you could change something about the service, what would it be?

13. Now that you have been through this experience, what do you think are the most important things someone with breast cancer needs to know...

Prompts

...About their diagnosis?

...About the operation(s) they could have?

14. Is there anything else you would like to add to what we have been talking about today?

Checklist (Post-Interview)

The involvement of the participant	
What kind of feedback they can expect to receive and when	
Briefly what will happen with the rest of the study	
Leave contact details with the participant and thank them for their help	
Write up any notes from the interview	

APPENDIX 7.4 Patient interview consent form

CONSENT FORM (patient interview)

Surgical Management Preferences and Choices in Breast Cancer: A qualitative and quantitative study.

If you wish to take part in the study, please read the statements below, and initial the boxes to the right.

Please initial box

1. I confirm that I have read and understand the information sheet dated 23rd January 2003 (Version 3) for the above study. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason ☐
3. I understand that it will be necessary for research staff attached to the study to access my medical records. I give permission for these individuals to have access to this data. ☐
4. I understand that sections of the research materials may be looked at by responsible individuals from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to this data. ☐
5. I agree to the discussion session being audio recorded. ☐
6. I would like to know the results of the interviews once all the data has been analysed ☐
7. I agree to my General Practitioner to knowing I am taking part in this study. ☐
8. I agree to take part in the above study. ☐

Name of respondent __________ Date __________ Signature __________

Researcher __________ Date __________ Signature __________

Appendix 8

Framework Example Patients

Framework Matrix example two patients from medium MR unit

REF NO FOR WRITE UPS	Op	Age (yrs)	time 1st theraputic OP to interview (days)	DMS	Background			DM & HCP style	
				ideal vs percieved vs coder imp.& Info seeking style	General i.e age, marital status, ethnicity employment, PHMx	Prior epectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	Communication & interpersonal skills DOCTOR	Communication & interpersonal skills NURSE
	3			4	5	6	7	8	9
1	Mx	42.9	28	Pt ideal= 2 Pt actual= 2 Coder DMS imp = 1 Coder info seeking imp = ACTIVE	MARRIED(3). Daughter(12). FHx: Mum, 42, 2 of mum's aunties & 3 cousins(1). PATIENT DETERMINED RE OP CHOICE FROM OUTSET(4,7).	Lot of prior experience; FHx: mum, 2 aunties & 3 cousins(1). Mum Mx @ 42, didn't need chemo, recurrence @ 63 'with a vengeance' , deceased shortly after(1). No friends have it(1). Br Ca aware 'big style', can't take HRT, regular checks(1). Abscess in other breast 2/12 prev, checked 'every day...obessed with it'(1). Knew not just and abscess, sticking through, quite hard, 'hoped I'd broke a rib'(2). Read stories in media(9). AWARENESS OF CHOICE, OPS & Rx's(1,4).	SYMPTOMATIC lump(2). GP next day(2). OPA 10/7 later(2), H'band present(3). DC, voiced suspicions(3). Pt knew wanted Mx(4). Saw BCN(3). Results 1/52(3). H'band, BCN, & clinic nurse present(5). DC confirmed Ca(4). pt chose Mx(4,7,8). In hospital 45 hours post op(7). Uneventful recovery(7). Grade 3, Ln clear(8). DXT(8). Seen oncologist, v. aggressive Ca, having chemo(9). Awaiting appt for 'gene test'(12).	DC: Pt 'got on fine', 'lovely man', 'v. caring', 'v.sincere'(6). DIRECT LANGAUGE USED(5). THOROUGH(4,5,6,78). SUGGESTED Mx was a 'v.big op'(5). 'definitely' LISTENED TO NEEDS & CONCERNS(8). Everyone was reassuring(6).	Saw both BCNs(6). Got on 'great' with both(6). DA came to see pt at admission(7). BCNS LISTENED TO NEEDS & CONCERNS, 'v. much so'(8). Everyone was reassuring(6).
2	Mx	59.7	34	Pt ideal= 3 Pt actual= 2 Coder DMSimp= 1 Coder info seeking imp = ACTIVE	MARRIED(1). TEACHER(8). Regular mammograms(1). FHx: Aunt(1). Neighbour = a confident(2).	Br Ca = a lump, something abnormal(1). 1ry or 2ndry(1). If 1ry expected a Mx(1). 'More difficult' if a 2ndry(1). GENETIC & NON-GENTIC FHx Ca 'So we were very...alert'(1): Aunt (Br Ca & Lung)(1). Husband's sister Br Ca (Mx, tamoxifen, died 7 yrs later from bone mets)(1). Husband - 1 cousin, Br Ca, had Mx, gave pt info(5), another cousin bowel Ca(1). EXPECTED CONS WOULD TELL HER WHAT TO HAVE (Mx)(4) & PREPARED SELF FOR IT(4).	Regular mammo(1). Xmas 03 noticed dimpling, no lump(1). Showed h'band(1), thought it was a muscle as large breasted(1), didn't think it was much(10). March 04, larger, GP REFERRED(1). OPA: DC(1,2). RESULTS IN 1/52(2) + H'band(2,3) & BCN (MB)(3). CHOSE Mx(4). IP 4/7(10). BCN visted pre & post op, brought info(5). Post op: bit painful under arm(7). OP RESULTS 2/52 (DC)(8): tests clear initally, but oncologist said 'something at top of femur'(10). MRI scan, awaiting results(10). SH FOR follow up(3).	DC: OPEN, THOROUGH(2-3,6,7,8,9,10). SIMPLE LANGUAGE(3,9): 'precise'(3) & clear'(3,9). OPEN CHOICE GIVER, NO PREFERENCE(2,8). 'v. nice..kind..good bedside manner'(2,6,9). 'gentle...helpful'(4). GOT ON WELL, 'could talk to him', DIDN'T feel intimidated(4) & UNDERSTOOD NEEDS & CONCERNS(8). SH: '...just as nice'(3) 'I felt really confident'(3). ONCOLOGIST: no bedside manner, didn't mince words, felt 'shell-shocked' afterwards(4).	Both: v. good & v. kind(3). Really helpful, 'I give them 10 out of 10'(3). 'I felt really confident'(3). UNDERSTOOD NEEDS & CONCERNS(8). MB KIND(6) & REASSURING(5,9). Calmed us down, soothing, helpful(5). DA, 'did the same thing'(5,6). KIND '...gave me other things for my bath ...really appreciated that'(6). BOTH EXPRESSED NO OP PREFERENCE(8).

REF NO FOR WRITE UPS	DM related to information					DM process
	Info seeking behaviour	Acessibility: general perception team vs other (who & what information)	Info relayed & given by team (how said) who, inc tools	Info content (What said). incl. asking quest	Priotity info needs (what need/want to know)	Understanding (Pts perception of HCP information & ID who)
	10	11	12	13	14	15
1	Looked on internet, got a lot of info, a little helpful(9).	Everyone was reassuring(6). Saw both BCNs(6)	DC: VOICED his suspicions, 'prepared me' FOR BAD NEWS(3). CONFIRMED Ca, SIZE, DESCRIBED OPS & SEs(4,5,8), went into 'a lot of detail'(6), EMPHASISED pt choice(4) + small ca & Mx = big OP. Discussed(5,8). CHECKED IF PT CHANGED MIND RE OP(7). BCN: WENT THROUGH WORST CASE SCENARIO, 'Way she talked ..made me think even more..cancer'(3). ENCOURAGED TO BE +VE, REASSURED 'not definite'(3). POST DIAG SPOKE LITTLE WITH BCN(7). **TOOLS**: CONS: drew diagrams(5) & family tree(8). BCN: contact card(7).	DC: v. suspicious(3). Knew at this point wanted Mx(4). BCN: not to worry, Rx has advanced, early stages OR '...might be nothing'(3). @ DIAG: 'definitely' Ca, 16mm, found early, ...either have 'lump removed' or 'whole breast off', ...YOUR choice(4). 'I think he..preferred...the lump removed'(4) COZ said Mx 'v. big op-'(5). Take out all Ln & explained RE numbness & post op sensation(5) 5 wks DXT WITH BCS(8) adj Rx's(8). Discsused 'genes test', strong chance carrying Br Ca gene(5,8). Just before op asked if wanted to change mind(7). POST OP: Grade 3 Ca, good job we moved quickly(8), 50:50 chance of chemo(9). Talked RE reconstruction post adj Rx's(12). BCN: didn't talk a lot with, wanted to go home(7). Gave contact card(7). ONCOL: v. aggressive Ca, chemo, said 'I must...know it...came from nowhere'(9).	HEREDITARY OR NOT: having a gene test(5). Reconstruction(12).	UNDERSTOOD WHAT WAS SAID RE DIAGNOSIS & Rx's, NOTHING SHE DIDN'T UNDERSTAND(6). AIDED BY PRIOR INFO(1,4) + CONS INFO: DIRECT LANGUAGE(5) & went into a lot of detail(4,5,6,78). PERCEIVED CONS PREFERENCE: 'I think he..preferred...the lump removed'(4), COZ said Mx v. big op(5).
2	INFO SEEKING STRATEGY: H'band came to consultation SO, both could pick up info, put together at home, get full picture(2). Husband's cousin (Ca), gave INFO(5). Picked up leaflets about Br Ca in clinic reception(9).	ACCESSIBLE. BCNS: could get them all any time, reassuring(5). Saw them every time to clinic(5). MB visited pre & post-op(5).	CONS: confirmed 'lump' (@ Bx)(1) & EXPRESSED SUSPICION OF Ca(1,2). CONFIRMED DIAGNOSIS, GAVE OPTIONS(2) & EXPLAINED IMPLICATIONS INC ADJ. Rx's(2-3, 7,8,10) & POST OP SYPMPTOMS(6). NON-DIRECTIVE(2,8,10) & EMPHASISED CHOICE(2). OPEN, HONEST, STRAIGHT FORWARD, KIND, 'good bedside manner'(2). THOROUGH(2-3,6,7,8,9,10). USED SIMPLE LANGUAGE(3): 'precise'(3) & clear'(3,9). CONS did most of the talking(6). BCNS: REASSURING(5,9): Calmed us down, soothing, helpful(5). STAGGERED INFO: EXPLAINED timescales, post op pragmatics(5). PRE-OP VISIT, gave info on exercises(5), pain control(6) & prosthesis(6). **TOOLS**: Diagrams(2,3), WRITTEN INFO RE ANAESTHETIC, PAIN CONTROL(6).	CONS: @ Bx:'90% that it was Ca'(1,2). @ DIAGNOSIS: 'Cancer' 1 1/2 inches, fast growing, I would need either WLE or Mx, he would do op(2). 'Didn't tell me which one to have...up to me to decide'(2), explained both equally(7,8,10). If WLE: how performed, DXT post op to prevent spread. WOULD HAVE GOOD RESIDUAL BREAST VOL(3), poss of Mx if Ca spread(3,8). Mx, how performed, scar afterwards, APPEARENCE: 'it would be flattened completely'(3). MIGHT NEED chemo/DXT(3). MADE AWARE OF numbness, seroma, lymphoedema, shoulder stiffness(6). He said he would take lymph glands out, test them, see if Ca spread(6). ANSWERED QUS(6). Said post op: good I had Mx, I would have needed one(7). BCNS: PRACTICAL INFO: how long in hospital, when pt could use hands, do jobs at home(5). PRE-OP, Visited pt, gave info on exercises(5), pain control(6) & prosthesis(6).	Use of arm post op(6). IMPORTANCE OF SELF O/E & EARLY REFERAL(10). TO BE GIVEN both options(10). SOME GUIDANCE FROM CONS SO NO NEED FOR 2ND OP LATER(10). PRIOITY NEEDS: 'Bedside manner' is important(11).	GOOD UNDERSTANDING OF BASICS RE CA & Rx(1,3,4) COZ: FHx(8), Husband & pt picked up info (appt) & put together at home (full picture)(2) & CONS USED SIMPLE LANGUAGE: 'We understood'(3) 'I think we understood all of what he said'(4).

