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# **Patient and clinician factors influencing the choice of breast cancer surgery: A Qualitative and Quantitative Study**

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**Volume 1**

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'The single biggest problem in communication is the illusion that it has taken place.'

~George Bernard Shaw

'Good communication is as stimulating as black coffee, and just as hard to sleep after.'

~Ann Morrow Lindbergh



CANCER RESEARCH UK



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## Publications and papers arising from this thesis

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### Publications

Why do hospital mastectomy rates vary? Differences in the decision-making experiences of women with breast cancer. Caldon LJM, Collins KA, Wilde DJ, Ahmedzai SH, Noble TW, Stotter A, Holt S, Sibbering DM, Reed MWR. *British Journal of Cancer* Vol 104, p1551-1557 (10 May 2011) doi: 10.1038/bjc.2011.141

Patients as researchers – innovative experiences in Health Service research. Caldon LJM, Marshall-Cork H, Speed G, Reed MWR, Collins KA *International Journal of Consumer Studies* 34 (2010) p547–550 doi: 10.1111/j.1470-6431.2010.00907.x

Changing trends in the decision-making preferences of UK women with early breast cancer. Caldon LJM, Walters SJ, Reed MWR. *British Journal Of Surgery* Vol 95 (3) p312-318 Mar 2008 DOI: 10.1002/bjs.5964

What influences clinicians' operative preferences for women with breast cancer? An application of the discrete choice experiment. Caldon LJM, Walters SJ, Ratcliffe J, Reed MWR. *European Journal of Cancer* Vol 43 (11) p1662-1669, 2007 DOI:10.1016/j.ejca.2007.04.021

Case-Mix Fails To Explain Variation In Mastectomy Rates: Management Of Screen-Detected Breast Cancer In A UK Region 1997-2003. Caldon LJ, Walters SJ, Reed JA, Murphy A, Worley A, Reed MW. *British Journal of Cancer*. 92(1):55-9, 2005 Jan 17. UI: 15611797

### Regional and national presentations

What is BresDex? Why we did it. invited presentation, Association of Breast Surgery Nursing Conference 2011, Manchester 16th-17th May 2011

Mastectomy or Lumpectomy who chooses? Invited presentation, British Association of Surgical Oncology/Association of Breast Surgery Joint Meeting, the Royal College of Surgeons of England 3rd November 2008

The choice of operation for breast cancer: Who decides? Royal College of Nursing breast care nurses' conference, the Royal College of Physicians, London. 1st December 2006

Changing trends in the decision-making preferences of UK women with early breast cancer.. British Journal of Surgery prize plenary session presentation at the British Association of Surgical Oncology ~ The Association for Cancer Surgery Scientific Meeting, London 27-28th November 2006

What influences Specialist Breast team Operative Preferences: Application of the Discrete Choice Technique. Oral presentation in the Alan Edwards Poster Prize plenary session at the British Association of Surgical Oncology ~ The Association for Cancer Surgery Scientific Meeting, London 14-15th November 2005

Case-Mix Fails To Explain Variation In Mastectomy Rates: Management Of Screen-Detected Breast Cancer In A UK Region 1997-2003. Association of Breast Surgery at the British Association of Surgical Oncology Annual Conference, Solihull 11th May 2005

Variance in the surgical practice of Trent Breast screening units. Parallel session presentation, Nottingham International Breast Cancer Conference. 18th September 2003

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Changing Patterns Of Surgery: The Trent Breast Screening Program 1997-2000. Parallel session presentation, Nottingham International Breast Cancer Conference 18 – 21st September 2001

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## Abbreviations

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BCN	Breast Care Nurse
BCS	Breast Conservation Surgery
BCT	Breast Conservation Therapy
Mx	Mastectomy
MR	Mastectomy Rate
ADMS	Achieved Decision Making Style
PDMS	Preferred Decision Making Style
NHS	National Health Service
NHSBSP	National Health Service Breast Screening Programme
MDT	Multi-Disciplinary Team
LRR	Loco-regional recurrence
LRRR	Loco-regional recurrence rate
QoL	Quality of life
MREC	Multi-Centre Research Ethics Committee
DoH	Department of Health
RCT	Randomised Control Trial
QA	Quality Assurance

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## Definitions

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Autonomous	Having autonomy; not subject to control from outside; the capacity of a rational individual to make an informed, un-coerced decision; central to the concepts of informed consent and shared decision making in medicine.
Breast Conservation Surgery	The local excision of the cancer with a margin of normal surrounding breast tissue.
Breast Conservation Therapy	The local excision of the cancer with a margin of normal surrounding breast tissue plus adjuvant ipsilateral chest wall radiotherapy.
Culture	The set of shared attitudes, values, goals, and practices which characterises an institution, organisation, or group.
Communication	the imparting or exchanging of information by speaking, writing, or using some other medium
Compliance	The act of conforming, acquiescing, or yielding.
Directed	Guided, regulated, or managed
Ethos	The fundamental and distinctive character of a group, typically expressed in attitudes, habits, and belief.
Facilitative	To make easier or less difficult; help forward (an action, a process, etc.)
Informed choice	Possessing sufficient and sufficiently reliable information or knowledge to understand an issue and make appropriate judgments or decisions regarding it.
Informed consent	A patients' agreement to undergo an operation or medical treatment after being informed of and understood and accepted the risks involved. The provision of informed consent is contingent on the individual concerned being in possession of all relevant facts at the time consent is given and to possess adequate reasoning capacity.
Informed compliance	The process of making 'right' choice in accordance with the authoritative knowledge and experience of clinicians, rather than being the result of patients' consideration of the evidence and their personal preferences.

Mastectomy	Refers to simple mastectomy; the removal of the breast alone
Paternalism	Behaviour which is undertaken regardless of person or group's will, by a person, organisation or state, which limits the person or group's liberty or autonomy for their perceived good; and which can be an expression of an attitude of superiority towards the person or group.
Patient-centred care	The experience (to the extent the informed, individual patient desires it) of transparency, individualisation, recognition, respect, dignity and choice in all matters, without exception, related to one's person, circumstances, and relationships in health care. (Berwick 2009)
Shared decision-making	The process by which patients are involved as active partners with professionals in clarifying acceptable treatment, management or support options, discussing goals and priorities, and together planning and implementing a preferred course of action. (Coulter 2011a)



**Background and aims** In women with breast cancers up to 5 cm diameter, breast conservation therapy (BCT) and mastectomy are equivalent for survival and morbidity; although recurrence and body image vary. This mixed-method study in a UK region (population 5 million) aims to identify reasons for mastectomy rate (MR) variation between units.

**Methods and findings** The study comprised five components; two in 14 units:

- (1) An audit of the NHS Breast Screening Programme (n=5060 cases from 11 screening units) established MR variation was not due to case-mix or caseload ( $p=0.001$ ).
- (2) A Discrete Choice Experiment (n=68/93) employing multinomial logistic regression confirmed clinicians surgical preferences (25 scenarios, n=1695) vary based on cancer (size, site and centrality,  $p<0.001$ ), patient (age and breast size,  $p<0.001$ ) and clinician variables (gender and clinician role,  $p=0.015$  and  $p<0.001$  respectively).

Three within units representing high, medium and low case-mix adjusted MRs:

- (3) A validated questionnaire established that patients (n=356) preferred and achieved more autonomy in treatment selection than before; particularly among those choosing mastectomy ( $p<0.001$ ).
- (4) Interviews with clinicians (n=26; 13 nurses and 13 doctors) highlighted variation in local ethos. Clinicians' focus in the low MR unit was the promotion of BCT and in others, autonomous decision-making. Communication strategies and processes optimised this.
- (5) Interviews with patients (n=65) demonstrated varied experiences between breast units. While patient factors influenced decisions, breast team factors predominated. Patients from the high and medium MR units described more informed autonomous decision-making processes and support.

**Conclusions** In this study low MRs were associated with clinicians preferring BCT and higher MRs with clinicians supporting patients' decision-making. Clinician factors related to treatment preferences associated with high MRs were not identified. This does not preclude their existence in other regions. Understanding surgical variation factors could facilitate treatment decision-making equity, but is unlikely to reduce MRs.

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## Chapter 1

### Introduction

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## LITERATURE REVIEW

Breast cancer is the most common cancer affecting women worldwide(WHO 2011) and the third most common cancer diagnosed in the UK; with 1 in 8 to 1 in 9 being diagnosed at some point in their lifetime, and approximately 49,000 diagnosed in 2008.(Office for National Statistics 2003;Office of National Statistics 2011)

### The history of breast cancer surgical options

Historically breast cancer was treated by the Halsted radical mastectomy, which was first performed in 1882. It involved the en-bloc excision of the breast, along with ipsilateral pectoralis muscles and axillary contents. This remained the standard of care for all stages of breast cancer until the mid-1960s, when aesthetic dissatisfaction, anecdotal reports(Fisher 2005) and new evidence about cancer metastases,(Fisher 1980) motivated some to pursue less extensive surgical alternatives. Subsequent evidence demonstrated no survival benefit among most treated by radical versus simple mastectomy (removal of the breast alone), and simple mastectomy became the standard of care.(Fisher 2005) Following this Breast Conserving Surgery (BCS) was developed; the local excision of the cancer with a margin of normal surrounding breast tissue. A Randomised Control Trial (RCT) commenced in 1976 and published in 1985, produced the first evidence demonstrating BCS was a suitable alternative to mastectomy among some women with breast cancer, and that when followed by adjuvant ipsilateral radiotherapy results were improved; so called Breast Conservation Therapy (BCT).(Fisher et al. 1985)

### The initial breast cancer treatment options today

The mainstays of breast cancer treatment today are surgery, radiotherapy, chemotherapy and endocrine treatments. There has been a recent expansion of treatment options including new surgical techniques resulting from the increased adoption of oncoplastic techniques into breast cancer surgery; with breast reconstruction, therapeutic mammoplasty and volume replacement techniques combined with BCT.(BAPRAS and the Training Interface Group in Breast Surgery 2007;Clough et al. 2010) The proportion of cancers potentially suitable for BCT has also been increased by the utilisation of neo-adjuvant chemotherapy(Kaufmann et al. 2003;van der Hage et

al. 2001; Wolmark et al. 2001) or endocrine treatment (Hind et al. 2007) to reduce cancer volume prior to surgery. Despite these advances most women undergo surgery as the initial therapeutic treatment for their breast cancer, and the most common surgical options remain mastectomy and BCT.

### **Neither BCT nor mastectomy are definitively superior options**

Over the last two decades evidence for survival equivalence for cancers treated with BCT or mastectomy has increased, with large long term RCTs conclusively demonstrating this in cancers up to 4-5cm diameter. (Blichert-Toft et al. 1988; Clarke et al. 2005; Fisher et al. 2002; Jacobson et al. 1995; Lichter et al. 1992; Poggi et al. 2003; Sarrazin et al. 1989; van Dongen et al. 2000; Veronesi et al. 2002) Evidence of survival equivalence at five years follow-up first emerged in 1985. (Fisher, Bauer, Margolese, Poisson, Pilch, Redmond, Fisher, Wolmark, Deutsch, Montague, & . 1985) The evidence was strengthened in the mid-1990s with the publication of two studies with longer follow-up; a large RCT - the National Surgical Adjuvant Breast and Bowel Project's Protocol (NSABP) B-06 (n=2105) (Fisher et al. 1995) and a smaller study by the National Cancer Institute (n=237) (Jacobson, Danforth, Cowan, d'Angelo, Steinberg, Pierce, Lippman, Lichter, Glatstein, & Okunieff 1995) with 12 and 10 years follow-up respectively. These findings were based on the treatment of cancers less than 4cm diameter (most less than 2cm). The results of the European Organisation for Research and Treatment of Cancer (EORTC) trial 10801 corroborated survival equivalence evidence in cancers up to 5cm diameter at 10-years follow up (n=868), (van Dongen, Voogd, Fentiman, Legrand, Sylvester, Tong, van der, Helle, van Zijl, & Bartelink 2000) as have others. (Blichert-Toft, Brincker, Andersen, Andersen, Axelsson, Mouridsen, Dombornowsky, Overgaard, Gadeberg, Knudsen, & . 1988; Lichter, Lippman, Danforth, Jr., d'Angelo, Steinberg, deMoss, MacDonald, Reichert, Merino, Swain, & . 1992; Sarrazin, Le, Arriagada, Contesso, Fontaine, Spielmann, Rochard, Le, & Lacour 1989) Twenty year follow-up results of NSABP B-06 (n=1851) (Fisher, Anderson, Bryant, Margolese, Deutsch, Fisher, Jeong, & Wolmark 2002) and the Milan study (n=701), (Veronesi, Cascinelli, Mariani, Greco, Saccozzi, Luini, Aguilar, & Marubini 2002) and eighteen year results of the National Cancer Institute study, (Poggi, Danforth, Sciuto, Smith, Steinberg, Liewehr, Menard, Lippman, Lichter, & Altemus 2003) confirm survival equivalence is sustained.

It is therefore accepted a large proportion of women diagnosed with breast cancer can be safely treated with either BCT or mastectomy. BCT is contraindicated when patient safety would be compromised; for example when cancers are large (typically over 4-5cm diameter) or multi-focal, or where there are contraindications to radiotherapy which would compromise disease control and survival. Relative contraindications to BCT are inadequate breast volume to permit an acceptable aesthetic outcome with BCT; typically when over 20% breast volume excised.(Bulstrode and Shrotria 2001) Volume excisions beyond this level require oncoplastic volume replacement techniques.(BAPRAS and the Training Interface Group in Breast Surgery 2007;Clough, Kaufman, Nos, Buccimazza, & Sarfati 2010)

Although survival is equivalent between BCT and mastectomy and most studies demonstrate equivalence in their impact on physical(Irwig and Bennetts 1997;McCready et al. 2005;Schain et al. 1983)and psychological morbidity(Carlsson and Hamrin 1994;Dorval et al. 1998;Fallowfield et al. 1986;Ganz et al. 2002;Irwig & Bennetts 1997;Moyer 1997;Sanger and Reznikoff 1981;Schain, Edwards, Gorrell, de Moss, Lippman, Gerber, & Lichter 1983;Stefanek 1993) in most realms, there are differences between the two options: Body image(Arndt et al. 2008;Carlsson & Hamrin 1994;Fallowfield, Baum, & Maguire 1986;Irwig & Bennetts 1997;Moyer 1997;Sanger & Reznikoff 1981;Schover 1994;Stefanek 1993) and probably sexuality are superior with BCT,(Arndt, Stegmaier, Ziegler, & Brenner 2008;Hack et al. 2006;Pozo et al. 1992;Schover 1994) while loco-regional recurrence rate (LRRR) is statistically significantly higher with BCT.(Clarke, Collins, Darby, Davies, Elphinstone, Evans, Godwin, Gray, Hicks, James, MacKinnon, McGale, McHugh, Peto, Taylor, & Wang 2005;Early Breast Cancer Trialists' Collaborative Group 2002;Jatoi and Proschan 2005;van Dongen, Voogd, Fentiman, Legrand, Sylvester, Tong, van der, Helle, van Zijl, & Bartelink 2000;Veronesi, Cascinelli, Mariani, Greco, Saccozzi, Luini, Aguilar, & Marubini 2002) Reflecting differences in extent of resection and radiotherapy doses, studies demonstrate different rates, but usually a two-fold increase in LRRR is identified with BCT.(Jatoi & Proschan 2005;van Dongen, Voogd, Fentiman, Legrand, Sylvester, Tong, van der, Helle, van Zijl, & Bartelink 2000;Veronesi, Cascinelli, Mariani, Greco, Saccozzi, Luini, Aguilar, & Marubini 2002) Most quote LRRR of approximately 2-5% with mastectomy and 10-12% with BCT;(Veronesi, Cascinelli, Mariani, Greco, Saccozzi, Luini, Aguilar, & Marubini 2002) some quote higher rates of around 12% and 20% respectively.(van Dongen, Voogd, Fentiman, Legrand, Sylvester, Tong, van der, Helle, van Zijl, & Bartelink 2000)

Despite discrepancies in LRRR, no impact on survival has been demonstrated at 10 years follow up.(Richards et al. 1995;Stewart 1995) However, a recent an overview by Clarke et al. published in 2005 of the RCTs including a meta-analysis (n=25 000), demonstrated LRRRs exceeding 10% at 5 years were associated with statistically significant increased breast cancer mortality at 15 years;(Clarke, Collins, Darby, Davies, Elphinstone, Evans, Godwin, Gray, Hicks, James, MacKinnon, McGale, McHugh, Peto, Taylor, & Wang 2005) and indicate one death for every four women diagnosed recurrent breast cancer. Therefore avoiding local recurrence should reduce mortality rates. Based on this, it is possible that studies may start to demonstrate survival inequality between BCT and mastectomy when the data of longer term follow up is available.

### **Patients benefit from being involved in treatment decision making**

The lack of a clearly superior treatment over all realms, and distinct differences between the two, led to a call for women diagnosed with breast cancer to be considered eligible for the provision of a choice between BCT and mastectomy where possible. This call followed evidence emerging from studies conducted over the same period, demonstrating patients who consulted with clinicians providing information and including them in treatment decisions achieved enhanced short and long term physical and psychological outcomes, compared with those providing treatment direction.(Andersen et al. 2009;Deadman et al. 2001;Fallowfield et al. 1994a;Fallowfield et al. 1990;Fallowfield et al. 1994b;Hack, Degner, Watson, & Sinha 2006;Kotwall et al. 1996;Molenaar et al. 2004;Morris and Ingham 1988;Morris and Royle 1987;Moyer 1997;Moyer and Salovey 1998;Schou et al. 2002;Stewart 1995;Street, Jr. and Voigt 1997;Wilson et al. 1988;Wolberg 1990) Specifically, patients experienced improved satisfaction with the process of care and surgery undertaken;(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) reduced regret about their surgery;(Fallowfield, Hall, Maguire, & Baum 1990;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Schou, Ekeberg, Ruland, & Karesen 2002) and improved short and long term 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)

The benefits of good doctor-patient communication and patients' inclusion in decision making have been demonstrated, even among those patients with reservations about choosing their treatment;(Fallowfield, Hall, Maguire, Baum, & A'Hern 1994a) although it is difficult to separate the contributions of good communication/information provision and participation in decision making to the positive effect. Fallowfield proposed in her follow up study, that optimal communication/information was the enhancing factor.(Fallowfield 1997) However evidence from a prospective mixed methods study by Deadman et al. investigating the psychological effects of breast cancer treatment among women (n=114), suggest the decisional role provides the enhancing impact. Their study comprised questionnaires and interviews at multiple time points between preoperative and 15 months post-operatively. Within the subset provided a surgical choice (n=80) patients were randomly allocated to take explicit responsibility for their own treatment decision (n=41) or receive a strong recommendation from their surgeon after being provided with full information about the options (n=39). Those provided a more autonomy exhibited psychological benefit associated with their decision involvement, over and above that achieved from undergoing their preferred treatment.(Deadman, Leinster, Owens, Dewey, & Slade 2001)

There is also evidence that partners of women with breast cancer can both benefit from their wives' more autonomous involvement in decision making(Ashcroft et al. 1985;Morris & Royle 1987;Morris and Royle 1988) and experience a negative impact from their partners diagnosis and experiences;(Bigatti et al. 2011;Wagner et al. 2006;Wagner et al. 2011) with increases in depression in this group.(Bigatti, Wagner, Lydon-Lam, Steiner, & Miller 2011;Wagner, Bigatti, & Storniolo 2006;Wagner, Tanmoy, Bigatti, & Storniolo 2011) Therefore, optimising patients' experiences and recovery are an important issue.

### **A change in the healthcare provision model**

The culmination of such evidence led to a change in the healthcare provision model of the UK National Health Service (NHS) from a paternalistic model where patients were treated as passive recipients of a service, to one where patients are considered partners in healthcare decision-making.(Department of Health 2001a;Department of Health 2001c;Department of Health 2008;Department of Health 2009;Rawling 1992;Royal College Of Surgeons Of England 2002) Patients' inclusion in treatment decisions is now enshrined in healthcare. The UK's Department

of Health (DoH) as NHS funding provider and policy generator, together with doctor's regulatory body - the General Medical Council (GMC), clearly state patients should be provided with adequate time, information and support to make fully informed treatment decisions. (Department of Health 2001a; Department of Health 2001c; Department of Health 2009; General Medical Council 2008; Royal College Of Surgeons Of England 2002)

The initial therapeutic treatment of primary breast cancer is classic example of a clinical context in which preference-sensitive healthcare decision-making is possible; with patients participating in treatment decision-making and choosing their preferred options. The adoption of such practices by specialist breast units preceded the more recent wider adoption of preference-sensitive healthcare decision-making by other specialities. The expectation is this approach will improve equity in healthcare, as well as optimise patients' satisfaction with both their treatment and the delivery of care. (Department of Health 2000; Department of Health 2001b; Irwig & Bennetts 1997; McCready, Holloway, Shelley, Down, Robinson, Sinclair, & Mirsky 2005)

### **Breast practice guidelines permissive to patient choice but wide variation in practice remains**

With evidence of the benefits of patient involvement in decision making, the optimisation of patient involvement in this has become a widespread priority (Association of Breast Surgery at BASO 2009; Blichert-Toft et al. 1998; Department of Health 2001a; Department of Health 2001c; Department of Health 2009; General Medical Council 2008; Kaufmann et al. 2010; National Collaborating Centre for Cancer 2009; Nattinger et al. 1996; Nayfield et al. 1994; Royal College Of Surgeons Of England 2002; Scarth et al. 2002a; Scarth et al. 2002b) which is enshrined within law, (Department of Health 2009; Nattinger, Hoffman, Shapiro, Gottlieb, & Goodwin 1996; Nayfield, Bongiovanni, Alciati, Fischer, & Bergner 1994) international consensus statements, (Blichert-Toft, Smola, Cataliotti, & O'higgins 1998; Kaufmann, Morrow, von, & Harris 2010) and national, (Association of Breast Surgery at BASO 2009; National Collaborating Centre for Cancer 2009; Scarth, Cantin, & Levine 2002a; Scarth, Cantin, & Levine 2002b) regional and breast unit treatment guidelines. Information about treatment variation and survival equality between BCT and mastectomy was converted into legislation in US states; compelling clinicians to disclose treatment options to breast cancer patients. The first was enacted in 1979. (Nattinger, Hoffman, Shapiro, Gottlieb, & Goodwin 1996; Nayfield, Bongiovanni, Alciati, Fischer, & Bergner 1994) Treatment guidelines state that when BCT is not contraindicated on clinical grounds,

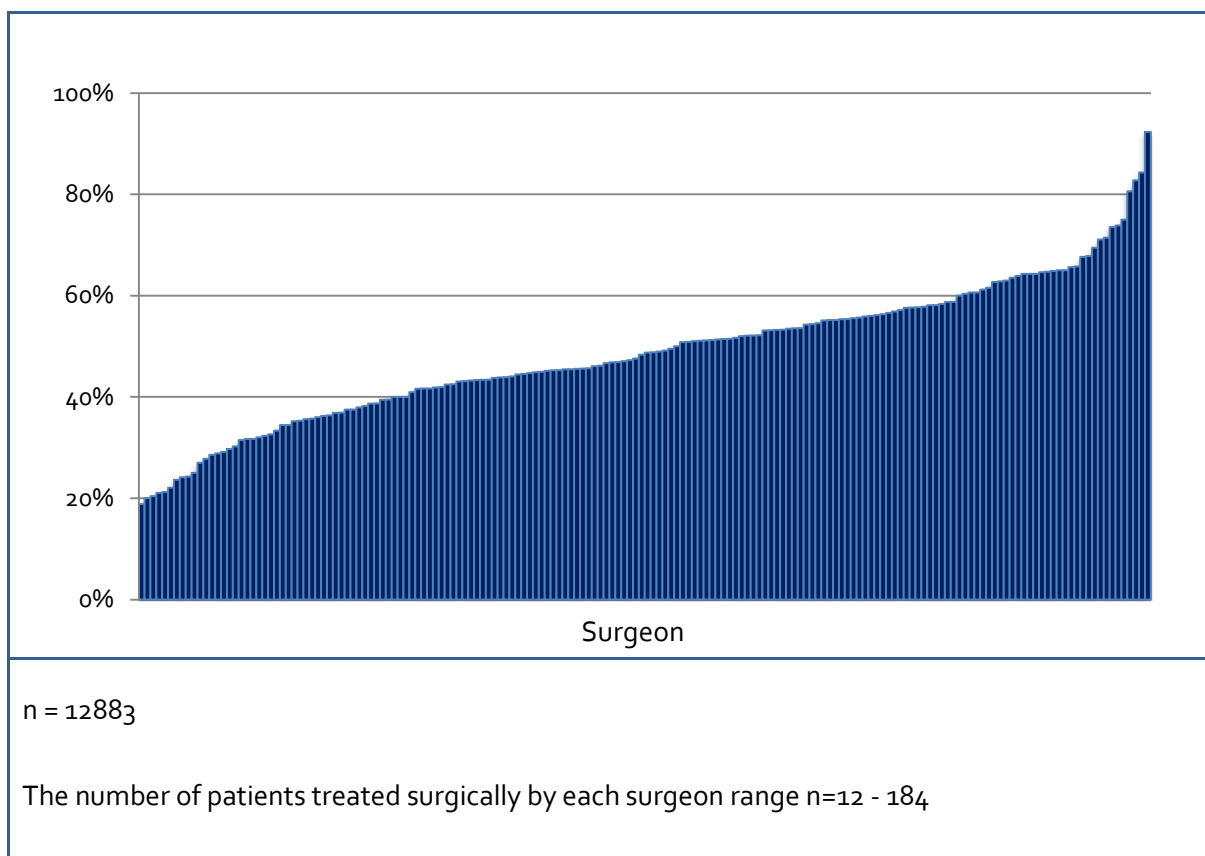


women with breast cancer should be offered a choice between BCT and mastectomy. (Association of Breast Surgery at BASO 2009; Kaufmann, Morrow, von, & Harris 2010; Scarth, Cantin, & Levine 2002a)

It was widely assumed that if breast cancer patients were provided greater patient autonomy in treatment selection, the majority would select BCT and practice variation would reduce. However, there remains evidence of highly variable practice among hospital breast units, with widely varying mastectomy rates (MRs) in the UK (Bates et al. 2009; BCCOM 2006; BCCOM Steering Group 2007; Money Penny 2004; Sauven et al. 2003; School of Health and Related Research 1998) and internationally; including the US, (Farrow et al. 1992; Mandelblatt et al. 2000; Morris et al. 2000; Morrow et al. 2001; Nattinger et al. 1992; Nattinger and Goodwin 1994; Samet et al. 1994) Canada, (Goel et al. 1997; Iscoe et al. 1994) Japan, (Ishizaki et al. 2002) Italy, (Grilli et al. 1994; Scorpiglione et al. 1995) and between countries. (van Nes et al. 2010) An example of this is illustrated in figure 1.1. The UK DoH expresses concern regarding such images. Its documents 'The NHS Cancer Plan' (Department of Health 2000) and 'NHS Performance Indicators - A consultation', (Department of Health 2001b) published in September 2000 and May 2001 respectively, referred to such images as a 'postcode lottery' of treatment, and proposed the adoption of breast unit mastectomy to BCS ratios as performance indicators, to discourage variation. Thomson's large audit of breast cancer practice variation in Scotland (n=23,786) demonstrated an association between deprivation and MRs; with these being higher among less affluent groups. (Thomson et al. 2001) In the US such variation has been associated with race, affluence and health insurance. (Goel et al. 2005; Morris, Cohen, Schlag, & Wright 2000; Prehn et al. 2002)

The majority of studies to date demonstrating breast cancer treatment variation conclude that significant variation in treatment exists, which cannot be explained by case-mix alone. These studies however base their conclusions on aggregated data analysis; amalgamating case characteristics across units or hospitals. By combining cases in this way, these studies fail to account for the case-mix of individual breast units and thus provide a potentially inaccurate representation of practice. They may reflect case-mix variation instead; especially if based on small numbers.

FIGURE 1.1 Variation in MRs between UK Surgeons - BCCOM Project Year 3: The management of primary breast cancers diagnosed in 2004 in the UK. (BCCOM Steering Group 2007)



Practice variation in the Trent region was consistently reported in annual Trent National Health Service Breast Screening Programme (NHSBSP) reports produced as part of the Quality Assurance (QA) process. A report published in 1998 commissioned by the North Trent Breast Cancer Group produced by the School of Health and Related Research (SchARR), demonstrated variation in unit practice among both screen and symptomatically detected breast cancers from the Trent region (1995 and 1997); with a similar but exaggerated pattern of variation among the symptomatically detected group. (School of Health and Related Research 1998) The report failed to include information on primary cancer characteristics, so it is unclear whether this reflects the tendency of symptomatically detected cancers to present at a larger size and more advanced stage, than screen-detected ones.

## Patients' preferences for treatments vary

There is strong evidence of the variability of patients' personal preferences for the two treatment options; some provided with an informed choice electing to have BCT,(Collins et al. 2009;Degner et al. 1997a;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Mastaglia and Kristjanson 2001;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Schou, Ekeberg, Ruland, & Karesen 2002) others mastectomy.(Collins, Moore, Clay, Kearing, O'Connor, Llewellyn-Thomas, Barth, Jr., & Sepucha 2009;Hack, Degner, Watson, & Sinha 2006;Janz et al. 2004;Keating et al. 2002;Lantz et al. 2005;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Moyer & Salovey 1998;Schou, Ekeberg, Ruland, & Karesen 2002;Street, Jr. & Voigt 1997) Patients' healthcare decisions are subject to many influences. In the context of breast cancer, at the time of diagnosis women possess pre-existing values, concerns and information(Fallowfield, Baum, & Maguire 1986;Hughes 1993;Lasry and Margoiese 1992) which can influence their treatment preferences; including prior information and experience of breast cancer,(Hughes 1993;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Nold et al. 2000;Schou, Ekeberg, Ruland, & Karesen 2002) body image values,(Carver et al. 1998;Collins, Moore, Clay, Kearing, O'Connor, Llewellyn-Thomas, Barth, Jr., & Sepucha 2009;Hawley et al. 2009;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 and Heltzel 1997;Wei et al. 1995) cancer recurrence fears(Collins, Moore, Clay, Kearing, O'Connor, Llewellyn-Thomas, Barth, Jr., & Sepucha 2009;Fallowfield, Baum, & Maguire 1986;Lasry & Margoiese 1992;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Schou, Ekeberg, Ruland, & Karesen 2002;Wilson, Hart, & Dawes 1988) and attitudes towards radiotherapy.(Collins, Moore, Clay, Kearing, O'Connor, Llewellyn-Thomas, Barth, Jr., & Sepucha 2009;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Schou, Ekeberg, Ruland, & Karesen 2002) Other issues associated with patients' surgical preferences are social responsibilities(Smitt & Heltzel 1997;Wilson, Hart, & Dawes 1988) and inconvenience of treatment regimens such as travel for radiotherapy;(Smitt & Heltzel 1997;Wilson, Hart, & Dawes 1988) the latter being amplified in isolated rural areas (Australia(Mastaglia & Kristjanson 2001) and Canada(Bathe and Brosseuk 1997;Goel, Olivotto, Hislop, Sawka, Coldman, & Holowaty 1997)).

It has been proposed that during the decision-making process, patients make trade-offs between their values, fears and information, and that the option chosen is governed by which potential loss or fear is paramount to the individual. For example, whether fear of breast loss or fear of cancer recurrence or death predominate.(Fallowfield, Baum, & Maguire 1986;Lasry & Margolese 1992;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Nold, Beamer, Helmer, & McBoyle 2000;Smitt & Heltzel 1997) Debate exists regarding whether such a “trade-off hypothesis” exists.(Fallowfield, Baum, & Maguire 1986;Lasry & Margolese 1992) If it does exist, factors within consultations such as clinician’s presentation of information and whether or not patients’ particular concerns or knowledge inaccuracies are addressed, might influence patients’ trade-offs and impact their decisions.

The influence of age,(Bleicher et al. 2008;Hawley et al. 2007;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Singh et al. 2010) race/culture(Bleicher, Abrahamse, Hawley, Katz, & Morrow 2008;Hawley, Lantz, Janz, Salem, Morrow, Schwartz, Liu, & Katz 2007;Hawley, Griggs, Hamilton, Graff, Janz, Morrow, Jagsi, Salem, & Katz 2009) and education(Bleicher, Abrahamse, Hawley, Katz, & Morrow 2008;Hawley, Lantz, Janz, Salem, Morrow, Schwartz, Liu, & Katz 2007;Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010) on breast cancer decision making are not clear. Audits of large datasets of treatment practice provide a conflicting picture. The evidence for an impact of education is stronger; some studies demonstrate when education level is corrected, age and race are no longer associated with MR variation.(Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010) Therefore education may be the key variable influencing these other factors.

There is also evidence that patients’ preferences are influenced by media information portrayal.(Collins et al. 1999;Hughes 1993;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;McKinlay et al. 1997;Nattinger et al. 1998) For example an epidemiological study from the US demonstrated a significant upsurge in MRs following Nancy Regan’s mastectomy for breast cancer.(Nattinger, Hoffmann, Howell-Pelz, & Goodwin 1998) This was most notable among women of a similar age and sustained for several years.

In recognition of varying patient preferences, lack of superiority of a specific treatment and demonstrable benefit of including patients in their treatment decisions, providing women with surgical choices for the management of their breast cancer is a recognised priority in patient care.

## Patients' decision-making styles vary

Patients' preferences for involvement in healthcare decision-making vary. The most commonly adopted terms are decision making preferences (DMP) or decision making styles (DMS). Three main patient DMS are described in the literature; active, collaborative and passive. Active decision-makers want to make their own healthcare decisions, collaborative decision-makers to share the responsibility, and passive decision-makers to defer it to others. These are often assessed using adapted versions of an instrument designed by Strull(Strull et al. 1984) and subsequently popularised(Beaver et al. 1996;Beaver et al. 1999;Davison and Degner 2002;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Hawley, Lantz, Janz, Salem, Morrow, Schwartz, Liu, & Katz 2007;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005;Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010;Wallberg et al. 2000) by Degner (the Control Preferences Scale).(Degner and Sloan 1992) A version of this five point DMS instrument is illustrated in chapter 4, figure 4.1.

Studies conducted in the 1990's reported that women with breast cancer preferred and achieved predominantly passive or collaborative roles in the selection of their surgery; with 50 to 70% preferring or achieving a passive role, and 20 to 30% a collaborative role.(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996;Bilodeau and Degner 1996;Luker et al. 1996b;Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010) The only study examining UK breast cancer patients' (n=150) DMS using the Degner card sort technique, demonstrated 20% had an active preferred DMS (PDMS), 28% a collaborative and 52% a passive PDMS.(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996) The literature suggests the healthy public tend to possess predominantly active PDMS,(Deber et al. 1996;Degner & Sloan 1992;Levinson et al. 2005;O'Donnell and Hunskaar 2007a;O'Donnell and Hunskaar 2007b;Rothenbacher et al. 1997) and that individuals diagnosed with a chronic(Deber et al. 2007;Giordano et al. 2008;Levinson, Kao, Kuby, & Thisted 2005;O'Donnell & Hunskaar 2007a;Rothenbacher, Lutz, & Porzsolt 1997) or life-threatening disease(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996;Butow et al. 1997;Deber, Kraetschmer, Urowitz, & Sharpe 2007) their PDMS shifts away from the more autonomous preferences toward more passive preferences. Beaver and Degner conducted a series of studies into PDMS among a variety of patient and non-patient groups around the same time period. Their studies demonstrated the predominant PDMS was active (64%) among healthy controls,(Degner & Sloan 1992)

collaborative (46%) among those with benign breast disease,(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996) and passive DMS (52%) among women newly diagnosed with breast cancer.(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996) Butow's study conducted around the same time supports this; demonstrating as patients' cancer prognosis worsens their PDMS shifts increasingly toward the more passive group.(Butow, Maclean, Dunn, Tattersall, & Boyer 1997) However, other studies among breast cancer patients exploring DMS in palliative treatment, fail to demonstrate a passive shift.(Grunfeld et al. 2006;Rothenbacher, Lutz, & Porzsolt 1997)

Recent studies from North America,(Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005;Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010) Australia(Mastaglia & Kristjanson 2001) and Hong Kong(Lam et al. 2003) suggest a reversal in the pattern of predominant passivity; with increased proportions preferring and achieving more active roles in breast cancer surgery decisions. For example Mastaglia's retrospective survey of consecutive women with early stage breast cancer diagnosed over a 6 month period in 1996-1997, who were identified through the Western Australia Cancer Registry (n=250/376), demonstrated 54% possessed an active PDMS for their breast cancer treatment, 36% a collaborative PDMS and 8% a passive PDMS.(Mastaglia & Kristjanson 2001) Singh et al. performed a meta-analysis on North American cancer patient DMS data (n=3276). They demonstrated a similar but less marked shift in DMS away from a predominantly passive PDMS of older studies. The meta-analysis showing 26% had an active PDMS, 49% collaborative and 25% a passive PDMS.(Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010)

Patient demographics have been variously associated with PDMS; more active PDMS associated with female gender,(Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010) younger age(Arora and McHorney 2000;Cassileth et al. 1980;Deber, Kraetschmer, Urowitz, & Sharpe 2007;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Hawley, Lantz, Janz, Salem, Morrow, Schwartz, Liu, & Katz 2007;Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010;Wallberg, Michelson, Nystedt, Bolund, Degner, & Wilking 2000) higher education(Deber, Kraetschmer, Urowitz, & Sharpe 2007;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Hawley, Lantz, Janz, Salem, Morrow, Schwartz, Liu, & Katz 2007;Singh, Sloan,

Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010;Wallberg, Michelson, Nystedt, Bolund, Degner, & Wilking 2000)and affluence.(Hack et al. 1994) However, not all demonstrate an age association.(Bleicher, Abrahamse, Hawley, Katz, & Morrow 2008;Kennelly and Bowling 2001;O'Connor et al. 2003a) The familiarity of decision making context may also exert an effect. For example Deber demonstrated a reduction in the PDMS of patients with chronic diseases, when they were asked to make a treatment decision in unfamiliar disease context, as opposed to one in their chronic disease.(Deber, Kraetschmer, Urowitz, & Sharpe 2007)

There is evidence that patients benefit from being involved in treatment decisions; with increases in satisfaction with their treatment and the process of its selection.(Bruera et al. 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) There is contention about whether an active achieved DMS (ADMS) per se is beneficial(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) or whether achieving congruence between ADMS and PDMS provides the most benefit in optimising short and long term recovery and satisfaction, and minimising regret.(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) Hack demonstrated improvements in these at three years, among patients with breast cancer (n=250) achieving a more active DMS; including statistically significantly better long term psychological adjustment, quality of life (QoL), and superior physical and social functioning.(Hack, Degner, Watson, & Sinha 2006) Charles demonstrated an amplification of the positive effect of involvement in decision making when congruence was achieved between patients' PDMS and ADMS.(Charles et al. 1999a)

Studies demonstrate clinicians often misallocate patients' decision making preferences.(Bilodeau & Degner 1996;Bruera et al. 2001;Bruera, Willey, Palmer, & Rosales 2002;Butow et al. 2004;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller

1997a;Gysels and Higginson 2007;Hughes 1993;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Montgomery and Fahey 2001;O'Connor et al. 2003b;Richards, Ramirez, Degner, Fallowfield, Maher, & Neuberger 1995;Rothenbacher, Lutz, & Porzsolt 1997;Strull, Lo, & Charles 1984) A large Canadian study (n=1012) among women with breast cancer found only 42% believed they achieved their PDMS.(Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a) This impacts on satisfaction; with dissatisfaction expressed among those who on reflection, feel they were excluded from the decision process(Bilodeau & Degner 1996;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Hack, Degner, Watson, & Sinha 2006;Rothenbacher, Lutz, & Porzsolt 1997) or asked to undertake a more active role than preferred.(Hack, Degner, & Dyck 1994;Hack, Degner, Watson, & Sinha 2006;Schain 1980)

It has been suggested that if women were provided with greater control in the selection of their surgery, MRs would fall, as women would wish to conserve their breasts. However there is no clear evidence to support this supposition: Some studies demonstrate significantly greater proportions of those preferring and achieving active roles in the selection of their surgery choose 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) others demonstrate more active DMS are associated with an increase uptake of mastectomy.(Collins, Moore, Clay, Kearing, O'Connor, Llewellyn-Thomas, Barth, Jr., & Sepucha 2009;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;Moyer & Salovey 1998;Schou, Ekeberg, Ruland, & Karesen 2002;Street, Jr. & Voigt 1997)

### **Patients becoming informed**

Three types of support needs have been identified for adaption to occur among individuals experiencing stressful situations; emotional, tangible and informational.(Schaefer et al. 1981)



When diagnosed with a benign disease(Cassileth, Zupkis, Sutton-Smith, & March 1980;Davis et al. 1999;Deber, Kraetschmer, & Irvine 1996;Jenkins et al. 2001;Jones et al. 1999;Strull, Lo, & Charles 1984) or cancer,(Bilodeau & Degner 1996;Blanchard et al. 1988;Butow et al. 1996;Cassileth, Zupkis, Sutton-Smith, & March 1980;Chen et al. 2008;Davison et al. 1995;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Fujimori and Uchitomi 2009;Galloway et al. 1997;Graydon et al. 1997;Hack, Degner, & Dyck 1994;Jenkins, Fallowfield, & Saul 2001;Jones, Pearson, McGregor, Gilmour, Atkinson, Barrett, Cawsey, & McEwen 1999;Luker et al. 1996a;Meredith et al. 1996;Sutherland et al. 1989;Vogel et al. 2008a) patients often desire extensive information. Miller described two types of patient information seeking behaviours and preferences. 'Monitors' were information seekers who gained psychological benefit from information. 'Blunters' who were information avoiders who wanted to be shielded from pertinent diagnosis and treatment information.(Miller et al. 1988) Although information acquisition is a prerequisite for more active participation in decision making,(Bilodeau & Degner 1996;Blanchard, Labrecque, Ruckdeschel, & Blanchard 1988;Fridfinnsdottir 1997;Hack, Degner, & Dyck 1994) patients' information seeking behaviour does not necessarily correlate with their PDMS.(Blanchard, Labrecque, Ruckdeschel, & Blanchard 1988;Cassileth, Zupkis, Sutton-Smith, & March 1980;Cox et al. 2005;Davison, Degner, & Morgan 1995;Ende et al. 1989;Fallowfield 2008;Hack, Degner, & Dyck 1994;Strull, Lo, & Charles 1984;Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till 1989) Some seem to adopt it as a coping strategy rather than a prelude to more active participation in decision-making.(Blanchard, Labrecque, Ruckdeschel, & Blanchard 1988;Cassileth, Zupkis, Sutton-Smith, & March 1980;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Hack, Degner, & Dyck 1994;Miller, Brody, & Summerton 1988)

Some studies demonstrate certain patient demographics are associated with higher information needs; such as younger age(Cassileth, Zupkis, Sutton-Smith, & March 1980) higher education(Cassileth, Zupkis, Sutton-Smith, & March 1980;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004) and greater affluence.(Meredith, Symonds, Webster, Lamont, Pyper, Gillis, & Fallowfield 1996) There is a mixed picture regarding associations between information needs and severity of illness; some demonstrate a reduction with increased severity of illness, others fail to demonstrate an association.(Blanchard, Labrecque, Ruckdeschel, & Blanchard 1988;Davis, Hoffman, & Hsu 1999;Jenkins, Fallowfield, & Saul 2001)

Studies demonstrate that patients primarily want their information needs met verbally through communication with their treating clinicians.(Bilodeau & Degner 1996;Cassileth, Zupkis, Sutton-Smith, & March 1980;Meredith, Symonds, Webster, Lamont, Pyper, Gillis, & Fallowfield 1996) They also show clinicians often underestimate patients' information needs(Bruera, Willey, Palmer, & Rosales 2002;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Jones, Pearson, McGregor, Gilmour, Atkinson, Barrett, Cawsey, & McEwen 1999;Laine et al. 1996;Richards, Ramirez, Degner, Fallowfield, Maher, & Neuberger 1995;Strull, Lo, & Charles 1984;Suhonen et al. 2005) and that even when efforts are made to provide adequate information, patients' recall is impaired in life threatening situations.(Cimprich 1993;Hughes 1993) Information absorption is hindered when individuals are provided information they find difficult or unpleasant,(Butler and Hailey 1996) or when they are overwhelmed by the provision of an excess of statements in a single consultation.(Fallowfield 2000) Despite such potential barriers to patients' absorption and recall of information in situations like a new cancer diagnosis, the information patients do recall can persist and gain importance over time; patients quoting their clinicians verbatim.(Fallowfield 2000)

Despite the potential limitations of recall, the provision of treatment information is frequently limited to the time of diagnosis, as patients are unable to receive their diagnosis without some discussion of management and prognosis. To counter such barriers, Fallowfield proposed '...information needs to be given systematically, at the right time and via several different routes, to maximise the chances for patients to understand the implications and make really informed choices.'(Fallowfield 1997) The breast care nurse (BCN) role has been developed as an integral component of the breast cancer speciality clinical team in the UK, to facilitate the provision of information and support to patients following diagnosis. Much of their time is initially spent ensuring patients acquire sufficient information to participate in treatment decisions. As options and their complexity increase, this is likely to gain importance.

Clinicians can also benefit from awareness that patients' recall is better with information provided at the start of a consultation, and if it is related to topics or issues subjectively prioritised by the patient.(Fallowfield 2000)

## How patients' options are decided

National guidelines state the therapeutic options of UK patients diagnosed with breast cancer should be routinely discussed and decided at individual case level by Multi-Disciplinary Teams (MDTs). (Association of Breast Surgery at BASO 2009) Patients are provided options based on evidence-based treatment guidelines utilising cancer characteristics, patient characteristics and co-morbidities as variables. Guidelines are designed to be flexible, to optimise patient involvement in decision-making. In addition to cancer variables known to influence survival (i.e. cancer size), the anticipated aesthetic outcome of the options are considered: For instance, BCT for a 40mm diameter cancer might be anticipated aesthetically unfavourable in a small breast, which could influence the team/clinician's operative preference or recommendation.

Although groups of clinicians in the form of MDTs determine patients' options, the actual presentation of these is by individual clinicians. If presented with options, patients' decisions are based on their personal preferences and knowledge; much of which arises from discussion in consultations with their treating clinicians (doctors and nurses). Currently there is limited information on these consultations and how they influence patients treatment decisions. It is possible clinicians portray their own particular preferences in these consultations.

## What are clinicians' preferences for decision-making and treatment?

Studies suggest clinicians' preferences and recommendations are associated with cancer characteristics, patient characteristics and clinician characteristics. (Collins, Kerrigan, & Anglade 1999; Grilli, Scorpiglione, Nicolucci, Mainini, Penna, Mari, Belfiglio, & Liberati 1994; Liberati et al. 1987; McKinlay, Burns, Durante, Feldman, Freund, Harrow, Irish, Kasten, & Moskowitz 1997) However, limited information is available on clinicians' preferences; whether they hold specific treatment preferences which might influence their consultations. Most studies available are based on practice audits or clinicians' stated preferences to clinical vignettes. (Grilli, Scorpiglione, Nicolucci, Mainini, Penna, Mari, Belfiglio, & Liberati 1994; Liberati, Patterson, Biener, & McNeil 1987; McKinlay, Burns, Durante, Feldman, Freund, Harrow, Irish, Kasten, & Moskowitz 1997) These note variability in clinicians' preferences within this theoretical context, but deduce little else.

A large mixed methodology study of US breast clinicians (n=128) suggested considerable variation in clinicians' treatment recommendations, based on their responses to video

presentations of diagnostic scenarios. In these patient characteristics such as age, ethnicity, socio-economic status, assertiveness and medical comorbidities varied. Clinicians' recommendations were associated with their level of experience and medico-legal awareness.(McKinlay, Burns, Durante, Feldman, Freund, Harrow, Irish, Kasten, & Moskowitz 1997) The study however did not provide more information than this, and the design did not permit demonstration of whether such preferences were reflected in clinicians' actual practice patterns.

Many studies into clinician preferences were conducted among convenience samples rather than specialists in the field of interest.(Collins, Kerrigan, & Anglade 1999;Ende et al. 1990;Porter and McMulkin-Tait 2004) For example Collins et.al. conducted a survey among a convenience sample of 40 staff and resident surgeons in a single US hospital in 1998; the clinicians were not breast specialists and 26 of the 40 participants were male. They were asked to imagine they were diagnosed with breast cancer and 50% said they would have a mastectomy.(Collins, Kerrigan, & Anglade 1999) Such studies may be interesting and highlight a personal or clinician bias toward a particular treatment. However, as the sample of clinicians studied had no involvement in breast cancer treatment, any revealed preferences would be unlikely to impact on actual patient decision making. The findings are therefore of doubtful clinical relevance to understanding specialist clinicians' preferences and practice in the field of breast cancer.(Collins, Kerrigan, & Anglade 1999;McKinlay, Burns, Durante, Feldman, Freund, Harrow, Irish, Kasten, & Moskowitz 1997)

The hospital influence has been investigated, and a conflicting picture is seen regarding whether surgeons' years of experience and hospital unit itself affect treatment practice. Iscoe's large Canadian cohort study conducted in the early 1990s among 14,570 women newly diagnosed with breast cancer, demonstrated variation in MRs was not related to breast unit workload, patient age, presence of on-site adjuvant therapies or size of town in which treatment took place. The only factor strongly linked with practice patterns, was the individual hospital's existing practice.(Iscoe, Goel, Wu, Fehringer, Holowaty, & Naylor 1994) Comparing the surgical treatment of breast cancer in two Canadian provinces in 1991, Goel demonstrated statistically significant lower MRs among patients treated by more recently qualified surgeons or those with an academic affiliation.(Goel, Olivotto, Hislop, Sawka, Coldman, & Holowaty 1997;Porter & McMulkin-Tait 2004) These differences may reflect their conduct against a backdrop of changing medical evidence; the study was conducted around the time conclusive evidence was emerging of survival

equivalence with BCT and mastectomy. A few studies illustrate higher BCT rates among female surgeons. (Gilligan et al. 2007; Mandelblatt et al. 2001; Schou, Ekeberg, Ruland, & Karesen 2002)

Another issue to consider is how patients and clinicians might influence each other's behaviour in consultations and decision making. Krupat et.al. conducted a study among US doctors (n=128) viewing videotaped consultations with simulated breast cancer patients. Patients had identical clinical presentations but differed in assertiveness, socio-economic status, education and race. Clinicians' preferences varied with disadvantage and race, but moderately assertive behaviour by disadvantaged patient groups independently moderated clinician's behaviour to provide more careful diagnostic testing. (Krupat et al. 1999) The study was however conducted among a predominantly non-specialist group; only 25% having 'some' breast cancer practice in the preceding 5 years.

### **Communication is more than just words**

Communication is defined as the 'the imparting or exchanging of information by speaking, writing, or using some other medium' (Oxford English Dictionary). Mehrabain demonstrated that what is perceived from a communication interaction is more complex than this definition suggests. (Mehrabian 1972) The perception of the receiver of communication is not simply a duplication of the overt verbal articulation of the intended message. According to Mehrabain, the vocalised words of communication comprise only a small a component (7%) of a communicated message. The more substantial impacts on what the receiver perceives comes from the nonverbal elements of communication such as positive and negative reinforcing noises (the umms, ah-hahs) and tone of voice (38%), and body language (55%). He also demonstrated that inconsistencies between the verbal and nonverbal elements of communication, can result in confused interpretation of the articulated verbal message. (Mehrabian 1972)

## Doctor-patient communication and decision making approaches

Two broad clinician consultation styles are described in the literature; doctor-centred and patient-centred.(Coulter 1999;Coulter et al. 1999;Elwyn et al. 1999;Elwyn et al. 2000;Elwyn 2008;McWhinney 1989;Silverman et al. 1998) The patient-centred style encourages patient participation in the consultation, involves the provision of explanations in plain English and focuses on the impact of the disease on the individual patient. In contrast, doctor-centred communication focuses on disease pathology, adopts bio-medical language and tends to exclude non-disease factors that may be of importance to the patient. Studies demonstrate patient-centred consultation styles and tailored decision making are preferred by patients(Dowsett et al. 2000;Frederikson 1995;Lerman et al. 1993;Maguire 1999;Vick and Scott 1998) and associated with better patient psychological outcomes.(Griggs et al. 2007;Lerman, Daly, Walsh, Resch, Seay, Barsevick, Birenbaum, Heggan, & Martin 1993;Roberts et al. 1994)

There is also a recognised spectrum of decision making approaches. Various terms are used for these, but for the purposes of this study we use the terms paternalism, shared decision making and informed choice.(Charles, Whelan, & Gafni 1999a;Charles et al. 1999b;Charles et al. 2000;Coulter 1999;Coulter, Entwistle, & Gilbert 1999;Elit et al. 2003;Elwyn, Edwards, Gwyn, & Grol 1999;Elwyn, Gray, & Clarke 2000;Elwyn 2008;Gafni et al. 1998;McWhinney 1989;Silverman, Kurtz, & Draper 1998) Paternalism and informed choice lie at the 2 ends of the spectrum. In paternalistic decision making, consultations are primarily disease focused and clinicians assume the dominant role; making decisions for patients. At the other end of the spectrum is informed choice. In this patients are left without any guidance to make a purely autonomous decision, having been provided with what is considered 'sufficient' correct information. Just as paternalism uniformly assigns patients a passive role in decision making irrespective of their potential preferences, so the informed choice model uniformly assigns patients an active (but unsupported) role. Though these approaches suit some patients, their untailored application is not sensitive to patients' PDMS. Between these extremes lies shared decision making, which theoretically enables a more tailored approach. This may involve a number of consultations between patients and clinicians. Shared decision making comprises a two way exchange of information, a period of deliberation by the patient, interspersed with further discussions with their clinicians plus others. Following this, patients declare their decision, and patient and clinician agree and implement a mutually acceptable treatment plan. The three decision making approaches are outlined in figure 1.2.

FIGURE 1.2 Classic decision making approaches

Paternalism	Shared decision-making	Informed choice
<p>Bio-medical information</p> <p>Assumes patient passivity</p> <p>Professional assumes decision-making role</p> <p>Non-tailored</p>	<pre> graph TD     A["2 way information exchange Clinician Patient"] --&gt; B["Deliberation Clinician Patient Others"]     B --&gt; C["Declaration of preference Clinician Patient"]     C --&gt; D["Agreement"]     D --&gt; E["Implementation"]           </pre>	<p>Patient given 'sufficient' information to make a choice</p> <p>Professional withdraws from decision-making process</p> <p>Assumes patients' active role in decision making</p> <p>Tailored ?</p>

Adapted from 'What do we mean by partnership in making decisions about treatment?' Cathy Charles, Tim Whelan, Amiram Gafni BMJ 1999;319:780-782

UK guidelines regarding informed consent to medical treatment published by the DoH,(Department of Health 2001a;Department of Health 2001c;Department of Health 2009) Royal College of Surgeons on England(Royal College Of Surgeons Of England 2002) and GMC,(General Medical Council 2008) are most consistent with the patient-centred consultation style and shared decision making approach. Although there is an impetus to promote shared decision making in cancer management, there is currently limited literature exploring shared decision making specifically in acute crisis situations like breast cancer diagnosis consultations; where newly diagnosed often distressed patients, are asked to make a high stakes decision within a relatively short timeframe (often 1 to 2 weeks). Most studies to date reporting benefits associated with shared decision making have explored this in chronic stable disease contexts;

such as hypertension, diabetes and cardiovascular disease etc.(Charles, Gafni, & Whelan 1999b;Deber, Kraetschmer, & Irvine 1996;Deber, Kraetschmer, Urowitz, & Sharpe 2007;Quill and Brody 1996)

If presented with options, patients' decisions are based on their personal preferences and knowledge; much of which arises from discussion in consultations with the treating clinicians (doctors and nurses). Currently there is limited information on these consultations and how they influence patients' treatment decisions.

### **Who has the power in consultations?**

The issue of power and communication within consultations is complex. Although patient preferences are recognised to influence decision making, the influence of the treating clinician cannot be overlooked. The evidence suggests clinicians exert a powerful influence over patients' treatment decisions.(Gort et al. 2007;Johnson et al. 1996;Katz et al. 2001;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Morrow et al. 2009;Nold, Beamer, Helmer, & McBoyle 2000;Schou, Ekeberg, Ruland, & Karesen 2002;Smitt & Heltzel 1997)

In 1974 Lukes theorised the existence of complex power relationships guiding behaviour and decisions. He described three potential levels of power relationships.(Lukes 1974) Canter transposed Lukes' theory to the clinician-patient interaction in the healthcare setting. He suggested that first dimensional power involves clinicians blatantly controlling patients decisions or actions; second dimensional power involves clinicians' exerting their influence in a more subtle way by control agendas, deliberately steering interactions and subjugating patients through the provision of insufficient clinical time, poor ambience, poor listening skills etc. Canter suggests third dimensional power comprises clinicians exerting a more imperceptible influence; clinicians supply the medical knowledge underpinning patients' understanding and perceptions, they therefore control patients' actions and choices. He argues that suggests third dimensional power can be difficult to recognise as it is so pervasive and connected with widely held knowledge itself, that patients can falsely believe they are behaving autonomously.(Canter 2001)



This theory has not been specifically explored in the context of breast cancer. However the evidence suggests patients' decisions are influenced by clinicians' overt recommendations and patients' perceptions of their preferences,(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) along with their perception of treatments' curative potential.(Katz, Lantz, & Zemencuk 2001;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Smitt & Heltzel 1997) The practice audits and quantitative questionnaire studies reporting these findings, attribute a powerful influence to clinicians' preferences, but provide little detail of underlying factors or the mechanism of influence.

### **Why variation in breast cancer surgery is an important issue**

Though the incidence of breast cancer is been increasing, mortality rates are reducing(Blamey et al. 2007;Coleman et al. 1999;Coleman et al. 2004;Hack, Degner, Watson, & Sinha 2006;Mandelblatt et al. 2003;Office of National Statistics 2005;Rachet et al. 2009;Street, Jr. & Voigt 1997) and women are surviving longer following their diagnosis. Based on current predictions, 64% of UK women diagnosed with breast cancer at this time point will be alive at 20 years, compared with 44% diagnosed in the early 1990s.(Coleman, Babb, Damiecki, Grosclaude, Honjo, Jones, Knerer, Pitard, Quinn, Sloggett, & De Stavola 1999;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) Optimising patient experiences and QoL in survivorship are therefore crucial; as the physical and psycho-social impacts of cancer diagnosis and treatment have a more protracted effect. The evidence demonstrates patient inclusion in treatment decision making provides patients with short and long term psychological benefits.(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) Therefore the provision and support of this role would seem especially important in the surgical treatment of breast cancers where patient preferences for different treatments are known to vary,(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 no single treatment is associated with a definitively more favourable outcome, as is found in the treatment in a large proportion of breast cancers (those under 5cm diameter).(Blichert-Toft, Brincker, Andersen, Andersen, Axelsson, Mouridsen, Dombernowsky, Overgaard, Gadeberg, Knudsen, & . 1988;Clarke, Collins, Darby, Davies, Elphinstone, Evans, Godwin, Gray, Hicks, James, MacKinnon, McGale, McHugh, Peto, Taylor, & Wang 2005;Fisher, Anderson, Bryant, Margolese, Deutsch, Fisher, Jeong, & Wolmark 2002;Jacobson, Danforth, Cowan, d'Angelo, Steinberg, Pierce, Lippman, Lichter, Glatstein, & Okunieff 1995;Lichter, Lippman, Danforth, Jr., d'Angelo, Steinberg, deMoss, MacDonald, Reichert, Merino, Swain, & . 1992;Poggi, Danforth, Sciuto, Smith, Steinberg, Liewehr, Menard, Lippman, Lichter, & Altemus 2003;Sarrazin, Le, Arriagada, Contesso, Fontaine, Spielmann, Rochard, Le, & Lacour 1989;van Dongen, Voogd, Fentiman, Legrand, Sylvester, Tong, van der, Helle, van Zijl, & Bartelink 2000;Veronesi, Cascinelli, Mariani, Greco, Saccozzi, Luini, Aguilar, & Marubini 2002) Yet despite guidelines(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;Royal College Of Surgeons Of England 2002;Scarth, Cantin, & Levine 2002a;Scarth, Cantin, & Levine 2002b) and laws(Department of Health 2009;Nattinger, Hoffman, Shapiro, Gottlieb, & Goodwin 1996;Nayfield, Bongiovanni, Alciati, Fischer, & Bergner 1994) with a focus on providing choices where possible, there remains evidence of persistent highly variable practice among hospital breast units, with widely varying MRs.(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)

### The gap in knowledge

Although the medical literature contains much about the impact of patient factors on treatment 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) it is hard to imagine this can fully account for the differences in treatment patterns noted among patients treated by different hospitals breast units.(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) Clinicians and the breast unit or hospital have been demonstrated to exert a powerful influence on patient decisions and practice patterns.(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) However, little is currently known about the surgical treatment preferences of specialist breast clinicians or the extent to which individual clinicians' treatment preferences and consultation skills combine with the patient factors noted, to contribute to patients' decision-making in breast cancer. Furthermore, studies at the onset of this programme of research centred purely on doctors and did not include the specialist BCN group. The evolving role of the specialist BCN within the breast MDT, in educating, informing and supporting patients, makes the inclusion of this occupational group mandatory in any study of clinician influences on patients' treatment decisions.

## RESEARCH QUESTIONS

- To what extent does inter-unit variation in the surgical treatment of breast cancer persist after correction for case-mix?
- Do clinician preferences influence patients' decision making in breast cancer?
- How do clinicians influence patients' decision making in the light of treatment guidelines?
- How is patient satisfaction with the decision making experience influenced by the above?

An inductive process was employed to identify the characteristics of the decision making process influencing the 2 dependent variables; surgical decision and patient satisfaction with their decision.

### **Primary end points**

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

To identify whether the above, influences patient satisfaction with decision making.

## **STUDY AIM AND OBJECTIVES**

### **Aim**

To identify whether variation in the initial therapeutic treatment of breast cancer, suggested by UK NHSBSP reports, persists following correction for case-mix and caseload; and identify whether specialist breast clinicians (doctors and nurses) possess particular treatment preferences which impact on patient consultations, treatment decisions and therefore MRs.

### **Objectives**

- Identify whether inter-unit variation in the surgical treatment of breast cancer persists after correction for case-mix.
- Identify whether clinicians possess preferences which influence patients' decision-making in breast cancer, and in what way.
- Identify how clinicians influence patients' treatment decisions in the light of guidelines.
- Identify how patient satisfaction with the decision-making experience is influenced by the above.

## **Adaption of the original wording of study research questions & objectives**

At the outset of the study, the study's research questions and objectives were stated in language more consistent with a purely quantitative approach; incorporating the term 'extent'. These were modified as the project progressed, to more accurately reflect the more qualitative exploration of the issues conducted within this programme of research.

The original wording of the research questions and objectives are shown below:

### **Original research questions**

- To what extent does inter-unit variance in the surgical treatment of breast cancer persist after correction for case-mix?
- Do clinician preferences influence patients' decision making in breast cancer?
- To what extent do clinicians influence patients' decision making in the light of treatment guidelines?
- To what extent is patient satisfaction with the decision making process influenced by the above?

### **Original research objectives**

- Identify whether inter-unit variation in the surgical treatment of breast cancer persists after correction for case-mix.
- Identify whether clinicians' preferences influence patients' decision-making in breast cancer, and in what way.
- Identify the extent of clinicians influence on patients' decision-making in the light of treatment guidelines.
- Identify the extent to which patient satisfaction with the decision-making experience is influenced by the above.

## STUDY OUTLINE

This thesis first explores whether breast unit case-mix and caseload explain variation in hospital breast unit MRs in a large UK region. It then goes on to investigate persistent MR variation from key stakeholder perspectives (patient, specialist doctor and BCN) employing a combination of quantitative and qualitative methodologies; including a Discrete Choice Experiment (DCE) among all the regions' breast units to investigate clinician preferences. In three units with confirmed high, medium and low MR practice, validated questionnaires are used to explore patients' roles and preferences for decision involvement using an information needs and decision making questionnaire (IDMQ), and patient and clinician beliefs, preferences and interactions are explored using one to one semi-structured interviews. Figure 1.3 outlines the study components.

## STEERING GROUP

Steering group meetings were held three times a year over the period of study design and recruitment. The members comprised nine individuals with multidisciplinary skills:

- Two surgeons: Miss Lisa Caldon (LC) and Professor Malcolm Reed (MWR)
- Two qualitative researchers: Dr Karen Collins (KC), Mr David Wilde (DW)
- Two health services researchers: Professor Sam Ahmedzai (SA) and Dr Bill Noble (BN)
- A statistician: Professor Stephen Walters (SW)
- And two consumer representatives: Mrs Hazel Marshall-Cork (HMC) and Mrs Gillian Speed (GS).

## PROJECT DEVELOPMENT

The programme of research was developed by LC and MWR, utilising the expertise of steering group members and others to develop specific components of the study: SA and BN (interviews); Dr Tony Stevens (interviews and patient questionnaire); SW (observational audit, DCE, patient

questionnaire); Professor John Brazier (DCE); Professor Chris McManus (psychological scales within the clinician questionnaire).

## CONSUMER INVOLVEMENT

This research study was developed with the assistance of two consumer representatives from the North Trent Cancer Research Network Consumer Research Panel, HMC and GS. In addition to reviewing and advising on the study design, individual components and documents, they participated in the early phase of thematic data analysis of the qualitative aspect of the study.

## SAMPLE

The study was conducted in the Trent region of the UK, which until recently was one of the eight National Health Service regions of England and Wales. Situated geographically in the centre and east of England, it has a population of around 5 million, approximately 2,500,000 women. (Office for National Statistics 2003) At the time of study design, Trent had one of the consistently highest overall NHSBSP detected MRs of the UK regions. Over the 3 year period between 1997/8 and 1999/2000 the regions' NHSBSP reports demonstrated a fall in the regions' median MR (from 45% to 33% respectively) to approach the National median (30%). However, significant inter-unit variation remained (21% to 46% in 1999/2000). This pattern of inter-unit treatment variation demonstrated within the region reflected the level of variation observed at National level in NHSBSP reports over the same time period.

## STUDY COMPONENTS

The regions' specialist breast surgery practice was comprised of 14 NHS hospital breast units and 11 NHSBSP screening units; some screening units covering the geographic area of two hospital breast units. The 14 breast NHS units possessed similar routine practice guidelines and had



similar access to radiotherapy and breast reconstruction. Samples depended on the specific component of the programme of research (see Figure 1.3 and table 1.1):

- The observational audit sample comprised all National Health Service Breast Screening Programme (NHSBSP) detected breast cancers detected within the Trent region between April 1997 and April 2002 (n=5060).
- The DCE sample comprised all permanent specialist members of the Trent breast units (doctors and nurses) n=98.
- The clinician interview, and patient questionnaire and interview samples were recruited from three purposively selected hospital breast units reflecting the range of residual treatment variation following case-mix correction; high medium and low MR practice. The clinician interview sample represented all permanent members of the three breast units' teams. Patients were purposively identified by their specialist clinicians as having been offered a choice of initial therapeutic treatment (BCT and mastectomy). A self-selected subgroup of patients recruited to the questionnaire phase agreed to participate in semi-structured interviews.

## ETHICS AND RESEARCH GOVERNANCE

The study is Multi-centre Research Ethics (MREC) approved (Trent MREC/02/4/114), and underwent Local Research Ethics (LREC) and Research Governance approval in all participating NHS Trusts. LREC approval was granted under the clause 'No local researcher guidelines, and therefore does not require LREC approval' for the breast units purely participating in the clinician aspects of the research study. The LREC & Research governance reference numbers and approval dates are found in appendix 1.

## FUNDING

This programme of research was funded by Cancer Research UK and the Royal College of Surgeons of England, through the award of research training Fellowships. The Royal College of

Surgeons of England part co-funded the observational audit and clinicians' Discrete Choice Experiment. Cancer Research UK funded the remainder of the study.

#### DISCLAIMERS

Cancer Research UK and the Royal College of Surgeons of England played no role in study design; collection, analysis or interpretation of the data; or the preparation of the thesis. The views expressed are those of LC and not necessarily those of Cancer Research UK and the Royal College of Surgeons of England.

FIGURE 1.3 Study components

Location	Method	Sample	Perspective	No.	Analysis	Objective
<b>All 11 Trent Breast screening units</b>	Observational audit	All primary breast cancers diagnosed April 1997 to April 2003 by the Trent NHSBSP	Breast cancer treatment data	n=5060	Logistic regression	Confirm whether MRs remain variable after correction for case-mix at individual level and identify 3 units representing the spectrum of MRs for additional study
<b>All 14 Trent Hospital breast units</b>	Discrete Choice Experiment survey (and psychological scales)	All permanent specialist clinicians (nurses and doctors) from the Trent region	Clinician s (nurses and doctors)	n=68/93	Multinomial (polytomous) Logistic Regression	Investigate potential clinician treatment preferences (doctors & BCNs) and influencing factors. Investigate whether psychological scale responses correlate with preferences.
<b>3 breast units representing practice variation; with high, medium and low case-mix adjusted MRs</b>	Semi-structured interviews	All permanent specialist breast clinicians	specialist breast clinicians (nurses and doctors)	n=26/32 13 BCN 13 doctors	The Framework approach	Identify associations /discrepancies in subjective perception of the consultation process and patient decision-making. Identify key factors influencing patients' treatment decisions and unit MR
	Semi-structured interviews	All patients identified as able to consent to a research study and provided with a choice of initial therapeutic treatment by their breast unit.	Patients	n=65		
	Information needs & decision making questionnaire (IDMQ)		Patients	n=356/697	Frequency, Chi-square, One way ANOVA	Identify at breast unit level in Trent, whether the DMS of patients in high medium and low MR units are uniform or not. Recruit to interview phase of section

TABLE 1.1 Patient and clinician recruitment by breast unit

	Low MR unit (Unit 3)					Medium MR unit (Unit 4)					High MR unit (Unit 10)				
	Target	Appr.	Recr.	Compl.	% of Target Compl.	Target	Appr.	Recr.	Compl.	% of Target Compl.	Target	Appr.	Recr.	Compl.	% of Target Compl.
Clinician survey	17	17	14	14	82%	4	4	4	4	100%	7	7	7	7	100
Clinician interview	17	17	14	14	82%	4	4	4	4	100%	7	7	7	7	100
Patient Questionnaire	100	242	120	113	113%	100	167	88	86	86%	100	288	165	157	157%
Agreed to interview			96					60					116		
Patient interview	20		20	20	100%	20			20	100%	20			25	125%
Overall study patient recruitment figures 697 approached, 373 agreed to participate, 356 returned completed questionnaires Appr. = approached, Recr.= recruited. Compl. = completed															

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## Chapter 2

### Case-mix adjustment audit

**Case-mix fails to explain variation in mastectomy rates:  
management of screen-detected breast cancer in a UK region  
1997-2003**

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## ABSTRACT

**Background** Wide variation in the surgical management of breast cancer exists at hospital, regional, national and international level. To demonstrate whether variation in surgical practice observed at aggregate level between breast units persists following adjustment for case-mix, individual patient-level data from the Trent Breast Screening Programme Quality Assurance database (1997-2003) was analysed.

**Method** Expected case-mix adjusted MRs were derived by logistic regression using the variables cancer size, site and grade, patient age and year of presentation, employing the region's overall case-mix adjusted practice as the reference population.

**Findings** The region's 11 breast screening units detected 5109 (3989 invasive) surgically managed primary breast cancers over the six year period. 1828 mastectomies were performed (MR 35.8%, 95% Confidence Interval: 34.5% - 37.1%). Significant variation in MRs observed between units (range 25% - 45%,  $p < 0.0001$ ), persisted following case-mix adjustment ( $p < 0.0001$ ). Two-fold variation in observed to expected unit MR coefficient is demonstrated overall (range 0.66 - 1.36), increasing to almost four-fold in cancers less than 15mm diameter (range 0.55 - 1.95).

**Conclusion** Significant variation in surgery for screen-detected primary breast cancer is not explained by case-mix. Further research is required to investigate potential patient and clinician causative factors.

## BACKGROUND

Variation in the surgical management of early breast cancer is widespread (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; Money Penny 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) and viewed as an inequality in healthcare. It has been highlighted in DoH documents as a reflection of a 'postcode lottery' of care. (Department of Health 2000; Department of Health 2001b) The adoption of mastectomy to BCT ratios as performance indicators of breast unit practice have been suggested to discourage variation. (Department of Health 2001b) However, most previously published studies highlighting variation base their conclusions on aggregated data analysis; amalgamating case characteristics across units or hospitals. Utilising raw treatment rates or combining cases in this way, they fail to account for the case-mix of individual units and provide a potentially misleading impression of practice; especially among small units.

Until recently, Trent was one of the eight NHS regions of England and Wales. Situated geographically in the centre and east of England it has a population of around 5 million, with approximately 2,500,000 females. (Office for National Statistics 2003) The UK NHSBSP was established in 1988. At the time of the study it invited all women aged 50 to 64 to attend for routine three yearly mammography. The eligible screening population in Trent was 441,000.

National and regional guidelines exist for the management of breast cancer in the UK now, but at the time of the study no national guidelines existed and each unit possessed their own set. These were designed to be permissive; their content and wording intended to facilitate optimal collaboration between patients and their clinicians in decision-making. Mastectomy was indicated where patient safety would be compromised by less extensive surgery; for example

where the cancer is large (usually over 4-5cm diameter), multi-focal (multiple areas in more than one quadrant of the breast), or where contraindications to radiotherapy exist which would compromise disease control and survival with BCT. Relative indications for mastectomy were lobular cancer, multi-centric cancer (multiple areas within a single quadrant of the breast), central cancer, BCT likely to result in an un-acceptable aesthetic outcome, and BCT where radiotherapy is likely to be associated with un-acceptably high complication risks. Guidelines also state patient preference is an indication for mastectomy, and larger cancers can undergo BCT when cancer to breast size ratio permits an acceptable aesthetic outcome and survival and local recurrence risks are understood and accepted.

The aim of this component of the study was to demonstrate whether variation in surgical practice observed at aggregate level between units over the Trent region in screen detected and symptomatic primary breast cancers, (School of Health and Related Research 1998) persisted following adjustment for the characteristics of cases managed by the individual units.

## METHODS

This observational study analysed QA data collected by the Trent Breast Screening Programme on women diagnosed with breast cancer as part of the UK NHSBSP between April 1997 and April 2003. These databases are an established part of the QA process of the NHSBSP, contain externally validated data and demonstrate high quality. Individual patient-level data from the database was anonymised prior to conversion into an SPSS data file. The password-protected database and outputs were stored securely.

Since the main outcome of treatment data was binary, i.e. whether or not the woman had a mastectomy, multiple logistic regression with SPSS for windows version 12.0 was employed to analyse the dataset at individual patient level to confirm whether observed unit level variations persisted following adjustment for case-mix (cancer size, site, patient age) and year of treatment. For the purposes of this study, maximum cancer size was defined as the greatest recorded diameter (invasive or non-invasive) where cancers comprised both invasive and non-invasive components. Year of treatment was included as a variable to reflect changes in evidence-based practice over time. Age, maximum cancer size and year of diagnosis were treated as continuous



covariates. Cancer grade was categorised into invasive grade 1, 2 and 3, and non-invasive. Cancer site was grouped into central and non-central.

Applying the logistic model at an individual patient level using Trent as the reference population, the individuals' probability of undergoing a mastectomy within the region was calculated given their clinical covariates. Expected individual screening unit MRs were calculated by the summation of individual patient-level probabilities of undergoing a mastectomy across that particular unit. The ratio of observed to expected mastectomies for each breast screening unit were then calculated for each breast unit. Observed to expected ratios above 1.0 suggest that after adjustment for case-mix, the unit has a higher than expected MR compared to the average (using overall case-mix adjusted practice in Trent as the reference population). Conversely, observed to expected ratios below 1.0 suggest a lower than expected MR compared to the average.

Case-mix adjustment was performed twice. The first analysis incorporated the variables cancer size, cancer site, patient age and year of screening. The second included cancer grade in addition. The first analysis reflects information uniformly available prior to surgical decision-making in all the region's units, and thus the variables upon which operative options are based. Cancer grade is documented pre-operatively in a proportion of cases, and if known, may influence guideline-based treatment decision-making in certain units.

## **FINDINGS**

During the period April 1997 to April 2003, 792,570 women were screened by Trent's 11 Breast Screening Units, incorporating 13 static sites and 9 mobile diagnostic units. Over the six-year period 5179 primary breast cancers were diagnosed through the programme, 5109 (3989 invasive) were managed surgically, 70 did not undergo surgery. Advanced disease or 'other clinical factors' were stated as the reason for not undergoing surgery in the majority of cases. These cases were distributed evenly over the region's units ( $p = 0.50$ ).

Breast units' performance over the six-year period was aggregated. Annual fluctuations were inherent within most services.

Table 2.1 describes the characteristics of the cancers detected by the Trent Breast Screening Program over the six-year period. Between 1997 and 2003, 1828 mastectomies were performed, giving an overall Trent region MR of 35.8% (95% CI: 34.5 to 37.1%).

TABLE 2.1 Clinical characteristics of Trent Breast Screening Program Quality Assurance database patients 1997 - 2003 (n=5109)

	Cases (n)	Mean	Median	SD	Min	Max
<b>Age at diagnosis (years)</b>	5109	59.1	58.8	6.2	45.3	95.0
<b>Maximum cancer size (mm)</b>	5062	18.5	15.0	14.3	0.5	220.0
	n					%
<b>Financial Year</b>	1997/1998				652	12.8
	1998/1999				802	15.7
	1999/2000				799	15.6
	2000/2001				917	17.9
	2001/2002				866	17.0
	2002/2003				1073	21.0
	<b>Total (n)</b>				<b>5109</b>	<b>100</b>
<b>Overall type of surgery</b>	BCT				3281	64.2
	Mastectomy				1828	35.8
	<b>Total (n)</b>				<b>5109</b>	<b>100</b>
<b>Invasive status</b>	Invasive & mixed				3989	78.1
	Non-invasive only				1120	21.9
	<b>Total (n)</b>				<b>5109</b>	<b>100</b>
<b>Cancer size (mm)</b>	<15				2329	46.0
	≥15-<20				995	19.7
	≥20-<30				1060	20.9
	≥30-<50				480	9.5
	≥50				198	3.9
	<b>Total (n)</b>				<b>5062</b>	<b>100</b>
<b>Cancer site</b>	Central/nipple region				288	5.6
	Non-central				4818	94.5
	<b>Total (n)</b>				<b>5106</b>	<b>100</b>
<b>Cancer grade</b>	Non invasive				1120	22.2
	Invasive grade 1				1209	23.9
	Invasive grade 2				1870	37.0
	Invasive grade 3				854	16.9
	<b>Total (n)</b>				<b>5053</b>	<b>100</b>

Table 2.2 and figure 2.1 illustrate observed unit MRs and those expected following case-mix adjustments for all cancers (n=5060). Table 2 presents the absolute values. Significant variation in MRs is illustrated across the 11 units, with individual unit MRs ranging from 25% to 45% ( $p < 0.0001$ ). Expected rates derived by logistic regression, using the region's overall case-mix adjusted practice as the reference population, demonstrate a two-fold variation in ratio of observed to expected unit MR (range 0.66 to 1.36). Units 6 and 10 demonstrate statistically significant lower (34%) and higher (36%) than expected rates respectively. In addition Unit 4 exhibits a 13% higher observed to expected MR ratio, though this just fails to reach statistical significance as the lower 95% confidence interval (CI) is exactly 1.00.

Figure 2.1 presents the same data graphically as a box and whiskers plot. The observed: expected ratios of the 11 individual breast screening units are represented by the boxes and the whiskers represent the 95% CI. Boxes located on  $y=1.0$  line demonstrate observed MR equalling that expected by the unit's case-mix (based on the overall practice of the Trent region). Boxes located above the  $y=1.0$  line demonstrate MRs higher than expected for the case-mix, and boxes below  $y=1.0$  line represent lower than expected MRs for the case-mix. Whiskers which do not traverse the  $y=1.0$  line are statistically significant. From this graphical presentation it can be seen that two hospitals have statistically significantly high and low MRs.

When case-mix data analysis was repeated including the cancer grade variable, 105/5109 (2%) cases were excluded due to missing or incomplete data. Comparison of the results of the two forms of data analysis revealed no difference in the ratio of observed to expected unit MRs when case-mix adjustment included or excluded cancer grade as a variable. Thus the observed variation in MRs across the 11 screening units demonstrated in Trent cannot be accounted for by cancer size, site or grade, patient age or year of screening.