REF NO FOR WRIT E UPS			Choice		Greatest influence over DM
	Options given (inc implications of options)	Time to make decision & feelings about amount of time	Feelings about choice	What would you advise? - Reply & reaction of HCP if asked for their preference	(& other influences)
	16	17	18	19	20
1	Aware that options were available early on, as soon as DC said he was suspicious, 'if offered the lump or full Mx', pt knew she wanted Mx(4). DC gave options WLE & Mx & implications(4,8) INC 5/52 DXT WITH BCS(8).	As soon as DC said he was suspicious, pt knew she wanted Mx(4). Pt chose Mx(4,7,8) & didn't change mind(7).	AWARENESS OF CHOICE, OPS & Rx's FROM PRIOR EXPERIENCE(1,4), SO Not surprised @ having choice(8). As soon as DC said he was suspicious, pt knew she wanted Mx, 'I wasn't playing at it (WANT IT) ...all gone'(4,8), never have peace of mind if BCS(5,8,10). NO DM DIFFICULTY(4,5,7,8,10). HAD AMOUNT OF CHOICE SHE WANTED(10).	NOT ASKED, AND NOT VOLUNTEERED DIRECTLY, BUT 'I think he (Cons) '...I think he would have preferred me to have the lump removed. INT: WHAT MADE YOU THINK THAT? Patient: He said it was a very big operation having a full Mx, ...I got the impression he thought I didn't need to have the whole Mx'(4,5).	PRIOR EXPERRIENCE & EXPECTATIONS/FEAR: STRONG FHx(1). Nothing specific that pt was told(9). 'from when he first told me that he was suspicious, I'd already made my mind up that, if I was offered the lump or the full mastectomy, it would be the whole ...I wasn't playing at it. It'd be all gone ...I could never have ...had as much peace of mind if I'd just had the lump removed, ...thinking, ..what if they've missed a little bit round it and...'Q(5)+(4-5,8,10).
2	WLE OR Mx(2). DIDN'T EXPRESS A PREFERENCE(2,8,10). THOROUGH RE IMPLICATIONS OF OPS AND ADJ. Rx's(2-3,6,7,8,9,10).	Straight away'(8). KNEW WANTED Mx AS EARLY AS GP VISIT(8). CHOSE Mx(4): '100% certain' (recurrence fears)(8). DIDN'T CHANGE MIND(8).	THOUGHT CONS WOULD TELL HER WHAT TO HAVE: 'but it was up to me really'(4). PRE-CONS THOUGHT: 'It'll be a Mx ..must do that ..must choose that'(4). '..wanted to get rid of it..what's the point of vanity(8). PT THOUGHT SOME GUIDANCE COULD BE GIVEN FROM CONS SO NO NEED FOR 2ND OP LATER(10).	did not ask, & RECEIVED NO-DIRECTIVE INFO, BUT THOUGHT SOME GUIDANCE COULD BE GIVEN FROM CONS SO NO NEED FOR 2ND OP LATER(10).	ENSURE COMPLETE REMOVAL & AVOID 2ND OP(8,9,10) 'that the lump was Ca I didn't see any other option really'(9) wanted to be '100% certain'(8), '..rid of it'(8). AESTHETICS = 2NDRY '..what's the point of vanity'(8).

REF NO FOR WRITE UPS	Factors associated with sat/dissatisfaction	1 thing to change	Feelings			Coping Mechanisms	Extra information	Field note info	Coder
	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine		Anything interesting, but which doesn't fit elsewhere!		
	21	22	23	24	25	26	27	28	
1	**SATISFACTION**: STAFF(6-7). OVERALL CARE: quicker than I expected(11), couldn't have been better if I'd gone private(10). **DISSATISFACTION**: Hospital food(10,11).	Every woman should have a mammo 2 x a yr, esp high risk women(11), coz 'a lot can happen in 23 months'(11).	When found lump, realised why she felt unwell for 2 months(10). AT DIAGNOSIS: '...it was like history repeating itself ...I was ...20 when my Mum had breast cancer, it was like I remembered everything ...but ...I don't think I had fit ...crying and sobbing and, I was positive and I knew I'd get through it. I was more worried about being put to sleep, the anaesthetic, than actually the cancer.'(4). Husband's main concern was I was still here(3). Didn't have any feelings, numb, v. quiet(6,7), thoughts RE practical matters, adj Rx, hair loss(6). Concerned RE daughter, thinking of taking out ins policy(12).	More worried RE anaesthetic than the cancer: 'terrifies me', friends mum died in theatre FOR MINOR OP(4). As soon as DC said he was suspicious, pt knew she wanted Mx, 'I wasn't playing at it, it's be all gone'(4). Could never have peace of mind if WLE, what if missed a bit(4-5,8,10).	Thoughts RE practical matters, adj Rx(6), hair loss(6,13). 'you can disguise the fact you have had an op'(6). Don't want a wig, cap/bandana instead(13). That will be most distressing part, though told it will come back thicker & curly, 'I think he(onc) is telling me fairytales'(13). Concerned RE being sick, not worried, I'll have 4/12s sleep(13). 5/52 RXT: have to go to WPH every day, 'little bit off putting'(8).	postive attitude(4). Practically minded(6). Sense of humour(13,14)			DW 15/10/04
2	**SATISFACTION**: Screening unit(2). TEAM COMMUNICATION & INFO GIVING STYLE CONS(2,3,4,6,8,9). BCNS(3,5,6,8,9). TEAM AS A WHOLE: 'I felt really confident'(3). SPEED OF JOURNEY(8). Written info useful(9). OVERALL CARE(9). **DISSATISFACTION**: Oncologist COMMUNICATION STYLE(4). Busy hospital ward, didn't sleep(9). MRI scanner 'claustophobic'(10).	NO CHANGE TO CONSULTATIONS(9). HOSPITAL: busy ward, didn't sleep(9).	AT HEARING NEWS 'shattered'(2). Husband has COPED worse THAN PT THOUGHOUT EXPERIENCE(6,7); They suffer 1/2 the pain(7). V. difficult to tell friends & kids teaches(8). '(friends)...thought I was on the death list...As soon as they hear big 'C' they think that's the end'(8).	FEAR OF RECURRENCE WITH BCS(8,9): '...I didn't see any other option...'(9) '...wanted to be'100% certain ...rid of it'(8). AESTHETICS = 2NDRY '...what's the point of vanity'(8).	NO COMMENTS.	TRUST IN TEAM & BEING INFORMED(2,3,4,5,6,8,9). SUPPORT H'BAND.	Bedside manner' is important(11).		DW 1/10/04 & Joint check 27/10/04

Appendix 9

Framework Example Clinicians

Framework Matrix example three clinicians from medium MR unit

HCP no.	HCP ID	Background			DM & HCP style	
		general i.e age, time in unit, other units etc.	Coping mechanisms re Job, bad news, etc.	Perception of team (Colleagues & environment)	Communication & interpersonal skills SELF	communication & interpersonal skills other DOCTOR
		1	2	3	4	5
1	BS013	Male. 12ys in breast unit. Job not too stressful except meeting targets. '...there's a sort of excitement about getting bad news'(8). It its really bad news may be apprehensive (esp if late/missed diagnosis) but not personnaly upset. Finds DCIS easier to talk about coz 'its bad..but...'(4)	DISTANCE Don't get too involved/close(4). DISCUSSES WITH Nursing Assistant (NA) & gets them to give POSTIVE feedback (re:consultation) '..say something you want to hear...'(6). RESIGNATION if went bady '..oh well thats 1 in...'(6). RELIANCE ON BCNS(1,4,5,15) TO FILL IN THE GAPS & 'pick up the pieces'QQQ(1).	Very busy unit. Teamworking, cross cover, no heirachy, good bunch, like-minded, relaxed(1). MDT makes feel 'confident' 'organised'(2) '..we're..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...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...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..but they do spend twice as long with them as I do so I assume they're saying more.'(1)	RECOGNISES SELF-LIMITATIONS '...a bit' 'pragmatic'(7), 'dogmatic'(15), '..doctor knows best..' (hopes not that bad)(7), 'probably biased... talking down to them in ...patient's eyes...', get to a certain point (in consultation) then can 'go no futher' QQQ(1,4)(15) SEEMS RESIGNED: if went bady '..oh well thats 1 in...'(6) & RELIES ON BCNS to 'pick up the pieces' QQQ(1,4) & I'm only the start of the information, dont leave with my last comment(4,5) they're (BCNs) the 'let out clause' QQQ(1,4)(+4,5,15) unlucky for us both to be having a bad day(6). Some excitement before a consultation coz have 'priveledged information'(4) & 'there's a sort of excitement about getting bad news'(8). DISCOMFORT WITH CANCER easier to talk about DCIS coz its more positive(3,4). No expectations of how consultation will go; 'often cant remember them' till i see their face, then 'it might come back to me...'(3).	Recongnises generation gap in consulting style between self and other consultants (1). Never observed them but they spend ~2x as long with patients, so presume they say more(1)
2	BS015	Male. 6 yrs in unit. Trainee @ NCH. THE ULTIMATE PROFESSIONAL. CONSISTENT MESSAGE balanced views, counselling skills, thorough, prepares ++ beforehand. COMFORTABLE IN ROLE.	PREPARATION: pre clinic read notes, plan OP slots, even if it means starting clinic later(2,10). EXPERIENCE 'You learn'(emontional side of breaking bad news). COMFORTABLE IN ROLE & confident of team standards(10).	Fantastic, PROUD of very good team, confortable(1). '..one of my colleagues..very good with his patients, but ...more matter-of-fact, gives...basic information and..might spend less time ...has a way of working that..a lot of the... extra...filled in by the bcns.'(1) ENCOMPASSSING DEFINITION OF TEAM. 'Can do people' do extra to achive the targets(1). ETHOS: CONSISTENT MESSAGE, protocol driven(2,27) - can cramp individual style(2) = reason why thinks the BCNs minimally affect pts DM(2).' ...that's a different style. I personally spend probably longer..if a patient needs five minutes..45 minutes that's fine...they'll..get the individual amount of time they need. I think we've developed a style in __ ...the..guidelines and protocols of the unit tend to be what we tend to say and we all try to sing from the same hymn sheet. ..in some ways that cramps style, as it doesn't allow individuality, and I think probably across the board the breast care nurses are very good at reinforcing our team message and..I personally don't think that they..make a great deal of difference to decisions because I think they just sing with the same hymn sheet as we do.' (BS015, high MR unit, p1-2)BCNs REITERATE MESSAGE @ VARIOUS POINTS = where teamwork is important(11). shared care with consultants...so careful to document accurately what discussed with pts(6).	CONSISTENT MESSAGE. CONFIDENT, BALANCED(25+ gen obs). THOROUGH prepares ++ beforehand(2,10,11). PERFECTIONIST: go through things to my satisfaction(11), DON'T ASSUME pt info/reaction(5)/info giving by colleagues(11), OPEN, HONEST(4,5): if asked direct question(4), but sometimes fudges answer - i.e. am i going to die? I certainly hope not.'(12). GOOD COMMUNICATION SKILLS(3,4,7,8,9,10,12,14). KIND, SENSITIVE, EMPATHIC & HOLISTIC (DESPITE TIME IN JOB) BUT KEEPS BOUNDARIES, RESPECTFUL OF PTS, COMFORTABLE IN ROLE & COUNSELLING SKILLS (learnt from courses)(7). GIVES TIME The 'clock is irrelevant to me' spend as long as the individual pt needs, even if it means overrunning(2).	BS013 very good with pts, but more matter of fact; gives the basic info, rest filled in by the nurses(2).
3	BS014	Female. 2 1/2 yrs as consultant, 1 yr as SpR in DCGH. Worked in Notts beforehand(5). MDT: Mon. lunch & Thurs. aft.(3). WORKLOAD increasing: >no. Ca's, extended screen age, >GP referrals(3). BCN NOT ALWAYS PRESENT 'nums are two few'(5). PROFESSIONAL(4,12), SENSITIVE & TRIEDS NOT TO, BUT GETS EMOTIONALLY INVOLVED. gets emotionally & mentally exhausted @ end of a results clinic coz trying to keep it very professional & give them hope(4). PERCIEVES SELF AS OPEN INFO GIVER(6,12,13,14,15) QQQ(15). CONFIDENT IN SELF & UNIT(3,4)HMC & LC ANALYSED DISPARITY IN OPINION LC. THOUGHT	SUPPORTIVE TEAM(1). DM DEVOLVED TO TEAM LEVEL: 'consensus of opinions', - esp useful with complex cases(3). PROFESSIONALISM(4,12). EXPERIENCE ...keep it 'under control' personal but to a limit, no point in me breaking down, cant take it all home with you(12). USES SMALL BREAKS IN CLINIC (take time dictating & nurse bring a cup of tea) if a really difficult consultation, but otherwise RESOLUTION 'next' (as no time)(6) - SEEMS CONTRADITCTORY WITH SENTITIVE. INVOLVED.	Very well organised, work as a team, supportive, flexibility & shared care(1), BUT TRY TO MAINTAIN CONTINUITY WHERE POSSIBLE(1). TARGET DRIVEN & PT FOCUSSED. Work hard (extra clinics etc.)(1,2) TEAM AVAILABILITY (BCNs & Sx) Q(2).. Adhere to BASO guidelines(2). Surgeons have individual style(2). BCNs role is to reiterate exactly what I have said(8) - BUT BCNs not in the consultation(5). UNIT LAYOUT NOT IDEAL, corridor walk 'probably not the best'(5).	THOUGHTFUL & CONCIENTIOUS: doing my job to the best of my ability(2) & work hard to keep it very professional(4) & give them hope(4,5). BUT CONTROLLING (general obs. over int.) NO NONSENSE APPROACH & LANGUAGE(4,5,6,11). HONEST(8). CARING(11). ?TAILORS CONSULTATION(4,5) & APPROACH, OR NOT: 'its my job to give you information (pt complains too much info) if 'you want to take it, its up to you'(6) & CAN MAKE ASSUMPTIONS RE PTS RATHER THAN INQUIRING i.e elderly, 'social problem'/illness (arthritis) & Mx direction(13). USES BODY LANGUAGE: eye contact(5) & COUNSELLING SKILLS(5). Readucate those with incorrect preconcieved ideas (Mx & no recurrence)(13). RECRUITS PT'S PARTNER TO get the patient to make '...the right decision.' QQQ(14)	DIFFERENT PERSONALITIES/STYLES(2), some talk a lot, give lot of info(2), and others give minimum info, leave rest to BCNs(2) (= HH), some develop 'good rapport' & 'empathise'(2), others 'keep it on a very professional basis'(2)