TABLE 2.2 Observed vs. Expected MR by screening unit 1997-2003: All cancers

Unit	Total cancers (n)	Observed (O) Mx (n)	Observed (O) MR (%)	Expected (E) Mx (n)	Ratio O/E	(95% CI)
1	209	89	42.6	77	1.15	(0.93 - 1.42)
2	310	106	34.2	114	0.93	(0.76 - 1.12)
3	415	159	38.3	138	1.15	(0.98 - 1.35)
4	723	250	34.6	221	1.13	(1.00 - 1.28)
5	367	148	40.3	139	1.06	(0.90 - 1.25)
6	840	213	25.4	321	0.66	(0.58 - 0.76)
7	345	118	34.2	124	0.95	(0.79 - 1.14)
8	253	94	37.2	79	1.19	(0.96 - 1.46)
9	916	390	42.6	367	1.06	(0.96 - 1.17)
10	235	106	45.1	78	1.36	(1.11 - 1.64)
11	447	140	31.3	155	0.90	(0.76 - 1.06)
Trent	5060	1813	35.8	1813	1.00	
<p>The expected numbers at each Breast Screening Unit are based on adjusting each unit's case-mix for age, cancer site, cancer size, year of screening.</p> <p>49 patients excluded due to missing data.</p> <p>Observed MR range 25-45%</p> <p>Mx = mastectomy</p>						

FIGURE 2.1 Observed: Expected MRs all Trent NHSBSP all cancers 1997-2003

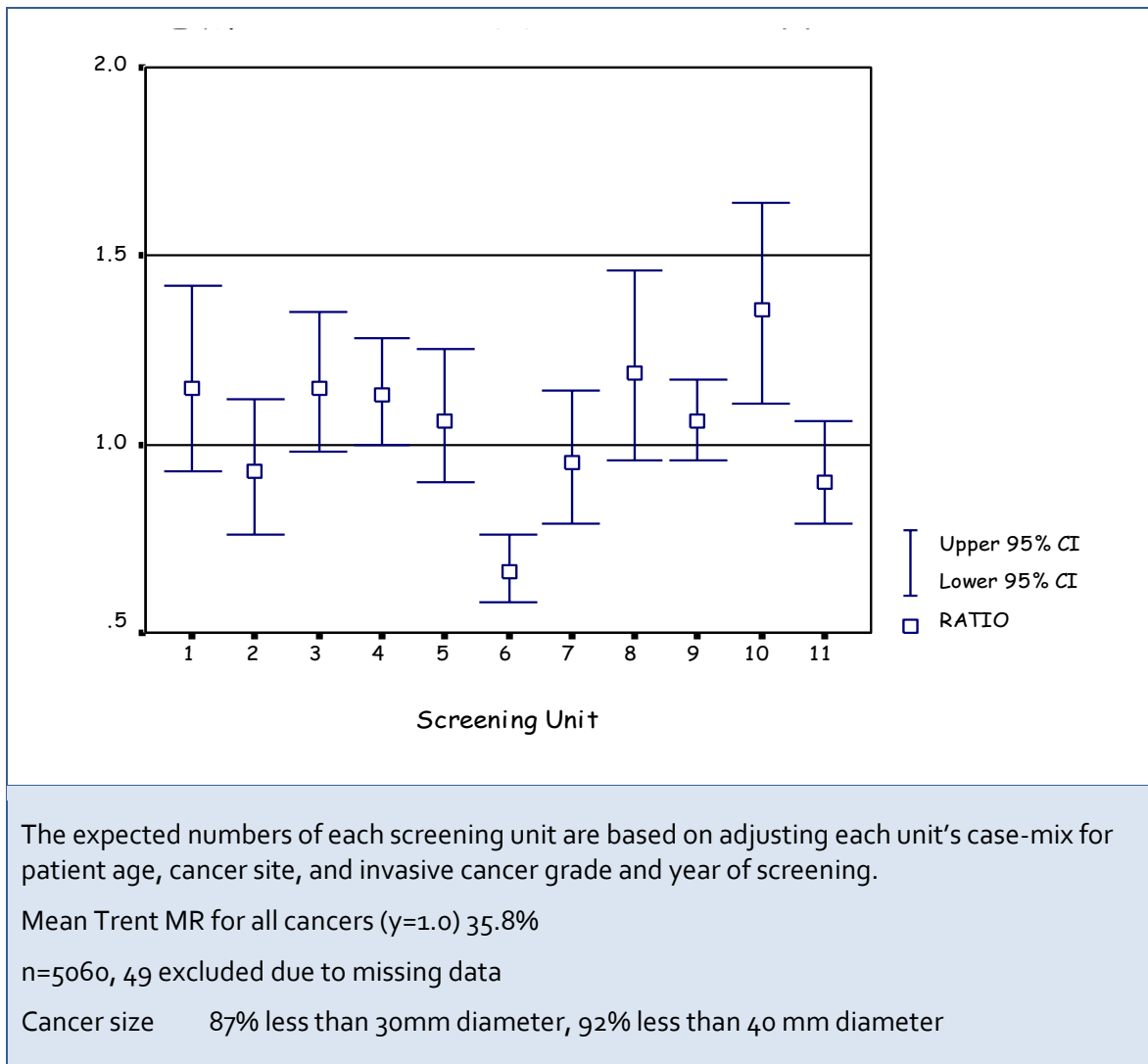
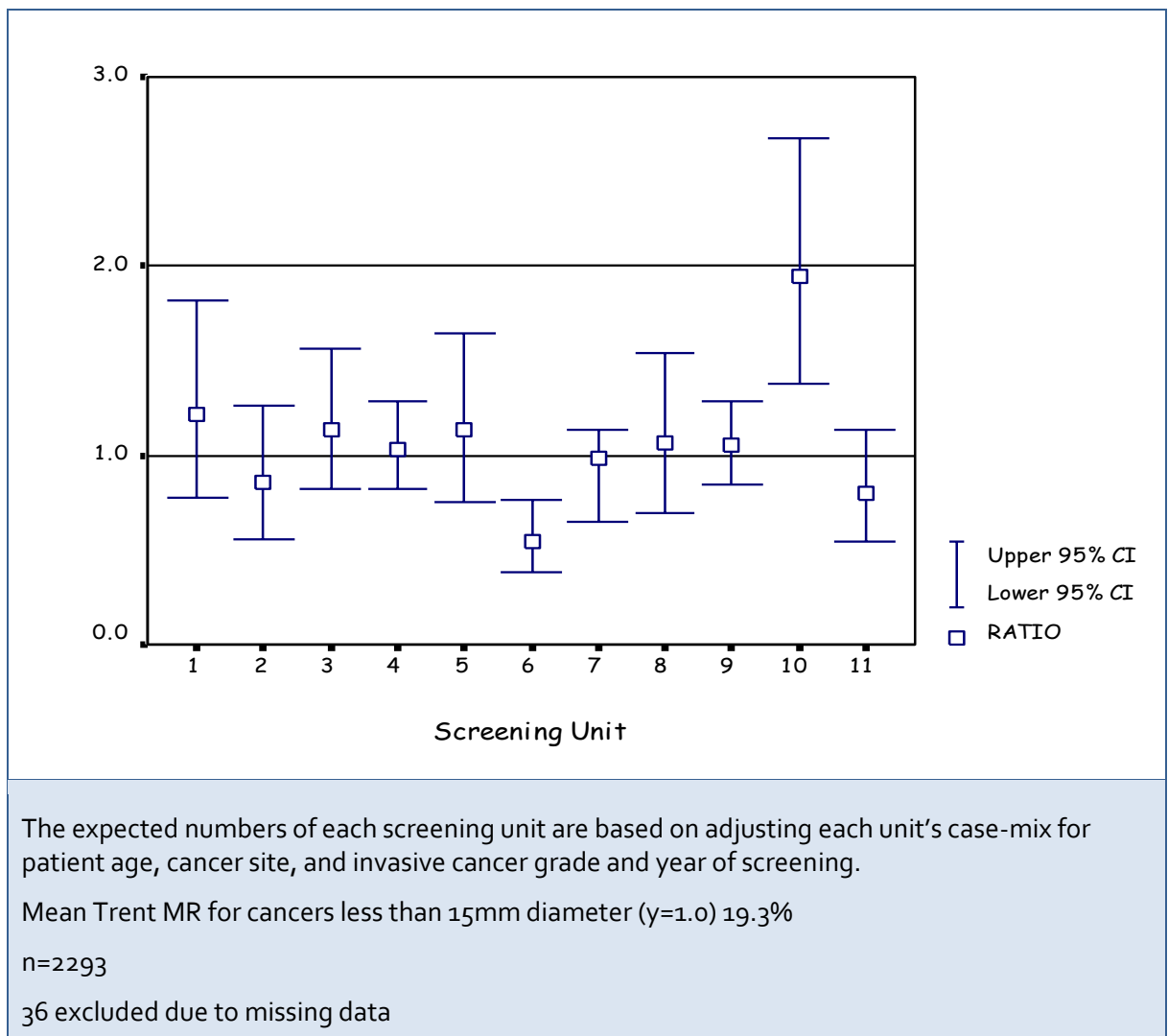


TABLE 2.3 Observed vs. Expected MR by screening unit 1997-2003: Cancers < 15mm diameter

Unit	Total cancers (n)	Observed (O) Mx (n)	Observed (O) MR (%)	Expected (E) Mx (n)	Ratio O/E	(95% CI)
1	96	24	25.0	20	1.22	(0.78 - 1.82)
2	148	26	17.6	30	0.86	(0.56 - 1.26)
3	192	40	20.8	35	1.14	(0.82 - 1.56)
4	417	82	19.7	79	1.03	(0.82 - 1.28)
5	136	28	20.6	25	1.13	(0.75 - 1.64)
6	323	33	10.2	60	0.55	(0.38 - 0.77)
7	142	27	19.0	27	0.99	(0.65 - 1.14)
8	131	27	20.6	26	1.06	(0.70 - 1.54)
9	405	87	21.5	83	1.05	(0.84 - 1.29)
10	111	38	34.2	20	1.95	(1.38 - 2.67)
11	192	30	15.6	37	0.80	(0.54 - 1.14)
<b>Trent</b>	<b>2293</b>	<b>442</b>	<b>19.3</b>	<b>442</b>	<b>1.00</b>	
<p>The expected numbers at each Breast Screening Unit are based on adjusting each unit's case-mix for age, cancer site, cancer grade and year of screening.</p> <p>36 patients excluded due to missing data.</p> <p>Mx = mastectomy</p>						

Forty-six percent (2329/5062) of patients had small cancers (less than 15mm diameter). The overall MR in this sub-group was 19.3% (442/2293); 95% CI: 17.9 to 21.1%, and practice again varied significantly ( $p < 0.0001$ ) across the 11 units (MR 10% to 35%). Within this sub-group, an almost four-fold variation in observed: expected MR ratio between breast units was demonstrated (range 0.55 to 1.95). Although in this sub-group of very small cancers, the majority of breast screening units' observed MRs were closer to those expected than was demonstrated in the analysis of all cancers. Table 2.3 and Figure 2.2 demonstrate variation in MRs for small (less than 15mm diameter) cancers.

FIGURE 2.2 Observed: expected MRs all Trent NHSBSP cancers < 15mm diameter 1997-2003



## DISCUSSION

The strength of this component of the study lies in the analysis of a high quality externally validated database, and the analysis of patient data at an individual level. By correcting for case-mix and comparing observed and case-mix adjusted MRs, a unit's MR is effectively adjusted for any variation in the type of cases presenting to them. To our knowledge this is the first study of this type demonstrating persistent breast cancer surgical treatment variation. The study

demonstrates 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 variation in treatment observed.

The conclusions drawn from this study are based purely on breast cancers detected by the breast screening programme and do not include those diagnosed through the symptomatic breast service. Thus the data analysis only accurately reflects unit practice in the screen-detected subgroup, where the majority of women (82%) are aged 50 to 64 and have relatively small cancers.(BCCOM Steering Group 2007) Although this study does not present information on the non-screen-detected breast cancer population, it is probable that symptomatic and screening practice is similar, as patients are treated by the same team of surgeons and BCNs. However, there is a possibility that the inter-unit variation in MR demonstrated by this study may be atypical of women with breast cancer; reflecting variability only within the screened subgroup. However a study performed at a similar time, highlighted a comparable pattern of treatment variation at breast unit level among cancers presenting to the UK symptomatic breast service.(Moneypenny 2004;NHS Cancer Screening Programmes and Association of Surgeons at BASO 2004;Sauven, Bishop, Patnick, Walton, Wheeler, & Lawrence 2003) The Moneypenny study included only those cancers presenting symptomatically over a 6 or 12 month period (financial year 2001 to 2002), to 85 UK breast units (n=7750 cases primarily surgically treated). The study presents raw uncorrected MR data with a MR range of 19 and 100%. Over the group, higher MRs were noted among larger cancers, but no correction for case-mix was performed.

For completeness, further research is ideally needed to determine whether or not unit variation exists in the non-screen-detected population. The acquisition of this type of high quality and comprehensive data is however a problem. Currently there is no national requirement to collect such detailed data on cancer and patient characteristics and treatment. Therefore breast unit databases containing this type of data are extremely variable in both their data fields and completeness; making such analyses difficult, if not impossible.

There are several potential limitations to this type of study and analysis. One is the use of an inappropriate data set with large amounts of missing data. We believe the study described uses robust data; the data has been rigorously audited by the QA service and validated both externally and by the surgeons of the originating breast units. In areas audited by the study the data was



98% complete; 109 cases (2%) were excluded from the analysis due to missing or incomplete data.

Overall cancer size used in the analysis performed was determined histologically, rather than being the radiological cancer size. Evidence suggests histological size and radiological cancer size correlate well, with good reliability of radiological assessment of cancer size based on ultrasound and mammography.(Pain et al. 1992) It is recognised however that the treatment decision would have been based on the radiological cancer size, and that the use of histological cancer size has the potential to over or under represent this.

The present study employed overall Trent screen-detected breast cancer population (1997-2003) as the reference population. An argument could be made that the reference population should be the overall treated UK NHSBSP population. This would require access to individual level data of the entire treated UK screen-detected population, and though the absolute level of observed to expected coefficients may have altered, the degree of variation between units' coefficients would not.

Another potential limitation of the study is that observations are based on the data of a single UK region. Trent as a region and its units may be atypical of other UK regions and their units. There is however evidence that such MR variation occurs throughout the UK at both regional and unit level, and in both symptomatic and screen-detected practice,(Association of Breast Surgery at BASO 2005;Association of Breast Surgery at BASO 2009;Money Penny 2004;Sauven, Bishop, Patnick, Walton, Wheeler, & Lawrence 2003;School of Health and Related Research 1998) to a similar degree as that identified in Trent. These are explored in the discussion.

It could be argued that the study concentrated on a small number of cancer characteristics and patient's age. Screening year was included as a proxy for time changes in evidence-based practice. It is recognised that clinical factors other than those included in the study's case-mix adjustment analysis, could fully or partially explain the pattern of treatment variation observed. The variables included within this analysis were chosen to reflect information which is routinely available at the time of treatment decision-making. The analysis performed was based purely on the information contained within an existing database; patients were not contacted for the purposes of this study. Therefore other variables of interest which were not recorded on the database were not available for inclusion in the analysis. Other variables of interest would include

cancer to breast size ratio, radiological cancer size, and patient information such as educational level, family income and decision-making style. Data such as postcode could have provided a surrogate measure of socio-economic profile and permit assessment of whether distance of patient's home to radiotherapy treatment centre influences treatment rates. This information was however not available due to issues of confidentiality and the requirement for the data to be anonymised at source.

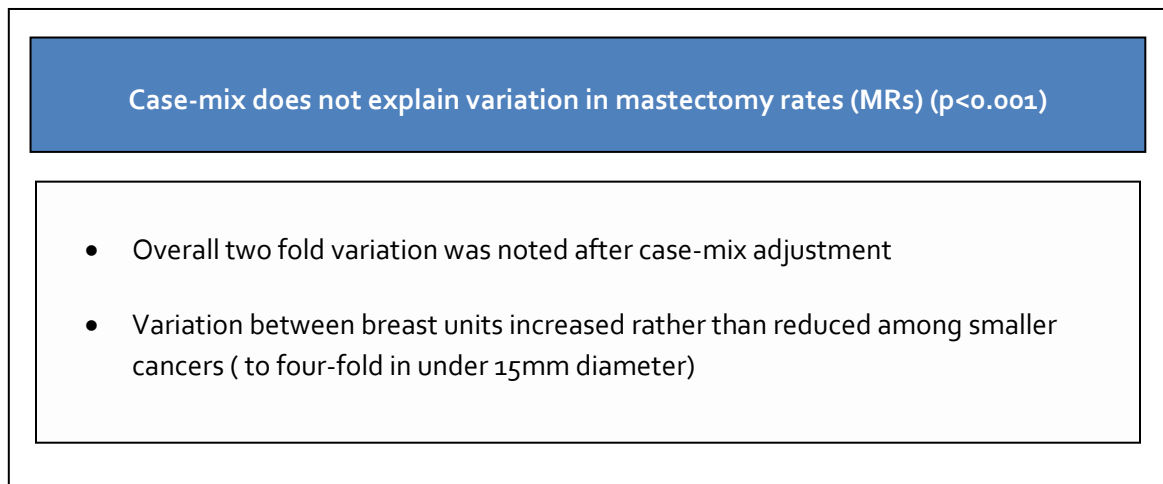
The study was conducted on a screen-detected population where approximately 87% of the women diagnosed with primary breast cancer had cancers less than 30mm diameter. On the basis of cancer size alone, the majority of women in this group were eligible for a choice of treatment. Within the sub-group with small cancers (total cancer size less than 15mm diameter) there is an almost four-fold variation in observed to expected coefficients following case-mix adjustment. This finding is concordant with data from another UK study by Sauven et.al. illustrating a similar degree of variation in treatment at regional level in the UK in the screen-detected sub-group with small cancers.(Sauven, Bishop, Patnick, Walton, Wheeler, & Lawrence 2003) The Sauven study however failed to adjust for case-mix.

## CONCLUSION

Using a robust, externally validated dataset, this study demonstrates the existence of statistically significant treatment variation in the surgical management of early stage breast cancer among this UK region's breast screening practice. Variation in observed to expected unit MR coefficient was two-fold overall (range 0.66-1.36) and increased to four-fold among very small cancers of less than 15mm diameter (range 0.55-1.95). The study conclusively demonstrates that case-mix can be excluded as a causative factor.

The explanation of wide variation in MRs remains unclear from both this component of the study and the available literature. Further research is required to investigate the other potential influences over the choice of breast cancer surgery. The other components of this study seek to elucidate the reasons for variation in the surgical treatment breast cancer from both the patient and clinician's (specialist doctor and nurse) perspectives.

FIGURE 2.3 Summary of case-mix audit findings



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## Chapter 3

### Clinician Survey

**What influences clinicians' operative preferences for women with breast cancer? An application of the discrete choice experiment and psychological profiling of specialist clinicians**

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## ABSTRACT

**Background** Little is known regarding cancer clinicians' treatment preferences. The aim of this study was to determine the impact of pre-operative variables over specialist breast clinicians' operative preferences using discrete choice experiment methodology.

**Methods** Cross-sectional survey of operative preferences to hypothetical scenarios based on; patient age, bra cup size, cancer size, site and centrality.

**Results** 73% response rate (68/93). Multinomial logistic regression was used to analyse data across scenarios (n=1,695) with allowance for response clustering, comparing equal preference for mastectomy and BCT, with preference for mastectomy or BCT. Increasing patient age, cancer size, central site, multi-centrality and reducing cup size, were all associated with preference for mastectomy, over equal preference, over BCT ( $p<0.001$ ). Doctors preferred specific treatments, females and nurses avoided mastectomy ( $p=0.015$  and  $p<0.001$  respectively).

**Conclusions** Clinician preferences were predominantly treatment guideline congruent, but significantly influenced by patient age, clinician gender and occupation. This methodology is capable of elucidating treatment preferences and could be applied elsewhere where treatment options and practice variability exist.

## BACKGROUND

In the UK, the appropriateness of therapeutic surgical options are routinely discussed and decided individual case level within MDT meetings.(Association of Breast Surgery at BASO 2009) Decisions about which to offer are based primary cancer characteristics, patient co-morbidity and evidence-based treatment guidelines. In addition to cancer variables known to influence survival, i.e. cancer size,(Blichert-Toft, Brincker, Andersen, Andersen, Axelsson, Mouridsen, Dombernowsky, Overgaard, Gadeberg, Knudsen, & . 1988;Clarke, Collins, Darby, Davies, Elphinstone, Evans, Godwin, Gray, Hicks, James, MacKinnon, McGale, McHugh, Peto, Taylor, & Wang 2005;Fisher, Anderson, Bryant, Margolese, Deutsch, Fisher, Jeong, & Wolmark 2002;Jacobson, Danforth, Cowan, d'Angelo, Steinberg, Pierce, Lippman, Lichter, Glatstein, & Okunieff 1995;Lichter, Lippman, Danforth, Jr., d'Angelo, Steinberg, deMoss, MacDonald, Reichert, Merino, Swain, & . 1992;Poggi, Danforth, Sciuto, Smith, Steinberg, Liewehr, Menard, Lippman, Lichter, & Altemus 2003;Sarrazin, Le, Arriagada, Contesso, Fontaine, Spielmann, Rochard, Le, & Lacour 1989;van Dongen, Voogd, Fentiman, Legrand, Sylvester, Tong, van der, Helle, van Zijl, & Bartelink 2000;Veronesi, Cascinelli, Mariani, Greco, Saccozzi, Luini, Aguilar, & Marubini 2002) the anticipated aesthetic outcome of the options is also considered:(BAPRAS and the Training Interface Group in Breast Surgery 2007;Bulstrode & Shrotria 2001;Clough, Kaufman, Nos, Buccimazza, & Sarfati 2010) For instance, BCT for a 40mm diameter cancer might be anticipated aesthetically unfavourable in a small breast, which could influence the team/clinician's operative preference or recommendation. Guidelines are designed flexibly to optimise patient involvement in decision-making while not compromising survival and recurrence; in recognition of the superior patient psychological outcomes associated with choice provision.(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)

If presented with options, patients' decisions are based on their personal preferences(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) and knowledge; much of which arises from discussion with the treating team's clinicians (doctors and nurses). Clinicians' stated or perceived treatment preferences and recommendations have been shown to exert one of the most potent influences over patients' treatment decisions.(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) However, limited information is available on such preferences. Most studies are based on doctors' stated preferences to clinical vignettes, and are not always conducted among those in the speciality of interest. The information gained from them is therefore of doubtful value. Also, although the studies note variability in doctors' preferences, they but deduce little else and they fail to include the BCN occupational group.(Collins, Kerrigan, & Anglade 1999;McKinlay, Burns, Durante, Feldman, Freund, Harrow, Irish, Kasten, & Moskowitz 1997)

#### Establishing preferences – Discrete Choice Experiment methodology

The Discrete Choice Experiment (DCE) is a member of the stated preference technique family; a rigorous survey methodology capable of establishing stakeholder (provider and consumer) preferences in controlled experimental conditions, through responses to hypothetical scenarios. The vast majority of DCE applications in healthcare up until the time of this study, focused upon eliciting the preferences of consumers for alternative treatments and service configurations.(Lancsar et al. 2007;Seston et al. 2007) The technique has steadily gained importance in the healthcare setting through the impacts their preference information has had on service planning and provision.(Lancsar, Hall, King, Kenny, Louviere, Fiebig, Hossain, Thien, Reddel, & Jenkins 2007;Ryan and Gerard 2003)

The superiority of the DCE over other stated preference techniques lies in its ability to establish the relative importance individuals or groups place on different attributes (variables) defining a good or service,(Ryan and Farrar 2000) and its ability to disaggregate total value (utility); permitting the estimation of individual attributes/variables impact on total value.(Longworth et al. 2001)

Examples of the application of DCEs to elicit the preferences of clinicians till now have remained relatively rare and, to our knowledge this was the first study to use the technique to assess the preferences of cancer clinicians for alternative treatment regimens.

To effectively capture preferences, the DCE design and scenario content must be plausible to potential respondents; containing realistic hypothetical scenarios comprised of variables individuals are willing to trade between to arrive at decisions. The majority of healthcare DCEs to date, have effectively forced respondents to choose between two or more options. However, it is recognised that such a design does not reflect all decision-making in healthcare. An opt-out response is sometimes necessary to improve realism and response rates. The opt out response commonly employed is a non-participation (prefers 'neither') response,(Ryan & Gerard 2003;Ryan and Skatun 2004) but equally could include an equivalent preference (prefers both equally) option.

The aim of this component of the study was to employ a cross-sectional postal questionnaire survey designed using DCE methodology, to determine the impact of key variables available pre-operatively, over specialist breast clinicians' (nurses and doctors) therapeutic operative preferences for the management of primary breast cancer. It was also designed to determine whether particular clinician psychological profiles were associated with their stated preferences. The psychological scales included the masculinity/femininity index,(Zeldow 1976) tolerance of ambiguity scale,(Budner 1962) Physician's Reactions to Uncertainty (PRU) Scale,(Gerrity et al. 1990) GHQ-6 (a subgroup of the GHQ-12),(Goldberg et al. 1997) and the Maslach Burnout Inventory.(Maslach and Jackson 1986)



## METHODS

### Sample

All 14 hospitals' specialist breast teams comprising the Trent breast service were recruited to the study. Ninety-seven eligible specialist clinicians (48 doctors and 49 nurses), were identified, 93 were invited to participate, as 4 were on long term sick leave during study recruitment. Eligibility was defined as a permanent specialist member of the breast team (nurse or doctor), routinely discussing surgical treatment options with patients diagnosed with breast cancer. Surgical trainees were ineligible due to their transitory role within teams.

### Instrument

The questionnaire comprised three sections; background information (age, sex, occupation, experience etc.), the DCE (25 hypothetical case scenarios) and a series of five psychological scales measuring parameters potentially influencing decision behaviour. Space was also provided for clinicians to provide additional comments.

### DCE scenario development

The chosen DCE design comprised the presentation of single scenarios and the incorporation of an opt-out or equivalent preference option (prefers both equally).[\(Ryan & Gerard 2003; Ryan & Skatun 2004\)](#) This less commonly adopted design was used in preference to the more conventionally applied pair-wise choice design,[\(Ryan & Gerard 2003\)](#) to more closely reflect the clinical decision-making context of interest, and therefore enhance response rates and elucidate clinicians' treatment preferences. It could be argued, respondents should be forced to make specific choices rather than defer to the perhaps easier decision of selecting the equivalent preference option. However, a number of clinical situations exist, e.g. breast cancers up to 4 and 5cm in diameter, where no clearly superior surgical treatment has been established in terms of its impact on mortality rates[\(Blichert-Toft, Brincker, Andersen, Andersen, Axelsson, Mouridsen, Dombernowsky, Overgaard, Gadeberg, Knudsen, & . 1988; Clarke, Collins, Darby, Davies, Elphinstone, Evans, Godwin, Gray, Hicks, James, MacKinnon, McGale, McHugh, Peto, Taylor, & Wang 2005; Fisher, Anderson, Bryant, Margolese, Deutsch, Fisher, Jeong, & Wolmark](#)

2002;Jacobson, Danforth, Cowan, d'Angelo, Steinberg, Pierce, Lippman, Lichter, Glatstein, & Okunieff 1995;Lichter, Lippman, Danforth, Jr., d'Angelo, Steinberg, deMoss, MacDonald, Reichert, Merino, Swain, & . 1992;Poggi, Danforth, Sciuto, Smith, Steinberg, Liewehr, Menard, Lippman, Lichter, & Altemus 2003;Sarrazin, Le, Arriagada, Contesso, Fontaine, Spielmann, Rochard, Le, & Lacour 1989;van Dongen, Voogd, Fentiman, Legrand, Sylvester, Tong, van der, Helle, van Zijl, & Bartelink 2000;Veronesi, Cascinelli, Mariani, Greco, Saccozzi, Luini, Aguilar, & Marubini 2002)or morbidity,(Carlsson & Hamrin 1994;Dorval, Maunsell, Deschenes, & Brisson 1998;Fallowfield, Baum, & Maguire 1986;Ganz, Desmond, Leedham, Rowland, Meyerowitz, & Belin 2002;Irwig & Bennetts 1997;McCready, Holloway, Shelley, Down, Robinson, Sinclair, & Mirsky 2005;Moyer 1997;Sanger & Reznikoff 1981;Schain, Edwards, Gorrell, de Moss, Lippman, Gerber, & Lichter 1983;Stefanek 1993) while evidence exists for the positive psychological influence of providing choices to patients.(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) Therefore, failing to provide respondents with the option to select the equivalent preference option and defer decision-making to the patient, would to be inappropriate in this context.

The conduct of a DCE can be divided into stages:(Ryan et al. 1998) Identification of key variables, assignment of levels to variables, combination of variables and their levels into scenarios for presentation, reduction of combinations to a practical number for presentation, the establishment of preferences and data analysis.

As the number of variables and their levels increases, the number of potential scenarios increases. Where there are V variables each with L levels the number of scenarios generated is:

$$L_1^{V_1} \times L_2^{V_2} \times L_3^{V_3} \dots \times L_n^{V_n}$$

Where  $L_n$  is the number of levels of the nth variable ( $V_n$ ). (Michaels et al. 2000)

The greater the number of variables and levels, the greater the information obtained, but the greater the size and complexity of the exercise. To minimise respondent cognitive fatigue and optimise response and completion rates, it is necessary to present individuals with a manageable

number of scenarios. This is achieved by limiting the number of included variables and levels, and the application of fractional factorial design (software package Speed);(Bradley 1991) which reduces the number of scenarios while retaining the ability to infer preferences for all. Its application assumes minimal significance of some or all interactions between variables.(Michaels, Brazier, Palfreyman, Shackley, & Slack 2000)

The crucial stage of DCE design is the identification of key variables capable of defining the subject of interest. By peer consensus, 5 variables routinely available pre-operatively were selected for inclusion and subdivided into plausible levels capable of being traded against each other in decision-making. Table 3.1 illustrates the variables and levels of the final applied DCE. The questionnaire's 25 scenarios were randomly generated from the reduction, by fractional factorial design (Speed)(Bradley 1991) of all possible combinations (1700 potential scenarios) of the orthogonal array of variables and levels generated by SPSS 'Orthoplan' software. The DCE questionnaire design considered the properties of orthogonality, and was balanced in terms of the number of times each level of an attribute was represented in a scenario. Table 3.2 shows the DCE scenario dimension levels generated by the SPSS 'Orthoplan' software for the applied DCE. The numbering of the assigned scenario dimension levels are shown in blue in the lower right in table 3.1's cells.

A pilot study with a group of experienced surgical trainees with a declared interest in breast surgery and BCNs employed outside the regional breast service, exposed the presence of a dominant variable level (multi-centric, multi-quadrant cancer centricity) in the initial set of cancer centricity variable levels. This skewed the results; making it impossible to interpret the influence of the other variables. It was therefore excluded from the final instrument.

TABLE 3.1 Discrete choice experiment variables and levels

Variable	Levels				
Patient age (years)	<40 1	40-<60 2	60-<70 3	70-<80 4	≥80 5
Total cancer size (mm)	<20 1	20 -<30 2	30 -<40 3	40 -<50 4	≥50 5
Bra cup size	A 1	B 2	C 3	≥ D 4	
Cancer site	Upper Inner (UI) 1	Upper Outer (UO) 2	Lower Outer (LO) 3	Lower Inner (LI) 4	Central 5
Centricity	Uni-focal 1	Multi-centric 2			
Blue numbers in the lower right of the cells represent assignment numbers for the SPSS generated scenarios noted in table 3.2					

TABLE 3.2 DCE scenario dimension levels generated SPSS 'Orthoplan'

Scenario	Age	Cancer size	Bra cup size	Site	Centricity
1	1	4	4	4	1
2	3	5	2	4	2
3	5	5	4	3	1
4	5	4	3	2	2
5	4	4	2	5	1
6	2	2	3	4	1
7	2	1	2	3	2
8	1	2	2	2	1
9	2	4	1	1	2
10	3	2	4	1	2
11	2	5	1	2	1
12	2	3	4	5	1
13	4	5	3	1	1
14	4	3	1	4	2
15	1	1	1	1	1
16	1	3	3	3	2
17	3	4	1	3	1
18	5	2	1	5	2
19	5	3	2	1	1
20	3	1	3	5	1
21	4	1	4	2	2
22	5	1	1	4	1
23	4	2	1	3	1
24	3	3	1	2	1
25	1	5	1	5	2

### Psychological scales

The five psychological scales incorporated into the questionnaire were chosen for their potential to influence medical decision-making:

Masculinity/femininity index: (Zeldow 1976) The eight item masculinity-femininity index generates a score between -24 and +24. Interpretation of the scale is dependent on the cultural context in which it is applied. In the UK, low negative scores indicate more traditionally feminine (nurturing) attributes and high positive scores more masculine (assertive) ones.

Tolerance of ambiguity scale: (Budner 1962) Budner's sixteen item tolerance of ambiguity scale generates a score between 16 and 112, where a higher score implies greater tolerance of

ambiguity and a lower score the converse. Individuals intolerant of ambiguity perceive ambiguous or uncertain situations as threatening.

Physician's Reactions to Uncertainty (PRU) Scale:(Gerrity, DeVellis, & Earp 1990) Gerrity's twenty-four item scale comprises two subscales measuring affective reactions to uncertainty specific to healthcare situations; the stress from uncertainty subscale (generating a score between 13 and 78) and reluctance to disclose uncertainty subscale (generating a score between 9 and 39). Higher scores respectively indicate greater stress from, and reluctance to disclose, uncertainty.

GHQ-6: A subgroup of the GHQ-12(Goldberg, Gater, Sartorius, Ustun, Piccinelli, Gureje, & Rutter 1997) were included in the questionnaire, consisting of the more 'external' or revealed representations of anxiety & depression (items 1,3,4,7,8 and 12), possessing greater potential to influence communication, than the more 'internal' or concealed items of the scale. Using this scaling system the six-item GHQ generated a score between 0 and 6. Higher scores indicate greater levels of anxiety and depression.

Burnout Inventory.(Maslach & Jackson 1986) The nine item abbreviated Maslach Burnout Inventory comprises subscales evaluating three components of burnout; emotional exhaustion, depersonalisation, and personal accomplishment; each generate a score between 0 and 18. Burnout is indicated by high scores in emotional exhaustion and depersonalisation and low scores in personal accomplishment.

Three of these comprise part of the UK GMC's performance procedures assessment of doctors; the GHQ-6, PRU Scale and the Maslach Burnout Inventory.

Theoretically it could be suggested clinicians would be more likely to favour and portray specific recommendations rather than favour greater patient autonomy if they demonstrated higher masculinity/femininity scores (more assertive) and PRU scores (more reluctant to disclose and more stressed by uncertainty), and lower tolerance of ambiguity scores (less tolerant). It could also be supposed that those with higher levels of depression (GHQ-6) and burnout (Maslach Burnout Inventory) could be less likely to provide optimal consultations for shared decision making.

## Establishment of Preferences

Clinicians were asked to indicate their operative preferences to hypothetical scenarios. Figure 3.1 illustrates a scenario example. It was emphasised clinicians should respond with their individual preferences, rather than with those of their breast team. They were also asked to base their responses purely on presented information, as other aspects of the cases were equal or insignificant. Three treatment options were presented; mastectomy, BCT, or equal preference for both mastectomy and BCT; equal preference representing providing patients with open choices. Extended treatment options (neo-adjuvant chemotherapy, primary breast reconstruction etc.) were excluded from the exercise.

FIGURE 3.1 Scenario example

Patient Age (years)	60 - <70
Total cancer size (mm)	<20
Bra cup size	C
Site	LI
Centricity	Uni-centric

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**  
☐

Since the outcome, preferred choice of surgery, was a 3-level nominal categorical variable (mastectomy, BCT, prefers both options equally), multinomial (polytomous) logistic regression (MLR) was used to look for associations between the outcome variable and the various clinical

characteristics given in the scenarios (age, bra cup size, cancer size, cancer site and centrality) and clinician characteristics (including age, experience, gender and psychological scale responses). A multinomial logistic model in STATA version 8 was fitted using the mlogit procedure, with 'prefers both options equally' as the reference or base category. (Stata Corporation 2003)

With a 3-level nominal categorical outcome, the multinomial logistic model will estimate, using maximum likelihood, two sets of regression coefficients for the explanatory variables: One for the effect of choosing mastectomy versus prefers both options equally, and a second set for BCT versus prefers both options equally. The regression coefficients, from the MLR model, correspond to the probability of each outcome category (mastectomy versus both options equally; BCT versus both option equally) relative to the base category. The exponentiated value of a regression coefficient, from this model, is the relative risk ratio (RRR) for a one unit change in the corresponding explanatory variable, where risk is measured as the risk of the category relative to the base category. The cluster option was used to take into consideration the lack of response independence (each responder valued up to 25 scenarios). This alters regression coefficient's estimated standard errors, p-values and confidences intervals, but not coefficient values themselves.

## FINDINGS

Sixty-eight of the 93 clinicians approached from the 14 hospital breast units of the Trent region, returned completed questionnaires (73% response rate): 34% male, 66% female, 48% nurses, 52% doctors (25 consultants, 3 Associate Specialists, 1 Staff Grade and 4 Clinical Assistants), mode age 41-50 (range 26 to 65), with a median 22 years post qualification experience (range 5 to 39 years) and 7 years specialist experience (range 0 to 26 years). Table 3.3 presents the characteristics of the 68 responders to the survey.

### DCE findings

The impact of clinical factors on clinicians' preferences



The 68 responders answered 1695 of 1700 (68 x 25) scenarios. In 890 (53%) scenarios responders preferred mastectomy, 397 (23%) BCT, and 408 (24%) preferred both equally. Overall 56/68 (82%) of responders demonstrated a preference for mastectomy in the majority of the scenarios they rated, 7 (10%) a preference for BCT and 5 (8%) an equal preference for mastectomy and BCT.

Table 3.4 summarises the results by scenario. Scenarios are displayed as individual rows. This form of data presentation highlights a lack of consensus in clinicians' preferences; for example in scenario 19, in a woman over 80 with a single 30 to <40mm diameter focus of cancer in the upper outer quadrant of her B cup breast, 32% of clinicians would prefer she had a mastectomy, 28% prefer she had BCT and 40% would leave the choice to her. The table also illustrates, some clinicians adhere rigidly to their preferences despite potentially consequent compromised recurrence and survival rates; for example, clinicians retaining their preference for BCT in scenarios 13 and 25, where cancers are over 50mm diameter and in scenario 25, the cancer is also multi-centric.

TABLE 3.3 Demographic data of clinician responders

Clinician characteristics		n	%				
Clinician age	26-30	2	(3.0%)				
	31-35	5	(7.6%)				
	36-40	13	(19.7%)				
	41-45	14	(21.2%)				
	46-50	14	(21.2%)				
	51-55	8	(12.1%)				
	56-60	9	(13.6%)				
	61-65	1	(1.5%)				
	Total	66	(100.0%)				
Clinician gender	Male	23	(33.8%)				
	Female	45	(66.2%)				
	Total	68	(100.0%)				
Clinician occupation	Doctor	33	(48.5%)				
	Nurse	35	(51.5%)				
	Total	68	(100.0%)				
		n	Mean	SD	Median	Min	Max
Year of qualification		64	1982	(8.4)	1982.5	1965	1999
Year commenced as a specialist		65	1995	(6.6)	1996.0	1977	2003
No. of years as specialist		65	8	(6.6)	7.0	0	26
No. of years' experience (since qualification)		63	22	(8.4)	22.0	5	39

TABLE 3.4 DCE results by scenario

Scenario	Age (years)	Total cancer size (mm)	Bra cup size	Cancer site	Centricity	Preference for Mx (%)	Preference for BCT (%)	Equal Preference (Mx & BCT) (%)
1	< 40	40- to <50	D	LI	Uni-centric	45.59	19.12	35.29
2	60- to <70	≥50	B	LI	Multi-centric	95.59	0.00	4.41
3	≥ 80	≥50	D	LO	Uni-centric	70.59	7.35	22.06
4	≥ 80	40- to <50	C	UI	Multi-centric	80.88	2.94	16.18
5	70- to < 80	40- to <50	B	Central	Uni-centric	94.12	0.00	5.88
6	40- to <60	20- to <30	C	LI	Uni-centric	1.49	71.64	26.87
7	40- to <60	<20	B	LO	Multi-centric	22.39	40.30	37.31
8	< 40	20- to <30	B	UI	Uni-centric	5.97	64.18	29.85
9	40- to <60	40- to <50	A	UO	Multi-centric	91.04	0.00	8.96
10	60- to <70	20- to <30	D	UO	Multi-centric	19.4	46.27	34.33
11	40- to <60	≥50	A	UI	Uni-centric	92.65	0.00	7.35
12	40- to <60	30- to <40	D	Central	Uni-centric	44.12	17.65	38.24
13	70- to < 80	≥50	C	UO	Uni-centric	83.82	4.41	11.76
14	70- to < 80	30- to <40	A	LI	Multi-centric	89.71	1.47	8.82
15	< 40	<20	A	UO	Uni-centric	1.47	66.18	32.35
16	< 40	30- to <40	C	LO	Multi-centric	41.18	25.00	33.82
17	60- to <70	40- to <50	A	LO	Uni-centric	86.76	2.94	10.29
18	≥80	20- to <30	A	Central	Multi-centric	79.41	1.47	19.12
19	≥ 80	30- to <40	B	UO	Uni-centric	32.35	27.94	39.71
20	60- to <70	<20	C	Central	Uni-centric	27.94	42.65	29.41
21	70- to < 80	<20	D	UI	Multi-centric	17.65	45.59	36.76
22	≥80	<20	A	LI	Uni-centric	11.76	50.00	38.24
23	70- to < 80	20- to <30	A	LO	Uni-centric	13.23	39.71	47.06
24	60- to <70	30- to <40	A	UI	Uni-centric	67.65	8.82	23.53
25	< 40	≥50	A	Central	Multi-centric	94.12	1.47	4.41

Responses were analysed across scenarios, to establish the impact of individual variables over clinicians' operative preferences. Equal preference, representing the provision of an open choice of surgery to the patient, was treated as the reference therapeutic option, and compared with preference for mastectomy and preference for BCT, using univariate (variables analysed as independent of the other variables) and multivariate analysis.

All 5 scenario variables independently demonstrated statistically significant association with preference both on their own and when combined together ( $p < 0.001$ ). The results of multivariate analysis are summarised in Tables 3.5 and 3.6. The RRR for the regression coefficients in Tables 3.5 and 3.6 are from the same model, but shown in separate tables for ease of understanding. Preference for mastectomy over choice, and choice over BCT, correlated positively with increasing patient age and cancer size, central cancer site, multi rather than uni-centric cancer, and reducing bra cup size. For example, other factors being equal, clinicians are over three times more likely to prefer mastectomy rather than choice, if a woman is aged between 60 and 70, than if she is under 40 ( $p < 0.001$ ). Consistent with evidence-based treatment guidelines, cancer size appears to exert the greatest influence over preferences: Clinicians are nearly 36 times more likely to prefer mastectomy rather than choice if a cancer is greater than 50mm in diameter, than if it is less than 20mm ( $p < 0.001$ ), and likewise, they are 92% less likely to prefer BCT over choice, if a cancer is over 50mm in diameter, than if it is less than 20mm ( $p < 0.001$ ). The goodness of fit of the model in Tables 3.5 and 3.6 was assessed by the pseudo  $R^2$ . The pseudo  $R^2$  value of 0.29 suggests the model with five covariates is about 29% better than the model with no covariates (the "constant-only" model), but is about 71% worse than the theoretical perfect fitting or predicting model (with a pseudo  $R^2$  value of 1.0).

TABLE 3.5 Influence of DCE variable over operative preferences: Relative Risk Ratio (RRR)  
Equal preference for both BCT and mastectomy vs. mastectomy preference

DCE variable		Relative Risk Ratio (RRR) Equal preference vs. Mx preference	[95% CI]	p =
<b>Patient age (years)</b>	<40 vs. 40-<60	1.42	0.91-2.22	<b>0.121</b>
	<40 vs. <60-70	3.26	2.03-5.24	<b>&lt;0.001**</b>
	<40 vs. <70-80	2.47	1.58-3.86	<b>&lt;0.001**</b>
	<40 vs. ≥80	1.64	0.93-2.89	<b>0.088</b>
<b>Total cancer size (mm)</b>	<20 vs. 20-<30	1.10	0.69-1.77	<b>0.680</b>
	<20 vs. 30-<40	4.92	3.17-7.65	<b>&lt;0.001**</b>
	<20 vs. 40-<50	15.55	8.85-27.33	<b>&lt;0.001**</b>
	<20 vs. ≥50	35.61	13.01-97.41	<b>&lt;0.001**</b>
<b>Bra cup size</b>	A vs. B	0.76	0.48-1.22	<b>0.225</b>
	A vs. C	0.46	0.29-0.73	<b>0.001**</b>
	A vs. ≥ D	0.35	0.22-0.57	<b>&lt;0.001**</b>
<b>Cancer site</b>	Central vs. UO	0.25	0.14-0.44	<b>&lt;0.001**</b>
	Central vs. LO	0.28	0.15-0.50	<b>&lt;0.001**</b>
	Central vs. LI	0.37	0.23-0.61	<b>&lt;0.001**</b>
	Central vs. UI	0.33	0.19-0.56	<b>&lt;0.001**</b>
<b>Centricity</b>	Uni vs. Multifocal single quadrant	3.22	1.98-5.26	<b>&lt;0.001**</b>
Multivariate RRRs after adjustment for the other clinical factors (patient age, cancer size, cancer size, bra cup size and centricity).				
* p ≤ 0.01				
** p ≤ 0.001				

TABLE 3.6 Influence of DCE variable over operative preferences: Relative Risk Ratio (RRR)  
Equal preference for both BCT and mastectomy vs. BCT preference

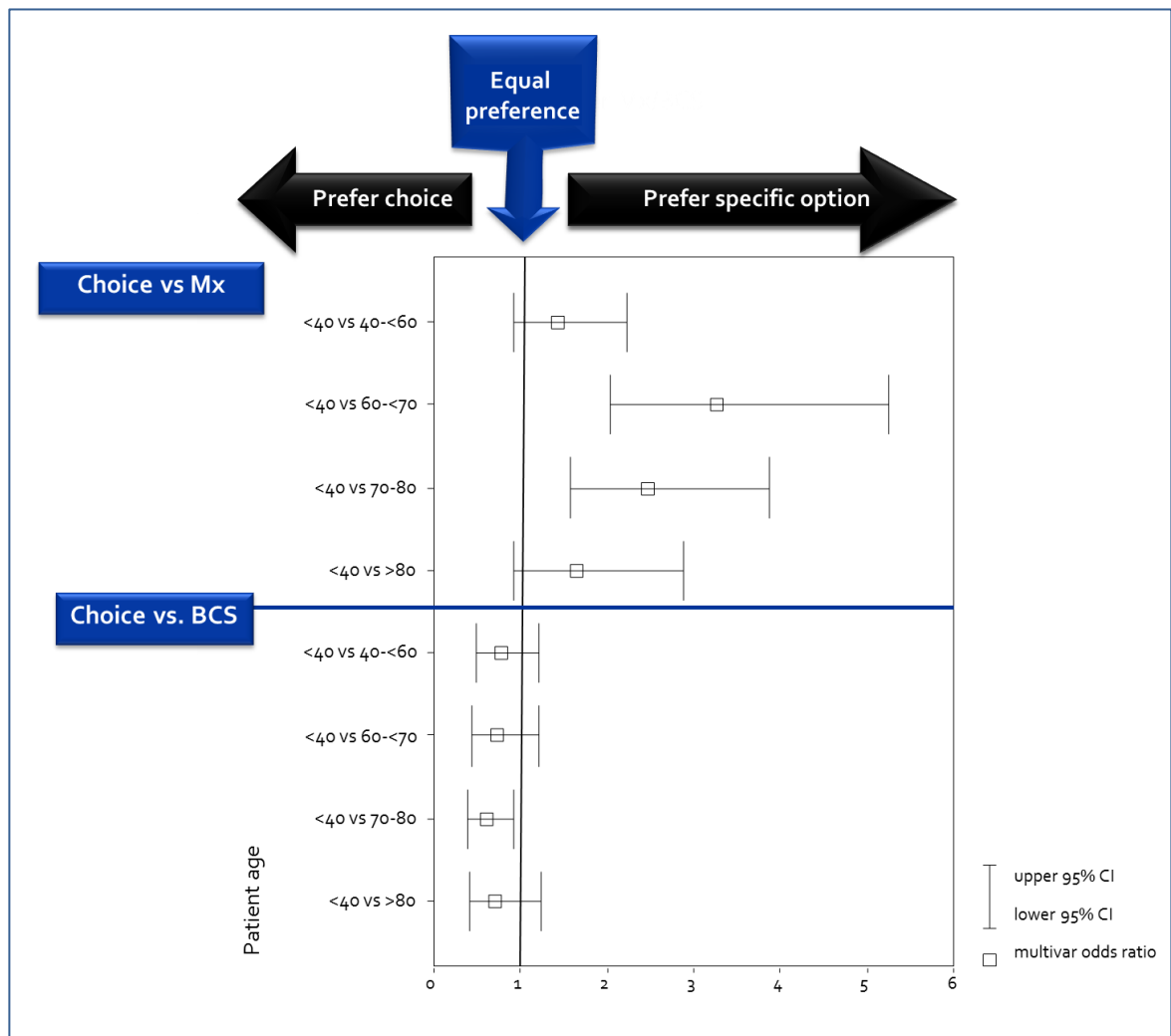
DCE variable		Relative Risk Ratio (RRR) Equal preference vs. BCT preference	[95% CI]	p =
<b>Patient age (years)</b>	<40 vs. 40-<60	0.77	0.49-1.22	<b>0.272</b>
	<40 vs. 60-<70	0.73	0.44-1.22	<b>0.233</b>
	<40 vs. 70-<80	0.60	0.38-0.93	<b>0.022</b>
	<40 vs. ≥80	0.70	0.40-1.23	<b>0.215</b>
<b>Total cancer size (mm)</b>	<20 vs. 20-<30	0.70	0.51-0.98	<b>0.035</b>
	<20 vs. 30-<40	0.30	0.19-0.47	<b>&lt;0.001**</b>
	<20 vs. 40-<50	0.10	0.04-0.26	<b>&lt;0.001**</b>
	<20 vs. ≥50	0.08	0.02-0.25	<b>&lt;0.001**</b>
<b>Bra cup size</b>	A vs. B	1.55	1.04-2.32	<b>0.033</b>
	A vs. C	2.86	1.63-5.03	<b>&lt;0.001**</b>
	A vs. ≥ D	2.95	1.55-5.62	<b>0.001**</b>
<b>Cancer site</b>	Central vs. UO	3.30	1.42-7.68	<b>0.006*</b>
	Central vs. LO	3.28	1.23-8.74	<b>0.018</b>
	Central vs. LI	2.72	1.50-4.93	<b>0.001**</b>
	Central vs. UI	2.73	1.07-6.97	<b>0.036</b>
<b>Centricity</b>	Uni vs. Multifocal single quadrant	0.39	0.21-0.71	<b>0.002</b>
Multivariate RRR after adjustment for clinical factors (patient age, cancer size, cancer size, bra cup size and centricity).				
* p ≤ 0.01				
** p ≤ 0.001				

#### Effect of patient age on preferences

Figure 3.2 and tables 3.5 and 3.6 illustrate how clinicians' preferences are influenced by a patient's age. The upper section of figure 3.2 compares clinicians who prefer choice with those who prefer mastectomy; the lower section, clinicians who prefer choice with those preferring BCT. Descending the vertical axis in each section preferences among for the youngest patients are compared with preferences among patients of increasing age. Boxes represent the ratios, whiskers the 95% CIs; those not crossing the vertical line at 1 are statistically significant. At the vertical 1 line, clinicians are just as likely to prefer choice as mastectomy (in the upper section) or BCT (in the lower section). To the left of 1 they prefer choices, to the right they prefer the specific treatment option. Figure 3.2 demonstrates other factors being equal, age statistically significantly influences preferences ( $p < 0.001$ ): Clinicians increasingly prefer mastectomy more as

age increases, but not in the over 80s. Among those preferring BCT, clinicians shift from preferring BCT to choices with increasing patient age, but the effect is less exaggerated than when choice and mastectomy are compared. The preference for choice over BCT only reaches statistical significance in the 70-80 year group.

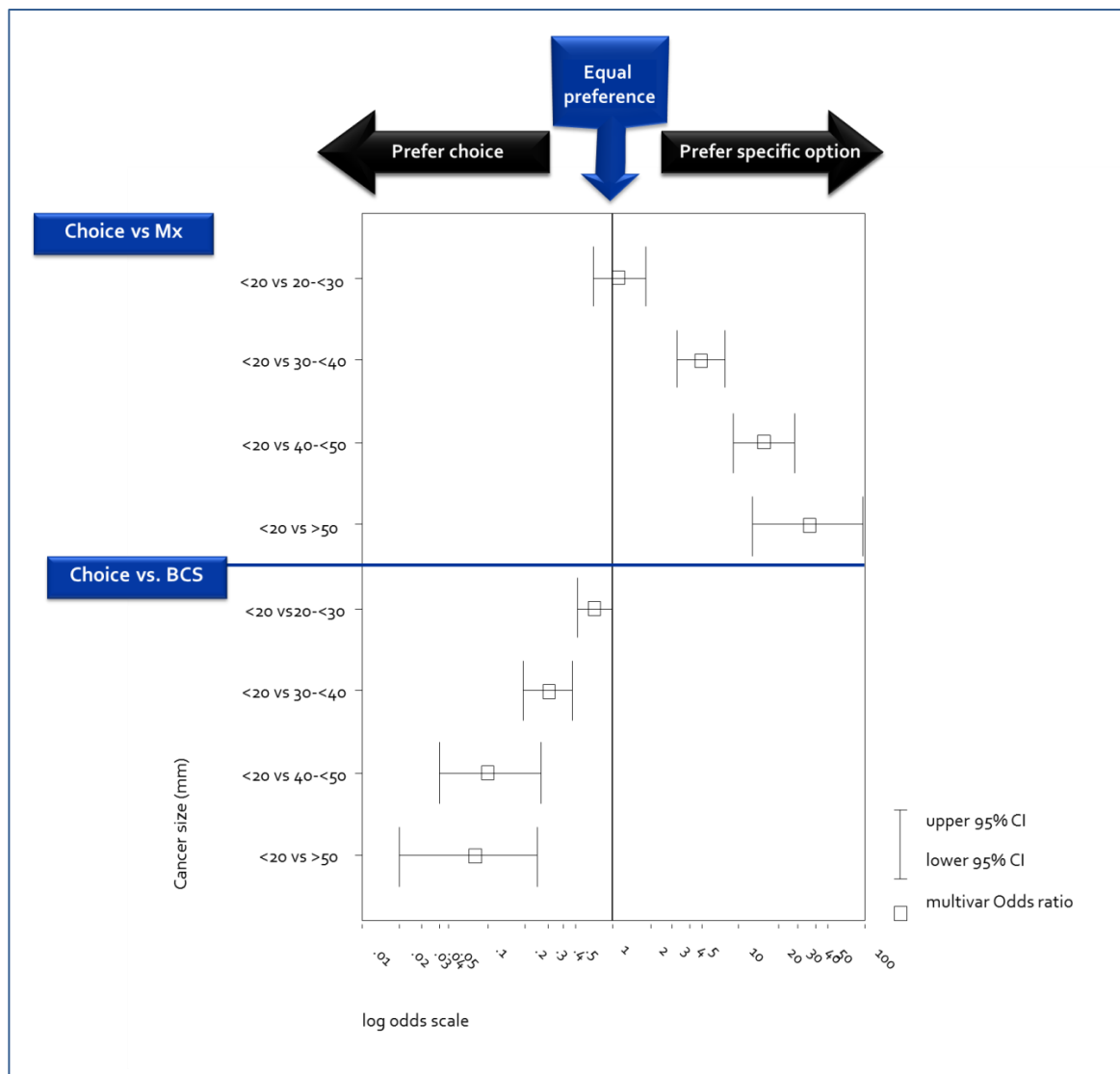
FIGURE 3.2 Effect of patient age on preferences



## Effect of cancer size on preferences

Cancer size significantly influenced preference ( $p < 0.001$ ). With increasing cancer size, clinicians increasingly preferred mastectomy rather than choices, or choices rather BCT. However, there was a 10mm diameter difference in thresholds for clinicians' shifting their preferences depending on whether they preferred mastectomy or BCT. Those preferring BCT shift toward choice when cancers exceed 20mm (size  $<20$  vs.  $20-<30$ mm RRR equal vs. BCT preference 0.70, 95% CI 0.51-0.98,  $p=0.035$ ) and among cancers less than 30mm clinicians start to shift from a preference for mastectomy to choice (equal preference vs. mastectomy preference in size  $<20$  vs.  $20-<30$ mm RRR 1.10, 95% CI 0.69-1.77,  $p=0.680$ , size  $<20$  vs.  $30-<40$  RRR 4.92 CI 3.17-7.65,  $p < 0.001$ ). Tables 3.5 and 3.6, and figure 3.3 illustrate the effect of cancer size on clinicians' preferences.

Figure 3.3 Effect of cancer size on preferences

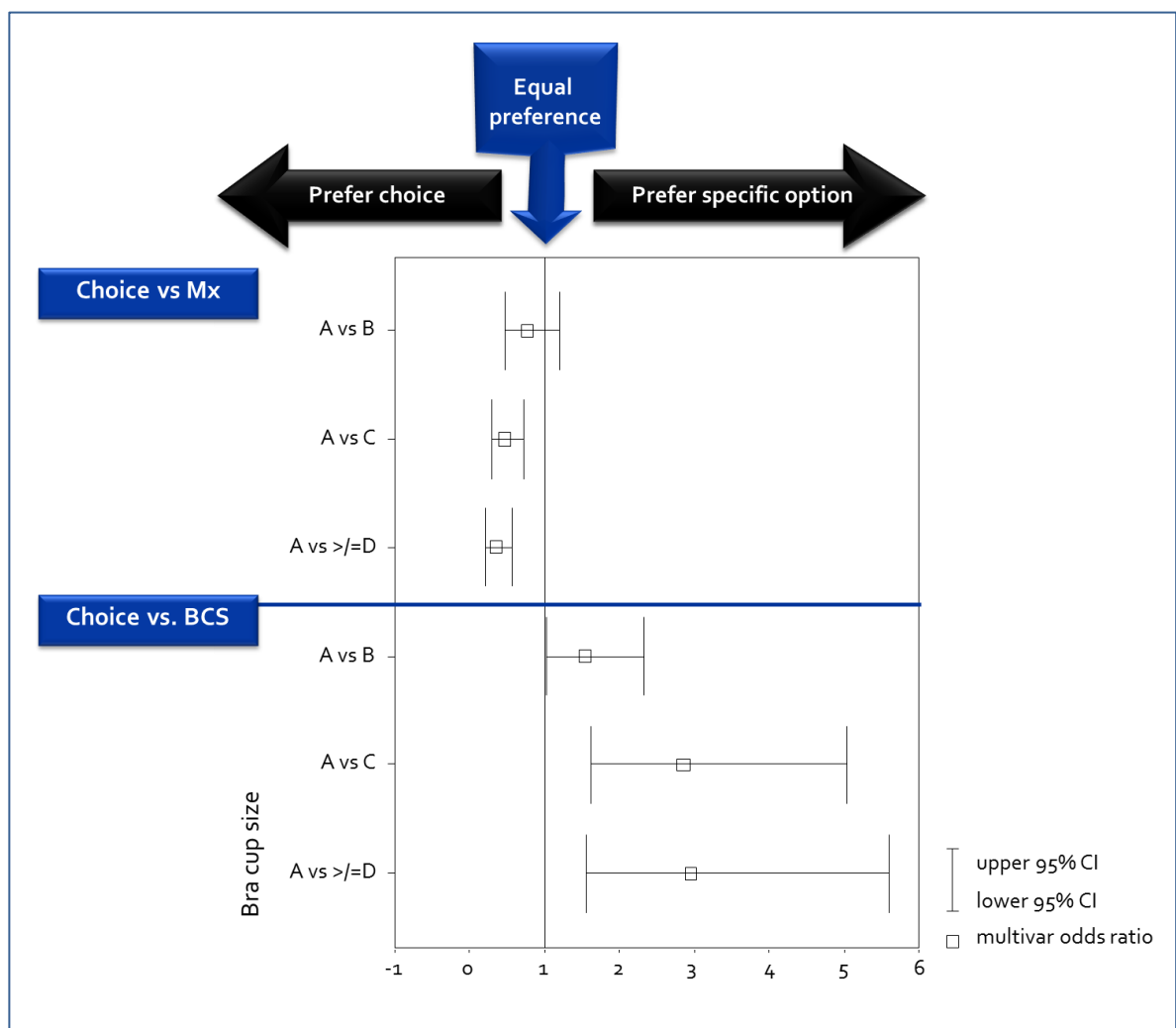




## Effect of bra cup size on preferences

Bra size significantly influenced preference ( $p < 0.001$ ). With increasing cup size, clinicians demonstrated an increasing preference for choice rather than mastectomy (A cup vs.  $\geq D$  cup;  $RRR = 0.38$ ,  $p \geq 0.001$ ) and BCT rather than choice (A vs. C;  $RRR = 1.43$ ,  $p = 0.025$ ). However, when cup size was analysed as a factor in isolation, in the largest size ( $\geq D$ ) clinicians prefer BCT and choice equally, rather than preferring BCT ( $RRR = 0.95$ ,  $p = 0.78$ ). Tables 3.5 and 3.6, and figure 3.4 illustrate the effect of bra cup size on preferences.

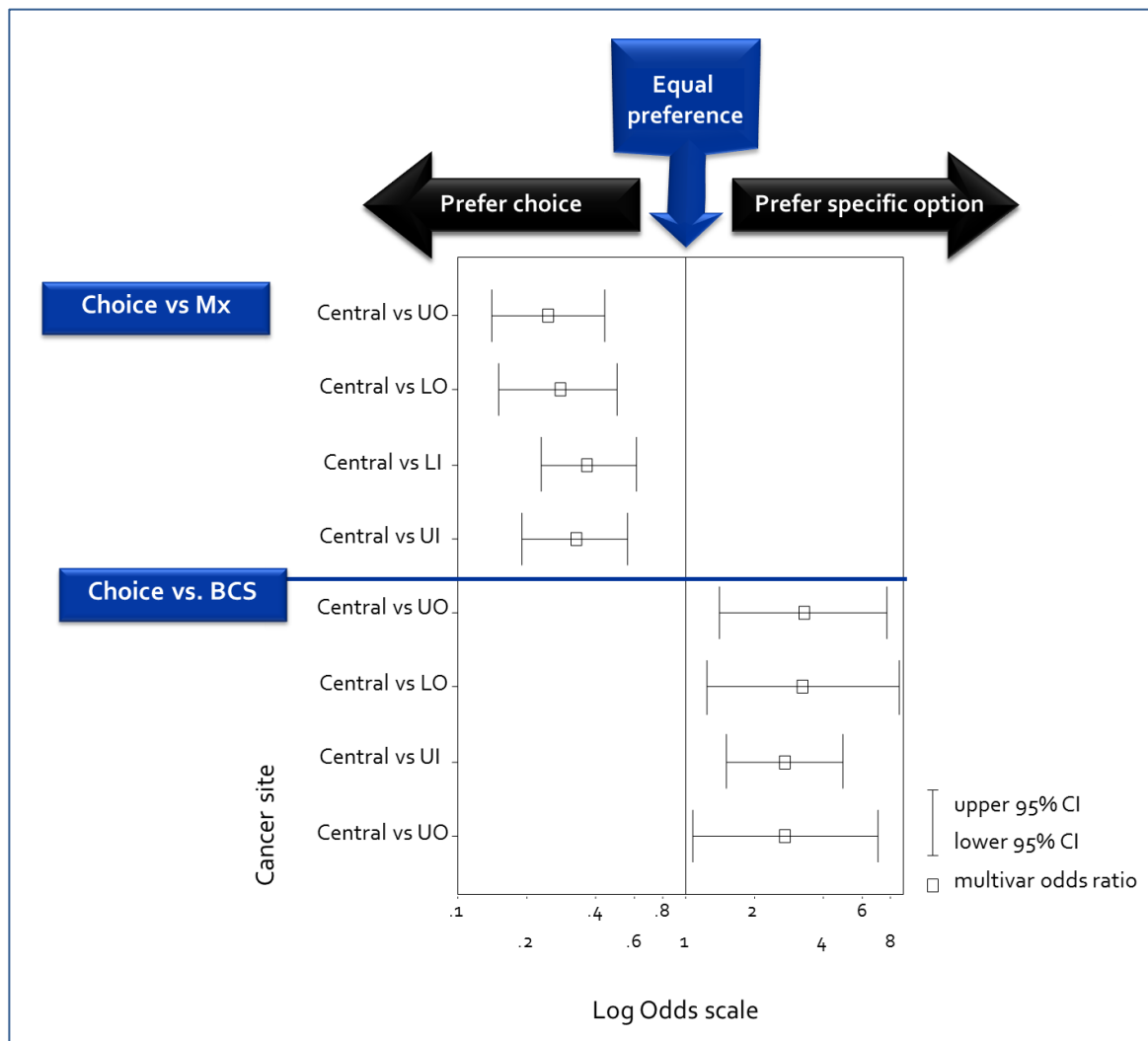
FIGURE 3.4 Effect of bra cup size on preferences



## Effect of cancer site on preferences

The cancer site within the breast significantly influenced clinicians' preferences ( $p < 0.001$ ); peripheral location was associated with clinicians more likely to prefer choices than mastectomy (i.e. central vs. UO;  $RRR = 0.25$ ,  $p < 0.001$ ) or BCT rather than choices (i.e. central vs. UO;  $RRR = 3.30$ ,  $p = 0.006$ ). All results were highly statistically significant ( $p < 0.001$ ) in the choice versus mastectomy analyses for all non-central sites. However significance levels of this magnitude were only reached in the central versus LI quadrant. Tables 3.5 and 3.6 and Figure 3.5 illustrate the effect of cancer site on preferences.

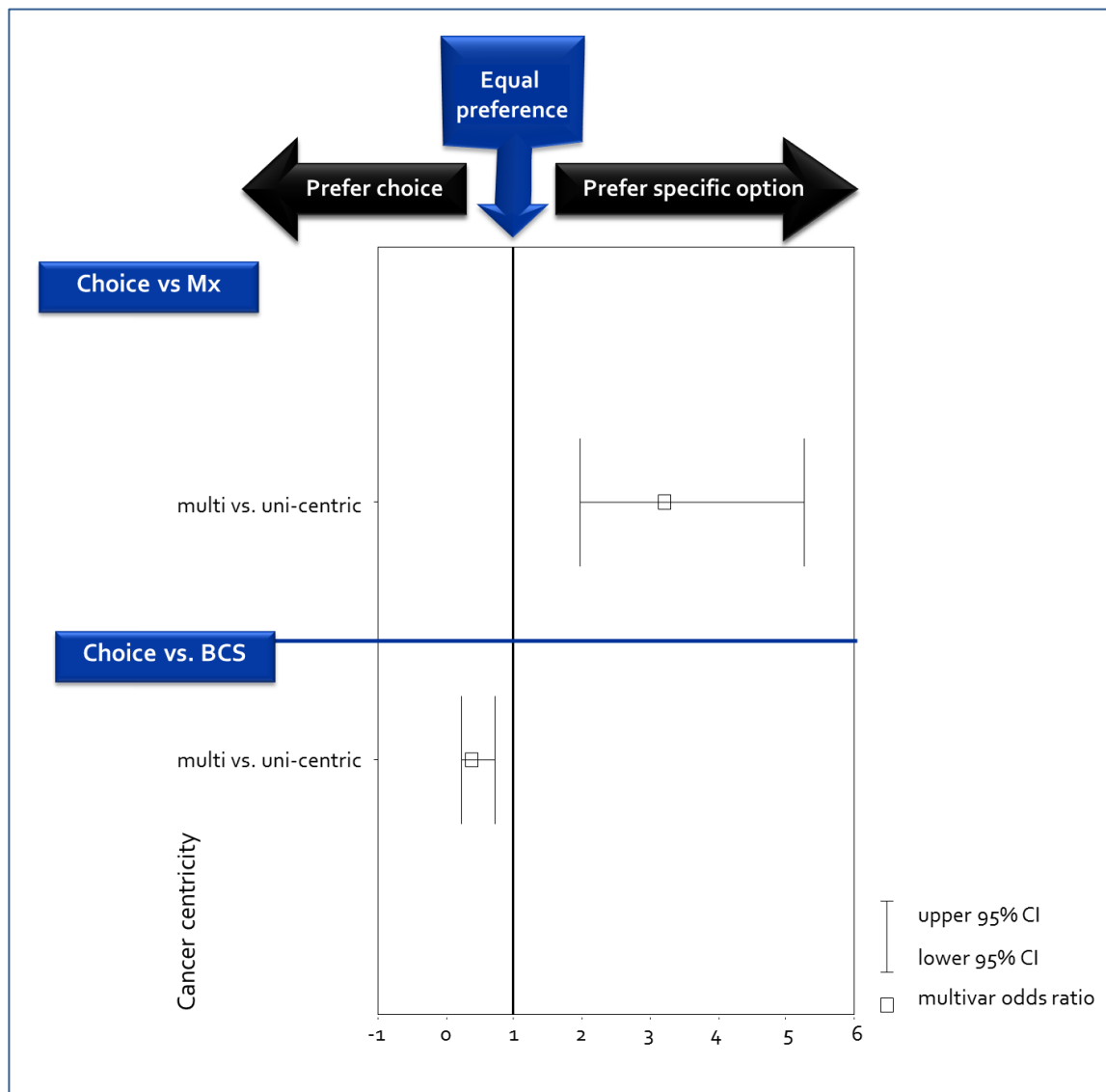
FIGURE 3.5 Effect of cancer site on preferences



## Effect of cancer centrality on preferences

Other factors being equal, cancer centrality significantly influenced preferences ( $p < 0.001$ ). Multi-centric cancers were associated with an increasing preference for mastectomy rather than giving choices; multi-centric versus uni-centric cancers choice versus mastectomy  $RRR=3.22$   $p \geq 0.001$ . Multi-centricity was also associated with a preference for giving choices rather than preferring BCT; multi- rather than uni-centric cancers choice versus BCT  $RRR=0.39$ ,  $p = 0.002$ . However, the preference for choice over BCT was only statistically significant in multivariate analysis. Tables 3.5 and 3.6, and Figure 3.6 illustrate the effect of cancer centrality on preferences.

FIGURE 3.6 Effect of cancer centrality on preferences



## The impact of clinician characteristics on preferences

When clinician factors were incorporated into multivariate analysis alongside the other variables, clinician gender and occupation demonstrated independent association with surgical preferences. The findings are presented in table 3.7 and 3.8. Other factors being equal, female responders were twice as likely as male responders to prefer choice than mastectomy (female vs. male clinician gender, RRR equal preference vs. mastectomy preference 0.51, 95% CI 0.29-0.87,  $p=0.015$ ). Occupational role was also associated with preferences; BCNs were more likely to prefer choice than mastectomy or BCT (nurse vs. doctor; equal preference vs. mastectomy preference RRR=0.37, 95% CI 0.21-0.64,  $p<0.001$ , and equal preference vs. BCT preference RRR=0.52, 95% CI 0.26-1.03,  $p=0.06$ ). In contrast, doctors were more directive; they tended to prefer specific operations (BCT or mastectomy) over more open choices.

However neither clinicians' age nor years of experience were associated with their treatment preferences; Age; choice vs. mastectomy RRR=1.0,  $p=0.77$ , choice vs. BCT RRR=1.0,  $p=0.29$ , experience; choice vs. mastectomy RRR=0.98,  $p=0.10$ , choice vs. BCT RRR=1.0,  $p=0.99$ .

The self-reported psychological scores of the respondents indicate that as a group the specialist breast clinicians possess conventionally feminine or nurturing attributes (gentleness, kindness, empathy etc.), tolerate ambiguity well both in healthcare and non-healthcare contexts and exhibit low levels of anxiety and depression, and high personal accomplishment. However they also demonstrate low to moderate burnout: Specifically, low levels of depersonalisation and moderate emotional exhaustion. Table 3.9 summarises the respondents psychological scale responses.

When clinicians' psychological scale responses were incorporated into multivariate analysis alongside the other variables, they were not associated with clinicians' treatment preferences. See tables 3.7 and 3. 8.

TABLE 3.7 Influence of clinician characteristics over operative preferences: Relative Risk Ratio (RRR) Equal preference for both BCT and mastectomy vs. mastectomy preference

Clinician variable		Relative Risk Ratio (RRR) Equal preference vs. Mx preference	[95% CI]	p =
Gender	Female vs. male	0.51	0.29-0.87	<b>0.015*</b>
Occupation	Nurse vs. doctor	0.37	0.21-0.64	<b>&lt;0.001**</b>
Age		1.00	0.97-1.02	<b>0.77</b>
Experience (years)		0.98	0.95-1.00	<b>0.10</b>
Masculinity/femininity index		1.05	0.96-1.14	<b>0.22</b>
Tolerance of ambiguity scale		1.05	0.97-1.14	<b>0.25</b>
PRU Scale, Stress scale		1.02	0.99-1.04	<b>0.31</b>
PRU Scale, Disclosure scale		1.00	0.93-1.07	<b>0.99</b>
GHQ-6		0.99	0.75-1.29	<b>0.91</b>
Burnout Inventory, Emotional Exhaustion		0.89	0.74-1.06	<b>0.19</b>
Burnout Inventory, Depersonalisation		1.00	0.89-1.13	<b>0.94</b>
Burnout Inventory, Personal Accomplishment		0.94	0.85-1.05	<b>0.30</b>
<b>Multivariate RRRs, after adjustment for clinical factors (patient age, cancer size, cancer size, bra cup size and centrality).</b> <b>*p≤0.05</b> <b>**p≤0.001</b>				

TABLE 3.8 Influence of clinician characteristics over operative preferences: Relative Risk Ratio (RRR) Equal preference for both BCT and mastectomy vs. BCT preference

Clinician variable		Relative Risk Ratio (RRR) Equal preference vs. BCT preference	[95% CI]	p =
Gender	Female vs. male	0.64	0.32-1.29	<b>0.21</b>
Occupation	Nurse vs. doctor	0.52	0.26-1.03	<b>0.06</b>
Age		1.02	0.98-1.06	<b>0.29</b>
Experience (years)		1.00	0.96-1.04	<b>0.99</b>
Masculinity/femininity index		1.00	0.91-1.10	<b>0.96</b>
Tolerance of ambiguity scale		1.00	0.92-1.09	<b>0.99</b>
PRU Scale, Stress scale		1.01	0.98-1.04	<b>0.61</b>
PRU Scale, Disclosure scale		1.03	0.96-1.09	<b>0.44</b>
GHQ-6		0.99	0.77-1.26	<b>0.92</b>
Burnout Inventory, Emotional Exhaustion		0.92	0.79-1.08	<b>0.31</b>
Burnout Inventory, Depersonalisation		0.99	0.85-1.14	<b>0.85</b>
Burnout Inventory, Personal Accomplishment		1.02	0.88-1.17	<b>0.83</b>
<b>Multivariate RRRs, after adjustment for clinical factors (patient age, cancer size, cancer size, bra cup size and centrality)</b> <b>**p≤0.05</b> <b>***p≤0.001</b>				

TABLE 3.9 Clinicians psychological scale responses

Psychological Scales	n	Mean	SD	Median	Min	Max
Masculinity / femininity index	67	-12.9	(3.4)	-13.0	-24.0	-6.0
Tolerance of ambiguity scale	67	44.0	(4.5)	44.0	33.0	55.0
PRU Scale, Stress scale	65	39.7	(11.9)	43.0	16.0	64.0
PRU Scale, Disclosure scale	65	18.4	(6.3)	18.0	9.0	35.0
GHQ 6	66	0.9	(1.4)	0.0	0.0	5.0
Burnout Inventory, Personal Accomplishment	66	14.8	(2.6)	15.0	7.0	18.0
Burnout Inventory, Depersonalisation	66	1.2	(2.1)	0.0	0.0	9.0
Burnout Inventory, Emotional Exhaustion	65	5.5	(2.8)	5.0	1.0	15.0

## CONCLUSION

To our knowledge, this is the first study to use the DCE technique to assess the preferences of cancer clinicians for alternative but equipoise treatment regimens. This study adopted the less commonly utilised single scenario with equivalent preference option DCE design(Ryan & Gerard 2003;Ryan & Skatun 2004) for greater realism to the specific clinical decision-making context of interest. The findings substantially increase our understanding of specialist breast clinicians' surgical preferences.

Three of the DCE variables were cancer characteristics available pre-operatively (cancer size, cancer site and centricity) which are included in treatment guidelines and therefore should influence practice. In addition, bra cup size is a surrogate measure of breast volume which is used alongside cancer size to permit the clinicians' evaluation of whether BCT will be aesthetically acceptable (<20% volume resection) or not.(Bulstrode & Shrotria 2001) The majority of clinicians' preferences were congruent with evidence-based guidelines: Preference for mastectomy rather than choice, and choice rather than BCT demonstrated positive correlations with increasing cancer size, central site, multi rather than uni-centric distribution, and reducing bra cup size; all to the  $p<0.001$  level. The overall preponderance toward mastectomy most likely reflects evidence-based decisions to scenario content (larger and multi-centric cancers), rather than signifying a particular bias in the clinician group. The main findings are summarised in figure 3.7.

Although the responses were generally consistent with guidelines, these are permissive to wide ranging responses, and the DCE uncovered several novel insights into specialist breast clinicians' operative preferences. For example, other factors being equal, clinicians increasingly preferred mastectomy with increasing patient age ( $p < 0.001$ ), but less so in the very old (over 80s). Age was also less influential among those preferring BCT; only achieving statistical significance in the 70-80 year group.

Cancer size significantly influenced preference ( $p < 0.001$ ); as cancer size increased, clinicians increasingly preferred mastectomy rather than choice, or choice rather than prefer BCT. But the DCE results also highlight that choice dominates over mastectomy and BCT at different cancer size levels: there was a 10mm diameter difference in clinicians' thresholds for their preferences, depending on whether they preferred mastectomy or BCT. Those preferring BCT start to shift toward choice when cancers exceed 20mm (Cancer size  $< 20$  vs.  $20 < 30$ mm RRR equal vs. BCT preference 0.70, 95% CI 0.51-0.98,  $p = 0.035$ ). Whereas clinicians start to shift from a preference for choice to mastectomy when cancers exceed 30mm (Cancer size  $< 20$  vs.  $20 < 30$ mm RRR equal preference vs. mastectomy preference 1.10, 95% CI 0.69-1.77,  $p = 0.680$ , size  $< 20$  vs.  $30 < 40$  RRR 4.92 CI 3.17-7.65,  $p < 0.001$ ). Such detail is unlikely to have been detected with other methodologies used to establish preferences in healthcare decision-making.

Some individual clinician variation was noted and occasional outlying responses identified. Some demonstrated preferences which lay outside evidence-based practice; for example, preferring BCT in cancers over 5cm despite clinical trial data demonstrating a survival disadvantage.(Blichert-Toft, Brincker, Andersen, Andersen, Axelsson, Mouridsen, Dombernowsky, Overgaard, Gadeberg, Knudsen, & . 1988;Clarke, Collins, Darby, Davies, Elphinstone, Evans, Godwin, Gray, Hicks, James, MacKinnon, McGale, McHugh, Peto, Taylor, & Wang 2005;Fisher, Anderson, Bryant, Margolese, Deutsch, Fisher, Jeong, & Wolmark 2002;Jacobson, Danforth, Cowan, d'Angelo, Steinberg, Pierce, Lippman, Lichter, Glatstein, & Okunieff 1995;Lichter, Lippman, Danforth, Jr., d'Angelo, Steinberg, deMoss, MacDonald, Reichert, Merino, Swain, & . 1992;Poggi, Danforth, Sciuto, Smith, Steinberg, Liewehr, Menard, Lippman, Lichter, & Altemus 2003;Sarrazin, Le, Arriagada, Contesso, Fontaine, Spielmann, Rochard, Le, & Lacour 1989;van Dongen, Voogd, Fentiman, Legrand, Sylvester, Tong, van der, Helle, van Zijl, & Bartelink 2000;Veronesi, Cascinelli, Mariani, Greco, Saccozzi, Luini, Aguilar, & Marubini 2002) Translated into practice, such preferences could compromise LRRR and mortality.