HCP no.	HCP ID		DM related to information		
		Communication & interpersonal skills other NURSE	Patients' prior information	Info relayed & given by team (how said). inc tools & inviting questions etc.	consitency/inconsistency of info relayed & given by team (how said) - HCP description over the interview
		6	7	8	9
1	BS013	not observed. The 'girls'(BCNs)(2) get more 'emotionally tied up' in their own and patient's emotions(4). TRUSTS BCNs SKILLS: INFO GIVING, SUPPORT(1,4,5,6), ENSURE PT UNDERSTANDING; they will 'suss them' (patient needing more help) & probably have conversation on a more similar 'level'(15) & patient may better express themselves/ask more questions etc.(6)	virtually nothing'..unless had a relative (with Ca)'(7). They use the word 'Massectomy' makes me think they don't know a lot(7). SOURCE: 'magasines, friends and old wives tales', some inaccuracies (younger ones know more) - so i tend to '..nip it in the bud' sweep the 'slate clean' '..forget that, that's not really the case, what really happens is...'(7)	DISCOMFORT AT USING THE TERM CANCER(4). Need to hit the right level of 'gravitas' 'it's bad & I'm sorry but...'(4), try to give news in nicest way(4). BLUNT: 'just forget that...'(7) 'there it is we can't change it we'll get on and deal with it for you'(4) '...I'll go straight to the point'(if questioned directly)(3). TRY TO BE HONEST try not to make promises I cant keep(4). TRY TO INTERPRET PATIENT REACTION & TAILOR ...go on 'with sympathy or fact'. CONTROLLING: sweep the slate clean(7) & CONFINES PT TO OWN (INFO GIVING) AGENDA: '...just forget that (prior info)...'(7) get them back to the bit in question if they're racing off(asking qus)(6) - SEE PRIOR INFO COLUMN. Focus on pt unless 'too distressed', then turn to h'band(5). Keep checking they understand(5) BUT FOCUS QUESTIONS on others in the room(6). REACTION TO OWN LIMITATIONS (PT EMOTION & NEEDS): can 'go no futher' and move them on to the BCNs to 'pick up the pieces' QQQ (1,4). TOOLS: pen thing(5,6).	FULL OF INCONSISTENCY: DISCLOSURE: 'honesty's best' 'openness'(3) VS DISCOMFORT AT USING THE TERM CANCER(4). Keep checking they understand VS focus mainly on others in room (if pt distressed) & redirects if racing off with Qus. DIRECTIVE VS ACCEPTING OF PT CHOICE: DIRECTIVE: 'ageist' with older women (if finding choice difficult steer them to what is 'easier for me' - Mx) & if Pterring to Mx, 'encourage them' by mentioning reconstruction. ACCEPTING OF ACTIVE DMS DESISIONS EVEN IF FOR NON-STANDARD Rx. (12,13) & its not what i think, it's what you want that's important(5).
2	BS015	good @ reinforcing the teams' message - sing from the same hymn sheet(2,27).	Variable: 'nothing' to 'everything'. Can be age related: older women-own or others' experiences, younger may have been on the net & know 'or think they know everything'(11). Info more accurate if have a friend or relative treated for br ca(11,26), esp if recently treated(11). Most know they wont necc need Mx(13)	Give pt time they need(3,8). '...**give a very balanced view**(options info)...'(25). If suspicious 'hints at' & asks 'anything else you'd like to ask me?'(4). GENTLE APPROACH Standard 'patter'(12,20) THOUROUGH EXPLANATION IN SIMPLE, CLEAR LANGUAGE & USES REITERATION(3,4,7,8,9,10,11,12,14), TAILORED TO PT RESPONSE & QUESTIONING(3,4,7). Explains what about to explain next(7,8,10) & first 'any questions?'(7). **brief summary 1st, then builds on**. Orders info (process & BCS 1st)(3,25). USES PAUSES (to absorb) & BREAKS (too upset)(7). COMFORTABLE WITH PT LED CONSULTATIONS (sometimes down ↔theoretical pathways)(4). on rare occasions if v.small ca and v large breast or unfit and need quick Op under LA (16,22), 'steer them (BCS)' Q(16) TOOLS: explains via **detailed drawings** & refers back/shows @ results '...remember what we ...'(9). Invites qus @ start and end(3,8) Tries to keep 'loose canon' relative's in check (checks pt wants answer)(9,10). IF PROBS DM: use examples & personalises(23,24).	CONSISTENT
3	BS014	good rapport, empathy, some keep it 'professional'(2). BCNS SUPPORTIVE(4).	varies depending on age(6), PT INTERPRETATION OF INFO(7) & geography - NCH vs DCGH & no. internet pages (> @ NCH)(6). Elderly 'pre-conceived notions'(6) &-I have to 'brain-wash' them into forgetting the way thing were done in the past(6,7). Info from fiends, family, personal experience, net(6). MEDIA CAN 'distort things'(7). COMPARES correct Vs incorrect info(6,7). MYTHS: DXT & hair loss(8). TIME/ENERGY CONSUMING IF 'KNOW' LOTS, easier to deal with those who know a little(7). **Takes time to check correctness and re-educate & explain why certain things not feasible** (esp net surfers)(7)	USES BODY LANGUAGE eye contact(5). DRIP FEED INFO UNTIL SURE OF DIAGNOSIS(3-4,7). DONT VERBALISE OUTRIGHT UNLESS PT AKS DIRECTLY COZ TIME CONSUMING & busy clinic & they will need > time(3,4). NO NONSENSE APPROACH & LANGUAGE(4,5,11), never directly disagree with Rx dont agree with(11). ??TAILORS CONS/INFO(4,5,12) OR NOT: ...my job to give you info (pt complains too much) if 'you want to take it, its up to you'(6). HONEST(8). Recap story. GIVE TIME(5,11) (COMPOSURE & QUS) wait for them to make the 1st move(5). OUTLINES CONSULTATION & Rx(5). GIVES REASSURANCE (prognosis & diagnosis)(4,5). USES REITERATION(5,8) & EMPHASIS: +ve side (to give hope)(5), choice(9,14) & time for DM(13,14). OFFERS CHOICE (IF APPROP.)(9). OUTLINES Rx ops(5). WANTS TO BE NON-DIRECTIVE, BUT CAN DIRECT DM BY: INFO RELAY/RESTRICTION(6,11,13), SCENARIOS(9,11,13)	INCONSISTENT/CONFLICT: COUNSELLING SKILL APPROACH Vs CONTROLLING CHOICE GIVING VS DIRECTIVE: PERCIEVES SELF AS OPEN INFO GIVER(6,12,13,14,15) QQQ(15) 'hope that I leave it to them Q(12) BUT SEEMS TO GUIDE PATIENTS TO BCS WHERE POSSIBLE(9,11,13,14) - 'I probably guided them...the majority (to BCS)' QQQ(13)(+9,11) & THE PASSIVE WOMAN who 'wanted' a Mx, whose husband wanted her to have BCS(13) 'I and to convince her that the Mx wasn't necessary & probably the husband's presence helped' Q(14). & collaborative patient who in the 1st instance says i wnat a Mx, i say '...no, no, lets just go through this' & re-educate them if they have a preconcieved idea Mx means it will never come back, and givce them the 3 years scenario(13). & i.e yong woman wanting Mx QQQ(9)