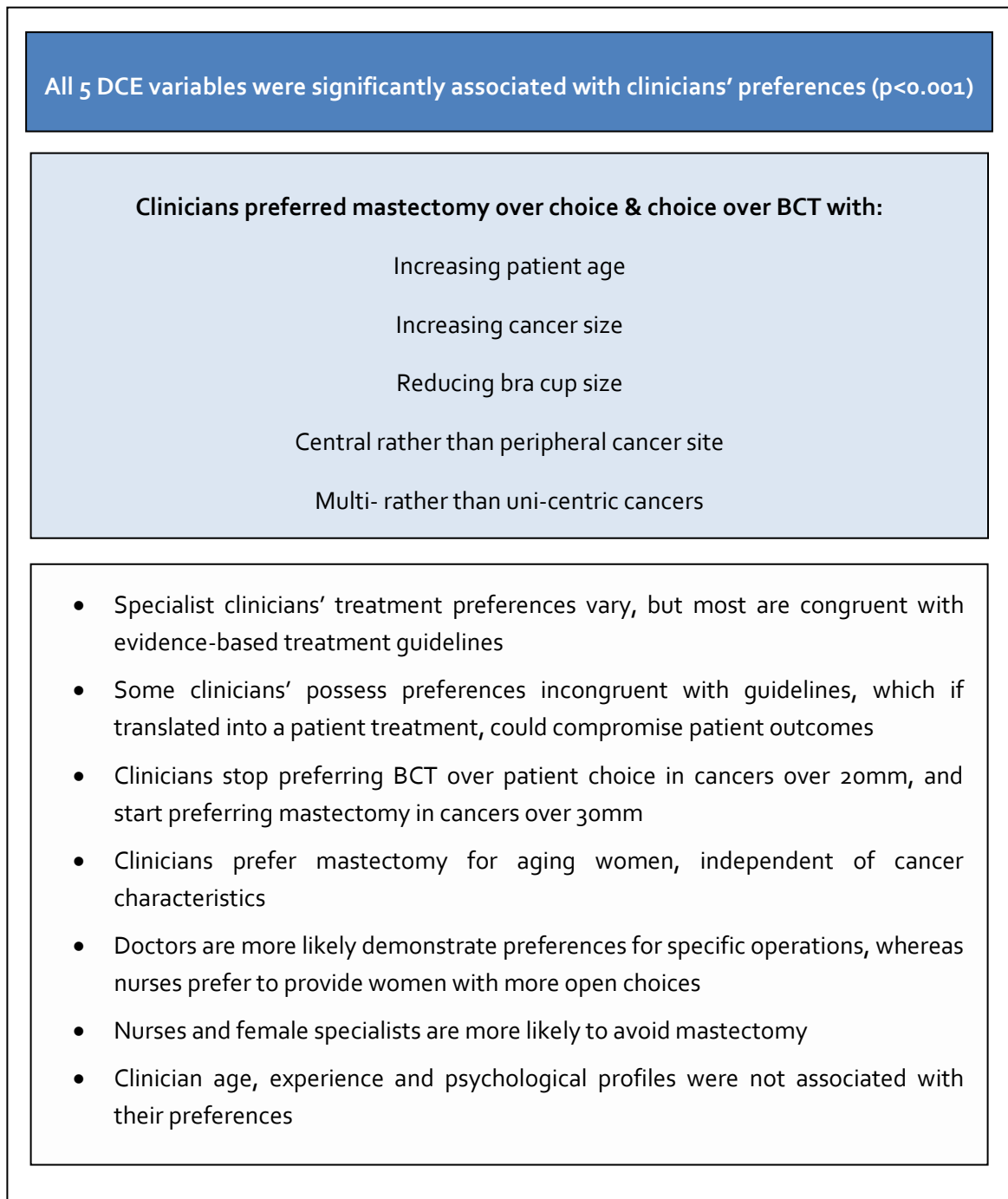


Clinician gender and occupational role were associated with preferences. Female gender and BCN role were associated with preference for choice and mastectomy aversion. The gender-role impact is difficult to separate. What might be interpreted as a gender effect may instead reflect occupational role; as BCNs were an all-female group, and participating doctors predominantly male. The occupational influence may reflect the role clinicians are often required to undertake in clinical practice; specific recommendations for doctors and supportive roles for nurses. No association was demonstrated between clinicians' psychological scale responses and preferences.

Another finding of the DCE was that, although the five DCE variables included in the DCE significantly influenced clinicians' treatment preferences ( $p < 0.001$ ), the low pseudo  $R^2$  value of 0.29, suggests these variables only account for 29% of the clinician responses. The majority (71%) were due to other factors not examined in the DCE.

Achieving greater understanding of clinicians' preferences and what influences these are important steps to understanding clinicians' impact over patient treatment decisions. DCE methodology holds promise for elucidating practice variation in wider healthcare contexts, where treatment variation and contention regarding best practice coexist.

FIGURE 3.7 Summary of findings of the specialist breast clinician DCE survey and psychological scale responses



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## Chapter 4

### Patient information needs and decision-making questionnaire (IDMQ)

#### Changing trends in the decision-making preferences of UK women with early breast cancer

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## Abstract

**Background** Women with early stage breast cancer are frequently offered a choice between BCT and mastectomy. Previous studies indicate a predominance of passive DMS among these UK patients. Study aim: To determine current UK DMS (preferred and achieved), DMS congruence and establish whether DMS are associated with operative choice and breast unit MR.

**Methods** This MREC approved study was conducted in three specialist breast units of a single large UK region, representing high, medium and low case-mix adjusted MRs. A postal questionnaire survey design was adopted utilising previously validated instruments.

**Results** Purposive sampling of 697 consecutive eligible patients (offered a choice between BCT and mastectomy), 356 (51%) completed questionnaires: Mean age 58.5 years (range 30.4-89.0), mean 6.9 weeks from surgery (range 1.3-48.6). Operation: 74% BCT (n=262), 26% mastectomy (n=94). Strikingly high proportions of active DMS demonstrated, particularly among the mastectomy (83% vs. 58%,  $p<0.001$ ) and high MR unit (80% vs. 54% and 52%,  $p<0.001$ ) groups. High concordance established between preferred and achieved DMS 61% (218/356); highest among active DMS (91%), and those choosing mastectomy (67% vs. 59%,  $p=0.070$ ).

**Conclusions** Greater proportions of active DMS were identified than in previous UK studies, especially among women choosing mastectomy and women from high MR units. The findings imply that providing greater autonomy in treatment selection to women suitable for BCT, may not reduce MRs.

## BACKGROUND

Over the past two decades healthcare provision has shifted from a paternalistic model towards a model where patients are viewed as partners in shared decision-making,(Department of Health 2001a;Department of Health 2001c;Department of Health 2008;Department of Health 2009;Rawling 1992;Royal College Of Surgeons Of England 2002)and providing patients with choices has become a recognised priority.(Association of Breast Surgery at BASO 2009;Blichert-Toft, Smola, Cataliotti, & O'higgins 1998;Department of Health 2001a;Department of Health 2001c;Department of Health 2009;General Medical Council 2008;Kaufmann, Morrow, von, & Harris 2010;National Collaborating Centre for Cancer 2009;Nattinger, Hoffman, Shapiro, Gottlieb, & Goodwin 1996;Nayfield, Bongiovanni, Alciati, Fischer, & Bergner 1994;Royal College Of Surgeons Of England 2002;Scarth, Cantin, & Levine 2002a;Scarth, Cantin, & Levine 2002b)

Patients' preferences for involvement in healthcare decision-making vary. Three main DMS are described; active, collaborative and passive; wanting to take control, share or defer making healthcare decisions. These are often assessed using adapted versions of a simple five point scale often attributed to Sutherland,(Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till 1989) but originally designed by Strull for use in a hypertensive outpatient study.(Strull, Lo, & Charles 1984) Its use was subsequently popularised by Degner who independently developed a tool with almost identical wording, but adopted a different administration technique.(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996;Beaver, Bogg, & Luker 1999;Davison & Degner 2002;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Hawley, Lantz, Janz, Salem, Morrow, Schwartz, Liu, & Katz 2007;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005;Luker, Beaver, Leinster, & Owens 1996a;Wallberg, Michelson, Nystedt, Bolund, Degner, & Wilking 2000) Degner's version (the Control Preferences Scale) published in 1992, involves a card sort technique: Participants are shown a series of paired cards depicting the scale options, from which they prioritise their PDMS and ADMS.(Degner & Sloan 1992) The various tools above utilise wording of the Control Preferences Scale, which is similar to the 5-point scale used in this study, and illustrated in figure 4.1. By convention the five items are collapsed into three for analysis; first two options are considered to represent an active DMS the third a collaborative DMS and the fourth and fifth passive DMS.(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996;Beaver, Bogg, & Luker 1999;Davison & Degner 2002;Gopal et al. 2005;Hawley, Lantz, Janz, Salem, Morrow, Schwartz, Liu, & Katz 2007;Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins

2004;Luker, Beaver, Leinster, & Owens 1996a;Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010;Wallberg, Michelson, Nystedt, Bolund, Degner, & Wilking 2000) Some use the convention of the first and fifth respectively active and passive DMS, and the middle three items collaborative.(Strull, Lo, & Charles 1984)

Studies conducted in the 1990's, reported women with breast cancer preferred and achieved predominantly passive or collaborative roles in the selection of their surgery.(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996;Bilodeau & Degner 1996;Luker, Beaver, Leinster, & Owens 1996b;Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010) This included the only previous UK breast cancer patient study (n=150) of treatment preferences. Using Degner's card sort technique, Beaver et.al. demonstrated 20% active, 28% collaborative and 52% passive PDMS.(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996) More recent literature suggests a probable shift in this groups PDMS toward more autonomous preferences;(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) more in keeping with levels seen in earlier studies among the healthy population.(Deber, Kraetschmer, & Irvine 1996;Degner & Sloan 1992;Levinson, Kao, Kuby, & Thisted 2005;O'Donnell & Hunskaar 2007a;O'Donnell & Hunskaar 2007b;Rothenbacher, Lutz, & Porzsolt 1997) However, the recent studies were conducted in other countries, therefore they may reflect geographic variation in preferences rather than a genuine shift in DMS over time. No recent UK data is available for comparison.

Improved satisfaction and reduced decision regret are identified among those achieving a more active DMS (even if it is not their PDMS), but the greatest benefits were demonstrated among those achieving their PDMS.(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) Many studies however demonstrate clinicians often misallocate patients' 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) which increases dissatisfaction 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;Rothenbacher, Lutz, & Porzsolt 1997)or asked to undertake a more active role than preferred.(Hack, Degner, & Dyck 1994;Hack, Degner, Watson, & Sinha 2006;Schain 1980). A large Canadian study (n=1012) among women with breast cancer found only 42% believed they achieved their PDMS.(Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a) There remains contention about whether an active ADMS per se or achieving congruence between ADMS and PDMS is preferable in seeking to optimise short and long term recovery, satisfaction and minimise regret. Hack's study among patients with breast cancer (n=250) suggests that achieving a more active DMS per se is beneficial; with statistically significantly better long term psychological adjustment, QoL, and superior physical and social functioning (at 3 years).(Hack, Degner, Watson, & Sinha 2006)

Information is a prerequisite for informed decision-making.(Bilodeau & Degner 1996;Blanchard, Labrecque, Ruckdeschel, & Blanchard 1988;Fridfinnsdottir 1997;Hack, Degner, & Dyck 1994) and Extensive information needs are often reported among patients with benign diagnoses(Cassileth, Zupkis, Sutton-Smith, & March 1980;Davis, Hoffman, & Hsu 1999;Deber, Kraetschmer, & Irvine 1996;Jenkins, Fallowfield, & Saul 2001;Jones, Pearson, McGregor, Gilmour, Atkinson, Barrett, Cawsey, & McEwen 1999;Strull, Lo, & Charles 1984) and those with cancer.(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, Trichtler, & Till 1989;Vogel, Bengel,

& Helmes 2008a) However, these are not necessarily associated with either the severity of illness(Davis, Hoffman, & Hsu 1999;Jenkins, Fallowfield, & Saul 2001) or PDMS.(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) Some employ information acquisition as a coping strategy, rather than a prelude to more active participation in decision-making.(Blanchard, Labrecque, Ruckdeschel, & Blanchard 1988;Cassileth, Zupkis, Sutton-Smith, & March 1980;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Hack, Degner, & Dyck 1994;Miller, Brody, & Summerton 1988)

It has been suggested that if women provided with more decision control MRs would fall; as given the choice most women would chose BCT. The evidence is however conflicting.(Collins, Moore, Clay, Kearing, O'Connor, Llewellyn-Thomas, Barth, Jr., & Sepucha 2009;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;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;Mastaglia & Kristjanson 2001;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Moyer & Salovey 1998;Schou, Ekeberg, Ruland, & Karesen 2002) Some studies demonstrate a significant preponderance to active ADMS and PDMS among patients having 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) others report the opposite.(Collins, Moore, Clay, Kearing, O'Connor, Llewellyn-Thomas, Barth, Jr., & Sepucha 2009;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;Moyer & Salovey 1998;Schou, Ekeberg, Ruland, & Karesen 2002;Street, Jr. & Voigt 1997)

The objectives of this component of the study were to establish the current nature of the DMSs of women recently diagnosed with breast cancer in the UK who were offered a choice of surgery. To establish how frequently women achieved their PDMS, and analyse how these were associated



with women's operative choices and their treating breast units' MR. The other objective was to investigate patterns of patient information needs and identify whether these were associated with patients' PDMS and ADMS, surgical treatment choice, or breast unit MR.

## **METHODS**

### **Setting**

#### **The identification and recruitment of three breast units demonstrating practice variation**

The audit phase of over 5,000 NHSBSP detected cancers presented in chapter 2, established that units case-mix and caseload did not account for the region's surgical variation. It also permitted the MR categorisation of hospital breast units for the in-depth phase of the study. The regions' specialist breast practice comprised 14 NHS hospital breast units and 11 NHSBSP screening units. All 14 breast units possessed similar practice guidelines and had similar access to radiotherapy and breast reconstruction. Following correction of their raw MRs for case-mix, three were purposively invited to participate in the in-depth components of the study; one each to represent the range of treatment variation - high, medium and low MR.

The audit phase of the study was conducted in two phases; an initial unit recruitment phase (using three years of data 1997-2001), and a subsequent full audit phase (1997-2003) which increased the case numbers and provided the power of the study; the findings of which are presented in chapter 2. The biphasic approach was necessitated by the time lag between audit data collection and availability and the attainment of project funding, and ethics and research governance processes involved in conducting the overall study in 14 hospital breast units.

#### *Unit Inclusion criteria for the in-depth phase of the study*

Specialist hospital breast units demonstrating high, medium or low MR practice, and with a consistent and stable specialist workforce over the period of the study (audit to completion); 1997 to 2004).

### *Exclusion criteria Unit for the in-depth phase of the study*

Units undergoing substantial changes in workforce between the recruitment phase of the audit (1997-2001) and unit recruitment to the in-depth phases of the study.

The exclusion criteria meant that unit 10 was not invited to participate in this phase, despite demonstrating the highest case-mix adjusted MR among all cancers and those in the less than 15mm diameter subgroup. Between the audit and in-depth unit phases of the study, the unit had undergone dramatic workforce changes; with approximately half the clinicians changing. The in-depth study could therefore not be considered reliably representative the high MR practice pattern being investigated.

The observed: expected MRs of the participating high (unit 4), medium (unit 3) and low (unit 6) MR units were 1.30 (95% CI 0.88-1.85), 1.03 (95% CI 0.78-1.35) and 0.48 (95% CI 0.28-0.75) respectively; based on the case-mix adjustment of cancers less than 15mm diameter (n= 1399) diagnosed through the region's NHSBSP (1997-2001); and 1.13 (95% CI 1.00-1.28), 1.15 (95% CI 0.98-1.35) and 0.66 (95% CI 0.58-0.76) respectively for all cancers diagnosed through the region's NHSBSP (1997-2001). The full data (1997-2003) are presented in chapter2.

All units had similar treatment guidelines and served a mixed rural and urban population. The low MR unit was based in a teaching hospital with 1,963 beds, NHSBSP population of 120,000 women per year, 5 full time consultants, 6 non-consultant grade breast doctors and 6 BCNs. Their radiotherapy services were located in a different hospital of the same city 3.4 miles away. The medium MR unit was based in a district general hospital with 609 beds, NHSBSP population of 40,000 women per year, 2 full time consultants and 2 BCNs. Their radiotherapy services were located in the adjacent city 14.3 miles away. The high MR unit was based in a district general hospital with 1,101 beds, NHSBSP population of 78,000 women per year, 3 full time consultants and 7 BCNs. Their radiotherapy services were located in a different hospital of the same city 3.7 miles away. The demographics of the three breast units recruited to this phase of the study as shown in table4.1

TABLE 4.1 Breast unit demographics

	MR unit		
	Low	Medium	High
<b>Hospital type</b>	Teaching	District general	District general
<b>No. hospital beds<sup>1</sup></b>	1,963	609	1,101
<b>Breast screening population</b>	120,000	40,000	78,000
<b>Team size</b>	large	small	medium
<b>Total permanent specialist clinicians (n)</b>	17	4	10
<b>Consultants (n)</b>	5	2	3
<b>BCNs (n)</b>	6	2	7
<b>BCN (Full Time Equivalent)</b>	4.2	2	3.8
<b>BCN : screening population</b>	1:28,571	1:20,000	1:20,526
<b>Distance and approximate journey time breast unit to radiotherapy unit<sup>2</sup></b>	3.4 miles Time: 6 min  Same city different hospital	14.3 miles Time: 22 min  Adjacent city	3.7 miles Time: 7 min  Same city different hospital
<b>Recruitment period (months)</b>	21	22	27
<b>No. patients approached for IDMQ</b>	235	139	260
<b>No. approached/month<sup>3</sup></b>	11.20	6.32	9.64
<b>No. cancers diagnosed treated by surgery in 2004</b>	675	140	368
<b>% patients approached from no. treated by surgery</b>	19.9%	54.12%	31.43%
<sup>1</sup> Average daily number of available beds by ward classification, NHS organisations in England, 2007-08. Published 26 September 2008, from <a href="http://www.performance.doh.gov.uk/hospitalactivity/data_requests/download/beds_open_over_night/bed_o8_detail.xls">http://www.performance.doh.gov.uk/hospitalactivity/data_requests/download/beds_open_over_night/bed_o8_detail.xls</a> <sup>2</sup> calculated breast unit site to radiotherapy unit site by <a href="http://www.theaa.com/route-planner">http://www.theaa.com/route-planner</a> <sup>3</sup> mean calculated on total no. patients approached and recruitment period			

## Questionnaire setting and sample

The questionnaire sample size was based on published literature available at the time of study design: Assuming a collaborative DMS of 50% at each breast unit, to estimate this proportion within +/- 10% (i.e. 95% confidence interval, 40 to 60%) required approximately 100 responders per breast unit. To gain 100 completed responses per unit, it was estimated 200 patients would need to be approached from each breast unit; allowing for a 50% response rate and a clustering effect, whereby women treated by a specific breast unit are expected to be more similar to other women treated by that particular breast unit, than they are to women treated by other breast units. If there were ordering across the three (high, medium and low MR) breast units with respect to the proportions of collaborative DMS at each unit, then with a sample size of 100 per unit, a 0.05 two-sided Chi-square test of trend in proportions would have 80% power to detect a difference in proportions characterised by this trend, assuming collaborative DMS proportions of 0.39, 0.50 and 0.61 respectively in the three breast units for an average collaborative DMS proportion of 0.50 across the 3 sites.

Purposive sampling was adopted: Consecutive eligible women were purposively recruited from three breast units purposively recruited to reflect the spectrum of surgical management variation; high, medium and low case-mix adjusted MRs.

### *Patient eligibility criteria*

Eligibility for inclusion in the study was defined as any female breast cancer patient within one month of diagnosis of breast cancer, capable of providing informed consent to participate in a research study, who had been offered a choice of initial therapeutic surgery (BCT and mastectomy) by a specialist surgical consultant or a doctor of longstanding involvement (i.e. Staff Grade, Associate Specialist or General Practice Clinical Assistant) in the recruiting breast unit. The wording 'offered a choice of initial therapeutic surgery (BCT and mastectomy)' was assumed synonymous with patients who did not require mastectomy on clinical grounds. However, during the recruitment phase, very low recruitment rates within the low MR prompted exploration of the eligibility criteria wording with the unit's clinicians. The eligibility criteria wording was subsequently amended to 'any female breast cancer patient within one month of diagnosis of

breast cancer, capable of providing informed consent to participate in a research study, offered surgery, who did not require a mastectomy on clinical grounds’.

Exclusion criteria included patients advised to have mastectomy on clinical grounds and those diagnosed with a current acute psychiatric illness liable in the opinion of the patient’s doctor to affect the patient’s ability to give fully informed consent. While it could be argued all newly diagnosed patients should be included in the study, it was considered inappropriate to explore patients’ involvement in decision making, when on clinical grounds this particular group were advised to have a mastectomy and not provided an opportunity to participate in the decision making experience being explored. There was concern this could potentially cause psychological distress.

Patients were not excluded on the basis of language, and arrangements were made for conversion of the study documents into the 5 main community languages (i.e. Arabic, Bengali, Cantonese, Somali, Urdu) if required.

#### *Patient identification and recruitment*

Eligible women were identified prior to initial therapeutic surgery by members of their treating breast team, and invited to participate in the study as soon as possible following their initial therapeutic surgery, either in person or by post. The recruitment pack contained an introductory letter from their consultant surgeon, a patient information leaflet, a study reply form to indicate their preference for participating and a freepost envelope.

Those agreeing to participate completed a consent form and study reply form indicating whether or not they wished to participate in the study. Once a positive response was received, patients were posted the questionnaire and consent form to confirm participation in the study and permit access to their medical record (to determine their surgical treatment details). Patients were asked to return the completed documents to the researchers in the enclosed freepost envelope. See Appendix 6.

## Instruments

A self-report postal information needs and decision making questionnaire (IDMQ) was utilised to identify patients' DMS and information needs. Adapted versions of two validated instruments used widely and internationally among cancer patients were utilised. A five-point scale for rating patient's preferences for participation in treatment decision-making which was adapted from Strull's original tool (Strull, Lo, & Charles 1984) was used to identify patients' PDMS and ADMS. Cassileth's 12-item information styles questionnaire (Cassileth, Zupkis, Sutton-Smith, & March 1980) was used to document patients' information needs. Figure 4.1 and table 4.8 illustrate the respective instruments. A further section of the questionnaire captured information on patient age, the patients' dates of diagnosis and surgery, type of initial therapeutic surgery undertaken and the surgical options discussed, plus the clinician role of the doctor providing information and options.

In the DMS section, patients were asked to separately indicate which particular statements most accurately described the role they preferred in deciding their breast cancer surgery, and the role they achieved. By convention the first two responses are considered active, the third collaborative, and the last two passive.

In the information needs section of the instrument, patients were asked to indicate the level of their information need on a three-point scale regarding each of the 12 items at the time of decision-making; I absolutely need this information, I would like this information, I do not want this information.

All data collected were anonymised and stored securely in password-protected databases. The data were analysed in SPSS version 12.0, using frequency, Chi-square, and one way ANOVA.

FIGURE 4.1 Decision-making styles instrument

Preferred DMS version

Please tick the box next to the statement that best describes the situation that you believe would be IDEAL.	$\mu$	$\partial$
I prefer to make the final selection about which treatment I will have.	A	A
I prefer to make the final selection of my treatment after seriously considering my doctor/nurse's opinion.	A	C
I prefer that my doctor/nurse and I share responsibility for deciding which treatment is best for me.	C	C
I prefer that my doctor/nurse makes the final decision about which treatment will be used, but seriously considers my opinion.	P	C
I prefer to leave all decisions regarding my treatment to my doctor/nurse.	P	P

Achieved DMS version

Please tick the box next to the statement that best describes the situation that ACTUALLY HAPPENED during your consultation(s).	$\mu$	$\partial$
I made the final selection about which treatment I had.	A	A
I made the final selection of my treatment after I had seriously considered my doctor/nurse's opinion.	A	C
My doctor/nurse and I shared the responsibility for deciding which treatment was best for me.	C	C
My doctor/nurse made the final decision about which treatment was used, but seriously considered my opinion.	P	C
My doctor/nurse made all the decisions regarding my treatment.	P	P

A = Active DMS  
C = Collaborative DMS  
P = Passive DMS

Classification convention  
 $\mu$  most commonly adopted  
 $\partial$  less commonly adopted

## FINDINGS

Between September 2003 and December 2005, 697 eligible women were identified and approached to participate in the study, 373 patients agreed to participate, 356 completed questionnaires were received (51% response rate). The mean age of the respondents was 58.5 years (range 30.4-89.0), 11% were over 70. The mean time between initial therapeutic surgery and return of completed questionnaire was 6.9 weeks (range 1.3-48.6 weeks); although the majority (98.9%, 352/356) returned the questionnaire within 24 weeks of their surgery. Overall, within the three breast units 74% (95% CI: 69-78%) of the responders underwent BCT (n=262) and 26% (95%CI 22-31%) mastectomy (n=94). Two of those undergoing mastectomy had immediate breast reconstruction; one from the high and one from the low rate unit (age 62.5 and 60.4 years respectively). Reconstruction was equally available in all the units at the time of the study. But over the study period few reconstructions were performed and these were almost exclusively done by plastic and reconstructive surgeons. Table 4.2 demonstrates the cancer size distribution of low and high MR unit IDMQ participants; demonstrating the patient populations had similar cancer size characteristics. Table 4.3 demonstrates the number of patient participants by age and type of initial surgery.

TABLE 4.2 IDMQ patients' cancer size characteristics by unit (low and high MR units)

Radiological cancer size	Low MR unit		High MR unit	
Size (mm)	n	%	n	%
≤10	33	29.7%	41	29.3%
10-19	49	44.1%	62	44.3%
20-29	19	17.1%	28	20.0%
30-39	7	6.3%	8	5.7%
40-49	1	0.9%	1	0.7%
>50	2	1.8%	0	0%
Missing data	2		17	
	Range 0-55, Mean 30.69, Median 14, mode 20		Range 0-40, Mean 15.49, Median 15, mode 30	



TABLE 4.3      Number of patient participants by age and type of initial surgery

		Patient Age			Total
		<50 yrs	50-70 yrs	>70 yrs	
<b>Initial therapeutic treatment</b>	BCT n (%)	45 (17.2%)	193 (73.7%)	24 (9.1%)	262 (74%)
	Mastectomy n (%)	23 (24.5%)	57 (60.6%)	14 (14.9%)	94 (26%)
<b>Total n (%)</b>		68 (100.0%)	250 (100.0%)	38 (100.0%)	356 (100%)
<b>Mean age of women having BCT = 58.3 (range 30.4 – 89.0 years)</b> <b>Mean age of women having mastectomy = 58.8 (range 33.7 - 80.0years)</b>					

## Decision-Making Styles

Table 4.4 demonstrates patients' preferred versus achieved DMS, and the concordance between their PDMS and ADMS. Overall, 61% (218/356) agreement was observed between patients' PDMS and ADMS (kappa 0.39  $p=0.001$ ). When women failed to achieve their PDMS, they tended to adopt more active (29.5%, 105/356) than passive roles (9.3%, 33/356). The attainment of patients' PDMS was associated with their PDMS; the greatest concordance being demonstrated among those preferring active roles (91.0%, 131/144). Those preferring either collaborative or passive roles were less likely to achieve their PDMS; 53.0% of those preferring a collaborative role in the selection of their surgery actually had an active role, and 31.1% of those preferring a passive role had an active role.

TABLE 4.4 Preferred versus achieved decision-making styles

		Preferred decision-making style (PDMS)			Total
		Active	Collaborative	Passive	
Achieved decision-making style (ADMS)	Active n (%)	131 (91.0%)	80 (53.0%)	19 (31.1%)	230 (64.6%)
	Collaborative n (%)	4 (2.8%)	51 (33.8%)	6 (9.8%)	61 (17.1%)
	Passive n (%)	9 (6.3%)	20 (13.2%)	36 (59.0%)	65 (18.3%)
Total n (%)		144 (100.0%)	151 (100.0%)	61 (100.0%)	356 (100%)
The black shaded cells on the diagonal indicate perfect agreement between the PDMS and ADMS.					
Kappa statistic for agreement = 0.39, $p<0.001$ .					

Concordance between patients preferred and ADMS was independent of operation choice ( $p=0.070$ ) and breast unit MR ( $p=0.533$ ). However there was a non-significant a trend toward greater concordance between PDMS and ADMS among those choosing mastectomy (67% vs. 59%), and the achievement of more passive roles than preferred among the BCT group (11% vs. 3%). Table 4.5 illustrates patients' PDMS versus ADMS by operation choice, and demonstrates these trends.

TABLE 4.5 Preferred versus achieved decision-making styles by operation choice

				Preferred Decision-making style (PDMS)			Total
				Active n (%)	Collaborative n (%)	Passive n (%)	
Operation choice	Mx	Achieved Decision- making style (ADMS)	Active	52 (96.4%)	18 (69.3%)	8 (57.1%)	78 (83.0%)
			Collaborative	1 (1.8%)	7 (26.9%)	2 (14.3%)	10 (10.6%)
			Passive	1 (1.8%)	1 (3.8%)	4 (28.6%)	6 (6.4%)
			Total	54 (100%)	26 (100%)	14 (100%)	94 (100%)
	BCT	Achieved Decision- making style (ADMS)	Active	79 (87.8%)	62 (49.6%)	11 (23.4%)	152 (58.0%)
			Collaborative	3 (3.3%)	44 (35.2%)	4 (8.5%)	51 (19.5%)
			Passive	8 (8.9%)	19 (15.2%)	32 (68.1%)	59 (22.5%)
			Total	90 (100%)	125 (100%)	47 (100%)	262 (100%)

The black shaded cells on the diagonal indicate perfect agreement between the PDMS and ADMS.

Chi square test p=0.070.

Table 4.6 summarises patients' ADMS by operation choice, and case-mix adjusted breast unit MR. Overall, 64.6% (231/356, 95% CI: 60 to 70%), of the sample achieved an active DMS. Active decision-making was particularly predominant among those women choosing mastectomy (83.0%), rather than those choosing BCT (83.0% vs. 58.0%, 25% difference, CI 14 to 34%,  $p<0.001$ ), and those from the high MR unit than those from the low & medium MR units (79.6% vs. 52.2% and 53.5% respectively,  $p<0.001$ ). Women choosing mastectomy and those from the high MR unit, also preferred a significantly more active DMS compared with those choosing BCT, and those from the medium and low MR units ( $p<0.001$  and  $p=0.015$  respectively).

TABLE 4.6 Summary of achieved decision-making style (ADMS) by operation choice, and case-mix adjusted breast unit MR

	Decision-making style (DMS)			
	Active	Collaborative	Passive	
<b>Overall achieved DMS (n=356)</b>	64.6%	17.1%	18.3%	<b>p=0.001</b>
<b>Operation choice and achieved DMS</b>				
<b>BCT choice (n=262)</b>	58.0%	19.5%	22.5%	
<b>Mx choice (n=94)</b>	83.0%	10.6%	6.4%	<b>p&lt;0.001</b>
<b>Breast Unit MR and achieved DMS</b>				
<b>Low MR (n=113)</b>	52.2%	23.0%	24.8%	
<b>Medium MR (n=86)</b>	53.5%	22.1%	24.4%	
<b>High MR (n=157)</b>	79.6%	10.2%	10.2%	<b>p&lt;0.001</b>
<b>P-values from chi-squared test.</b>				

Table 4.7 illustrates patients' ADMS by operation choice and case-mix adjusted unit MR; highlighting the predominance of the active DMS among patients choosing mastectomy treated at the high MR breast unit. Those choosing mastectomy and those from the high MR unit, also preferred a significantly more active DMS compared with those choosing BCT, and those from the medium and low MR units (p<0.001 and p=0.015 respectively).

TABLE 4.7 Achieved decision-making style (ADMS) by operation choice and case-mix adjusted breast unit MR

				Achieved Decision-making style			Total
				Active n (%)	Collaborative n (%)	Passive n (%)	n (%)
Breast unit MR	Low	Type of surgery	Mx	16 (59.3%)	5 (18.5%)	6 (22.2%)	27 (100.0%)
			BCT	43 (50.0%)	21 (24.4%)	22 (25.6%)	86 (100.0%)
			Total	59 (52.2%)	26 (23.0%)	28 (24.8%)	113 (100.0%)
	Medium	Type of surgery	Mx	26 (89.7%)	3 (10.3%)	0 (0%)	29 (100.0%)
			BCT	20 (35.1%)	16 (28.1%)	21 (36.8%)	57 (100.0%)
			Total	46 (53.5%)	19 (22.1%)	21 (24.4%)	86 (100.0%)
	High	Type of surgery	Mx	36 (94.7%)	2 (5.3%)	0 (0%)	38 (100.0%)
			BCT	89 (74.8%)	14 (11.8%)	16 (13.4%)	119 (100.0%)
			Total	125 (79.6%)	16 (10.2%)	16 (10.2%)	157 (100.0%)
The percentage figures within the brackets correspond to the proportions across each row of the table							

The study was not designed to look at age as an independent variable, however younger women were found to prefer more active roles in decision-making ( $p=0.041$ ), as illustrated by the mean age of the DMS groups; active 57.4 years, collaborative 58.4 years and passive 61.1 years. However, age was not associated with the ADMS ( $p=0.252$ ), operation choice ( $p=0.716$ ) or breast unit MR ( $p=0.371$ ). Table 4.8 illustrates the mean ages of the PDMS and ADMS styles.

TABLE 4.8 Achieved and preferred decision-making style (DMS) by patient age.

	DMS			
	Mean age (standard deviation) at operation			
	Active	Collaborative	Passive	p=
<b>Achieved DMS (n=356)</b>	58.0 (9.1)	58.5 (8.9)	60.2 (12.0)	<b>p=0.252</b>
<b>Preferred DMS (n=356)</b>	57.4 (9.9)	58.4 (8.7)	61.1 (11.0)	<b>p=0.041</b>

### Information needs

Consistent with previous studies among cancer patients, the patients participating in this study expressed high information needs. The majority stating they 'absolutely needed' (items 1 to 6 and 9) or 'would like' (items 7, 8, and 10 to 12 to 6) all the information items presented in the instrument. The only item where the need for information was expressed less consistently was item 12; examples of cases where the surgery has not been effective.

There was however a trend toward the desire for greater information related to specific information items among those who preferred an active decision-making style (items 1 and 3; possible side effects and whether or not the diagnosis was cancer,  $p=0.051$  and  $p=0.028$  respectively), those choosing BCT (item 6; exactly how the surgery will affect their body,  $p=0.049$ ) and a possible trend among those from the higher MR units (items 11 and 12; examples of cases where the surgery has been or not been effective  $p=0.060$  and  $p=0.066$  respectively). The full results are presented in full in table 4.9.

TABLE 4.9. Information needs questionnaire items, responses and associations with breast unit MR, treatment, and preferred and achieved Decision-Making Style (DMS).

INFORMATION ABOUT...	Level of information need				Association with			
	Absolutely need (%)	Would like (%)	Do not want (%)	Missing (%)	Unit MR p=	Treatment p=	PDMS p=	ADMS p=
1. What all the possible side effects are.	62.4	36.8	0.8	0	0.452	0.245	0.051	0.377
2. What the surgery will accomplish.	77.5	21.9	0.6	0	0.614	0.681	0.069	0.169
3. Whether or not it is cancer.	88.2	11.2	0.6	0.3	0.414	0.740	0.028 *	0.130
4. What the likelihood of cure is.	78.1	20.5	1.1	0.3	0.227	0.979	0.336	0.201
5. Which parts of the body will be involved?	77.2	21.9	0.6	0.3	0.615	0.742	0.088	0.292
6. Exactly how the surgery will affect my body.	73.0	26.4	0.6	0	0.720	0.049 *	0.114	0.553
7. What the daily (or weekly) progress is.	41.9	55.6	2.2	0.3	0.626	0.182	0.459	0.983
8. What the specific medical name of the illness is.	36.5	58.4	4.2	0.8	0.202	0.288	0.182	0.213
9. Whether it is inherited.	57.3	40.7	2.0	0	0.474	0.301	0.727	0.251
10. How effective the surgery has been for other patients	38.2	57.0	4.8	0	0.381	0.140	0.184	0.626
11. Examples of cases where the surgery has been effective.	28.1	58.7	13.2	0	0.060	0.925	0.646	0.757
12. Examples of cases where the surgery has not been effective.	19.9	47.8	32.0	0.3	0.066	0.911	0.217	0.911
*p<0.05								

## CONCLUSION

Using validated tools with a track record in this context,(Cassileth, Zupkis, Sutton-Smith, & March 1980;Strull, Lo, & Charles 1984) this study demonstrates a significant shift in the DMS of UK women with breast cancer eligible for surgical choices. They indicate the majority women want to be comprehensively informed about their diagnosis and options, and over 80% want to participate in selecting their breast cancer surgery (active or collaborative). Only a minority wanted clinicians to make decisions on their behalf. This group of participants preferred and achieved more active roles than demonstrated in previous UK(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996) or international studies.(Janz, Wren, Copeland, Lowery, Goldfarb, & Wilkins 2004;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005;Mastaglia & Kristjanson 2001) The active shift was amplified among those choosing mastectomy ( $p<0.001$ ) and those from the high MR unit (active PDMS  $p=0.015$ , active ADMS  $p<0.001$  respectively). Most previous studies demonstrate more active DMS among the BCT group.(Degner & Sloan 1992;Mastaglia & Kristjanson 2001) But a more recently published study report findings analogous with ours;(Davison & Degner 2002) indicating mastectomy will continue to be chosen by a subgroup of women given choices.