HCP no.	HCP ID			DM and Pt DMS when recog,descript.& impression	
		info content (What said). incl. asking quest	Priotity info needs (what need/want to know)	Active DM	Collaborative DM
		10	11	12	13
1	BS013	Give a 'bit of insight'(1st visit), more 'if they involve me in conversation'(3). DISCOMFORT WITH WORD CANCER, USES EUPHAMISMS WHICH CREATE CONFUSION 'lump..shadow..things have come back positive'(4) ...they often reply 'does that mean I've got a growth doctor?' 'so...at some point I feel i've got to mention the word cancer'...(4). PATERNALISTIC LANGUAGE/STYLE. RESTRICTED INFO GIVING(5) & DIRECTIVE WITH OPTIONS: might say '...perfectly reasonable' to '..take away the bad bit...'(WLE)(5) ...dont have to loose your breast/can keep your shape...and not mention Mx again...unless they (pt) 'bring up the topic...' QQ(9). DXT to 'sterilise' rest of breast(5,8). WL=as good as mx or wouldn't give a choice(8). Mention 'all the facts' including 'the negative'(13); 'surveillance thereafter' & recurrence(13) = tricky coz you're 'sort of saying...it might not work (BCS)'(8). TRY TO REINFORCE PERCIEVED PREFERENCE if pt edging to Mx '...might encorage them by mentioning reconstruction.'QQ(13). Info given 'depends on how much they keep questioning'(5). Encourage time to decide & to discuss/question with BCN(5,6). TOOLS: my own way '...pen-thing'.	varies' have to 'tease it out' rather than having a 'hit list'(7). Safe environment(unit) (7). RELY ON BCNS TO IDENTIFY AND DEAL WITH Nurses will 'suss it'(6)	Patient wants herbal Rx. Its my job to make sure she understands what she is doing(12) not to force people(12). No evidence that non-conventional Rxs work better, but a positive attitude may give her a chance(immunity & cancer) so cant discount(12,13). If there's something they want me to do 'that's reasonable, that's their way of dealing with their illness, then i'll do that..'(12)	so common, no one stands out. they're 'more straightforward'(13). They just want to know the facts, both sides, pros-cons, where thinds might go wrong/further surgery(13). If they're erring I way I might encourage them (Mx with reconstruction)(13).
2	BS015	Brief summary then '...its a breast cancer.'(7,12) NO EUPHAMISMS (avoid confusion)(12). 'I will give you all the information i can to try and make that choice'(7). Explain what about to explain next, but first 'any questions?'(7). Ca info (size, site)(3,8), need and OP(8), choices & explain why(8,14); the 1st option is...(BCS)(3,8,25), '.. the alternative...(Mx) QQQ(8). The 2 ops = survival, 1 not superior or wouldn't give a choice.' QQQ(8). EXPLAINS re margins, poss 2nd op, DXT & why. +talks re lymph nodes, drains, arm exercises, occ need DXT with Mx(8,10), discuss surgery date(3). Always recommned write their Qus down so dont forget(8). Adj. Rx. depends on results & why(8,10). BCNs will see next(8,10)	Ca INFO Are you sure its Ca? How long has it been there?(12) is it growing fast?(9,12). TREATMENT am I going to loose my breast/hair? Will i need Chemo? PROCESS When will my OP be?(9). PROGNOSIS(9,12) Am I going to die?(12) WIDER ISSUES HRT? Daughter's risks?(9)	CLEAR EGS. One congruent with opinion (had a choice) -Previous br Ca wanted Mx ...before '...I'd even go the word Mx out'(17). Other eg. Incongruent had BCS then refused DXT (cosmetic fears). COMFORTABLE WHEN DM CONGURENT WITH SAFETY '...theres no reason for me to try and talk them out of it...' coz choice, DISCOMFORT WHEN INCONG WITH SAFETY no choice(23)/complmentary therapies(18). Tend to be highly educated, too much information(18). Aware of DMS straight away: they say '..I want...I've decided...' early in my standard patter(20).	EG & SPOKE GENERALLY. they're the easiest(21), most satisfying(22): shared discussion & you can take them to a different level - they weigh up what is said and may seek your approval for their choice(21) '... you give the information and it's acted upon and sensible questions are asked..' DRAWS COMPARISON WITH PASSIVE & ACTIVE QQQ(22). May not be aware of DMS (passive or collaborative) at the time, as take time to make a decision(22). Stress there is time(21).
3	BS014	IF SUSPICIOUS dont volunteer,unless pt asks directly; then say 'my suspicions ar quite high'(3). PRIOR TO CONS: PREPARES PT 'bring someone' to next cons(7). @ DIAGNOSIS: 'its a cancer'(4,5) & tell them the options(5), pros & cons(14), BUT give +ve side, not -ve(5). EXPLAIN aim of OP to rid Ca & adj. Rx is prevent coming back(5,7). Talk re adj side effects(7). IF CAN'T MAKE DECISION tell them not to worry, PLENTY OF TIME, TILL morning of surg(5). WON'T 'convey my choice'(9,10) BUT SEEMS DIRECTIVE TO BCS IF POSSIBLE OPTION (SEE INCONSISTENCY COLUMN).. IF ASKED say 'your choice', 'I don't know...'(9) '...you have to chose what's right for you', so have no regrets(9). If a young woman says I'll have a Mx (for peace of	CURE / PROGNOSIS(7,8). HAIR LOSS(8) - seem preocupied with hair loss & chemo(8)	Clear eg. Surfed net, brought papers. Locally advanced ca needed chemo and refused, pt had own business - no time for our Rx, uncoperative with team(11). Really difficult(11,12) nothing I said was right unless it sounded right to her(11). Compromised what did but told her (the patient) '..I don't like to treat a patient with my hands tied behind my back...'(11). ACTIVE DM'S: FELT HELPLESS WHEN PT DOESN'T FOLLOW ADVICE(11). RECOGNISE: early on this person is '...going to give you a hard time...'(12). ARE ADAMANT(12), VERBAL(12), not very open(11). Can spend > time 'convincing' them if wrong info or want Rx that's not right for them(15) & need >time to go through everything(12,15). Try & get	no eg. Easier situation(13) some make decision there and then(13), or take longer (if 2 minded)(13). RECOGNISE: early; make decsion after results and explained pros & cons(14).

HCP no.	HCP ID		DM process		
		Passive DM	understanding (HCPs perception of Pt understanding of info)	Options - factors underlying options given	Time to make decision & feelings about amount of time
		14	15	16	17
1	BS013	cant think of any. Try to move them from passive to collaborative.. Think I convert most(14), if not try to involve their relatives(14). If they leave the decision to me 'got to be sure they understand what they are doing.'(13). Dont like it when its my choice 'hangs over me'(14) if recurrs(BCS) or if regret(Mx). 'I try & sense what they would like'QQQ(14) i.e. old folks - simplest (Mx) over & done with(14)...but may be what it simplest for me SEE WHAT WOULD YOU ADVISE COLUMN.	limited amount can 'absorb & understand'(5). Sometimes they're 'totally vacant' other times 'right there with you'(6). AWARE THAT EUPHAMISMS CREATE CONFUSION 'lump..shadow...things have come back positive'(4) ...they often reply 'does that mean I've got a growth doctor?' Pts dont understand choice well, esp those with an 'old-fashoined frame of mind' (8). Keep checking they understand(Pt & rels)(6). Confers with NA 'do you think she understood?'(6)..hope they pick that up with the nurse (poor understanding)(9).	Never tell them about WLE without mentioning Mx in case of a nervous disposition & '...want to be rid of it doctor...'(9). BUT CAN GIVE LIMITED INFO RE OPTIONS, ONLY MENTIONS AS you dont have to loose your breast.....unless they (pt) 'bring up the topic...' QQ(9). Age might come into it, but doesn't excude them from WLE(9). Guidelines: standard reasons: acceptible cosmetic result with reasonable margins, prox to nipple etc.(9)	a lot decide that morning' 2-3hrs min I hope. may go home & think about it. At end of clinic BCN tell him '..she's decided...'(15)
2	BS015	NO EG. No matter what you say they reply '..what do you suggest?'(23) & keep bouncing back (BCN & Dr)(22). May not be aware of DMS (passive or collaborative) at the time, know when OP day & still no decision(22) - then go through again & get nurse involved again(23,24). Stress there is time(21, 23,24), one not better than other, use examples ...some women choose...because...(23,24), try to personalise & pick up reasons why they might choose one or the other(24). Tend to be older, not very confident(24).	Understands why at times don't listen well (stressful situation)(5). The 'red mist' can come in/'shutters come down' when the word cancer is mentioned know not going to get much in(11). Even if not taken much in, BCNs REITERATE INFO @ VARIOUS POINTS(11). Most understand 'breast cancer' & will need an OP: sometimes need to clarify cancer is always malignant(13). Poor understanding that have a choice and I won't direct(14).	Team decision @ MDT based on guidelines & initial clinical & rad. assess(box 'suitable for choice')(6). Everybody who doesn't need a Mx ..gets a choice Q(15,16) & if they really want one (& its not offered) team will look really hard to see if can change that Q(16). ONLY MX: >5cm independent of Ca:Br=Mx. BCS only - anecdotal cases only: old, unfit with small Ca & woman with enormous breast and very small UOQ Ca(14,15). I wouldn't say (to a patient) '..you shouldn't have a Mx because its too small (the Ca).' QQ(15) BUT MIGHT 'steer them (BCS)' Q(16) by stressing smallness(22).	70% (Active & collaborativeDMs) have probably decided before they leave the room'(25). A small proportion undecided - esp if not got partner there(25). Even most passives made a decision by end of PAC after extra time with BCN(24)
3	BS014	EXAMPLES USES ARE WHERE PARTNER MORE ACTIVE IN DM THAN PATIENT RATHER THAN PATIENT NECESSARILY PASSIVE(14,15). 2 examples. Partner can either be a help or hinderence(14): Corrects family if feels they are trying to take the upper hand(14) (UNLESS AGREES WITH THEM - one eg. here). one eg 'passive' patient(suitable for BCS) who 'wanted a mastectomy', husband wanted her to have a WLE '...i had to convince her that the the Mx was not necessary & probably the husbands presence there helped for her to decide in favour of the WLE' QQQ(14) in this case the husband helped the patient make	Patient only takes in a small amount ~30% (refers to non-specifically to studies)(7,8). Symptomatic patients take more in then screening, as more prepared as found a symptom and been thinking about it(4,8). The diagnosis 'cancer' HINDERS INFO ABSORPTION QQ(7) its the reason suggest bring another set of ears with you for the results(7). Mammos(5) & Pictures drawn in consultation can help remind then what been saying(6,7). Poor undestanding re adjuvent Rx: DXT- will my hair fall out(8).	ONLY BCS: 'Don't...'(9). Where there is choice, offer it(9). CHOICE: to all except Mx on clinical grounds: ONLY Mx: >3cm 'I think', close to the nipple, Ca:Br size ratio, cosmetically unacceptable' result(9).	Some give the decision there and then (@ diagnosis)(13), esp collaboratives(15) & will go through the consent form @ then(5) BUT encourage the active and collaborative to really consider(15) The '2-minded' may wait till the OP day(13). "I do give them that time and I give them the choice ...[if] they've decided on a particular operation, doesn't mean that I will hold them to it. They could still the operation or what they want right up 'til the morning of the surgery so they know that they have that time to decide." [BS014, high MR unit, p13](13)