The evidence suggests when patients achieve their preferred or an active role in decision making they are more satisfied with both their treatment and the decision making process, and possess less regret,(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) and that this is amplified when congruence between PDMS and ADMS is achieved.(Charles, Whelan, & Gafni 1999a) The majority of patients in the study either achieved their preferred or a more active role. Only 9.3% achieved more passive roles than preferred. Highest rates of concordance were demonstrated among those preferring active roles. Where discrepancies existed, passives were shifted toward more active roles, and collaboratives shifted in either direction. The latter finding is consistent with other studies published since the onset of this study.(Vogel et al. 2008b)

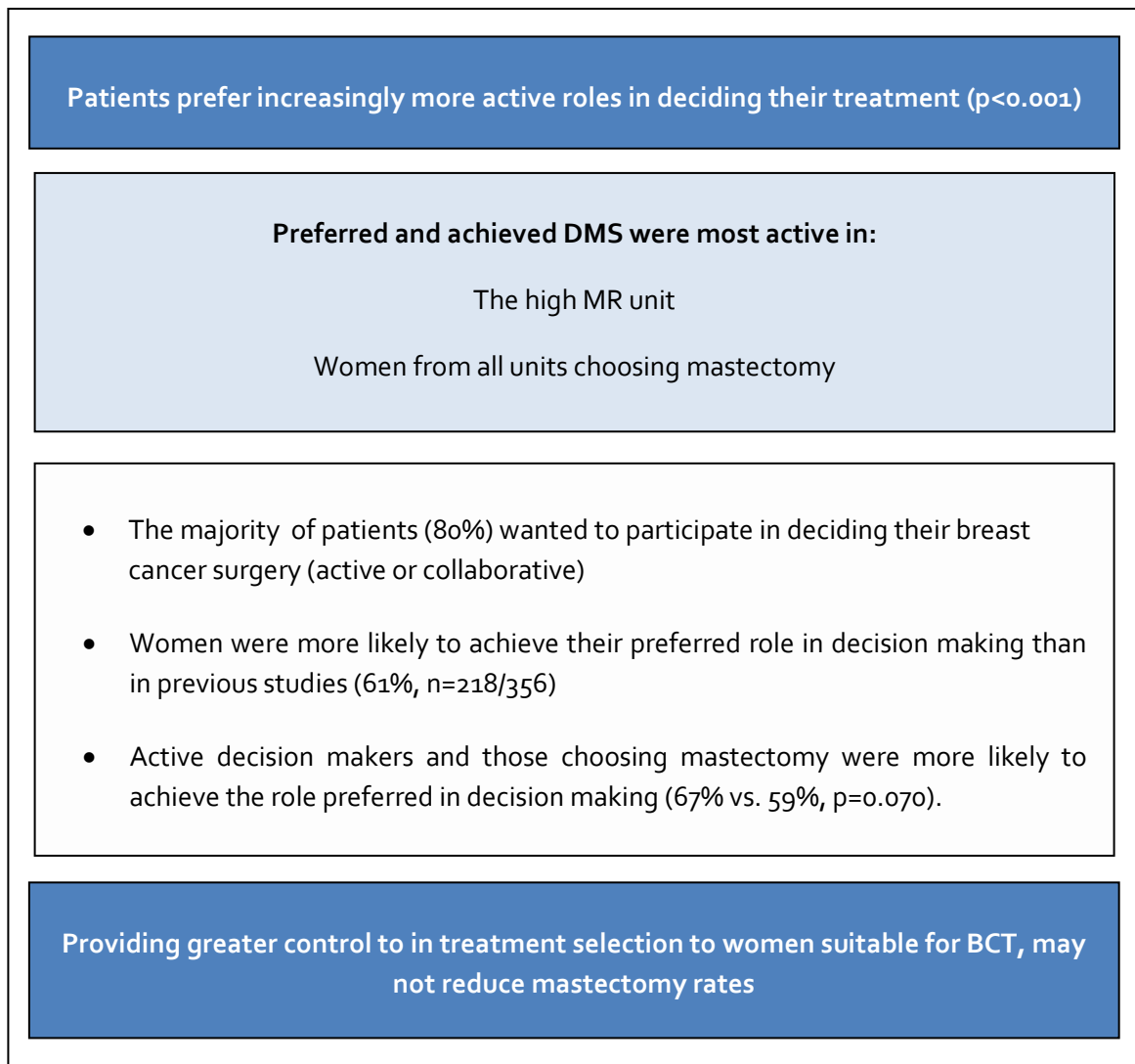
In accord with other studies among cancer patients, our participants displayed high information needs. These were predominantly unrelated to their PDMS or ADMS, their units' MR and



treatment decision. A few exceptions were noted: the BCT group wanted more information about the impact of surgery on their body ( $p=0.049$ ), and 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). The findings are summarised in figure 4.2.

The limitations of the questionnaire include its administration after the decision-making episode and the overall response rate of 51%. These are explored in the discussion chapter. Our response rate is however comparable with similar studies. Such limitations may affect the generalizability of the study; as with all research, the findings may be characteristic only of those participating in the research study.

FIGURE 4.2 Summary of DMS and information need findings



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## Chapter 5

### Clinician semi-structured interviews

**Why do hospital mastectomy rates vary? A qualitative study  
of clinicians' attitudes to surgical decision making for women  
with early breast cancer**

---

## **Abstract**

**Background** Widespread variation exists in hospital breast unit MRs. Clinicians are known to exert a prominent influence over treatment, but the mechanism and intent are poorly understood. The aim of this component of the study was to explore the possible association between MRs and clinician beliefs and decision making approaches.

**Methods** Semi-structured interviews were conducted with 26/31 specialist clinicians from three hospital breast units with high, medium and low (case-mix adjusted) MRs from a single UK region; 13 BCNs and 13 doctors. Interviews were recorded, transcribed verbatim and analysed using 'Framework'.

**Findings** Four key themes defined breast units' decision making culture and were associated with variation in hospital breast unit MRs; breast unit ethos, definition of eligibility for choices, clinician beliefs and routine processes.

The four themes were mutually interdependent, with the overall ethos dominant. Clinicians from the different breast units described an ethos central to their practice at individual and unit level. These were either primarily outcome-based with a focus on mastectomy avoidance (low MR unit) or primarily process-based, focussed on patient involvement in decision making (medium and high MR units). These defined the group of patients clinicians identified as suitable for choices. The ethos was associated with specific clinician beliefs (regarding clinician-patient roles in decision making, optimum management, patient preferences and decision making capacity); and were reinforced by the units' routine processes (offering options, providing information and recommending treatment). Their effects were either exacerbated or tempered by decision support and timescales provided.

**Conclusions** This chapter reports new findings which elucidate some of the overt and subtle, interdependent clinician and breast unit factors associated with variation in hospital MRs. Although some individual variation was noted, consistent distinct differences were observed between different breast units' clinicians. In the units studied, lower MRs were associated with a preference for BCT and a more paternalistic approach to consultations and decision making dominated by recommendations, and less provision and support of shared decision making, which was compounded by rapid timescales to consent.

## BACKGROUND

The UK's DoH,(Department of Health 2001a;Department of Health 2001c;Department of Health 2009) Royal College of Surgeons on England(Royal College Of Surgeons Of England 2002) and GMC guidelines(General Medical Council 2008) regarding informed consent to medical treatment are most consistent with a patient-centred consultation style and shared decision making approach. Evidence-based breast cancer treatment guidelines state clinicians should offer a choice of BCT and mastectomy to patients, when BCT is not contraindicated;(Association of Breast Surgery at BASO 2009;Kaufmann, Morrow, von, & Harris 2010;Scarth, Cantin, & Levine 2002a) reflecting the shift from paternalism to partnership.(Department of Health 2001a;Department of Health 2001c;Department of Health 2008;Department of Health 2009;Rawling 1992;Royal College Of Surgeons Of England 2002) Such guidelines were designed to facilitate maximal patient control over decisions without compromising mortality and morbidity.(Fisher, Anderson, Bryant, Margolese, Deutsch, Fisher, Jeong, & Wolmark 2002;van Dongen, Voogd, Fentiman, Legrand, Sylvester, Tong, van der, Helle, van Zijl, & Bartelink 2000) This is usually interpreted as choice for uni-focal or multi-centric cancers up to 4-5cm diameter with no contraindications to radiotherapy.

Despite this, the surgical treatment of this common cancer remains highly variable(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;Monypenny 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) with no clear explanation for it. Patients' healthcare decisions are subject to many influences related to patient concerns and fears.(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) The evidence also suggests patients' decisions are influenced by clinicians' overt recommendations and patients' perceptions of their preferences,(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) along with patients' perception of treatments curative potential.(Katz, Lantz, & Zemencuk 2001;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Smitt & Heltzel 1997) Although limited detail is available from these predominantly audit-based studies. At the onset of this study, limited information was available about clinicians' preferences and recommendations. Most was based on quantitative methodologies and theoretical questioning. Iscoe suggested a 'hospital affect'(Iscoe, Goel, Wu, Fehringer, Holowaty, & Naylor 1994) and quantified its degree of impact, but did not define the factors causing it. Some have suggested clinician preferences are associated with clinician characteristics; such as experience level,(McKinlay, Burns, Durante, Feldman, Freund, Harrow, Irish, Kasten, & Moskowitz 1997) time since qualification,(Goel, Olivotto, Hislop, Sawka, Coldman, & Holowaty 1997) gender,(Gilligan, Neuner, Sparapani, Laud, & Nattinger 2007;Mandelblatt, Berg, Meropol, Edge, Gold, Hwang, & Hadley 2001;Schou, Ekeberg, Ruland, & Karesen 2002) academic affiliation(Goel, Olivotto, Hislop, Sawka, Coldman, & Holowaty 1997;Porter & McMulin-Tait 2004) and medico-legal awareness.(McKinlay, Burns, Durante, Feldman, Freund, Harrow, Irish, Kasten, & Moskowitz 1997) However, most provided little detail and insufficient information, to permit understanding of the factors or mechanism underlying the influence. Also, most studies were conducted among convenience clinician samples rather than specialists.(Collins, Kerrigan, & Anglade 1999;Ende, Kazis, & Moskowitz 1990;Porter & McMulin-Tait 2004) So although interesting, they are of limited value, as revealed preferences are unlikely to affect specialist practice.(Collins, Kerrigan, & Anglade 1999;McKinlay, Burns, Durante, Feldman, Freund, Harrow, Irish, Kasten, & Moskowitz

1997) Additionally, studies to date investigating clinicians' impact on patient treatment have focussed on doctors; BCNs been neglected, but represent a potentially key clinician group in this decision making context.

As well as limited information on the relevant clinician stakeholders' preferences, there is minimal information about the mechanism by which clinician preferences and influences are mediated. The evidence suggests clinicians' consultations are the key encounters through which an influence is mediated. But there is sparse specific relevant information on how preferences manifest within them, or how they impact on patient decisions in the context of wider non-clinician/unit influences.

Much has been written about different styles of communication (doctor vs. patient-centred) and healthcare decision making (paternalism, shared and informed choice),(Coulter 1999;Coulter, Entwistle, & Gilbert 1999;Deadman, Leinster, Owens, Dewey, & Slade 2001;Elwyn, Edwards, Gwyn, & Grol 1999;Elwyn, Gray, & Clarke 2000;Elwyn 2008;Fallowfield, Hall, Maguire, Baum, & A'Hern 1994a;Hack, Degner, Watson, & Sinha 2006;McWhinney 1989;Moyer & Salovey 1998;Silverman, Kurtz, & Draper 1998;Stewart 1995;Street, Jr. & Voigt 1997) and patients are recognised to prefer patient centred consultation styles.(Dowsett, Saul, Butow, Dunn, Boyer, Findlow, & Dunsmore 2000;Frederikson 1995;Lerman, Daly, Walsh, Resch, Seay, Barsevick, Birenbaum, Heggan, & Martin 1993;Maguire 1999;Vick & Scott 1998) However, the impact of these on patients' decisions especially in situations where there is no globally superior treatment (like the surgical treatment of breast cancer), are not well understood or documented. Patient-centred consultations encourage patient participation and seek to tailor explanations and discussion of the impact of the disease and treatment. Doctor-centred consultations and paternalistic decision making involve clinicians assuming the dominant role, are primarily disease focused and tend to exclude non-disease factors of potential importance to patients.(Charles, Gafni, & Whelan 1999b;Charles, Gafni, & Whelan 2000;Coulter 1999;Coulter, Entwistle, & Gilbert 1999;Elit, Charles, Gold, Gafni, Farrell, Tedford, Dal Bello, & Whelan 2003;Elwyn, Edwards, Gwyn, & Grol 1999;Elwyn, Gray, & Clarke 2000;Elwyn 2008;Gafni, Charles, & Whelan 1998;McWhinney 1989;Silverman, Kurtz, & Draper 1998) At the other end of the spectrum of decision making approaches is informed choice, where patients are given 'sufficient' information to make a choice but no guidance, and assumes patients play an active decisional role. These approaches suit some patients, but tend to be applied irrespective of patient PDMS. Between these extremes is

shared decision-making where patients and clinicians participate in two way information exchanges, the patient deliberates, has further discussions with their clinicians and others, they then declare their preference, and the parties agree a treatment plan. This form of decision making seems more patient-centred and suited to tailoring.

Lukes' theorised the existence of complex power relationships guiding behaviour and decisions, which Canter transposed into the clinician-patient interaction in healthcare. (Canter 2001; Lukes 1974) Three levels are suggested; first dimensional power involves clinicians blatantly controlling patients decisions or actions; second dimensional power involves clinicians' exerting their power in a more subtle ways by control agendas, deliberately steering interactions and subjugating patients through the provision of insufficient clinical time, poor ambience, poor listening skills etc.; and third dimensional power comprises clinicians exerting a widely pervasive, more imperceptible influence: As clinicians supply the medical knowledge underpinning patients' understanding and perceptions, they control patients' actions and choices, so patients can falsely believe they are behaving autonomously.

There is little published knowledge regarding treatment preferences of clinicians as individuals or as members of specialist teams within hospital breast units. There is also limited information regarding the beliefs and motivations underlying them, and how they are communicated to patients and influence decisions and therefore both hospital treatment rates and practice patterns, in the wider context of other non-clinician/unit influences. Other issues include; a lack of understanding of the message clinicians intend to communicate in these contexts; how overt or subtle do recommendations or preferences have to be for patients to perceive or comply with them; how systematic and intentional are recommendations or preference communications; and do clinicians working as part of a breast unit team hold similar preferences? This chapter describes the findings of interviews with specialist breast clinicians (doctors and nurses) exploring their treatment preferences and the breast cancer treatment decision making process from clinicians' subjective perspective, to identify the key themes associated with variation in breast unit practice patterns.



## METHODS

### Study design

Semi-structured qualitative interviews were chosen to explore how specialist clinicians influenced patients' choice of surgery (BCT or mastectomy). This methodology was chosen as it permits the acquisition of targeted rich data on pre-determined topics of interest, while synchronously permitting sufficient flexibility to capture allied emergent themes.

### Setting and sample – Breast unit recruitment

This component of the study was conducted in the same three purposively selected specialist hospital breast units as the patient questionnaire and interview components of the study, which are described in chapters 4 and 6; i.e. units representing high, medium and low case-mix adjusted MRs.

*Clinician inclusion criteria:* Any specialist BCN, surgical consultant or doctor of longstanding involvement in the breast unit (i.e. Staff Grade or Associate Specialist)

*Clinician exclusion criteria:* Non-specialist and non-permanent members of the breast team (including trainee surgeons who play only a transient role in the unit).

All 31 permanent specialist clinicians of the three breast units' were invited to participate in this component of the study. Potential participants were contacted via post, following an initial study recruitment meeting. The study invitation pack contained a covering letter, information sheet, study reply form and freepost envelope. Those indicating a willingness to participate in one to one interviews were contacted by the research team to arrange an interview at a time and place to suit the clinicians' convenience. Interviews were conducted with the 26 agreeing to participate. This group comprised 13 specialist doctors and 13 BCNs; of which 19 were female (13 BCNs, 3 consultant surgeons, 2 associate specialists and one GP clinical assistant) and 7 male (6 consultant surgeons and one GP clinical assistant). Non-responders included 2 BCNs, and 3 male doctors. Only one was a consultant surgeon who (at the onset of the study) gave his recent retirement as the reason for not participating. Table 5.1 outlines the occupational role, gender and breast unit of responders and non-responders.

TABLE 5.1 Breast unit and clinical role of responders and non-responders

		Low MR unit		Medium MR unit		High MR unit	
		Interviewed (female)	Approached	Interviewed (female)	Approached	Interviewed (female)	Approached
Clinician role	BCN	6 (6)	6	2 (2)	2	5 (5)	7
	Consultant surgeon	4 (2)	5	2	2	3 (1)	3
	Associate Specialist	2 (2)	2				
	GP Clinical Assistant	2 (1)	4				
	Total	14 (11)	(17)	4 (2)	(4)	8 (6)	(10)

## Data

The interview schedule was developed by the research team comprising experienced qualitative researchers, two surgeons, one BCN and two consumer representatives who had previously been diagnosed and treated for breast cancer. The interview schedule was piloted on one specialist consultant breast surgeon and one BCN from other breast units from the region. The final interview schedule was developed following minor amendments. The schedule was designed to explore the breast unit guidelines, structure and processes; including the process from assessment to diagnosis and consent at individual clinician and breast unit level. Questions were focussed on how decisions about patients' options were made, the content and style of information presentation in consultations; clinician thoughts about the surgical treatment of breast cancer and patient involvement in decision making in this context; and what they felt had the greatest influence over patient decision making. It also contained a critical incident technique, where clinicians were asked to describe interactions with active, collaborative and passive patients. The interview schedule and consent form are located in appendix 5.

Interviews lasted between 44 and 120 minutes (median 73 minutes), were digitally recorded and transcribed verbatim. Field notes of the interviews and communication with the clinicians were also kept.

### **Qualitative data analysis options**

At the time of study development, two forms of data analysis were commonly used in health and social services qualitative research; 'Framework' and computer assisted approaches such as QSR NUD\*IST. Computer assisted approaches were more commonly used and offered greater speed of analysis, but in our view offered less potential depth and flexibility of data analysis. Although more labour intensive and time consuming, it was felt Framework would permit us to remain grounded in the data throughout analysis; retaining the voice of the individual while crystallising their message. It would also assist the subsequent triangulation of the study data from the different methodologies and stakeholder perspectives. This was felt crucial to optimising understanding of a complex issue such as decision making. A comparison of the two potential analytical approaches considered (QSR NUD\*IST and 'Framework') is summarised in table 5.2.

### **Analytical approach (the 'Framework' approach)**

'Framework'(Pope et al. 2000;Richie et al. 2003;Ritchie and Lewis 2003) was used to analyse the interview transcripts and field notes generated by the study. This method of data analysis was chosen for both the clinician and patient interviews of the study in view of its capacity to; analyse large volumes of qualitative textural data in a rigorous, comprehensive and systematic but flexible way; synchronously permit the extensive exploration of the data within and across both themes and cases; and retain the link between each comment and the source data to permit deeper analysis in the context of the interview flow. See table 5.2.

TABLE 5.2 Comparison of the two potential analytical approaches QSR NUD\*IST &amp; 'Framework'

QSR NUD*IST	'Framework'
Breaks up the original transcripts by themes identified by the researcher (after initial manual coding).	Mechanism to condense data while retaining the individual respondent characteristics.
Pulls out information coded manually (initially)	Manually identified themes and code to plot in the Framework matrix
Data extracted in one dimension	Data extracted in two dimensions from the outset. Theme vs. participant (characteristics etc.)
Does not condense the data to a manageable size needed to analyse a large number of interviews	Condenses data to a more manageable size for subsequent analysis – while retaining the respondents 'voice' (if summarise in their language)
	Permits within & between respondent analysis
Dissociates data from the source	Retains link with source data throughout for ease of comparison in data analysis & permits comparison on different levels/groups i.e. decision-making & different MRs, etc.
	Permits ready identification of pages data summarised from (rigor) and quotes. Links
	Very good when looking at complex relational data
Less time and labour intensive!	More laborious and time consuming!!

The research focus and nature of the questions of applied and policy-relevant research means, it is by definition more structured than is the norm among other forms of qualitative research. A priori needs strongly inform both the data collection and analysis of health services research, it therefore tends to be more targeted and explicit in its focus. The Framework approach was developed in the UK by the National Centre for Social Research, as a structured approach to qualitative data analysis. It was specifically designed to accommodate these needs. The data management/summarising phase of the analysis, leads to the development of a grid structure or matrix constructed of themes (in columns) and participants in (in rows). This facilitates the exploration of complex relational data, while retaining the link to the original data. The reduction and matrix arrangement of these extensive textural datasets into summarised versions facilitates exploration of the data in a flexible way; enabling both within and between exploration at many

different levels; thematic, individual participant, breast unit, operation choice etc. Framework was therefore the appropriate choice for the analysis of the qualitative data of this study.

Five stages of Framework are traditionally described, although the process can be halted at any point after the completion of stages two to five. Figure 5.1 outlines the steps involved in Framework analysis.

#### Stage one: Data management

This stage of the Framework approach traditionally consists of five steps of data analysis, resulting in the construction of a matrix in which all the qualitative data is summarised by theme and participant into individual cells. The steps comprise:

##### i. Familiarisation and Identification of a thematic Framework

The familiarisation phase and generation of the thematic structure involve the researchers becoming immersed in the raw data by studying the research proposal's aims and objectives, published literature, interview schedule, and listening to the interviews, reading identical random subsets of interview transcripts and field notes. Through this process of focussing on a priori and recurring issues, views and experiences emerging from the participants' data; permitting the key ideas, concepts and recurrent themes of the research to be identified. The identification of these lead to the construction of a detailed index which will permit the data to be subsequently examined and referenced in a systematic way; labelling the data into manageable chunks for subsequent retrieval and exploration.

This step was conducted by three researchers (LC, DW and KC) and two consumer representatives (HMC and GS). The main column headings of the Framework matrix were developed from subsequent discussions of their interpretations. Appendix 8 provides a clinician Framework matrix example.

## ii. Index & code individual transcripts

The thematic framework or index created was then applied systematically to the full textual dataset. Individual transcripts were analysed and annotated with numerical codes and short textual descriptors from the index in the margin of the transcript. Single passages of text often encompass a large number of different themes; each was documented. Most (65.2%, 45/69 patient interviews) were facilitated by listening to the particular interview audio recording while analysing the verbatim transcript.

## iii. Pilot charting and adapt the thematic index

A number of individually charted transcripts which were coded and charted by more than one researcher (LC, DW and KC). They were then examined and discussed and the thematic framework adapted in light of gaps and overlaps identified through the piloting process. At the end of this phase the final version of the thematic index was created which was subsequently applied to the full set of qualitative data. Figure 5.2 illustrates the final version of the Framework patient data analysis theme headings & code numbers of the thematic index applied to the participant interview transcripts.

## iv. Charting

The indexed verbatim interview transcript data were then rearranged grouped and distilled into summaries of the views and experiences documented within the transcripts of the individual participants. Figure 5.3 outlines the agreed charting conventions and abbreviations employed during the charting process. The distilled summaries were then incorporated into the relevant part of the thematic framework. At the end of the charting phase for each participant, the completed charting was re-examined to ensure it accurately reflected the patient's account. During this process attempts are made to retain the patient's language within the distilled summary. In this way the final Framework matrices were constructed by the repetition of the process for all the participant transcripts and data. Some themes overlap and therefore the data occasionally appear in more than one thematic column. The final version of the matrix structure was therefore comprised of individual rows representing individual participants, and columns the

different themes and subthemes. An example of a clinician interview Framework matrix is found in appendix 8.

v. For inter-rater reliability; different raters code and chart a random overlap sample

As an on-going process to minimise bias and improve the reliability of the data analysis, 30% (n=8/26) of the interviews conducted were independently coded, charted by one clinical (LC) and one non-clinical (DW) researcher. The provisional chartings were subsequently discussed between the researchers and any discrepancies in analysis resolved. The information gained through this process was utilised to inform subsequent data analysis.

Stage two: Exploring descriptive accounts.

Following completion of the coding and charting phase, the Framework matrices were explored within and across themes, clinicians and breast units. In this stage the descriptive summaries of patients' views and experiences contained within the Framework matrices were explored for similarities and discrepancies, to understand why the accounts from the individual participant interviews and breast units were different or similar, and investigate the reasons for variation in experiences and views. This led to identification of factors describing clinicians' beliefs, motivations and practices. Only those related to the remit of understanding variation in practice were analysed further. Once identified, emergent themes, subthemes and factors were developed using the Framework matrix. The structure of the thematic matrices facilitated the process and depth of data exploration and analysis. The findings are presented below.

Stage three: Investigating explanatory accounts

Exploring the data for similarities and differences between groups; seeking to identify explanations for the findings of data analysis.

Stage four: Developing explanations.

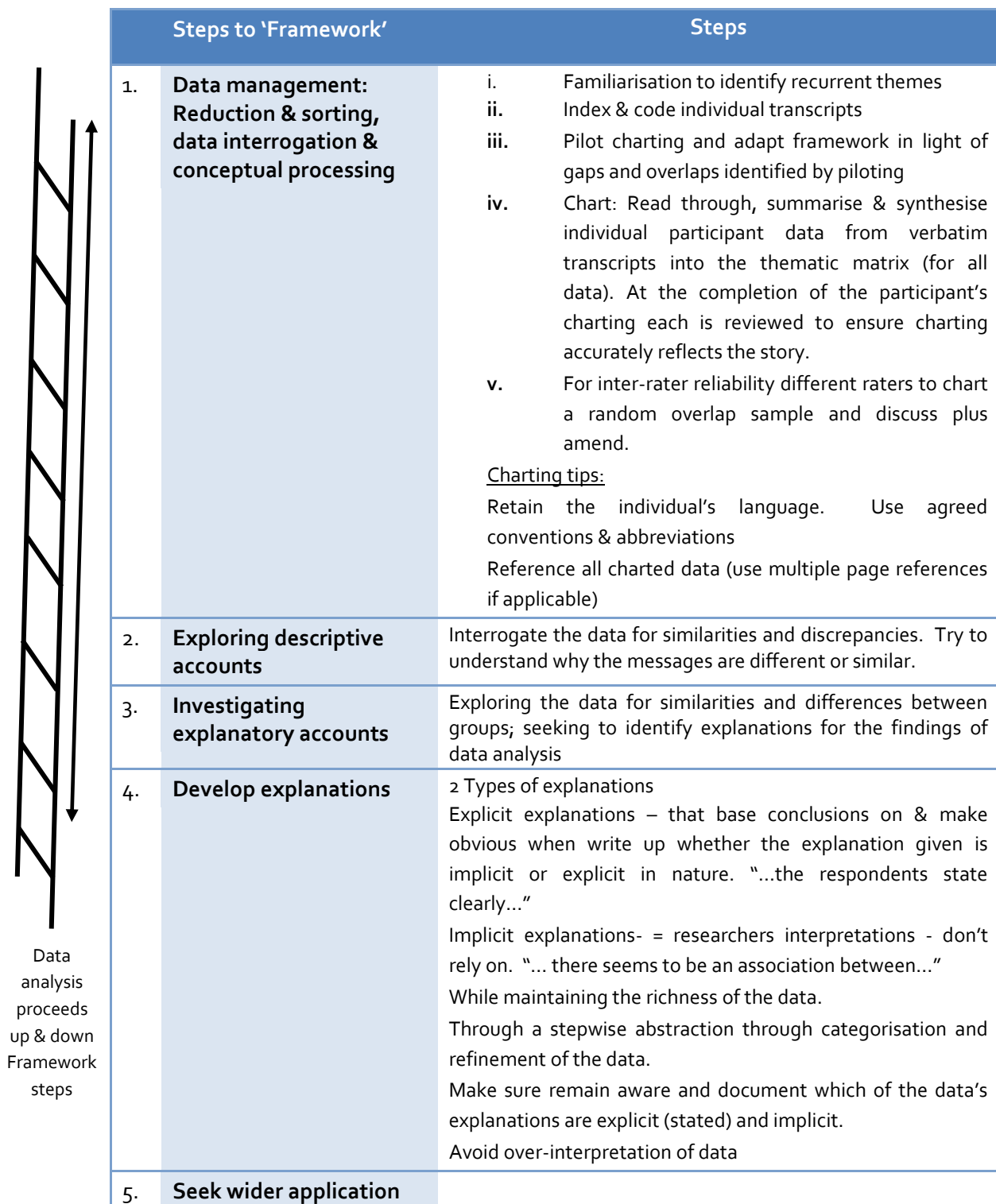
Traditionally two types of explanations are developed through a process of stepwise abstraction, categorisation and refinement of the data. Explicit or stated explanations are where conclusions drawn from the data are based on participants explicit and clear statements. In contrast, implicit explanations are based on researchers' interpretations of participant views or experiences; the latter being less reliable than explicit explanations.

Stage five: Seeking wider applications.

The fifth and final phase of Framework which can be completed, consists of looking at how the explanations generated by the data analysis could be applied more widely.



FIGURE 5.1 Steps involved in Framework analysis



Adapted from 'The Analytic Hierarchy' by Richie and Lewis. (Ritchie & Lewis 2003)

FIGURE 5.2 Final Framework Clinician data analysis theme headings

UNIT ID					
CLINICIAN ID					
BACKGROUND	1) <u>GENERAL</u> Information about time spent in unit, work in other units, MDTs, structure of pathway, etc.	2) <u>COPING MECHANISMS</u> Pressures of job, dealing with bad news, etc.	3) <u>PERCEPTION OF TEAM</u> What colleagues working styles are like, how they get on with them, work environment, atmosphere, physical characteristics, etc.		
COMMUNICATION & INTERPERSONAL SKILLS	4) <u>SELF</u> Communication & interpersonal skills, self-perceptions, work ethos.	5) <u>DOCTORS</u> Communication & interpersonal skills, perceptions of doctors, their work ethos.	6) <u>NURSES</u> Communication & interpersonal skills, perceptions of nurses, their work ethos.		
DECISION-MAKING RELATED TO INFORMATION	7) <u>PATIENTS' PRIOR INFORMATION</u> Patients' knowledge, information, perceptions prior to meeting them.	8) <u>INFORMATION RELAYED &amp; GIVEN BY TEAM</u> Manner in which information is delivered, what tools / strategies used in delivery, inviting questions.	9) <u>CONSISTENCY / INCONSISTENCY OF INFORMATION RELAYED &amp; GIVEN BY TEAM</u> Differences and similarities of information delivery.	10) <u>INFORMATION CONTENT</u> What was actually said to the patient, questions asked to patient.	11) <u>PRIORITY INFORMATION NEEDS</u> What Clinicians perceived patients wanted or needed to know about their cancer and its treatment
CRITICAL INCIDENT INFORMATION	12) <u>ACTIVE DECISION MAKER</u> Summary of incidence, characteristics of decision maker, how soon recognized and did it change the consultation approach	13) <u>COLLABORATIVE DECISION MAKER</u> Summary of incidence, characteristics of decision maker, how soon recognized and did it change the consultation approach.	14) <u>PASSIVE DECISION MAKER</u> Summary of incidence, characteristics of decision maker, how soon recognized and did it change the consultation approach		
DECISION-MAKING PROCESS	15) <u>UNDERSTANDING</u> Clinicians perception of patient understanding of information.	16) <u>OPTIONS</u> Clinician and patient actors underlying options given.	17) <u>TIME</u> Clinician perceptions of how much time & patients' feelings & feedback about amount of time given to make decision.		
CHOICE	18) <u>FEELINGS ABOUT CHOICE GIVING</u>	19) <u>CLINICIAN ADVICE</u> What Clinicians advise - replies & reactions when asked for their preference.	20) <u>MAJORITY PATIENT DECISION-MAKING STYLE PERCEIVED BY CLINICIAN</u> Bullet pointed choice vs. perceptions of patients seen in clinic.		
21) GREATEST INFLUENCE OVER DECISION-MAKING					
22) FACTORS ASSOCIATED WITH SATISFACTION / DISSATISFACTION					
23) ONE THING TO CHANGE					
24) EXTRA INFORMATION					
25) FIELD NOTE INFORMATION					

FIGURE 5.3 Adopted Framework charting conventions and abbreviations

Font	format	Meaning	Notes
<b>Regular</b>		Summarised verbatim text	Summarise in respondents language
<b>'quote'</b>		Direct quote	Pertinent & short, can part quote and summarise to retain meaning while condensing text
<b>(number)</b>		Page number referral	Use all
<b>CAPS</b>		Charters comments/data analysis	i.e. INCONSISTENT MESSAGE, CONTINUED IN COLUMN Z, REFER TO COLUMN X ETC.
<b>Q</b>		Q = good quote QQ  QQQ  QQQQ = must use quote	Be very choosy. Only use the QQQQ if it warrants it.
<b>&lt;CAPS&gt;</b>		3 <sup>rd</sup> person views	
<b>(i)</b>		Implicit data	Everything else = explicit
<b>Abbreviations</b>			
<b>BCN</b>		Breast care nurse	
<b>HCP</b>		Health Care Professional (Clinician)	
<b>CONS</b>		Clinician	
<b>Rx</b>		Treatment	
<b>Mx</b>		Mastectomy	
<b>BCS</b>		Breast conservation surgery	
<b>FHx</b>		Family history	
<b>PMHx</b>		Past medical history	
<b>DM</b>		Decision-making	
<b>DMS</b>		Decision-making style	
<b>DCIS</b>		Ductal carcinoma in situ	
<b>IP</b>		Interpersonal skills	
<b>T2o</b>		Tamoxifen	

## Transcription conventions

Quotations in the findings section appear indented. Words appearing between two square [] brackets indicate where notes of clarification have been added by the author(s). Ellipsis points indicate where a quotation has been abridged. Italics indicate words stressed by interviewees. Following each quotation, the participant's identification number will be reported along with their gender, clinical role, and breast unit MR classification. This is followed by the page number(s) identifying the extract within the flow of the interview.

## FINDINGS

Four key themes emerged from the clinician interviews; breast team ethos, eligibility for choices, clinician beliefs and routine processes. These themes were overlapping and mutually interdependent. The breast team ethos was the central theme dominating and interlinking the others, and driving the decision making culture in each unit. This was associated with specific beliefs, which determined who was eligible for choices and reinforced many of the routine processes adopted by the units; which reinforced attainment of the unit ethos. Some variation was noted between clinicians of the same unit. Clinicians were aware of diversity within their unit. However this diversity and their understanding of it were framed in terms of the unit ethos. Consistent distinct differences were observed between the units; with the low MR unit findings being dissimilar to those of the more concordant medium and high MR units. Some of the differences noted were more obvious among particular clinicians and in certain contexts, others were more subtle.

### BREAST TEAM ETHOS

'Ethos' refers to the fundamental and distinctive character of a group, typically expressed in attitudes, habits, and belief'. Clinicians acknowledged the existence of a predominant shared ethos within their breast units, which developed out of close working relationships, and was central to their practice.

I think what happens with time is that people who work in a team sometimes get a similar style or a similar way of approaching things. ...people influence one another...the team, so it's likely that we have the same feelings about how things should be done... after long discussions you get closer in your beliefs and your styles... [BS037, female consultant surgeon, low MR unit, p2]

The focus of the ethos was either the attainment of a particular treatment (outcome-based ethos) or form of decision making (process-based ethos). These defined and dominated the decision making culture of the units. The low MR unit clinicians' outcome-based ethos focussed on mastectomy avoidance where possible. See Table 5.3.

...it's fairly cut and dried the recommended treatments, you know,...we have a protocol and we all do the same for the first recommendation...the type of surgery... [GPA003, female GP clinical assistant, low MR unit, p12-13]

Contrastingly, the prevailing ethos of the medium and high MR unit clinicians was primarily process-based, focused on the facilitation of more autonomous patient involvement in decision making; with the provision of treatment choices where possible, and active support of shared or informed decision making.

...the surgeons and the nurses as a team...sing from the same hymn-sheet...explaining the options...the information...they need to make the decision...I wouldn't say anybody says, "I think this is best...it's my opinion." [BCN002, female nurse, medium MR unit, p1]

TABLE 5.3      Breast unit ethos and MR unit

Low MR unit	Medium and high MR units
Outcome-based ethos; focussed on the maximisation of a particular treatment (BCT)	Process-based ethos; focussed on facilitation of more autonomous patient decision making

## ELIGIBILITY FOR CHOICES

One of the most prominent and fundamental differences between the low MR unit and others was their interpretation of which patients were eligible for choices. Units possessed similar guidelines, but clinicians' interpretation varied by unit; therefore patients with similar cancers could be offered different options in the different units. Medium and high MR units considered the overwhelming majority eligible for genuine treatment options and offered them to those not requiring a mastectomy on clinical grounds.

...once you've excluded those to whom you're gonna say 'You should have a mastectomy,' everybody else gets the choice. ...I would still say to a woman with a 3mm tumour there are two choices: one is wide excision, the other...mastectomy. I wouldn't say, 'You shouldn't have a mastectomy because it's so small...' [BS015, male consultant surgeon, high MR unit, p15-6]

Contrastingly, most low MR unit clinicians felt a small proportion were suitable for genuine choices; and found the concept of offering choices to those who were suitable for BCT perplexing.

...personally...I've always tried to conserve breasts for people, I find the concept of open choice when it's perfectly possible to do a simple breast conserving operation with radiotherapy giving the same results as mastectomy...rather peculiar. [BS029, male consultant surgeon, low MR unit, p26]

They reserved options for a narrower subgroup; those with cancers considered less definitive cases for BCT (i.e. larger or central cancers). Patients with screen-detected or small cancers (up to 30 or 4mm diameter) were typically only offered BCT rather than options.

...Who would get breast conservation? ...smallish tumours with regard to the size of the breast: now this might include a tumour perhaps as big as 3cms or even 4cms...if it was a big enough breast... But usually tumours around less than 2 or 3cms, one quadrant, not multi-focal. [BS020, male consultant surgeon, low MR unit, p13]

On occasions all clinicians discussed options strictly outside breast unit guidelines. This invariably meant choices for multifocal, multi-centric or larger cancers, which were less ideal for this option. They did this to accommodate strong patient preferences (all units) and avoid being directive (medium and high units).

...I think...[we] offer wide local [BCT] for some larger tumours than other units. ... that's one of my suspicions as to why we do have a higher rate here. [BS028, male associate specialist, low MR unit, p8]

TABLE 5.4      Eligible for choices and MR unit

Low MR unit	Medium and high MR units
Only offered BCT for small (up to 3-4cm diameter) peripheral cancers (most clinicians).  Choices reserved for cancers 'borderline' for mastectomy	Choices offered to all in whom BCT is not contraindicated

CLINICIAN BELIEFS

Five clinician belief subthemes underlay the different breast teams'/clinicians' particular ethos; beliefs regarding clinicians' role in deciding treatment, optimum management, patient preferences, patients' decision-making capability and reflexivity regarding decision making beliefs. Table 5.5 summarises these subthemes and factors.

**Beliefs about the clinicians' role**

The various units' clinicians perceived their role in treatment decisions differently among patients suitable for BCT. Medium and high MR unit clinicians believed their role was facilitating more autonomous informed patient decision making. To them it encompassed providing time, information and support, so patients' gained sufficient knowledge and confidence to explore and make preference-based decisions based on their individual concerns and circumstances.

I'm pleased...[if] we've encouraged her to make decisions ...and take her time rather than rush...and bully her into one decision or another... [BS003, male consultant surgeon, medium MR unit, p12]

In contrast, the vast majority of low MR unit doctors believed their role was the provision of the specialist's expert opinion regarding optimum treatment. They volunteered these with varying strength from more permissive recommendations to a clear forceful opinion.

...we just push it quite, quite, quite hard and say that "this lesion is perfectly compatible with doing a local operation..." [BS029, male consultant surgeon, low MR unit, p24]

...I usually go straight to the point to discuss which is the optimal option when I see somebody, but if I know somebody has had trouble accepting things then I...try to be more helpful with giving them options and helping them decide. [BS037, low MR unit, p12]

Clinicians' role beliefs affected their feelings about consultations with patients possessing different DMS. They were most ease in consultations with patients who reinforced their clinician-patient role beliefs. Low MR unit surgeons often found the passive sub-group the most comfortable. Those with a process-based ethos preferred two way discussions with patients engaging in decision making.

...[a] passive...makes it easier...because I don't need to go into all the rigmarole and be swirling around on a hook the whole time. At the same time, I wouldn't short change them, I'd give them the same information... and...would emphasise...I'm trying to do the best for them by doing the least mutilating surgery that's possible. [BS029, male consultant surgeon, low MR unit, p24-25]

'...you can take collaborative to a different level...in general...those...are the easiest...it's a shared dialogue back and fore...you discuss the pros and cons of each and she comes to a decision in consultation with you, as opposed to 'I'm having this,' or 'I haven't got a clue,'...you give...information...it's acted upon...sensible questions are asked...you...feel...if she decided...mastectomy...or...wide excision it was for good reasons... [BS015, male consultant surgeon, high MR unit, p 21]

As with most themes, subthemes and factors, some variation was seen; some from the low MR unit clinicians shared beliefs more in common with those of the other units. These expressed satisfaction about consultations with their more active patients; especially when they chose BCT.

I like it when there are puzzles, I like it when you have to think, 'Yeah, I understand her decision,' and I think I'd have understood it both ways, but I felt that she had listened, taken everything on board, and...worked it out for herself what was best. [BS023, low MR unit, p19]

### **Beliefs about optimum management**

Clinicians were united in their motivation to 'take care' of their patients and provide what they perceived was the optimum management; to minimise the negative impact of diagnosis and optimise recovery. Discrepancies were noted however between the different teams in what they felt the optimum management was and the approaches adopted to achieve it.



...most of the time...I feel sorry for them...the majority are going to be knocked for six...so you feel...apprehensive and sorry...I suppose...my discussion about treatment really starts from a presumption that the patient probably doesn't want a mastectomy... [BS020, male consultant surgeon, low MR unit, p5-6]

...you just want to make sure that you've done your best for them really...you want to ensure that whatever you tell them is going to add to their care rather than detract from it...give them plenty of support...Because ultimately you want the best care for your patients...and I think the better informed they are, [the]...better recovery, whatever surgery you're having. [BCNo26, female nurse, high MR unit, p11]

Clinicians had different opinions of mastectomy as an option. None portrayed a preference for it per se, but almost without exception low MR unit clinicians were particularly negative about it; and used adjectives like 'horrible' [BS022, female consultant surgeon, low MR unit, p11] and declared it should be avoided where possible. Low MR clinicians believed BCT was the optimum management and it should be performed where feasible. In contrast medium and high MR unit clinicians firmly believed that only informed patients could decide what the optimum treatment was based on their individual preferences, concerns and circumstances. They focussed on the literature demonstrating the positive impact of patient involvement in decision making; optimising psychological recovery and minimising regret. They therefore declared optimum management was patients making informed treatment decisions. So although they could voice a personal dislike of mastectomy, they felt this should not be permitted to bias patients' decisions. They felt the important issue was individual patients' determination of treatment acceptability; and they should be permitted to freely undergo their preferred treatment without persuasion or pressure. They recognised this could result in some patients with cancers suitable for BCT, choosing mastectomy.

...if...a lesion is suitable for breast conservation surgery...I don't think that we would tell the women [what to do]...I don't think it's fair...women choose breast conservation over mastectomy or mastectomy over breast conservation for different reasons. ...I often tell the patients ..."You have to choose what is right for you, what you feel...you...could live with...and ...wouldn't have any regrets about it.' ...as a woman they do tend to say, 'What if it was you?' and I turn around and say, 'I don't know how I'm going to react sitting on that side,...so I cannot tell you ...you must choose what is right [for you], not your daughter...your mother...your husband...' [BS014, female consultant surgeon, high MR unit, p13]

Although these clinicians felt that patient involvement in decision making was optimum, they recognised that some experienced discomfort or difficulty in the short term while making decisions. They however weighed this against their belief that the longer term positive benefit of

patients undergoing the treatment which is right for them, was the more important issue. They sought to alleviate short term discomfort with the provision of information, time and support.

### **Beliefs about patients' treatment preferences**

Clinicians recognised patients possessed different motivations and preferences for specific treatments. These varied in complexity and extent, often by unit. Most low MR unit clinicians described more simplistic impressions of most patients' motivations; the primacy of breast preservation and impressions of patient passivity dominated other potential considerations. In contrast, medium and high MR unit clinicians' described patients' treatment preferences in a more detailed and complex way. They discussed the frequent coexistence of numerous issues and preferences within individual patient considerations, and how these could vary in relative importance as patients weighed up their preferences against treatment facts during deliberation.

...[some people say] 'It can't be as bad if I'm being given a choice...so I'll have a wide excision,' and then other people say for the tiniest cancer of 3 mms, 'I want a mastectomy.' ...they're so different and they've got different reasons. [BCNo22, female nurse, high MR unit, p17]

Typical issues included those relating to body image, recurrence, radiotherapy, social circumstances and responsibilities, travel issues etc. Some described some (especially younger) patients with large or multi-centric cancers wishing to preserve body image against potentially increased mortality risks.

...on a couple of occasions a couple of ladies have said to me, 'I would rather die than lose my breast,'... [BCNo25, female nurse, high MR unit, p2]

While others possessed more fatalistic attitudes; focussing on recurrence and patients describing sacrificing what they perceived as the 'vanity' of breast preservation for maximised disease freedom.

...sometimes, there's two things: one is 'Cut it off, doctor, and then it's gone' and...another ...underlying thing...people feel...if they don't have a mastectomy, they're chickening out...this is the price they've got to pay for being cured...for...some...there is a sense that, '...if I have a mastectomy everything'll be all right, if I go for the vain option then it'll come back and it'll be my fault because I've been vain...' [BCNo01, female nurse, medium MR unit, p22]

## Beliefs about patients' decision making capability

Clinicians recognised that in order to make treatment decisions patients needed to be able to assimilate and weigh up complex, often new information. However they held different impressions about patients' capability of doing this. These were linked to their impressions about patients' decision making preferences. Clinicians of individual units tended to hold similar impressions, although some variability was noted.

Clinicians unanimously reported that many patients requested recommendations in the first treatment consultation. However their interpretation of these and their responses varied. Most low MR unit clinicians fairly uniformly believed these recommendation requests reflected patients' overwhelming unease about decisions making and an inability to assume this role.

...very often...they say, "...hang on a minute, you're the surgeon... Why are you giving me a choice, I don't know anything about this...you tell me...I don't know." ...choice is a very difficult issue. And...it's all been drummed into us ad nauseum...everybody has to be given a choice but they find it...a difficult concept... [BS029, male consultant surgeon, low MR unit, p16]

Medium and high MR unit clinicians recognised that many patients seemed initially surprised by the offer to choose their treatment and that some found this role difficult or challenging; patients seemed to feel a responsibility to make the 'right' decision; and often they needed to be reassured that there was no 'right' or 'wrong' option.

...they feel...because they're given this choice, they have to make the right choice, and I say to them that whatever you decide is the right choice ultimately... I think patients often say that's the hardest thing, having a choice... [BCN026, female nurse, high MR unit, p9]

But they felt these initial reactions and requests for recommendations represented an automatic response to a fear-provoking diagnosis and ignorance of the options and process, rather than necessarily reflecting patients' ability or willingness to engage in decision making.

...we get...quite a lot of...patients who...say, we'll have whatever you recommend...[but a] vanishingly small number... who...think...doctor knows best... [BS003, male consultant surgeon, medium MR unit, p13]

They believed that if they explained the rationale behind providing a choice and provided tailored consultations with sufficient reassurance, time, information and support; such requests usually became superfluous, and the majority demonstrated their decision making capability.

...our job as nurses really is to go through the choices ...give them the pros and the cons of both...and ...sometimes have to go through that several times. ....they're so different...you have to be sure...when they're given a choice that they...know both sides of the coin so that they can make an informed decision. And hopefully they will. [BCNo22, female nurse, high MR unit, p17-18]

Clinicians described a spectrum of patients' desire for involvement in treatment decisions.

...it's an individual reaction. You get some people who can't cope with the choice and they'd rather that the doctor just said to them, 'This is what you need,' and then you get people who are so indecisive it's awful. ...and equally other people are quite relieved that they're given a choice... [BCNo22, female nurse, high MR unit, p17]

Deciphering patients' decision making capability varied; active decision-makers were generally easier to recognise, collaborative patients could take much longer and differentiating between these and passive patients could take until the day of surgery.

....it can be difficult...you know when you've got an active one because they'll tell you...a collaborative one or a passive you may not know before they leave the room...the collaborative one may take a little while ...but will be taking on board what you've said, will listen to what the breast care nurse has said and come to a decision...passive ones remain undecided...you realise it's passive later on when they haven't made a decision. ...the passive...tend to be the ones that will come...bouncing back... [BS015, male consultant surgeon, high MR unit p 21-22]

They also recognised their initial impressions could be incorrect; falsely based on patients' acute reaction to their cancer diagnosis, rather than their decision making desire or capability.

...quite a lot of patients will fit into this [passive] group: they'll either positively fit into this group by saying, 'What do you think?...you're the doctor, you decide,' or will just not really be part of the discussion...they'll just sit there and soak up the information ...not take much part in it, possibly because they're a bit shell-shocked in what's going on. Now it could be that they should be seen again to make sure that they aren't a more active person anaesthetised at the time by the information that they've been given, but I suppose I tend to rely on them coming back ...for more information... [BS020, male consultant surgeon, low MR unit, p17-18]

However clinicians often based their approach to consultations treatment planning and presentation of information on these initial impressions. The low MR clinicians recognised it could also influence the choices they offered; they might not discuss options if the patient seemed passive even if they were eligible for a choice.

I think what they're like to start with influences you...if they are withdrawn and anxious...you may go a bit more carefully...if they're particularly articulate you might go into more detail...what you're doing and why ...I'm influenced by how they seem to me,...patients who don't seem to be particularly worried or concerned might not

get...much...if I thought they were this group of [passive] patients...I probably would not try to get to the position to say, 'We could do this and this, the choice is yours,'...I think...I would try and point out what seemed to be the most obvious, appropriate procedure... [BS020, male consultant surgeon, low MR unit, p17-18]

Patients' decision making capability seemed a non-issue to some of the more directive low MR unit doctors; as they explained most seemed happy with the treatment plans they provided.

I would never over-ride their wishes...patients do tend to make a final decision, or at least they're happy with the decision that's made shall we say, which I suppose means something similar though not quite the same. [BS020, male consultant surgeon, low MR unit, p15-16]

Some seemed articulated inaccurate understandings of the collaborative DMS and shared decision making. They focused on the gravity of diagnosis dictating patients' desire for the expert to assume this responsibility, this eclipsed other considerations.

...most...seem to accept...what you suggest, that, if it's small enough ...just have the lump out...if they're collaborative they're agreeing, you're sort of making the decisions together...they want you to...recommend, and...say that's fine. But ...passive...you tell them what you recommend...they say, 'Well you're the doctor...just do what...' there's not that much between them. ...they take it much more seriously if it's something like breast cancer, they don't want to mess around...they want to get on and do the right thing at this early stage...so...usually, they go along with you...accept what you recommend... [GPA003, female GP clinical assistant, low MR unit, p12]

They believed only the minority who actively requested more information or discussion wanted to decide their treatment, and if patients genuinely wanted this role they felt it would become obvious.

I get a lot of passive patients. ...they say, "Whatever you think, doctor. We don't know anything...if you think that's the best thing for me...do whatever you think to cure it..." They've looked nothing up,...perhaps haven't spoken to anybody, and they're quite prepared to go along with it. [BS029, male consultant surgeon, low MR unit, p24]

### **Reflexivity regarding decision making beliefs**

Reflexivity was noted among clinicians of the units. They recognised alternatives to their beliefs or consultation approach and decision making behaviour; recognising a minority with these in their own unit. The minority with these incongruences of beliefs and decision making behaviour

(in low MR unit) or consultation styles (high MR unit) however remained subject to the predominant ethos of the unit; their view coloured by the unit culture. In the high MR unit a single consultants' consultation style was recognised to be inconsistent with their beliefs and the unit culture/ethos. To harmonise their patients' experience they developed a compensatory approach.

...we're...much the same age group but there's probably a 15-year spread with me...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...with sympathy or fact, to a certain point and then I think I can go no further...that's when I move them on to the breast care nurses to pick up the pieces, so there are different styles...they do spend twice as long...as I do so I assume they're saying more. ...I generally confer with the nurse assistants who...have been with us for a long while and I might say...'Do you think she understood?...Did I put my foot in it ...?'...Did I get it wrong?' ...if I don't think it's gone well it...gets it off your chest...and they may say 'well you've done better, ah well - that's one in a hundred or one in fifty.' But of course there's a let-out clause, if I've done badly is the breast care nurse going to do badly as well? ...unlucky both of us having a bad day... (BS013, male consultant surgeon, high MR unit, p1 & p6)

...one of my colleagues...he's very good with his patients, but he is much more matter-of-fact, gives the basic information and...might spend less time with an individual patient...and...a lot of the... extra will be filled in by the breast care nurses. ...that's a different style. I personally spend probably longer... 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, male consultant surgeon, high MR unit, p1-2)

A minority of individual low MR unit doctors expressed personal beliefs more consistent with the process-based ethos of the other units and incongruence with the predominant belief system and culture of their particular unit. The degree to which they differed from their unit colleagues varied. The consultant of the group adapted the units' routine processes of care to deliver their own patients a process more consistent with the attainment of their personal process-based preferences. Both the clinician and their colleagues recognised these differences.

...personally, I think that we should talk about mastectomy for any patient...even if they've got the tiniest small tumour...ideal for wide local. ...I always say that there's two options: we can either remove the whole breast or we can just take the tumour and small tissue around where the tumour is and, if...I think a wide local is by far preferable, I would say '...in your case, this is probably the better option...' and 9 times out of 10 they'll go for a wide local, but I think we're still obliged to talk about either option... I certainly know one of the consultants [here] does say...'we'll be able to treat this, just take the lump

away,' and not really talk fully about the other option,...although I think they try and remember ...they should mention mastectomy... another one probably does that...too. [BS028, male associate specialist, low MR unit, p8-9]

...one or two of the consultants here are more into giving patients free choice, having long discussions...than I probably am. Not that I don't give them a choice but,...some are less directive...and virtually ...prepared to sit there and say, "Well, we'll do what you want and I'm not going to tell you what to do." [BS029, male consultant surgeon, low MR unit, p2]

There might be slightly different attitudes in terms of what you say to the patient, what the degree of choice that you might offer, or the degree of advice...you might offer...probably minor differences between people... [BS020, male consultant surgeon, low MR unit, p3]

BCNs recognised such differences and some described a preference for the less directed process; but accepted operating with the confines of their unit or clinicians' constraints.

...some...will bring them back the following week following discussion of treatments...they're given...written information so they can go away home and think about it and read the information and then they come back. ...I think that's a good way of doing it because at...diagnosis they can't always think straight...they don't take on board everything...and I think they need that week to get their head round everything... And you often find that when women do come back the following week they are very much more focused, they've obviously had time to think,...talk to people, get on the website, get information...they want...then...we can plan surgery. ...Some [consultants]...don't do that: they see them at the time of diagnosis...and...are not seen again by the consultant... [BCN038, female nurse, low MR unit, p3-4]

TABLE 5.5 Clinician beliefs associated with differing unit ethos

Low MR unit	Medium and high MR units
<b>Beliefs regarding clinicians' role</b>	
The clinicians' provide an expert opinion regarding optimum treatment	The clinicians' role is to facilitate patients selecting their preferred treatment
<b>Beliefs about optimum management</b>	
Optimum management is BCT and its uptake should be maximised	Optimum management is patients choosing their own treatment wherever possible; to optimise psychological recovery and minimise regret
Mastectomy should be avoided where possible	Only patients can determine their preferred treatment
<b>Beliefs about patients' treatment preferences</b>	
Most patients prefer BCT	Individual patient preferences vary depending on multiple pre-existing subjective factors, including experiences and concerns
<b>Beliefs about patients' decision making capability</b>	
Most patients want expert guidance from their specialists, or are unable to make treatment decisions due to lack of knowledge and experience	Patients' preferences for deciding their own treatment vary, but most are capable of making treatment decisions, given the appropriate time and support resources
<b>Reflexivity regarding decision making beliefs</b>	
Reflexivity; some incongruence in beliefs of a minority of clinicians in context of unit ethos recognised by clinicians. But ethos predominates	Reflexivity; some incongruence in consultation styles of a minority of clinicians in context of the unit ethos recognised by clinicians. But ethos predominates



## ROUTINE PROCESSES

Breast units' routine processes were underpinned by their beliefs and concordant with their ethos. They also reinforced the units' decision making culture. These were defined by four subthemes; the process of offering options, the process of communication, the process of recommending treatments, and the process of decision making and establishing consent. Table 5.6 summarises the process subthemes and factors.

The low MR unit's processes differed from the generally more analogous medium and high MR processes. Although inevitably some variation was seen among clinicians from the same breast unit; a minority of mainly low MR unit clinicians with more process-based personal beliefs, were selective about which of their units' routine processes they adopted.

### **Process of offering options**

Clinicians described entering consultations with a treatment discussion plan. As described above, the group considered eligible for choices varied according to their clinicians' interpretation of established breast unit guidelines. Patients' treatment options were decided at different levels in the different units. Standard practice in the medium and high MR units was to discuss and determine these options at MDT level, prior to the results appointment. Clinicians described reassurance stemming from the team nature of decisions; especially complex ones. The high MR unit also employed an additional step. During initial clinical assessment they routinely documented patients' suitability for surgical options (based on cancer size: breast volume and site) on a standardised proforma which was used in conjunction with the more widely utilised radiology and histopathology information, to guide MDT decisions.

I feel very, very confident that it's not my judgement, it is our judgement...not a unilateral decision, it's a consensus of opinions... The straight-forward ones are no problem...the complicated ones...you don't feel '...have I made the right decision...?' (BS014, female consultant surgeon, high MR unit, p3]

The low MR unit did not routinely discuss cases preoperatively in the MDT. Options were instead determined by individual doctors, based on their triple assessment findings.

...I will have seen the result and...aim...to tell them the result and then try and formulate a treatment plan...I'll already have decided what I think...probably serves them best...before I go in... it'll either fall into a group where they need to have a mastectomy

because it's big or...multi-focal, or they need to have, or...can have a wide excision...that would be the preferential treatment...or it could be either [option]...from its position or...size. [BS020, male consultant surgeon, low MR unit, p6-7]

They explained this approach was partly dictated by the high volume workload of the unit, which necessitated prioritisation of MDT cases to those most likely to benefit from discussions between surgical and non-surgical clinicians; for example post-operative results and adjuvant treatment planning. Most considered routine pre-operative MDT case discussion superfluous, as clear guidelines indicated the obvious recommendation. The approach was also partly necessitated by 'hot' pathology reporting in some clinics, which meant, some patients could be given their diagnosis and treatment options on the day of initial assessment.

...we try and do a one-stop clinic where possible. So patients would expect on the whole to go out with a diagnosis at the end of that session. It is very, very occasional that we ever wait for an MDT discussion before letting the patient know the diagnosis... [GPA005, female GP clinical assistant, low MR unit, p3]

BCNs from the different units talked about their participation in determining patients' treatment options. Those from the medium and high MR units described a less hierarchical relationship between the two occupational groups and greater contribution to this both in clinics and MDTs.

### **Process of communication**

Clinicians recognised patients' view of their clinicians (particularly their doctors) as experts; meant patients arrived expecting to listen.

...the surgeons...they are the person that the patient is coming to see; ...the GP's said, 'I'm going to refer you to...Mr \_\_\_\_\_. They'll be able to help you.' And that's the person they're expecting to see...the person who they listen to...their consultant...the expert. [BCN001, female nurse, medium MR unit, p26-27]

These expectations meant clinicians possessed the power to influence patient decisions not only by determining patients' options, but their communicated of them.

...I think in general the breast team must have the biggest influence because partly it's...deciding who isn't suitable for choice... And there are ways and means,...I like to think that I give a very balanced view...and I think other people don't ...I think it's almost a case of, '...there's a choice you can have...breast conservation therapy or if you *really* want...you can have a mastectomy,'...I think this is where you can tell it and how you sell it. [BS015, male consultant surgeon, high MR unit, p25]

Some reflected on the tendency of developing a replicable way of communicating, but emphasised the importance of retaining sensitivity to individual patient needs and tailoring communication accordingly.

...having done it for a long time...you do tend to have set speeches...it is hard to avoid that. But...I...hope that I am sensitive to the needs of an individual patient ...some patients you will need to spend longer and go into more detail and others...don't want that detail... Having...broken the ice with the introductions...the crucial thing is to...go straight for the fact that unfortunately...this is cancer and try and avoid euphemisms and skirting around it.... I would obviously try and be gentle, factually correct... and then I think you really have to assess what the response is...and...often it will be yeah, I know...that's what you implied last week ...we've got our head around that. Where do we go from here? So you can then move on to treatment options and I suppose my usual spiel...I would try and emphasise the positives, overall breast cancer has a good prognosis compared to many cancers, most ladies are successfully treated and then enter into the different treatment modalities... [BS003, male consultant surgeon, medium MR unit, p4-5]

- **Consultation style**

Clinicians' consultation styles were consistent with their personal and unit beliefs about patients' decision making capability and preferences, and patient-clinician roles in treatment determination. There was a spectrum observed between the directive presentation of predetermined specific treatment plans, to the more facilitative presentation of open options. These gave the impression of varying degrees of patient- versus doctor/clinician-centred consultation styles. Consultation styles of clinicians of the same units tended to lie predominantly around one region of the spectrum. Low MR unit clinicians clustered predominantly toward the more directive end of the spectrum, and the others toward the less directive, more facilitative end. Some were more overt examples of these approaches and clinicians also described different adherence to their usual style. The less informing consultation styles, with less opportunity for patient-directed discussions were often expressed alongside the belief that clinicians' role was to provide recommendations.

...I'm rightly or wrongly, usually very anxious not to take ladies breasts off at all if I can avoid it so I tend to be directive towards doing as little as possible consistent with curing the disease,...personally I don't give them a choice really in terms of saying...we can remove your breast or...I don't give them...carte-blanche and say, "...we can do this or that, you decide." ...some...[surgeons] are really quite non-prescriptive... [BS029, male consultant surgeon, low MR unit, p24-25]

They believed most patients did not want options or the details of treatments, so did not routinely volunteer this information. They usually reserved less didactic, more comprehensive options and consultations for patients actively seeking more information and demonstrating an obvious desire for involvement in decision making.

...I think [it is important] to try and get the message over to them...it's...cancer...they need an operation...though of course many won't really be interested...they'll switch off somewhere along the line and just want to get on with it really. ...some will want a bit more detail about the operation that's on offer, some...will just be happy to know the diagnosis, happy to know what you offer...and leave it at that...but some that will want to know a little bit more...and...be part of the decision making...' I think they form quite a small group...because obviously they are going to have to ask for more information about what a mastectomy is, what the benefits are...the disadvantages are, and...with the wide excision...radiotherapy and things.' [BS020, male consultant surgeon, low MR unit, p10 and p16-17]

They relied on patients to disagree with proposed treatment plans and seek more discussion or other options if they desired this.

...he tends to explain...we could...remove this lump without removing the whole of the breast, and...explain his reasons why. ...some...he'll ask...how they feel about that and...the majority are quite comfortable with that decision...but some...might want to discuss the option of mastectomy and so...generally...they are given that option to have alternative surgery if they feel strongly about that. [BCNo41, female nurse, low MR unit, p12]

In contrast most medium and high MR clinicians sought to communicate in a way that was more conducive to patient participation in treatment decision making. They recognised that time-pressure could hinder this and emphasised the importance of creating an unrushed, open environment from arrival to leaving, where patients felt at ease; to facilitate the exploration of information and development of decision making confidence.

...I just don't know how they do it ...I've seen them when they [the consultants] ...must be feeling really frustrated...and...patients come in and they greet them as if they're the only person they've got to see and give them all the time and make them feel that this is all they've got to do and it's their time and they've got as long as they want. [BCNo01, female nurse, medium MR unit, p5]

I'll spend as little or as long as I need to and the clock is irrelevant to me, if a patient needs five minutes to be told the diagnosis of breast cancer, their choices, that's fine, if a patient needs 45 minutes that's fine, and I won't be throwing them out the door because I've got the next patient waiting...they'll...get the individual amount of time they need. And if that means over-running...that means over-running..., but everybody knows that if they see me they'll get the time they need... [BS015, male consultant surgeon, high MR unit, p2]

The vast majority...come through the fast-track clinic... They know...it is going to be quite a long afternoon... The other person...in clinic is...our Health Care Assistant...patients come in, we try and keep things as relaxed and unhurried and friendly as possible, and since...we've had this new building, it's...quieter,...more relaxed, and that seems to have filtered through to the patients. ...I think...that environment...matters as much as how you greet them and how you are with them...' [BCN001, female nurse, medium MR unit p2]

'I like to take the patient away from where they've been [for their diagnosis and]...use the quiet rooms...and...give...a bit of time—I don't come straight in—...sometimes they just want a hug,...a bit of quiet time,...a drink,...and then I'll come...ask...if they want to go through everything again now or...at a later point...quite a lot...want to go through it again then, because they've not always understood and quite often...if you've managed leave the patient a little while, they might have gone through a very tearful moment and then sat down and discussed it with whoever they're with, and...have some questions. ...And if the patient really can't cope at all, I won't go through anything...at that particular time, I'll just sit with them...just let them cry or be angry...whatever they need... [BCN037, female nurse, low MR unit, p12-13]

Those adopting more facilitative approaches described a more extensive exploratory aspect to their consultations; including carefully checking and rectifying patients' understanding and knowledge.

I hope...I leave it to them to make the decision...that I don't push them in any particular direction. ...there are some who in the first instance will say, 'I want a mastectomy' ...[and] I will say...let's just go through...why you're choosing one over the other,' and if they have this preconceived idea that, '...if I have the mastectomy I'll get rid of the disease and it'll never come back,'...re-educate them... [BS014, female consultant surgeon, high MR unit, p13]

Those seeking engage their patients in decision making expressed patients often had difficulty in absorbing and assimilating information initially, and they wanted to ensure they were informed but not overloaded or overwhelmed with information.

I think assimilation of [that] kind of information is difficult and you only know over the time what's been taken in and what hasn't. ...I ...think, if you're told you've got breast cancer, for an awful lot of people that's enough, anything else said after is just, goes way over their head, and is forgotten or ...not taken in, because...when you're told you've got cancer you think, '... am I gonna die? What does this mean? Am I...gonna see my children grow up?'...that kind of stuff... [BCN002, female nurse, medium MR unit, p10]

They recognised information provision had to be tailored; varied in pace and pitch according to patients' needs and explained the informing process often needed to be slowed; resisting the urge to relay too much on the first day.

...if somebody's getting really upset I will stop and say, 'Do you want us to finish here?' ...I think we all make mistakes over the years...and you've felt it's part of your job to give them all the information before they leave, and don't let them go until they've got it all, but,...I go with my instincts [and stop for now].... [BCNo23, female nurse, high MR unit p7]

Those adopting more facilitative approaches also sought to discuss issues which might impact on decision making, and described identifying potential barriers and attempting to overcome them. Typical barriers to BCT included inconvenience or travel for radiotherapy. They also described trying to focus patients on the longer term physical and psychological consequences of their decisions, not just immediate reactions.

...she said, '...I want...a mastectomy, I don't want to have to ... travel [for radiotherapy] ...' So Mr \_\_ said, '...travelling doesn't have to be a problem...we can provide transport.' ...And...he went through...each step of both options and [said]...you may well decide to have a mastectomy because it means...you can avoid the five weeks of treatment...yes, it's a difficult five weeks, there's lots of travelling, [but] it does come to an end. If you have the mastectomy that's fine and...it's often a gut reaction to say, 'Just cut it off, get rid of it' but...you've [also] got to think how you're going to feel afterwards... [BCNo01, female nurse, medium MR unit, p20]

Clinicians' approaches to identifying and overcoming of potential barriers varied from informative countering to insistent direction. The transition point between them could be overt or subtle; related to the degree of direction employed and adoption of active listening skills with the timely provision of appropriate responses.

...if I think...they're going towards a mastectomy when they have...got a tumour which is suitable for a wide local excision, I would try and find out their reasons why they were bothered about the other operation and try and put the fact straight if they still think, 'Oh, that must be more risky,...if you don't remove all the breast,'.... [I] try and make sure they do have all the facts as clearly as possible to try and help them make their decision. [BS028, male associate specialist, low MR unit, p13-14]

...I will create a...a scenario where I will say, '...you choose a mastectomy and three years from now you get a recurrence, you may turn around and say, "...I could have had a breast for three years...why did I choose a mastectomy?...On the other side, you choose for breast conservation surgery and three years from now you have...a recurrence and you have to have a mastectomy, "Well, I should have had the mastectomy then," but the positive side...is that for three years you would have had a breast.' ...You have to choose what is right for you, what you feel that you would, could live with,...that you wouldn't have any regrets about...' And I think that...helps them to decide one way or the other. [BS014, female consultant surgeon, high MR unit, p9]

Even clinicians who tried to tailor their consultations described fairly rigid adherence to their usual more directive or facilitative consultation style; even when it did not necessarily suit their

patients. However if patients' unease (vocal or non-vocal) was persistently evident, they could alter their style. There were differences however in when clinicians would do this. Medium and high MR unit clinicians tended to reserve a more directive style for much later in the decision making journey; concerned genuinely passive patients could be difficult to differentiate from those merely anxious and shocked around diagnosis. By deferring directedness, they sought to avoid biasing decision making in the non-definitively passive group. Low MR unit doctors described responding to very clear active preferences, and more experienced low MR unit BCNs were willing to adopt consultation styles responsive to perceived patient preferences; but if this meant countering the doctor's treatment plan, would usually first seek their approval.

Patients' clinical and cancer characteristics, and clinicians' perceptions about patients' PDMS could influence consultation styles. Even those believing strongly in patient choice could describe struggling to present truly unbiased options to patients with very small cancers of a few millimetres, and could describe being more directive in these circumstances. They emphasised cancer characteristics (small size, impalpable) and patients' presentation (screen-detected or 'early' diagnosis), in addition to providing the usual reassurance about BCT safety, while trying to avoid overriding patients' sense of decision making autonomy. There may however, have been differences in when clinicians employed this form of emphasis; as some low MR unit clinicians referred to cancers up to 3-4cm diameter as small and unsuitable for options.

...screen-detected cancers...of a few millimetres. We'll put the emphasis strongly on breast conservation...[emphasising] the size of the tumour, method of diagnosis, size in relation to the breast... [BS004, male consultant surgeon, medium MR unit, p17]

However a few medium and high MR unit clinicians felt it was unfair to selectively bias decision making even among those with the smallest cancers.

...it's very hard when you're in the thick of it to sit back and look objectively at the kind of information that's being given and how it's put...it does kind of concern me that smaller cancers that are picked up on screening I think there is a tendency to subtly steer those patients towards breast conservation rather than a symptomatic lump cancer where we may not push them so much towards conservation... [BS003, male consultant surgeon, medium MR unit, p14]

Consultation styles also seemed to be associated with doctor's age among the male subgroup. In particular the three older male consultant surgeons (one from the high MR and two from the low MR units) seemed less comfortable using words like 'cancer' with their patients and provided less extensive information. Their level of directedness however remained consistent with the others

from their unit. The high MR unit doctor described their self-awareness that their consultation style was sub-optimal for their process focussed beliefs and ethos. They therefore counterbalanced this with heavy reliance on BCNs to go through everything in more detail and provide patients with sufficient opportunities to explore the options. They provided patients with a brief discussion of the options available and ensured they knew more extensive discussion with their BCN would follow.

Clinicians recognised to aid absorption, information often needed reiterating.

...our job as nurses really is to go through the choices...the pros and the cons of both...and they sometimes have to go through that several times. ...you pitch it at the level that that patient wants, you sometimes do have to use diagrams....especially at that first consultation, because their mind's just whizzing round and...you need written information, you need pictures, they need to take that home to get their heads round it... [BCNo22, female nurse, high MR unit, p17-18]

As well doing this verbally, many employed tools to emphasise salient points, explore information needs and reinforce the clinicians' message. Some used the patient's mammograms or histopathology reports.

It would depend thing on...what message I was trying to get across. ...in screening patents...mostly they're very tiny tumours,...I...probably subconsciously try to emphasise ...this is a ...tiny thing...within the breast: ...if I want to emphasise the smallness of the cancer I'll often show them on the x-ray and...say, 'You'll need to come really close to this because it's so small' to get that positive message over. [BSoo4, male consultant surgeon, medium MR unit, p11]

Others produced freehand drawings and wrote down salient points as they discussed the options; this way information was reinforced with an individualised concrete tool. This was used to focus discussion and taken home for later reiteration. Many felt these were the most valued tools.

I draw little diagram of the breast and the axilla...show where the lymph glands are, why we're removing them ...I think one of the useful things is that rather than keep it as an abstract thing, that you've got wide excision versus mastectomy and the pros and cons of each, if you've written it on a piece of paper and then...they can point that the thing, 'If I have that treatment...what about radiotherapy etc.?' And it just acts as a kind of freehand for both of us, particularly since some of the terms they may not...know...[or] understand...to start with... [BSoo4, male consultant surgeon, medium MR unit, p11]

BCNs also used printed leaflets and provided the opportunity to view treatment outcome photos.



- **Information content**

There was a range seen in the comprehensiveness and extent of consultations content; including the options discussed, detail provided and emphasis placed on individual information components. This was influenced by clinicians' predominant beliefs, and point on the facilitative-directive spectrum described earlier. Most low MR unit routine consultation information content comprised a greater emphasis on general reassurance but a briefer and less comprehensive provision of clinical information focussed on their preferred treatment. In contrast, the other units' consultations, though providing reassurance, did so as a component of more extensive, comprehensive detailed factual information set; aware that restricted information could hinder and bias decision making. These provided the impression of different degrees of clinician directedness in consultations and decision making.

...I think they need...a lot of information on the two types of surgery really. And know that equally, there is no better surgery, long-term outcomes, it's what you live with, or what you feel you can live with afterwards [that is important]. [BCNo26, female nurse, high MR unit, p12]

...my own views ...it'll either fall into a group where they need to have a mastectomy ...or they can have a wide excision...if it could be either or it's better treated by wide excision, I'd usually go along those lines and say, 'We'd recommend removal of the lump and this can be done by a wide excision - we remove the lump and we take a margin round it that is adequate. ...There is an alternative option to that and that is removal of the whole breast, but in your case this isn't absolutely necessary but it is something you might want to consider – some ladies do ...so...wide excision...would be an entirely reasonable and safe way forward.'...and we'll fix a date...for your surgery and you'll have a bit of time with the breast care nurse to go through what I've said.' Then I'll go through the operation and sign a consent form with you.' [BS020, male consultant surgeon, low MR unit, p6]

Many low MR unit clinicians routinely recommended what they considered the most suitable treatment, which they normalised; explaining most patients underwent this standard option.

...I...usual say..."Look, you have a small lump, it's two centimetres...in this unit...about sixty per cent of patients end up having a conserving operation, forty per cent or...less...end up having a mastectomy... We're trying to do a safe operation...saving the breast... Course, we respect your view if you...feel more comfortable having everything removed... [BS029, male consultant surgeon, low MR unit, p24-25]

If the cancer was considered suitable or borderline for BCT, mastectomy was often mentioned to acknowledge and discount it rather than provide it as an option. Some neglected to mention it unless patients raised, it and when it was discussed it was often characterised it as excessive.

They could also skirt over the possibility of further surgery for insufficient margins and the inevitability of radiotherapy with BCT.

...in general, I think that as surgeons we maybe don't talk about radiotherapy after a wide local in enough detail and what that actually involves...we often say to patients, '...we can just take some of the breast but you will need radiotherapy afterwards.' I always try and say to patients, 'Well it does involve coming up for...treatments once a day for five weeks,' and I think often we...pass over on that... [BS028, male associate specialist, low MR unit, p7-8]

Clinicians often stressed the importance of using clear unequivocal language to minimise misinterpretation. But some low MR clinicians seeking to provide reassurance, underplayed diagnostic and treatment information, used equivocal language or adopted euphemisms.

some people...say, 'Gosh, you do use the word cancer a lot,' and I say, '...at the end of the day...people know what cancer is,...if you say...tumour, tumours can be benign, ...harmless,...serious...different implications...[to] different people...whereas a cancer is a cancer... [BCN002, female nurse, medium MR unit, p12]

...I say to the patient...though initially ...there was some feeling that this was not serious, the x-rays have suggested that it was suspicious and ...the needle tests have drawn off some abnormal cells and so it is something that isn't just an ordinary lump, it is a bit more serious and probably does mean that it's a malignant lump, a little cancer...or a cancer. [BS020, male consultant surgeon, low MR unit, p6]

Clinicians expressed patients were often surprised by the offer to choose their treatment and that patients' lack of knowledge and confidence, as well as understanding about why they were given a choice could act as barriers to involvement.

I think sometimes they don't get the options - 'Well he said I can have the smaller operation or a mastectomy, why?' Why have they got choice? And some people say, '...I don't...know, he's the doctor,' - I don't think that tends to happen much now, [but] there's certainly some people say - 'How am I expected to choose when I don't know anything about it?' and I feel it's our responsibility to actually inform the patients..., there is a choice and why there's a choice, and ...[say], yes the doctor does know best but if there was a best option the doctor would be saying 'You should have this because it is the best option,' whereas the two options he's described to you both are equal in terms of you living to be a hundred, for example, therefore...your own personal choice comes into it. ...sometimes you have to reiterate that, but most people understand. [BCN002, female nurse, medium MR unit, p12]

Clinicians felt survival equivalence was the key issue to most patients given a choice. They recognised patients often possessed concerns about the safety of treatments, and that they could have difficulty grasping the concept of the equal safety and survival equivalence of BCT and mastectomy. This information was therefore provided clearly and emphasised,

I think some patients...find it difficult to understand that just doing the wide excision is as safe as...mastectomy, and I always try and emphasise...the two options are just the same in terms of the cancer coming back. ...I think some patients do still find that concept difficult because they think surely taking...all of the breast, is...safer. [BS028, male associate specialist, low MR unit pg]

Therefore also explained and emphasised why options were being offered early in their consultations, and stressed the importance of patients deciding their own treatment. They reassured them that no treatment was superior or 'right'.

...I've had to say quite categorically...'It's not what I would do...I can give you the information...the good and the bad..., but I'm not the one that's got to wake up every morning to the surgery...get dressed and undressed with the surgery. You are,...that's why it's got to be your decision... [BCN022, female nurse, high MR unit, p26-27]

...when patients are struggling for example about, how can one be the same as the other, I do bring in the fact that there has been a lot of research and wide local excisions, as long as you get clear margins plus you give the radiotherapy, is the same in terms of survival as a mastectomy. That's why there is a choice and that's why it comes down to personal preference because at the end of the day any decisions that are made, the women are going to live with them for the rest of their lives, and it's not my breast and it's not my decision,...it's how they feel and what they want. And...some people say, 'Well, my husband would want this,' or 'Such-and-Such would want that,' and I say, '...discuss these things with your family, but at the end of the day it's your breast, it's your decision, and you are the only one that will live with the consequences of...the decision..' [BCN002, female nurse, medium MR unit, pg]

Those encouraging patient participation in decision making also described reassuring patients they had time to make a decision; that it was not expected today and specifically outlined the timescales for decision making and what would be happening in the interim.

...you...stress...I've just told you...upsetting news, I don't expect you to make a decision now... [BS015, male consultant surgeon, high MR unit, p 21-22]

...when you talk to ladies, they just, they really want to know when are they having it done...I think [it's]...very important for them, to know exactly when they're having the surgery. I think the choice...just adds to anxiety sometimes on that initial consultation because they've just been told they've got cancer, they need an operation, there's two things we can do. And that just sends them off in a... 'Oh, God, what would you do?' ...obviously you don't ever say, 'You need to make a decision' on the day of diagnosis... [BCN026, female nurse, high MR unit, p12]

Recognising there was a lot of information to impart and absorb, some provided an initial brief summary, and then built on that framework in a stepwise manner within the consultation. Providing, exploring and reiterating information and encouraging questioning. They believed this assisted information absorption and patients' acquisition of a firm knowledge base and

confidence from which they could consider their options and preferences. They explored the options, the pros and cons, provided clear information on issues which differentiated between the two; for example the possibility of requiring further surgery if resection margins were inadequate, and that radiotherapy was an integral part of BCT and this involved 4 to 5 weeks of outpatient treatment.

...I'll sit down and...say, 'OK, there is a lump here, it's a small lump and it's about 1½ centimetres,'...That's about that [*demonstrates*] size,' and [to]...a patient with a choice, I will say "you need an operation ...there are choices ...and you will have that choice. I will give you all the information I can to try and make the choice. The first option is an operation where we remove the lump with a margin of tissue all the way around it, the important thing being that we get the lump out with a nice safety margin of normal tissue all the way around.' And I might say to them, 'From ...what we can feel and what we can see on mammograms and scans, you look perfectly suitable for that operation.' After the operation the pathologist will check down the microscope that we've got the...area out with a nice safety margin all the way around. Nine times out of ten ...there's not a problem -...occasionally they ...see something ...we can't predict before the operation, in which case we have to think again, and that's an important built-in safety guard. ...And I'll explain...'You will require radiotherapy following that operation,'...then I will say, 'The alternative to that would be to remove all the breast tissue, what we call a mastectomy. Those two operations are equal: one isn't better than the other - if one was better than the other I wouldn't give you a choice...but in this situation there are two equal options...'In a minute I'm going to get you to see one of the breast care nurses, who's going to go through what I've said in some more detail, put a plan together about you coming into to hospital and give you a lot of information to go home with. ...and...I will usually say, 'I've already said to you that after the local operation you will need radiotherapy: you could still require radiotherapy after a mastectomy but it's less likely. ...and you may end up with another quarter of an hour of different questions or...one minute of further questions, depending on individual ladies and their information needs. ...the last thing I always advise women is...when they go home they'll think of lots of things they meant to ask, and to write them down on a piece of paper so when they next come and see us they've got a checklist of questions to ask us.' [BS015, male consultant surgeon, high MR unit, pg-]

All units tended to use vague terms which covered local recurrence and survival. Medium and high MR unit clinicians tended to distinguish between local recurrence and survival; adopting phrases that informed patients that survival was equivalent, but there was a slightly higher chance of local recurrence with BCT - while not quantifying this. While the low MR clinicians typically grouped them, rather than disengaging the concepts; using phrases like the 'treatment outcomes' were the same or there was the same risk of the 'cancer coming back'.

Those adopting more facilitative approaches encouraged patients to spend time considering the options and emphasised the specialist support available for this process.