HCP no.	HCP ID	Choice			Greatest influence over DM
		feelings about choice giving	What would you advise? - Reply & reaction when asked for their preference	Majority Patient DMS percieved by HCP: numbered choice vs. critical incident technique.+ comments	
		18	19	20	21
1	BS013	More difficult ones: explaining why they have a choice..will often say 'what do you think'(5). Like to think we offer a choice where appropriate(10) its a team decision (what to offer) which takes the dogmatic, biased approach 'I might have as an individual out of it' QQQ(10). AMENABLE TO CHANGE patients can 'reverse our decision (MDT)'(10) would not do anything would not condone(12), but do anything thats reasonable, thats their way of dealing with it(12) & not refuse/presude too hard (Mx) as long as understands the risks & takes responsibility for the decision(10).	No it isn't what I think, its what you want...' Got a choice, don't have to decide now(5). We wouldn't give a choice if one was better(8). 'I try & sense what they would like'QQQ(14) Get the feeling that old folks want simplest (Mx) done & dusted(14) & dont like doing Mx in younger women QQ(14) that probably makes me ageist(14). But I may do what it easiest for me (Op/Follow up/DXT), and not what will suit them best(14). Dont like it '(14) but willing to make the decision but 'got to be sure they understand what they are doing.'(13).	2 (11) VS collaborative ...thy're so common no one really stands out.	1. Family history (prior knowledge). 2. Surgeon. 3. BCN (14) - 'their bias if there is one, could be tipping the balance' (15)
2	BS015	No problem(17) & if no real choice but Pt wants BCS will reevaluate (as a team) Q(16).	Sometimes is age related (older pts more trusting of doctors & go along with you). STEPWISE GUIDANCE: 1. Stress there is time(21, 23,24) & explain why a choice; equal Rxs, & people have personal preferences etc.(14) 2.if stuck use examples...some women choose'...& what might influence their feelings' QQQ(14)(14,23,24) & try to personalise & pick up reasons why they might choose one or the other(24). 3. I cant remember when i had to say '..OK then i'll decide, we'll do blah-blah...' QQ(24). if I had to i would err toward BCS(24) but try +++to avoid directing(23,24)	2 VS Collaborative	Breast team (UNIT + NATIONAL LEVEL), coz 'they decide the proportion of women who aren't... suitable for a choice...'(25) (+26) & it's '...the way you tell it & how you sell it...' (balanced Vs. unbalanced info), 'I suppose we all do it subconciously, we always mention BCS first.' QQ(25). in cases where small screen-detected cancers think 'by stressing smallness' pts feel happy having BCT (22). NON-TEAM INFLUENCES: Personal experiences of friends and family(26)
3	BS014	As a team, and self individually offer choice where suitable(9,10), coz patients have different reasons for choices make(9). PERCIEVES SELF AS OPEN INFO GIVER(6,12,13,14,15) QQQ(15). BUT CAN BE DIRECTIVE(13,14): (if not suitable for WLE, guides to Mx)(13). Hope the BCNs 'allow the patient to make their decision'.	I will help them to come to a decision, EMPHASISE 'your choice', not sure how I would react if sitting on that side...'(9) & WON'T 'convey my choice'(9,10) OR make DECISION for them(10,13). Emphasies time to chose(5,11). BUT CONFLICTING PICTURE OVER INTERVIEW - COMPARE WITH WHAT SAID - INCONISTENCY WITH HOW ADVISES THOSE WITH A CHOICE WHO DO NOT ASK FOR OPINION.: CAN BE DIRECTIVE(13,14) BY: INFO RELAY/RESTRICTION(6,11,13), SCENARIOS(9,11,13) i.e yong woman wanting Mx QQQ(9) & USE	1 VS. NOT STATED DIRECTLY ??collaborative the majority (IMPLIED BY DMS & TIEM TO MAKE DECISION).	OVERALL MAIN INFLUENCE 'the surgeon' (IMMEDIATE STRONG REPLY): "I hope that I leave it to them to make the decision, I hope that I don't push them in any particular direction [but]...I think the majority do tend to be ...guided by what is told to them..." (16). Feels sometimes those who are biased toward Mx give one-sided information(16) rather than the '2sides of the coin'(16). NON-TEAM: families & partners, children(16)

HCP no.	HCP ID	Factors associated with sat/dissatisfaction	1 thing to change	Extra information	Field note info	coder
		Process contact & outcome				
		22	23	24	25	
1	BS013	**SATISFACTION**: team work, team runs well. If feel patient understands & takes reponsibility for decision. If given information well BUT ??HOW BOTHERED AS if bad one '...oh 1 in a...' **DISSATISFACTION** targets +++ =some stress.	1. Brand new customised clinic (compared with higgeldy-piggledly one) Personally likes ('quaintness') BUT recognises not so good for patients(15). 2. Luxury of having the BCN in at consultation - BUT likes fact can ask NA FOR NON-THREATENING opinion & patient would have less time to make dacision & not ge the chence to talk on a diffenent level			LC
2	BS015	**SATISFACTION**: PROFESSIONLISM (OWN & TEAM) & TEAM ETHOS, FUNCTIONING. **DISSATISFACTION**: workload, resources, targets (but achieve) & LACK OF CONTINUITY (INDIVID CASES).	The ability to offer all women who require a Mx immediate reconstruction without it affecting their OP date(27)	Odd case will play on your mind: the very young(3). Patients reactions; nothing surprises me - seen every reaction and not always expected, even if seen woman before(5)		LC 1st code. Edited & ammended LC&DW
3	BS014	**SATISFACTION**: Team(1,2). OWN PROFESSIONALISM(4,12). **DISSATISFACTION**: inadequate time slots for pt consultation(16). Prefer to have BCN in with her(5). UNIT LAYOUT (distressed patients having to walk down the corridor)(5). WHEN PT DOESN'T FOLLOW ADVICE(11).	Workload - inadequate time to see each pt for as long as want, coz of the volume for work (given a 5 min slot for 2 new pts and 15 minutes for a results pt)(16)	PERCIEVES NON CHOICE SURGEONS AS THOSE WHO DIRECT TO Mx, NOT NECC THOSE WHO DIRECT TO BCS(16+ GEN IMP). feel surgeons who want patients to go down 1 route give very restricted information(13). DIAGNOSIS = 'bombshell' to screening pts(4). ABRUPT IN MANNER IN PARTS OF THE INTERVIEW. ? LANGUAGE BARRIER OR MEANING AS SAID		LC & DW SEPARATE CODES. + HMC REVIEW. COMPARED BY LC & DW. RE-SENT TO HMC FOR CONSENS

Appendix 10

Coded interview transcript example

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)
*VENUE: [redacted]
*DATE: 11/06/2004
*ID. Patient [redacted]
*INTERVIEWER: DJW

INT: Right, OK. Start, thanks for being interviewed. I want to start with question one. If you could tell me a little bit about what you knew or understood about breast cancer before you realised there was something wrong with your breast?

RESP: Well, as I said, the erm, thing I understood that if I did find something wrong, they did the initial biopsy and then if needs be, a full mastectomy. I haven't, I mean I do know people that's had breast cancer. My daughter-in-law's mum had it and she's fine. Erm, but not knowing an awful lot about it.

INT: Right.

RESP: And of course I didn't realise there was anything wrong anyway.

INT: Right, were you picked up on screening?

RESP: It was picked up on the mammogram, yeah.

INT: Right, OK.

RESP: There was no lump, I'd got no lump or anything and it was, I thought actually I'd finished going for screening at sixty-five.

INT: Right, yeah.

RESP: Not realising it they've now taken it to seventy.

INT: That's right, yeah.

RESP: So, of course I went and had it done and I thought, "Oh that's fine, now, I may get another one before I'm seventy, I might not.' Erm, and then of course ten days later they sent for me to go to the City because I'd bee to the mobile one at the GRI.

INT: Oh right, yeah.

RESP: The screening.

INT: Uh-huh.

RESP: And they sent for me back and as I say, I went into see Dr Turnball and she showed me the plates, the left side, the old plates and the new plates and then the same with the right side and on the middle plate there was, you could see this sort of white, just a white mass and she said, "That is what we're looking at."

INT: Right, hmm.

RESP: She then did a scan and erm, picked I up on the scan so she knew where she was going in to take the cells from. As I say, she took the cells off and then they went to be analysed.

INT: Right, OK. Dr Turnball, is she the radiologist?

RESP: She's a, a consultant radiologist, yeah.

INT: That's right, yeah. So is there, has anybody in your own family, immediate family had breast cancer?

RESP: No.

INT: No, OK. And you said, have you had any friends or..?

RESP: As I say, my daughter-in-law's mum, she had breast cancer and my daughter-in-law's had two lumps removed but they were benign. And my sister did, my eldest sister years ago, years and years now. I think she had two lumps removed but they were benign.

INT: Right, OK.

RESP: So there's nobody really in the family.

INT: Your daughter-in-law's erm, mum had it, you said?

RESP: Yeah.

INT: Yeah, and what did she have, did she have a mastectomy or..?

RESP: No, I think she had the wide local.

INT: Right, OK.

RESP: As well. And then, radiotherapy.

INT: Afterwards, yeah.

RESP: Afterwards.

*Q1 PLEASE TELL ME ABOUT THE TIME FROM WHEN YOU FIRST REALISED THERE WAS SOMETHING WRONG WITH YOUR BREAST TO THE TIME YOU WENT TO HEAR ABOUT YOUR RESULTS?

INT: And erm, so when, when you got the letter back from the, the erm, the mammography, the mobile unit to go and, to go to the hospital, what went through your mind then?

RESP: I thought, you know, I don't really think I thought there was anything wrong, but I know when I was having it done the girl had a bit of a job one side to just get it right and I suppose in my own mind I thought, "Well, probably the plates hadn't taken properly." Because normally if you go to the City breast screening you, you wait until you know that the plates are OK, well of course in the mobile one

INT: You don't.

RESP: They, you don't know.

INT: No, course.

RESP: So, I sort of thought, "Well," you know "It's erm, it's probably nothing, it s probably just that something's not taken right or something."

INT: Right.

RESP: That was what I was thinking in my own mind.

INT: Hmm.

RESP: And ten when I went to see Dr Turnball, I think I thought, "Well, there's no lump" You know, and she said more or less straight away, "Well, it's not a cyst." And I just thought, "It s probably tissue or something."

[illegible] (2)

INT: Right.

RESP: Ever the optimistic! I think, well you do. I think you ve got to, you know, "It can t be anything"

INT: Hmm-hm.

RESP: So, when I went back...

INT: Is this, is this, did she say this before she'd done the tests and things?

RESP: She did say when she'd done the erm, scan, she did say, "It's not a cyst."

INT: The scan, right

RESP: But she didn't sort of say anymore. Erm, she just said, "I can't," well she was going to, she said "I'm going to give you a local anaesthetic and no the needle biopsy" But then she said, "Are you on any medication" And I said, "Yes, I'm on Warfarin." [?] "Ah, that squashes that idea, I can't do that because you ll bleed too much."

(5)

INT: Right, OK.

RESP: Erm, but she said, "I can take some cells off." So she then looked again on the scan to know just where she was going in. Erm, and she drew the cells off. A mean that was, that was really, didn't really hurt, no more than having a blood test. Erm, and she just, you know, said, "Right, they'll give you an appointment for when you come back to see the consultant to get your results." Which was only a week afterwards.

INT: Yeah, hmm-hm.

RESP: So err.

INT. So, erm, and this point had you spoke to anyone about what your thoughts might be or..?

RESP: No. I don't think I did.

INT: No.

RESP: You know, I just thought, "Ooh well," you know, "Hope against hope everything's going to be alright."

INT: And so when you came home from that, that consultation with Dr Turnball, had you started to think anything else, that might be something a bit more serious or..?

RESP: Well I suppose it's crossed the back of your mind, erm, I think, because Norman went with me to that one, but he didn't go in with me of course, he just waited. Erm, and we just said, well, you know, we'd just got to wait and see, it's only a week, it's not going to be that long.

INT: Yeah.

RESP: you know, it, just hope for the best and you know, we discussed it, naturally it's on your mind, you're thinking about it, sort of at the back of your mind, you try to do everything that will take it away.

INT: Yeah.

*Q2. AND WHAT HAPPENED WHEN YOU WENT TO THE CLINIC AND WERE TOLD YOU HAD BREAST CANCER?

RESP: So I didn't, because I know on the morning we went, went back to see, for the results, my daughter said to me, she went with me then and she conned her dad into doing some wallpapering for us so as she could come with me. And erm, she says, "Oh, well knowing you it'll be a cyst, Mum, or something." Because some years ago I had problems with abscesses in my groin but, touch wood, they all cleared up.

INT: Yeah.

RESP: Erm, I said, "Well it might just be tissue, Karen." I mean, this was a discussion that was going as we walked up the breast care unit. And then sat, we went in and we just sat and then they came and called me and she said, "Shall I come in with you?" I said, "No, I'll be alright." And the nurse said to her, "Yes, you can do if you'd like to." And I said well, "It's my daughter." She said, "Ooh, that's fine." So of course she came in with me and she sat and she listened because...

INT: Is this when you saw Mr Sibering?

RESP: No, I saw Dr Wheheadner.

INT: Dr Wheheadner sorry.

RESP: Then, because he was on holiday, I didn't actually see Mr Sibering until I was in hospital.

INT: Oh, I see, til the day of the operation.

RESP: Til I'd gone in.

INT: OK. So when you saw Miss Whehecdner what happened then? When you went in to see her?

⑬ RESP: She said, erm, "we've got your results from the cells that were taken off and I'm afraid they are cancer." So, that's when I went blank then. Erm, and she said, she sought of went on quite quickly because if I suppose if I wasn't her patient in a way, but she said, she sort of got a piece of paper and she said, "You've got two options. There's the full mastectomy or the we can do the wide wide local which we will take off a wide area round it. And we shall also take some from the lymph nodes." And then she sent on, you know, sort of carried on a bit more and Veronica, the breast care nurse.

INT: Veronica Rodgers?

RESP: Yes. She was in with her. And I, I said well, "Do I have to make my mind up now?" and she said, "No, no no no, there's no need to make your mind up now, you've got," you know, "You've got time." So she then gave me, she said, "Oh it'll be April the 30th that you come in."

INT: Right. Which was how, how long after that?

RESP: Erm, think it was the Tuesday after Easter so about a fortnight, that was all, two weeks, yeah. Yes because we was going to London on the Friday. So it was the weekend of the marathon, yeah. Erm so that was, that was right. It was a Tuesday after Easter, whatever date that would be and I went, it was only literally a fortnight, I wouldn't have thought it was any more.

INT: Right, OK.

RESP: Before I was due to go in. So we then, she says, "Have you got any questions?" Well I sort of...

INT: Yeah.

RESP: I just couldn't think of anything.

INT: No, it's a bit difficult, isn't it?

RESP: And my daughter said to her, well, well then she said about having, "You may have to have chemotherapy, you may have to have radiotherapy." And Karen was a bit concerned with the radiotherapy, with the Warfarin but they mix OK. And she said, "Yes, that's fine." And she sought of asked, sort of one or two questions because she'd gone through a similar thing really because she'd got abnormal cells and had to have a hysterectomy. ⑮

INT: Right.

RESP: When she was thirty-seven. So I think she was more geared for questions, as I say, I just blank, I couldn't think of anything.

INT: Yeah, it's a huge shock, isn't it? A huge shock.

RESP: Of course it wasn't what I was expecting to hear, not really, I must admit. ㉒

INT: No, yeah. Um, so when you're actually in the room with Miss Wheheadner, there was yourself and your daughter, Veronica?

RESP: Veronica

INT: And Miss Wheheadner, was anybody else there, do you remember?

RESP: I've got a feeling there could have been a nurse as well.

INT: A clinic nurse?

RESP: Yeah.

INT: In a sort of uniform then?

RESP: Trying to think. Yeah. I think there were possibly one of the erm, nurses. Apart from the one that actually, you know, called me in.

INT: Right, OK.

RESP: To go and see her. Yes, I feel sure there was. But Veronica was making notes while Dr Wheheadner was talking and that, you know.

INT: Yeah.

RESP: And the she said, well, "If you do think of anything, I'm here all morning," you know, "And I will see you again," you know, "But go with Veronica now and.." So we, we then went with Veronica to the other room. ⑦

INT: The quiet room?

RESP: The quiet room.

INT: With seats and sofas and stuff?

RESP: Hmm. And she says, "Well first of all make yourselves a cup of coffee, just, you know, make yourselves a drink and I'll be back in one minute." And she came back and she sort, she was marvellous really because she just sat and went through it all again with me soes it literally started to sink

INT: Yeah.

RESP: In a bit then

INT: Yeah, a bit of repetition.

RESP: That's right, yeah. So, erm, but she was, she was brilliant and I've seen her one, two, I've seen Veronica twice and I saw Karen when I went back to Mr Sibering's clinic, Karen was there and I think I saw Jill, I think it was Jill when I went to see Dr [? 14.00] the oncologist

INT: Right, OK.

RESP: I think I've done my rounds of them. I don't know!

INT: You've seen nearly all of them, I think there's four of them there.

RESP: Well Veronica, I saw Veronica at the clinic but she was busy with somebody else when I went back to see Mr Sibering erm. I didn't see any, I didn't see any of them while I as in, not in hospital but Mr Sibering came most days. His favourite saying was, "How, how high will that arm go, how high?"

INT: Arm, yeah.

RESP: You know

*Q3. AND WHAT HAPPENED WHILE YOU WERE TALKING ABOUT WHAT TREATMENT YOU COULD HAVE?

INT: Erm, when Miss Wheheadner was actually talking about the treatment options you could have you said she had a piece of paper, did she draw a diagram?

RESP: Yes, she drew diagrams, yeah

INT: Did she show you any, any mammograms or any pictures or anything like that?

RESP: Not mammograms she didn't, no.

INT. No, just the diagram?

RESP: Just she drew sort of, she put err, 'mastect...', 'mass' then she drew the, the, like the wide local excision, what they'd do and how they'd take it from the lymph nodes.

INT: Hmm-hm.

RESP: Erm, I don't think there was, I don't think she drew any more. She went in, you know, quite in detail of the options so, you know, so, erm, so it just concerned me because I didn't know whether I'd got to give her an answer there and then.

⑫ [illegible]

INT: Yeah, of course.

RESP: Which I couldn't do anyway, so erm.

INT: Did the idea that you had a choice of treatment, did that surprise you or shock you in anyway? ⑥

RESP: Well it surprised me really, I thought you'd be told, "Right, we're going to do this or we're going to do that." Of course they've said since, gone are those days that they can do that now.

⑩ ⑫ 6: [illegible]

INT: Yeah.

RESP: You know, they've got to sort of give this preference. I mean we did talk about it when I came home, not particularly that day but the day that I went for pre, I think it was. They talked about it more then and Karen says well, she went with me that day as well and she said, "The thing is, what you've got to think, Mum, before is, are you going to have that done now or are you going, if it had not got it all are you going to want to have more surgery following it?"

INT: Is that what they told you, is that what..?

RESP: Well that's what, as I said, if it came back erm, when they'd done the wide local, if it came back that there were more cells there, they would then have to go on and probably do a full mastectomy. SO it was knowing, right, do I go ahead and have the full one and be done with it

INT: Right yeah

RESP: Or do you take a chance in, virtually, isn't it?

INT: Yeah. That it might possibly recur again.

RESP: That's right. But, err.

INT: How do you feel you got on with Miss Wheheadner.

RESP: She was alright, yeah, she was.

INT: Do you think she listened to your needs and your concerns and..?

RESP: I think so, I think, you know, if I could have come out with more questions she would have been there for me

INT: Yeah

RESP: Erm, and she would have answered them and I think with the same, you know, "If you do think of anything, please come back because I'm here all morning, please come back and I'll try and answer any more questions that you've got." So I mean, she did give me the time and, you know. But as I say, I just, I must admit I just couldn't take it in at the time so.

INT: And while she was telling you about your diagnosis and your treatment options, how much did you understand about what you were being told?

RESP: I think I understood most of it, I mean, I understood, yes, right it was cancer. Erm, and I understood that I'd, I'd got the two choices that err, erm, yeah, I think I took, you know I, understood the majority of it. I did take that in, I mean, admitted as I said, I'd got, it'd got no questions because none was forth coming at that time.

INT: Hmm, no. Is there any information you think you didn't understand at all, or found confusing later on or..?

RESP: No, I don't think so because I've got that many booklets somewhere as well.

INT: They give you a big pack, don't they?

RESP: I've got a wallet full in there, first of erm. I mean Veronica gave me two well she gave me the wallet. The wallet's been very good because it came, you know, it, you can keep everything and sort of, keep everything in it and err, and I've collected more along the line since then of course

INT: Is this what the breast care nurses gave you?

RESP: This is, not that, err, this is basically, physio, yeah they gave me the support group and gave me the breast unit treatment diary which has got your exercises and everything and a guide to cancer services in Derby. Erm, which I've sat and read through you know.

INT: I was going to ask you, did you, did you find any of that information particularly useful?

RESP: Yes I, I did find quite a lot of it because I thought, erm, in the treatment book I mean, you've got, you know, if you'd had forgotten what the physio had told you I mean, you could look up your exercises and what have you and erm, it explained to you about, you know, the difference between the wide local and the mastectomy which I did sit and, I mean I must admit I've sat and read them.

INT: Yeah

RESP: And it does explain, you know, what to expect after the operation and everything so I did find them all, you know, sort of very useful erm. Let me see, oh yeah, that was, that's bit more of it, the radiology bit. But err yeah, so, I mean, I came away with that and I mean Veronica gave me her card, if I felt I should need to talk to her and she has rung me, she rang me on Friday to see how I was going on and...

INT: Right

RESP: Erm, make sure I was all right you know. Which I thought, I thought was very caring

INT: Hmm, absolutely.

RESP: I really did, you know, because I didn't expect that, I thought "Well I shall probably see her when I eventually have to go back to clinic for another appointment."

INT: Yeah.

RESP: But erm, no, she says, "I'll ring you, I'll ring you again in a few weeks when you've started your treatment." You know, so, I just found them all very caring and very eager to help, is the word.

INT: Yeah, hmm-hm.

RESP: So.

INT: When you were speaking to Miss Wheheadner about the treatment you were going to get, you were going to have the wide local or mastectomy...

RESP: Hmm.

INT: Erm, did you get, at any time did you get the impression that there might be erm, she might have a preference for one kind of treatment or one treatment was better than the other?

RESP: Not really, no, no

INT: That's good

RESP: No, there was no sort of persuasion there and the same as when I saw Mr Sibering on the Friday morning, there was no, "ell I think, you know, it might be better if you have this done or it might be better if you have that done." I mean they basically said "We can't make your mind up for you."

INT: Hmm hm.

RESP: Which I suppose they can't because people will soon say, "Ooh, well, I needn't have had that done."

INT: Yeah, course

RESP: You know

INT: And when you saw Veronica afterwards, you know, after you'd been to see Miss Wheheadner

RESP: Yeah.

INT: What sort of things did you talk about then?

RESP: Well she sort of started from scratch again and went through it all with me, erm, and she sort of said, you know, that the preferences that you've got erm, and said basically, she explained it all to me again which by then it started to sink in a bit.

INT: Hmm

RESP: At that point. We were quite a little while and as I say, Karen asked her more questions and then we sort of talked in general, so she was putting you at your ease, you know, before you started again and so, I felt, you know, that it was a help because by then I was beginning, as I say, beginning to take it in

(2) BCN

INT: Yeah.

RESP: So err, I think that talk definitely helped with that and you were sort of away from the clinical bit as well in that room, you know.

INT: Yeah, bit more pleasant, isn't it really.

RESP: It is really, yeah

INT: Yes

RESP: Yeah.

INT: It's not someone sitting behind a desk or something

RESP: Yeah, that's right.

INT: Erm, let me see, where are we? We've been talking that much!

RESP: Yeah, sorry.

INT: When do you think, no, no, it's fine. Through out the consultation err, who, with Miss Wheheadner, who did you think asked most of the questions and who did most of the talking?

RESP: My daughter.

⑩

INT: With the questions?

RESP: Asked the questions

INT: And Miss Wheheadner did...

RESP: She answered her, yes, she answered her erm, because I told her it was my daughter anyway. Erm, and she answered, oh yes, she answered her and what have you.

OP

INT: And you said about a week later you went in for your, two weeks later.

RESP: Two weeks I went, I went for pre-clark [?] in, erm, oh, we talked about stopping my Warfarin on the Monday, I had the last doe on the Monday because I was having the operation on the Friday so I went for pre-clark in, on the Wednesday. And the first thing the nurse said to me, "Have you stopped your Warfarin." I said, "Yes. I had my last dose on Monday." "Oh well, I think you'll have to come in today." I says, "Pardon?" This was twelve o'clock, lunchtime.

INT: What, to have the operation?

RESP: No, they wanted me to go in that day sees they could get me heparin converted [?].

INT: Oh right, OK.

RESP: And she said, "We want you here for four o'clock." But that just hit me like a bomb. I think it hit me worse than knowing what it was.

INT: Yeah.

RESP: And, anyway, she carried on, she did some blood tests and what have you. The I had to go, she said, "Well, would you like to go and sit tin the waiting room because the physio will come and fetch you in a minute and then you've got to see the breast care nurse again." And erm, so I went out to the waiting room and Karen was sat there and she says, 'Whatever's the matter, Mum?' I says, "I've got to come in today." She says, "Pardon?" she says, "And you're not having your op til Friday, that's ridiculous." So, we sat there, anyway and, and then we went with the breast care nurse, err, physio, and we went up to the quiet room and she was going over one or two things and then all of a sudden it just hit me what this nurse had said. I just broke down. And she said, "Whatever's the matter Brenda?" And Karen said, "That's the first time I've seen my mum cry." And she said, "It's because they've told her she's got to come in today."

INT: Hmm hm.

RESP: She said, "Today?" And anyway, she went out and she saw Veronica and Veronica then got on to Mr Sibering and he said, "That is ridiculous," he said, "It would do more harm than good to put her on heparin today because she would bruise to high heaven."

INT: Right.

RESP. He says, "Tomorrow, yes, but not today." I went in Thursday, afternoon actually.

INT: Oh so you didn't.

RESP: So I didn't go in on the Wednesday no.

INT. OK, right.

RESP: So then I saw.

INT. You must be relieved.

RESP. Oh! Then Veronica came and as I say, she'd got on to Mr Sibering and erm, "No, my word, we don't want her in today. No, that's stupid." So she said "Tomorrow but," she said, "You'll have to ring up to find out what time they want you." So erm, anyway, I rang about twelve o'clock. I think I had to be there between two and three, something like that.

INT: Right.

*Q4. SO, PLEASE TELL ME WHAT OPERATION(S) YOU HAD FOR YOUR BREAST CANCER?

RESP: But then Veronica, the physio went and Veronica came in again and she made the form out, similar to this one, put in that I was going to have the wide local excision but she said, "You haven't signed anything yet so," she said...

INT: You can change your mind

RESP: I can change your mind, you can change your mind. So she sat basically and went through things again with us and erm, she said, "You've no need to make your mind up til the last minute." But I had to go, so of course it was a bit of a rush Friday morning then. Erm but veronica, she went through, you know, everything again with us. So then I went in Thursday and, as I say, I said to the sister, I said "I just don't know, I just cannot make my mind up." "Don't worry, I'll get Mr Sibering to come and have a word with you." And he came at eight o'clock on the Friday morning.

INT: On the Friday morning, so you went in, did you go in on the night time?

RESP: I went in Thursday afternoon.

18

INT: Yeah

RESP: They gave an injection Thursday night and then of course cut the Ted socks [?] on, then I had to go, he came at eight o'clock. I was the second one in theatre that morning. Erm, as he sat on the bed talking to me, quite a little while, then I signed the consent form. Erm, he went out the curtains, the anaesthetist came in to talk to me.

INT: They'll be a queue!

RESP: Outside the curtains there was a nurse form the breast care unit to take me up there but I a got to have this needle put in and I still hadn't had a wash by then and I thought, "This is ridiculous." So then went charging of up to the breast care nit in a wheelchair and then they did. I was up there quite a while as well and they did all sorts of scans and then they gave me a local anaesthetic and then they put this needle in you see.

INT: To help guide them.

RESP: 'X' marks the spot I think it said on the end of it! Erm, so we're coming back down from there and I sort of having to hold my arm like this because I doren't put it down because this needle was sticking.

INT: Oh yeah, right.

RESP: It was padded round it.

INT: Yeah.

RESP: But the radiologist that did it he says, "Do not let anybody move that needle," he says, "because it's vital it stops where it is."

INT: Hmm.

RESP: So I'm sort of coming down the corridor like this and the porter's saying to me, "Can you put your arm down, love, we've got to get through this door." I says, "I can't." And he looked at me. Anyway, when I went to theatre and Jo, the sister was there, she says, "Are you alright, Brenda?" I says, "Yeah," I says, "But I can't put me arm .." So she had to come and help me put the gown on for theatre.

INT: Oh yeah.

RESP: Erm, and then of course they took me to theatre in a wheelchair and we're going through the doors and I'm, we were like this, it was funny really when I think about it, it didn't feel funny at the time.

INT: No, but looking back.

RESP: When I look back, and the porter's saying, and Jo says to him, "You'll have to open both doors to get her through, because she can not put her arm down." "Oh," he says. "Oh." Then we got to theatre and they put me on this trolley and I'm still having to keep me arm up here and this chap's trying to put things on me. I says, "I can't put me arm down." He says, "It's alright love, I realise you you've got a needle in there." Your know, so, all trying to put the ECG things on me back, you know, and what have you Oh dear, as I say, it didn't seem funny at the time but, it was when I think about it afterwards.

INT: In-between seeing Miss Wheheadner and going in for your operation, did you talk to anybody else about erm, your diagnosis and what treatments you might have? Discuss with your family or friends?

RESP: Well we talked, Norman and I talked about it.

INT: Hmm.

Joanne

RESP: And as I say, Karen did come and, the day we came, on the Wednesday about, "Well nobody can make your mind up, only you, Mum, but if needs be are you going to want to have to lots of surgery." And I said, "I don't know Karen." So basically I think, I talked about it with Karen and my son, of course although my son's away. We talked about it and, erm, I went, I say, we went to London the weekend of the London marathon because he was running in the marathon so that took it off me a bit but I was able to talk to my daughter-in-law. We sat and talked one night. Erm, because she was a staff nurse on intensive care.

INT: Right.

RESP: And with her own mum going through it as well.

INT: So what was her, what was her take on things?

RESP: Well she said, she said, "Well, my mum had the wide local, but," she says, "There again mum, I can't tell you what to do." But she said, you know, "You're a bit old which, you'll be led which way to go." Sort of thing, you know. As I say, I, I, it just seemed like a burden on me for a day or two before, because I kept thinking I've got this decision to make and I can't do it.

Q
(18)

INT: Hmm

RESP: You know. Erm, but we did, and we did it and we made the right decision.

(+21)

INT: Yeah. So, erm, you been, you've been, you've had your operation, what happened after your operation when you came round, were you, were you OK, were you alright?

RESP: Yes, I was fine. Well they, they were, they were, Norman and my daughter were laughing when they came because Norman had rang up in the morning to see what roughly what time I was going down.

INT: Yeah.

RESP: And Jo had told him I was the second one on the list so she said, "Well I should.." Norman, what time did she tell you ring back?

RESP2: Err, nine, err, two o'clock.

RESP: Two o'clock. Erm, but at about half past one, quarter to two, she actually came and rang him, she went and rang him and said, "She's back." I think she'd waited til I'd come round a bit and then she says, I can only remember her saying, "I must go and ring your husband." And she dashed off and she just said to him, "She's round, she's come back, she's round, she's OK, you can visit when you like." And he says, "Well, we'll leave her a little while before we come." And I think they came, what time did you come love? About four?

RESP2: I don't know, after four.

RESP: Yeah, and both of them were amazed to see me sat up in bed, or propped up in bed, where I'd got two slices of toast on a plate because I was absolutely starving.

INT: You'd had nothing from the previous night, had you?

RESP: Well, when you have your meal and whatever, six o'clock.

INT: Yeah, it's a long way to go, it's like twenty-four hours almost.

RESP: And then one of the health care assistants came and said, [whispers] "Would you like some toast?" I says, "Ooh, I would please." And yeah, I think I only ate a slice of it but it was something.

INT: Yeah.

RESP: And then they brought me a drink, a hot drink, because I'd been having water. Erm, I was so thirsty, I've never drunk so much water. Erm, and I didn't drink that. I went to sleep again and Karen and Norman just sat there, you know. I come round and then, I sort of felt fine, really, afterwards, no problem.

INT: Hmm. Did you see Mr Sibering at any point, did he come round afterwards?

RESP: Not that night. No, I saw him Saturday morning.

INT: Right.

RESP: he, he had a habit of, I used to say, I've got a mouthful of breakfast and he'd come, any time after eight o'clock and you'd probably just put some breakfast in your mouth and he's come and, you know, he just. He come Saturday morning and he just said, "Everything's gone fine, I just want you to keep moving that arm for me." He looked at the drains, erm, he says, "Just be careful when you move that you've got two drains." Well they told me that on the Friday after dinner because they'd come and give you one of these little gift bags now to put your bottles in.

INT: They put them in Christmas bags at Christmas

RESP. Yeah. Yeah. He asked me if I wanted it back when I came home, I said, "No thank you! You can have it!" I don't really want to see one again, you know

INT: No.

RESP: Erm, and he sat and talked to me and he said, "Just, just please keep moving that arm." And he sort of patter, he's got such a nice...

INT: Bedside manner.

RESP: Bedside manner. He sort of touches you on your shoulder and said, "Good girl," you know "You're doing OK." I mean erm, as they came most mornings, even the Bank Holiday Monday I think he came and err, then on the Wednesday I was moved off Ward Two up to Ward Sixteen because they were waiting for surgical beds and they said, you know, one's sort of self nursing ones, they were very sorry that they'd got to move us. Must admit it was quieter up there because there was only three of us in the bay and it was a six-bedded bay. So I did get some sleep then.

INT: And then how soon after that did you, how long were you in hospital?

RESP: Eight days.

INT: Eight days, then you went home?

RESP: I came home.

INT: And when did you next go back for a consultation?

RESP: Erm, came home on the Friday, the following Friday to my operation and then I went back on the Thursday.

INT: Hmm.

RESP: The 13th of May I went back.

INT: To get your results?

RESP: Erm, and I went because I had to go to physio first so we did like a u-turn round the whole of the hospital because physio's up there and surgical thing's way up the other side of the hospital.

INT: Hmm, I know.

RESP: So I felt a bit. And I'd got myself churned up anyway.

INT: Yeah.

RESP: Not knowing.

INT: Because you'd been getting the results from what they'd took from your cancer.

RESP: From Mr Sibering, yeah.

INT: Of course.

RESP: And err, but Norman went in with me to see him and we went in the examination room first because he didn't do stitches on the outside he did steristrips.

INT: Hmm.

RESP: And erm, I didn't have my last drain out until the Friday I came home because they doren't take that out because, until my Warfarin had levelled. And we went in and he came through, as I say Karen, the breast care nurse, was with him. And he's got a very junior doctor with him but he said "Do you mind?" and I said, 'No.' Erm, and he, he just, he said, 'Let's have these steristrips off now I'll be very gentle," he said. But I didn't know that he was actually so gentle I didn't realise he's pulled them off and there was just a couple of lose ends of stitches sticking out and Karen just trimmed those off. He says, right, "Get dressed and then come through and we'll have a little chat."

INT: Hmm. And what did he say when you went through.

RESP: So we went through and err, he said, well of course we get the paper out again and we have more drawings and he said right, he said, "Let me tell you one thing to start with." So I said, "Right." He said, "The surgery you've had is it, there won't be any more surgery."

INT: Hmm.

RESP: And I just went [sigh].

INT: Hmm

RESP: I looked at Norman and he looked at me and then he gets his bit of paper and he says, "Right, this is what we've done, they've taken that away, this is a good area and that is fine." And he draws four little round things, "They're your lymph nodes and there's a bit in one of them."

INT: Ahh.

RESP: "But," he says, "We're not worried about that little bit," he said, "Because you're radiotherapy will blast that." And he said, "You'll go on from me to see Dr Otymia [?].

INT: The oncologist.

RESP: The oncologist.

INT: Hmm

RESP: "And he will discuss options with you about chem..." he said, "There'll probably be some medication, tablet wise, but it will be him to decide and also chemo or radiotherapy or both."

INT: Oh right.

RESP: Erm, then he said to me, "Have you got any questions?" As said, "I haven't," I says, "All I want to say is thank you and you've given me the answers what I wanted."

INT: Yeah.

RESP: I say, "You've told me there's no more round that outside." And you know he says, "Well," he says, "You will see me," he says, "I shall see you every three months to start with and then it will gradually get to six months and you'll have another mammogram in twelve months." And so, we'd more or less, well, we came out with Karen, Karen came out with us and she said, "Do you want to go away again and discuss things." I said, "Not this time, Karen," I says, "He's given me the answers."

INT: Hmm

RESP: I says, "The one thing I was dreading he's answered." Which to me, you know is, I didn't need to know anymore really.

INT: Yeah.

RESP: And I went the, I think I went the following week, I think I be, either there or the DRI, I went to the DRI the following week, yes, to see Dr Otymia, the consultancy with him. As I say, Jill was there for that one.

INT: Hmm.

RESP: And erm, he says, "Right, decision time again," he says. Not more!

INT: Never made so many decisions in your life then!

RESP: I haven't! not just off the cuff like that. And he said, "Well," he said, "We can offer you the chemotherapy," and he said, "We have to offer it you now," he said, "Because some ladies want everything." I said, well then he went on to tell me, explained it all to me, the process of chemotherapy and ending up with radiotherapy but he said that, "The difference that it will make to you will be five per cent."

INT: If you have the chemo?

RESP: If I had chemo

INT: Right, say five per cent of extra cover, if you like, preventing it coming back.

RESP: Hmm. He said, "You have to weigh that five per cent up against the side-effects."

INT: Yeah, and were they going to be quite severe? OK.

RESP: He says, "Of course it's a six month course in different cycles and they do so many days and then you have a break and then so many more days and then you've still got your six weeks radiotherapy at the end of it."

INT: Right.

[illegible]

RESP: So, he said, "Of course," he said, "One of the side-effects as you probably know is losing your hair," he says, "But don't worry about that," he says, "Because we give you a chip ~~a week~~, you go somewhere in town and go and get one." I says, "Oh, thank you." He says, "But then of course it does grow back," he says, "It might grow back a different colour."

INT: OK.

RESP: "Could be red," he says, "Could be red." I says, "Oh thank you." And it's this colour and anyway we smiled about it and I said...

INT: It grows back stronger and curlier.

RESP: Yeah. I know there was a lady in there that had had, she a had actually breast cancer, a year err, nine years before. She'd had a lump nine years before and they'd given her some chemo before she went in to have, and then she had a full mastectomy and erm, she, she said when she come in hospital it was first time she'd been anywhere without a wig and hers was really, I mean, I wouldn't have thought it, I would have thought she'd just had it cut short, but it really was quite nice. And I said, "You're never going back to wearing a wig again are you?" So she said, "No, not now." So I said "Well, if it's only going to give me that benefit, I think my answer is no, I will stick with the radiotherapy."

INT: Yeah.

RESP: So he says, "Well I'm going to put you on some medication as well," but I can't have the, I can't think what it is, the normal one, tamaz, tom...

INT: Tamoxifen.

RESP: Tamoxifen. Can't have that because that doesn't like the Warfarin.

INT: Right.

RESP: But he gave me irrimidet [?].

INT: Right.

RESP: That's just one a day for the next five years.

INT: And have you started your radiotherapy now then?

RESP: No.

INT: No, when's that start?

RESP: Your guess is as good as mine!

INT: Oh, Right.

RESP: I've had the planning done so, I had to go back, I saw him one week, I went back on the Monday and had the first bit done where I was all nicely marked up with purple and bits of microcord and, "Will you try and not lose those until you come again." So then I had to go back on the Friday and they did the, the rest of the measuring up and put the, what they call the tattoos, where they put the die in and scratch your skin.

INT: Yeah.

RESP: The permanent one. So err, from then which is, will be err, fortnight on Friday since I had that done but, I mean you've got conflicting erm, conflicting reports about how long you're going to be. I 25
mean one told me it could be three weeks, the one last week, oh, on the Friday, I said to her, "Oh," she said, "Well all these x-rays we've taken go to Dr Otymia now. He decides on the treatment and then

they go to the planning people." She says, "I could ring you up next Friday and say you've got to come" you know, sort of "on the Monday." Well that didn't happen but then when Veronica rang me last week she said it's usually about four weeks

INT: Right

RESP: After the planning. But I don't know. But then there's been conflicting reports that they are behind.

INT: Ah right, OK.

RESP: Apparently there was quite a piece in the Telegraph, in the local paper. I don't, we don't have it so I don't know but that was up to six weeks.

INT: Oh, you must be sick.

RESP: So, you know, we were going, it's a bit, you don't know what to do really because we were going to try and have a few days away in-between before I start the radiotherapy because, I thought, well once you start that it's every day.

INT: Yeah course.

RESP: For six weeks.

INT: And you've got to keep it going really and...

RESP: Apart from Saturday and Sunday of course

INT: Give them a call, give them a call and just say, well, you're thinking of having a few days away, is it alright you know

RESP: I'm going down, I'm going on Monday, I've got to have my iron ore checked for my Warfarin so I thought, it's only just down the corridor, junction eleven at the DRI, I might just have a walk down and see if there's somebody, you know, I could have a word with and erm, you know, say, well, we think you know, I'm not pushing for it or anything, I just...

INT: No, not all.

RESP: Wanted to book, you know, a few days away.

INT: Absoutely. I'm sure they'll understand. I'm sure they'll be fine.

RESP: Yeah

INT: Um, let me see. In-between sort of erm, the consultation with Miss Wheheadner to the point when you had your operation, did you look for any information about breast cancer and treatments erm, in magazines, books, videos, TV programmes, did you call the support group at all?

RESP: No, I haven't called it.

INT: OK, right

RESP: No

INT: Erm, seems a strange question, but do you feel you had the amount of choice that you wanted?

RESP: I think so, yes. I think I had more than. I think it's nice that you do have the choice. Well probably not nice is the right word but, I think it's nice, better than somebody just saying to you, "Right, we're going to do this," or "We're going to do that."

INT: Hmm.

RESP: Erm. I mean with something, I mean the only other major operation I've had is gall stones, the gall bladder out but, I mean that, that is something you don't have to make a decision about, you know But I do think you were given enough preference and enough information quite honestly

INT: Do you feel you had enough information to make your choice?

RESP: I think so.

INT: Hmm-hm.

RESP: I mean it's a very personal decision, isn't it, really?

INT: Yeah, absolutely. And, what do you think was the most important thing that you were told or read or heard that helped you make your decision what treatment to have?

RESP: I think it was when Mr Sibering said on the Friday that it, there was a very good erm, of what's the word for it? Sort of, feedback that it was very successful what I was having done, the wide local. You know, they'd had very successful...

INT: Results.

RESP: Results from having it done that way

INT: That kind of thing, yeah.

RESP: Erm, and as I say, he didn't, didn't push me at all it was just with him saying that I think that made me make the decision, yes, that that's what we'd go, go along with

INT: Right, OK. Looking back from when you were first diagnosed until now, how do you feel about the care you've received?

RESP: I feel as though I've had great care taken of me. Everybody's been very caring, from the staff on the ward upwards. I must admit and I don't think you could have had anybody better, with a better bedside manner that Mr Sibering and the breast care nurses have been there for you.

INT: And has your care met your expectations do you think?

RESP: I think in some ways it's gone above.

INT: Right.

RESP: And that phone call from Veronica last week made a great difference, it really did

INT: Yeah.

RESP: Because I didn't expect it.

INT: No.

RESP: I thought, you know, I shall see her again when I go to clinic probably, erm. I think, you think you come out of hospital and that's, you know, apart from what other treatment you've got to receive erm, and your appointments are made for you and everything, I mean, that is the thing, I mean, at each time I've gone the appointments have been given you. Before I'd even had the operation I'd got my appointment for when I saw him afterwards, you know. Veronica gave it me, erm. I think it must have been on the Wednesday when I went for me pre-clarking [?]. She says, "And this is your appointment to see Mr Sibering afterwards."

INT: Hmm-hm

②

RESP: You know, I though, forward planning, you know! No I think, I have had brilliant care

INT: If you were told you had the power and money to change one thing about the service, the breast service at Derby City General, what do you think it would be?

RESP: Ooh, dear, that's a hard one. I don't know, I honestly don't know the answer to that one. As I say I just couldn't find anything really that I would want to change because, as I say, everybody was just so caring

*Q5. NOW THAT YOU HAVE BEEN THROUGH THIS EXPERIENCE, WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW?

INT: Hmm. That's OK. Um, now you've been through this experience what do you think are the most important things someone with breast cancer needs to know about first of all, their diagnosis?

RESP: As it was explained to me I think that was important

INT: Hmm.

RESP: That it's explained to them and people have the time to sit and spend with them

INT: Yeah, hmm.

RESP: Because if you're not expecting it

INT: Yeah.

RESP: I mean, if I'd had a lump...