...I reiterate...it is not my decision, it is for them to decide, and that they don't have to decide today, they can think about it and take away all the information...see the breast care nurse...they have time to think, speak to their family and then make their decision...[and] it should be their decision. [BS014, female consultant surgeon, high MR unit, p13-14]

Clinicians explained patients' pre-existing level and accuracy of knowledge about breast cancer and its treatment varied greatly. BCNs in particular spent a substantial proportion of their consultations checking, correcting and building patients' knowledge; recognising patient involvement required the possession of sufficient accurate knowledge.

...it really does vary tremendously. Some people know absolutely nothing about breast cancer...about options. A lot of people have heard about mastectomy but some...haven't got a clue...or they've got information but they're not correct... I think the majority...fall in between... you need to assess their level of knowledge and if it's not so great...inform...and...If it's incorrect...correct it...because at the end of the day their...decisions are...based on their...information so it does need to be correct. [BCN002, female nurse, medium MR unit, p10]

...patients'll tend to come thinking, 'If I've got breast cancer I'll need to have a mastectomy.' ...depend[ing] on...personal experiences, whether they've got a family member... sometimes there's myths...you need to put straight and it's building that trust...relationship...that you are dispelling myths rather than trying to say, '...no, that's not right'... [BCN037, female nurse, low MR unit, p17-18]

Over the three units, clinicians expressed a desire to provide a consistent message to patients. BCNs reiterated and reinforced the intended message of the doctor-patient consultation. Their consultation topics and content therefore echoed those of the doctors.

...[the BCNs] go through what we've meant by the options and reiterate things... [BS020, male consultant surgeon, low MR unit, p19]

If the particular unit ethos was not being followed, BCNs tended to refocus their consultation in line with their units' ethos (choice or BCT). For example, if medium or high MR unit patients felt they had been recommended a treatment plan rather than genuine options, BCNs refocused patients on making their own decisions and provided information to do so.

...sometimes...[there is] the sense of '...I haven't really considered a mastectomy because the surgeon's advised...wide local excision' and I would just elaborate on that a little bit...emphasising...there is always a choice...I'd never take a decision from them there and then...don't need to make a decision today...' [BCN025, female nurse, high MR unit, p15]

Even when patients wanted decisions made for them, medium and high MR unit clinicians tried to ensure patients possessed and understood the information pertinent to the treatment options.

...patients...from that era where the doctor knows best and you don't ask questions, ...where they're given a choice [and] ...they just want it decided for them. ...[we spend time] trying to get them to think about the different aspects of it...in some cases...[the doctors] say, 'Well,...it is up to you...to decide what you [want,' but] ...on occasion some may say, '...I think x is best'... So...I just try to make sure they understand the implications of...what is being done. For example...with...conservative surgery...the possibility...they might need another operation if the margins aren't clear... And [I] probably would again point out that there is a choice, but try to ascertain that they are comfortable with what they've [having] done and know...the implications of that particular...decision... [BCNo39, female nurse, low MR unit, p15]

On occasions the clinicians from all three units described discussing options strictly outside breast unit guidelines at the patients' request; BCT when the cancer was multifocal, multi-centric, or large. They described outlining options in a similar way to normal but highlighted why BCT was a less clinically appropriate option in this context, and emphasised the potential consequent problems.

...[even] when you feel strongly that...the best recommendation would be a mastectomy. ...we might say that...'If you feel strongly that you would like to preserve as much breast tissue as possible...we will try and work round that...my job is just to make sure you're aware of the pros and cons of any decision. [BS023, low MR unit, p9]

...we would never paint it as a 'you must have this or...that'...it's not a problem...if a woman says 'I won't have a mastectomy' I will explain...the reasons why we think she should...but would never make her feel that somehow she was being...silly... [BS003, male consultant surgeon, medium MR unit, p8]

### **Process of recommending treatments**

All doctors provided treatment recommendations sometimes when patients' cancers were suitable for BCT. But one of the most notable differences between the low versus other units' was their clinicians' attitude and practice regarding the provision of recommendations (reluctance versus inclination or enthusiasm) and the stage of the decision making journey they would provide them (early versus late).

Reflecting their beliefs about decision making, most low MR unit clinicians talked comfortably about providing their expert opinion of the most appropriate treatment in response to patients' requests for recommendations. Self-reflection could contribute to this practice.

...quite a lot of patients will fit into this group [passive patients] ...I suspect I'd fit into that group...if I was given a load of options by somebody who I considered...knowledgeable in

the field,...I'd have to...ask them...what they thought was the best... [BS020, male consultant surgeon, low MR unit, p19-20]

The forcefulness of recommendations varied with their strength of belief in their unit ethos. Some described providing forceful recommendations when cancers were suitable for BCT.

...we just push it quite, quite, quite hard and say that "this lesion is perfectly compatible with doing a local operation..." If they...want a mastectomy for various reasons,...I suppose you might go along with that...if they were desperate... [BS029, male consultant surgeon, low MR unit, p24]

Their impression of patient desire for recommendations was often so predominant, that many volunteered them early in the first treatment discussion rather than waiting for their request.

...some patients will just be happy to know the diagnosis, happy to know what you offer, whatever it is, and leave it at that, 'You know best, doctor'...which is I suppose why I try and pre-empt that a little bit by giving them a bit of an inkling to start with...what would be easy to choose, and then back off if they say, 'Well actually, I want a mastectomy...' [BS020, male consultant surgeon, low MR unit, p11-12]

Most medium and high MR unit clinicians however described trying to avoid the provision of recommendations in all but the most definite examples of passive patients and deferring direction to a later stage: The reasons provided being concerns they correctly identified true passive decision-makers who needed these, and concern that once given recommendations, patients ceased to consider options and risked experiencing later regret.

...often...they want to be told what to do. So...listen ...But you try not to be influential, I ...say, it's, ultimately it's your choice... [BCN026, female nurse, high MR unit, p9]

...some ways these are the hardest people to deal with because they...expect you to just decide what is best for them ...in...mastectomy versus wide excision, one of the most important things is their own concern about cosmesis, which I cannot know. ...the patient I've got in mind...presented with a screen-detected cancer and I think she probably only said about five words during...the whole consultation, and just...nodded and looked...blank at everything we said,...it was very difficult to know how much she'd taken in,...and at the end she...said, 'Well, what should I do? What do you think? and it was almost, because of the way that we approach it and explain that there is a treatment choice and that it's different from one individual to another, [she] seemed not to even have heard that... I find that the hardest group to deal with because I want them to at least have some input into it, I want to get a feeling from them how important the cosmetic issue is for that individual... Part of the problem of course is that you have a limited timeframe in which all this can happen,...people are often coming in quite quickly and...have a limited time in which these choices are made. And...we need to know that they've had sufficient time, that ...they're making, or ...we're making the right decision on their behalf. [BS003, male consultant surgeon, medium MR unit, p18-19]

Rather than provide recommendations, this group persisted trying to inform, engage and support patients in decision making; adapting their usual stepwise process of information provision, to do so; reiterating information, encouraging self-reflection and consideration in the context of patients' subjective preferences. They also emphasised the individuality and long term nature of such a decision and the time available for the process. If this did not assist patients, they sought to identify patients' preferences, concerns and fears and encouraged patients to consider the information in the context of these. Typical discussion foci were breast loss, radiotherapy, the possibility of further surgery and cancer recurrence.

The other thing that comes in...is the possibility of a second operation...how would you feel about the possibility of a second operation if it needed?' 'How would you feel about having, definitely having radiotherapy...just go through and pick up the reasons why they might choose one or the other. [BS015, male consultant surgeon, high MR unit, p 24]

Using this process these clinicians recalled few instances where patients were unable to make decisions. They however recognised this process could require substantial time commitment.

I can't ever remember a case where I had to say, 'OK, then, I'll decide, we'll do blah-blah.' At the end of the day you usually get it from the patient... It can take a lot of work and effort sometimes and, occasionally it does mean...on the morning of the operation...I go round and do the final consent...and if they've got any indecision...I would usually...get one of the breast care nurses to come...and chat to the patient...and then come back to see them...to give them even more chance to, not just have me,...somebody else talking to them. [BS015, male consultant surgeon, high MR unit, p 24]

Clinicians from all units who readily volunteered or reluctantly provided recommendations, expressed concern patients could subsequently regret decisions made for them because of unidentified concerns or preferences. Despite this, most low MR unit clinicians still described a readiness to universally recommend BCT; believing it more acceptable to patients.

...the people you're least sure you've done the right job for are the [ones] ...you've made the decisions for...it really only may turn out afterwards that that might not be the decision that they would have made...if they'd been given time or the ability.... they're totally shocked as a result of being told...that they've got cancer and...they appear passive...the patients who tell you what they want, even though it might not be what you want to offer...at least it's their preferred option. So I think you feel a bit more...certain that you're doing the right operation for that person... [BS020, male consultant surgeon, low MR unit p20-21]

To minimise this risk, some described adopting a tailored approach to their recommendations.

With ... passive decision makers it's a bit difficult because I have to make the decision for them...I have to fish out all the details that would enable them to decide...and make the



decision...knowing how they would feel on certain aspects of their life or what is important to them... the fact that they're saying, 'You can make the decision for me,' doesn't necessarily mean that they will be happy with it. So [I]...have to make sure that they're going to be happy... [BS037, low MR unit, p13]

However, if any doubt remained, clinicians recommended BCT to passive patients; as it could be converted to mastectomy if necessary, but the reverse was not possible.

...one of the things I'll often say to...this kind of [passive] person is ...'Some people find...they cannot come to a decision.' ...where there's a clearly a choice I usually say, 'If you're still in two minds ...you're often better going for the wide excision...because...a mastectomy's an irreversible thing, once a breast's removed that's it. [BS004, medium MR unit, p 19]

The unit's ethos was usually reinforced by one or both specialist clinician groups. In the low MR unit this usually meant emphasising direction toward BCT; sometimes if the doctor had not promoted it.

Some low MR unit BCNs described feeling constrained and uncomfortable limiting their discussion extent to the doctor's treatment plan if patients wanted to explore wider options than those offered by the doctor. Many adhered to the doctors' remit, but some more senior BCNs more freely and extensively followed the patients' lead; but described a tension between their desire to reinforce the doctor's message and not confuse patients, with the desire to provide patient support and advocacy.

...I think we can be there to help them through how they...make their decision...discuss it,...making sure that they understand what the consultant said to them and giving them the right information...support them while they make that decision. [BCN042, female nurse, low MR unit, p32-33]

### **Process of decision making and establishing consent**

Variation was seen between the units in clinicians' perception of the process of decision making and (establishing) consent. As with the other subthemes and factors, variation was mainly unit dependent; with low MR unit descriptions differing from those of the more similar medium and high MR units. Some from the low MR unit seemed to view consent as an isolated event, establishing permission to treat according to a treatment plan determined and recommended by the treating specialist clinician. Clinicians from the medium and high MR units consistently

viewed establishing consent as a process requiring a variable period of time, governed by and requiring patients' acquisition and consideration of appropriate and adequate information. This was reflected in the journey timescales and processes clinicians described from diagnosis to confirming treatment and establishing consent. This process was generally much swifter in the low MR unit. The organisational structure of clinics meant patients usually had fewer routine consultations in the timeframe between assessment and consent.

...once they've been told [their diagnosis]...I won't routinely arrange to see them again. ...there are exceptions...But they are the minority and I'm prompted to do that in patients who I can see is not taking in it or just being knocked for six by a diagnosis...or by the breast nurse who'd picked up that...I don't tend to...bring them back because the clinics are busy enough, and I'm not sure they need it really... [BS020, male consultant surgeon, low MR unit, p8]

This rapidity was exacerbated within the one-stop clinics of the low MR unit; which could mean some patients were assessed, diagnosed, had treatment discussed and were consented on the same day. Some also used the BCN consultation immediately after the diagnosis, to establish treatment consent.

...I say to the patient ...'You came with a lump in your breast today...it...isn't just an ordinary lump, it is a bit more serious and probably does mean that it's a malignant lump, a little cancer...or a cancer. Now we need to recommend some treatment...we'll fix a date for you to come in for your surgery and you'll have a bit of time with the breast care nurse to go through what I've said.' Then I'll go through the operation and sign a consent form with you. [BS020, male consultant surgeon, low MR unit, p6]

This was the only preoperative doctor-patient consultation for many of those patients. The sense of process rapidity could be compounded by patients' lack of preparedness for their diagnosis.

...it's...largely a single visit clinic... So...they're not prepared... Some patients are utterly shocked, had no idea at all that it could be [cancer]....because of the...compressed time scale of the whole system...there's not much warning... [BS029, male consultant surgeon, p5]

Some BCNs also expressed discomfort regarding the time-pressured decision making processes which could rush patients. They were particularly uncomfortable about the practice of consenting on the day of diagnosis; believing patients had insufficient time to make choices.

...the ladies can be diagnosed and consented all on the same day. ...it still doesn't sit comfortably with me...that somebody can be diagnosed and be able to make a decision about surgery all on the same day. It doesn't always happen but it happens quite a lot,...there's two particular consultants that work that way. And...I think it's difficult for us...breast care nurses and the patient's advocate, and...I have tended to say [to the

patient] at that point, '...you don't have to make a decision today, you can go away and think about it, and come back.' And some of them will say, 'Oh, no, it's, I'm quite happy,' but...I still don't feel comfortable about that, and that's something...I think we [nurses] all feel that way..' [BCNo42, female nurse, low MR unit, p8]

Some low MR unit clinicians adopted a comparatively slower approach, with an additional doctor-patient consultation a week following diagnosis, to permit additional discussion. This was preferred by the BCNs.

...some consultants will bring them back the following week following discussion of treatments...they're given...written information so they can go away home and think about it and read the information and then they come back. ...I think that's a good way of doing it because at...diagnosis they can't always think straight...they don't take on board everything...and I think they need that week to get their head round everything... And you often find that when women do come back the following week they are very much more focused, they've obviously had time to think,...talk to people, get on the website, get information...they want...then...we can plan surgery. ...Some [consultants]...don't do that: they see them at the time of diagnosis...we...sit down and talk to them, and...some are not seen again by the consultant... [BCNo38, female nurse, low MR unit, p3-4 ]

The other units described routinely incorporating more consultations between assessment and consent, and routinely consented patients closer to the time of surgery; in pre-assessment clinic or on admission.

...we'll go through the results, plan,...a date for surgery...negotiate it directly with them... they'll usually go and have a chat with the breast care nurse alone in a quiet room...immediately after that. ...anyone having surgery will come to a separate [pre-assessment] clinic...and we...almost always get to see them again on that day which is quite useful as well because it's an opportunity for the questions that they didn't think of the first time... And...that'll be the time when we tend to make that final choice between us and we do the consent forms at that stage. ...there will of course be some people who haven't made their mind up by then;...they need...more time so we'd...[consent] when they're admitted. [BSoo4, male consultant surgeon, medium MR unit, p2]

BCN consultations immediately following diagnosis was routine practice in all units. But the medium and high MR had more routine consultations a few days after diagnosis, prior to consenting. Their rationale being that most patients required sufficient time and opportunities to gain adequate knowledge confidence, and explore their preferences. This slight delay also allowed patients a little time to take in their diagnosis and permitted the resumption of information exploration and discussion, without the time constraints or acute patient distress of the first meeting.

It varies tremendously,...there are some patients who are so gobsmacked by the diagnosis that they can't think or ask anything and it may be the partner who is doing all

the questioning or it may be that they are both gobsmacked and I think we all accept that it is a...gradual process and that very often you won't cover half the ground at the first visit. ...they...go with the breast care nurses...and consolidate what has been said and...may have...subsidiary questions...which...the breast care nurses may deal with it. ...pre assessment clinic...is another opportunity to meet the surgeon and...go over in more detail and do the consent. [BS003, male consultant surgeon, medium MR unit, p5]

High MR unit patients were offered the opportunity to have these additional consultations in their own home rather than at the hospital. BCNs believed the home environment facilitated greater patient confidence and freedom exploring their needs and agenda.

...a lot of [home] visits...tend to be...a newly-diagnosed ...patient [who] didn't want to stay or I felt that they haven't totally understood what has been said...the home visit...will give the woman and her family an opportunity to be on their own ground and...that sometimes helps, they feel more secure in their own home...more comfortable to open up to you... Most of the time...it's a much easier interview, they have settled down by that stage, they are starting to think a little bit more and question, but it's on their time not yours. ...led by the patient, not by us. [BCN023, female nurse, high MR unit P7]

Clinicians from all units described a sense of time-pressure in their consultations as a result of high workloads.

...the most I've probably had in one clinic is 9 patients diagnosed in one afternoon. Now to see them one after the other, if I'm not ready to see the next patient for diagnosis, that slows the clinic down, it makes the patients' waits longer, and it increases patient anxiety. ...I think...we do see an awful lot of cancers:...more than the recommended number...that should be seen by a breast care nurse... [BCN037, female nurse, low MR unit, p4]

...sometimes...you've got three, four patients to see,...it's a bit like a conveyor belt and even though...you're delivering the same information...you don't perhaps get as involved...as...when you've got more time... [BCN025, female nurse, high MR unit, p4]

BCNs in particular described difficulties balancing consultation workloads and desire to not keep anxious patients waiting, with the desire to provide individual patients with sufficient time.

...the more time you've got to spend with the patient the better. If you know when you come into work on the Tuesday that, somebody might be on holiday so there might be only three of you, so...you've got to see three women yourself that morning, you just know you're not going to have that [time]...well you make time but you feel under pressure because you're aware that there might be somebody else waiting to be seen. ...there's that sense of...I've got people waiting. [BCN026, female nurse, high MR unit, p4]

...some of the difficulties are the numbers of patients coming through, and that's always going to be the problem, ... it's a high turnover ... outpatient workload, and sometimes if you're in a busy ... clinic and there's a lot of patients out there waiting and you can see that the waiting room's packed, seeing people and spending time with them can be quite

difficult. Some people might take half an hour of your time, if they've got a lot of questions or they're very upset, and you do feel under pressure. [BS004, male consultant surgeon, medium MR unit, p4]

They also described how the emotional nature of their work could compound time-workload pressures to impair their ability to support individual patients.

To be honest, I'm going from one patient diagnosis of cancer to another...thinking, '...I need to get organised...ready for the next...[sometimes]...I just need to stop,'...I'm only human,...I...wasn't ready to take the next patient on board...I wouldn't be able to give to that patient the right bit of me, the right bit of information. [BCN037, female nurse, low MR unit, p14]

Clinicians recognised that patients required different time-spans for decision making; some volunteering swift decisions, others taking longer. But medium and high MR clinicians almost always discouraged quick decisions and encouraged patients to thoroughly consider the treatment facts and their decision before committing to a treatment and being consented. They were concerned rushing decisions could lead to regret.

...we do sometimes see people who appear to...jump to a decision and then may change it, so even in that situation...we wouldn't make the final decision until they'd seen the breast nurse and then we'd seen them in the pre-assessment clinic... [BS003, male consultant surgeon, medium MR unit, p10]

Low MR unit clinicians in contrast often consolidated decisions early by consenting. Some BCNs felt this could have negative consequences.

...personally I prefer them to come back the following week...because...on the rare occasion that there is a problem...you have to pick up the pieces...and start from scratch. ...that has happened a couple of times and it's caused us quite a few problems... [BCN038, female nurse, low MR unit, p3-4]

TABLE 5.6 Routine processes and decision making culture subthemes and factors.

Low MR unit	Medium and high MR units
Process of offering options	
Individual clinicians decide eligibility for options based on interpretation of breast unit guidelines	MDT decides eligibility for options based on interpretation of breast unit guidelines. Standard documentation of suitability for options at initial clinical assessment (high MR unit)
Process of communication	
Consultation style	
Consultations more consistently directive and focused on clinician preferences	Consultations more consistently focused on facilitating decision making
Less routine checking of understanding	Often comprehensive checking understanding
Consultation style consistent with their belief that most patients are passive	Consultation style consistent with the view that most patients are capable of treatment decision making with support
Information	
Content more focused on BCT. Mastectomy mentioned to discount it	Content focused on BCT & mastectomy; including the pros, cons and possible outcomes
Provide less comprehensive information set dominated by reassurance	Provide reassurance as part of a more comprehensive information set
Emphasise BCT as the best/standard option	Emphasise choices and safety of BCT.
Process of recommending treatments	
Most routinely volunteer recommendations of the 'standard'/optimum treatment.	Most reluctant to provide recommendations. Instead adopt a stepwise process to promote decision making
Most provide early in the initial consultation	Tend to defer till for late in the decision making journey if patients cannot decide
Process of decision making and establishing consent	
Increased time pressure in clinics and decision making, due to workload, consultation styles, routine appointment system & timeframe to establishing consent	Often adopted strategies minimise time pressure in clinics and decision making through consultation styles, additional routine appointments and emphasising time for consent
Timeline from 1 <sup>st</sup> assessment to diagnosis & consenting usually shorter (at diagnosis or 1 week later)	Not same day diagnosis and longer journey to making decision & consenting; routinely at pre-assessment clinic or on the day of surgery
BCNs consent for some doctors.	Doctors always consent patients.
BCNs have one routine consultation prior to (and sometimes incorporating) consenting.	BCN consultation immediately following diagnosis and one or more routine additional BCN consultations.

## CONCLUSION

This component of 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. A number of interdependent key differences were observed between the breast units in whom case-mix was excluded as a cause of variation. Some were overt, others more subtle. These created a decision making culture within each unit which provided the backdrop for patients' experiences of decision making. These are summarised in table 5.7. As reflecting any real life situation, many of the qualitative findings expose a spectrum of beliefs, attitudes, and behaviours. Some variation was noted between clinicians of the same unit. Clinicians were aware of diversity within their unit. However this diversity and their understanding of it were framed in terms of the unit ethos. Like the third dimensional power in Lukes' power theory,(Lukes 1974) this culture was so pervasive, there were certain things clinicians believed, described and accepted, which other units might question. Despite this diversity, distinct and consistent differences were noted between the units; with the low MR unit differing from the more comparable medium and high MR units.

There was a cohesive and specific ethos within each breast unit regarding the management of women with breast cancer suitable for BCT. Clinicians, as individuals and as members of a breast unit team, described the central focus of their ethos on the provision of the optimum management to patients, in order to optimise well-being and minimise the negative impact of a potentially life-threatening diagnosis. However two notable differences existed between them. They differed in what they believed optimum management was. As teams, they either viewed this as either a particular outcome (BCT where possible in the low MR unit) or a particular process (the facilitation of more autonomous patient decision making in the medium and high MR units). This impacted the patient groups they identified as suitable for options; which resulted in a much smaller subgroup of patients in the low MR unit being provided with genuine options. They described not providing choices, but rather BCT as a treatment plan, to women with what they considered small (up to 3-4cm) and/or peripheral cancers. The other units described providing choices to this patient subgroup.

Underlying and concordant with the ethos, the groups of clinicians from the different units tended to hold a particular set of beliefs. These included not only what they believed was optimum management, but what they felt patients wanted in terms of particular treatments and whether they believed patients wanted a role in choosing their treatment and had the capability

to do so. They possessed different beliefs about the roles of patients and clinicians in the decision making process; predominantly believing clinicians role was either to provide the expert opinion (low MR unit) or provide patients with the tools to facilitate them making their own choices (medium and high MR units). The unit ethos, beliefs and preferences also influenced the options and information routinely presented to patients, and the way they were communicated; directive versus facilitative. This was reinforced by the routine processes adopted within units. The effect of these various factors were either amplified or diminished by the time clinicians provided for the process. For example, patients' journey from initial assessment to diagnosis and consent was usually swifter in the low MR unit and did not afford as many routine consultations prior to consent; some had one-stop clinics where assessment to consent all happened on the same day.

There was considerable overlap between the four key themes identified from the clinician interviews. None were mutually exclusive, all were interdependent; though ethos was the strongest theme and could steer even those who were less committed to it. In terms of the relationships between the four themes; clinician beliefs fed into the ethos which was central and dominant within the individual units, the ethos governed who was considered eligible for options and who was considered too definitively suitable for BCT that no options were provided. The ethos and beliefs fed into the units' process of what information was presented and how it was presented, and the process of how decisions and consent were made. These individual factors contributed toward the differing decision making culture of units. The result clinicians tended to describe was, decision making by varying degrees of informed consent or informed/uninformed compliance; depending on the clinician and unit. Despite such notable differences between them, clinicians and teams within units had identical motivations; they wanted to provide what they considered the optimum management of their cancer to patients and minimise the negative impact of this diagnosis.

Among the study population from this UK region, the uptake of BCT reduced when clinicians provided and supported greater patient knowledge acquisition and promoted greater patient decision making autonomy.

This component of the study is based on self-report interview data, rather than direct observation of clinicians' consultations with patients. This could be viewed as a potentially limitation. This is explored in the general discussion.



TABLE 5.7 Summary of the key similarities and differences identified by the clinician interviews

Key similarities	
Primary motivation to provide their patients with breast cancer optimum management and minimise the negative impact of this diagnosis.	
Key differences	
1.	Which patients teams/units/clinicians identify as suitable for treatment options/choices
2.	Breast unit ethos' central focus; outcome-based (a specific treatment) or process-based (more autonomous patient decision making)
3.	Clinician/units' central belief; optimum management is a specific treatment determined by the expert clinician (BCT where possible at the low MR unit) vs. the treatment preferred by the patient (more autonomous patient decision making at the medium and high MR units)
4.	Depth and extent of information provision (options, language and comprehensiveness)
5.	Directive vs. facilitative approach & recommendations (reluctance vs. inclination or enthusiasm, and early vs. late)
6.	Mechanisms of patient decision making support vary in comprehensiveness and whether or not routine part of the process
7.	Timescales and process of establishing consent for treatment

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## Chapter 6

### Patient semi-structured interviews

Why do hospital mastectomy rates vary? A qualitative study  
of the decision-making experiences of women with breast  
cancer

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## ABSTRACT

**Background** UK national guidelines state when BCT is not contraindicated, women with breast cancer should be offered a choice between BCT and mastectomy. Despite this, surgical treatment variation between hospital breast units is widespread. The aim of this component of the study was to determine the relationship between breast unit MRs and patients' experience of information provision, consultations with their treating clinicians and decision-making experiences.

**Methods** This MREC approved study was undertaken in three purposively selected breast units from a single UK region identified to have high, medium and low case-mix adjusted MRs. Semi-structured interviews were conducted with 65 women the breast unit clinicians identified as having been provided with a choice of breast cancer surgery (BCT or mastectomy). Interviews were digitally recorded, transcribed verbatim and analysed using the Framework approach.

**Findings** The decision-making experiences of women from the medium and high MR breast units were similar, and these were dissimilar to those of the low MR unit. Treatment variation was associated with patients' perception of the most reassuring and least disruptive surgical option; the content and style of consultation information (equipoise or directed); level of patient participation in decision-making; and the time and process of decision-making. The provision of more comprehensive less directive information, together with greater autonomy, time and support of independent decision-making were associated with a lower uptake of BCT.

**Interpretation** Variation in MRs between units was associated with clinicians' information provision and consulting style, and patients' treatment decision-making experiences. More comprehensive information provision and the promotion of greater patient autonomy were associated with higher MRs. The findings suggest that improving informed decision-making and increasing patient autonomy in the selection of the treatment, is unlikely to increase the uptake of BCT among women suitable for this option.

## BACKGROUND

Research demonstrates neither BCT nor mastectomy are superior in their impact on mortality (in cancers up to 4-5cm diameter),(Blichert-Toft, Brincker, Andersen, Andersen, Axelsson, Mouridsen, Dombernowsky, Overgaard, Gadeberg, Knudsen, & . 1988;Clarke, Collins, Darby, Davies, Elphinstone, Evans, Godwin, Gray, Hicks, James, MacKinnon, McGale, McHugh, Peto, Taylor, & Wang 2005;Fisher, Anderson, Bryant, Margolese, Deutsch, Fisher, Jeong, & Wolmark 2002;Jacobson, Danforth, Cowan, d'Angelo, Steinberg, Pierce, Lippman, Lichter, Glatstein, & Okunieff 1995;Lichter, Lippman, Danforth, Jr., d'Angelo, Steinberg, deMoss, MacDonald, Reichert, Merino, Swain, & . 1992;Poggi, Danforth, Sciuto, Smith, Steinberg, Liewehr, Menard, Lippman, Lichter, & Altemus 2003;Sarrazin, Le, Arriagada, Contesso, Fontaine, Spielmann, Rochard, Le, & Lacour 1989;van Dongen, Voogd, Fentiman, Legrand, Sylvester, Tong, van der, Helle, van Zijl, & Bartelink 2000;Veronesi, Cascinelli, Mariani, Greco, Saccozzi, Luini, Aguilar, & Marubini 2002)or morbidity(Carlsson & Hamrin 1994;Dorval, Maunsell, Deschenes, & Brisson 1998;Fallowfield, Baum, & Maguire 1986;Ganz, Desmond, Leedham, Rowland, Meyerowitz, & Belin 2002;Irwig & Bennetts 1997;McCready, Holloway, Shelley, Down, Robinson, Sinclair, & Mirsky 2005;Moyer 1997;Sanger & Reznikoff 1981;Schain, Edwards, Gorrell, de Moss, Lippman, Gerber, & Lichter 1983;Stefanek 1993) (except 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) Therefore guidelines state, when BCT is not contraindicated on clinical grounds, women with breast cancer should be offered a choice between BCT and mastectomy.(Association of Breast Surgery at BASO 2009;Kaufmann, Morrow, von, & Harris 2010;Scarth, Cantin, & Levine 2002a) Despite this widespread emphasis,(Association of Breast Surgery at BASO 2009;Blichert-Toft, Smola, Cataliotti, & O'higgins 1998;Department of Health 2001a;Department of Health 2001c;Department of Health 2009;General Medical Council 2008;Kaufmann, Morrow, von, & Harris 2010;National Collaborating Centre for Cancer 2009;Nattinger, Hoffman, Shapiro, Gottlieb, & Goodwin 1996;Nayfield, Bongiovanni, Alciati, Fischer, & Bergner 1994;Royal College Of Surgeons Of England 2002;Scarth, Cantin, & Levine 2002a;Scarth, Cantin, & Levine 2002b) practice remains variable.(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;School of Health and Related Research 1998;Scorpiaglione, 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)

It was widely supposed that if women were given more choice over their surgery, the majority would select BCT. The evidence regarding this is conflicting.(Collins, Moore, Clay, Kearing, O'Connor, Llewellyn-Thomas, Barth, Jr., & Sepucha 2009;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;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Lantz, Janz, Fagerlin, Schwartz, Liu, Lakhani, Salem, & Katz 2005;Mastaglia & Kristjanson 2001;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Moyer & Salovey 1998;Schou, Ekeberg, Ruland, & Karesen 2002;Street, Jr. & Voigt 1997)

Patients' breast cancer surgery decisions are subject to numerous influences,(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 & Margoiese 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) and impacts from age,(Bleicher, Abrahamse, Hawley, Katz, & Morrow 2008;Hawley, Lantz, Janz, Salem, Morrow, Schwartz, Liu, & Katz 2007;Molenaar, Oort, Sprangers, Rutgers, Luiten, Mulder, & de Haes 2004;Singh, Sloan, Atherton, Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010) race/culture(Bleicher, Abrahamse, Hawley, Katz, & Morrow 2008;Hawley, Lantz, Janz, Salem, Morrow, Schwartz, Liu, & Katz 2007;Hawley, Griggs, Hamilton, Graff, Janz, Morrow, Jagsi, Salem, & Katz 2009) and education(Bleicher, Abrahamse, Hawley, Katz, & Morrow 2008;Hawley, Lantz, Janz, Salem, Morrow, Schwartz, Liu, & Katz 2007;Singh, Sloan, Atherton,

Smith, Hack, Huschka, Rummans, Clark, Diekmann, & Degner 2010) have been demonstrated. The media has an influence,(Collins, Kerrigan, & Anglade 1999;Hughes 1993;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;McKinlay, Burns, Durante, Feldman, Freund, Harrow, Irish, Kasten, & Moskowitz 1997;Nattinger, Hoffmann, Howell-Pelz, & Goodwin 1998) as do patients' social responsibilities; leading some to opt for more simplified treatment package.(Smitt & Heltzel 1997;Wilson, Hart, & Dawes 1988)

However, clinicians and units have been shown to exert an influence over patients' treatment decisions, by recommending a particular treatments or communicating preferences,(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 through women's perception about the curative potential of treatments.(Katz, Lantz, & Zemencuk 2001;Kotwall, Maxwell, Covington, Churchill, Smith, & Covan 1996;Smitt & Heltzel 1997) Limited data are available on how patient and clinician/unit factors combine to influence treatment decisions, or what impact different consultation styles (patient vs. doctor-centred) or decision making approaches (paternalistic, shared and informed choice)(Charles, Whelan, & Gafni 1999a;Charles, Gafni, & Whelan 1999b;Charles, Gafni, & Whelan 2000;Coulter 1999;Coulter, Entwistle, & Gilbert 1999;Elit, Charles, Gold, Gafni, Farrell, Tedford, Dal Bello, & Whelan 2003;Elwyn, Edwards, Gwyn, & Grol 1999;Elwyn, Gray, & Clarke 2000;Elwyn 2008;Gafni, Charles, & Whelan 1998;McWhinney 1989;Silverman, Kurtz, & Draper 1998) have over decisions. However patients are demonstrated to prefer patient-centred consultation styles(Dowsett, Saul, Butow, Dunn, Boyer, Findlow, & Dunsmore 2000;Frederikson 1995;Lerman, Daly, Walsh, Resch, Seay, Barsevick, Birenbaum, Heggan, & Martin 1993;Maguire 1999;Vick & Scott 1998) and decision making approaches,(Charles, Whelan, & Gafni 1999a) and these have been associated with better information recall(Fallowfield 2000) and patient outcomes.(Griggs, Sorbero, Mallinger, Quinn, Waterman, Brooks, Yirinec, & Shields 2007;Hack, Degner, Watson, & Sinha 2006;Irwig & Bennetts 1997;Lerman, Daly, Walsh, Resch, Seay, Barsevick, Birenbaum, Heggan, & Martin 1993;Mandelblatt, Edge, Meropol, Senie, Tsangaris, Grey, Peterson, Jr., Hwang, Kerner, & Weeks 2003;McCready, Holloway, Shelley, Down, Robinson, Sinclair, & Mirsky 2005;Roberts, Cox, Reintgen, Baile, & Gibertini 1994;Street, Jr. & Voigt 1997)

As the interaction between the two groups takes place in consultations, understanding patients' experience of consultations with their clinicians and how these influence their treatment decisions is important. The aim of this component of the study was to explore the consultation and treatment decision-making experiences of women newly diagnosed with breast cancer, to identify key themes associated with variation in breast unit MRs. The study was conducted among patients eligible for a choice of surgery (BCT or mastectomy), from three breast units of a single UK region identified as having high, medium and low case-mix adjusted MRs.

## **METHODS**

### **Study design**

Qualitative research methodology was employed to explore how specialist clinicians influenced patients' choice of surgery (BCT or mastectomy). Semi-structured interviews were chosen to capture rich data on the topics of pre-determined interest, while providing sufficient flexibility to capture emergent themes in allied areas of interest.

The interview schedule (see appendix 7) was developed by the research team; including experienced qualitative researchers, two surgeons, one BCN and two consumer representatives who had previously been diagnosed and treated for breast cancer. The interview schedule was piloted on one breast cancer patient.

### **Setting and sample**

This component of the study was conducted in the same three purposively selected specialist hospital breast units from the Trent region of the UK, as the patient questionnaire and interview components of the study described in chapters 4 and 5; i.e. units representing high, medium and low case-mix adjusted MRs.

Reports of similar studies suggest that interviewing approximately twenty patients per breast unit achieves response saturation.(Marshall 1996) A sampling frame (figure 6.1) was employed to

purposively recruit women from the questionnaire phase of the study balancing treatment choice and breast unit. Potential participants were identified by their unit as having been offered a choice between BCT and mastectomy, and able to provide informed consent to participate. Patients were approached following their surgery. The recruitment process and eligibility criteria are fully described in the patient questionnaire section of the thesis (chapter 4). Participants self-selected to participate in both the questionnaire and interview phases (n=274/357). Interviews were restricted to a defined eight month period by the employment of a single interviewing researcher. Ninety eligible participants were recruited during the eight month interview period. Two withdrew, leaving a potential eighty-eight eligible participants. Limited recruitment of patients choosing mastectomy meant the sampling frame could not be filled in the timeframe of this component of the study. However, response saturation was achieved with the interview of sixty five patients.

FIGURE 6.1 Patient interview sampling frame

		Breast unit			Total
		Low MR unit	Medium MR unit	High MR unit	
Initial therapeutic treatment	BCT (n)	10	10	10	30
	Mastectomy (n)	10	10	10	30
Total (n)		20	20	20	60

The participants were aged median 58 years (range 33-73 years). The mean time between surgery and interview was six weeks (range 1.9-20.6 weeks). Overall, 75% of participants underwent BCT (n=49) and 26% mastectomy (n=16). Twenty patients were interviewed from the low and medium MR units, and 25 from the high MR unit. Seven, seven and two patients had undergone mastectomy respectively from the high, medium and low MR breast units. The interviewed patient characteristics are summarised in tables 6.1, 6.2 and 6.3. Tables 6.1 and 6.2 illustrate the groups characteristics. Table 6.6 provide information at individual participant level on age operation, PDMS, ADMS, breast unit and time between operation and interview.



TABLE 6.1 Characteristics of patients interviewed (n=65)

		Median	Range		
Age (years)		58	33 - 73		
		Mean	Range		
Time surgery to interview (weeks)		6.0	1.9 - 20.6		
(n= )					
Operation	BCT	49			
	Mastectomy	16			
PDMS	Active	29			
	Collaborative	25			
	Passive	11			
ADMS	Active	44			
	Collaborative	12			
	Passive	9			
High MR unit				Medium MR unit	Low MR unit
Patient operation by breast unit	Mastectomy (n)	7	7	2	
	BCT (n)	18	13	18	
	Total (n)	25	20	20	

TABLE 6.2 Interview patients by initial therapeutic treatment and age

			Patient Age			Total
			<50 yrs	50-70 yrs	>70 yrs	
Initial therapeutic treatment	BCT (n)		10	37	2	49
	Mastectomy (n)		6	9	1	16
Total		(n)	16	46	3	65
median age 58 years (range 33 to 73 years)						

TABLE 6.3 Summary of Interview participant characteristics by breast unit and time of interview

Unit	Patient no.	Op	Age (yrs)	PDMS	ADMS	Time surgery to interview (days)
Medium MR unit	1	Mx	42.9	2	2	28
	2	Mx	59.7	3	2	34
	3	Mx	45.2	3	1	53
	4	BCT	58.1	4	4	29
	5	BCT	62.1	3	3	28
	6	BCT	56.8	2	3	32
	7	Mx	46.1	2	2	29
	8	Mx	58.2	2	2	25
	9	Mx	50.8	2	2	35
	10	BCT	54.7	2	2	15
	11	BCT	47.0	5	1	35
	12	BCT	69.4	4	3	18
	13	BCT	70.7	2	2	49
	14	BCT	60.2	3	3	15
	15	BCT	43.1	3	3	115
	16	Mx	73.4	4	3	60
	17	BCT	50.0	4	4	90
	18	BCT	62.0	3	3	63
	19	BCT	58.5	2	5	39
	20	BCT	58.2	2	2	21
High MR unit	21	BCT	54.5	4	2	144
	22	BCT	58.9	2	2	109
	23	Mx	62.6	2	2	49
	24	BCT	43.0	2	2	35
	25	Mx	60.9	4	1	86
	26	BCT	57.8	3	2	90
	27	BCT	61.6	3	1	55
	28	BCT	60.6	3	2	58
	29	Mx	48.6	2	1	38
	30	Mx	62.6	2	2	31
	31	Mx	64.7	3	1	38
	32	BCT	61.5	2	2	47
	33	BCT	57.5	3	1	66
	34	BCT	55.5	3	2	37
	35	Mx	65.5	2	2	37
	36	BCT	57.8	3	2	26
	37	BCT	67.6	2	2	40
	38	BCT	57.9	1	1	51
	39	BCT	71.7	2	2	36
	40	BCT	57.4	2	3	41
	41	BCT	42.5	2	2	49
	42	BCT	60.8	4	1	28
	43	BCT	61.1	5	5	38
	44	BCT	57.9	2	5	38
	45	Mx	46.0	3	2	38
Low MR unit	46	BCT	59.4	2	1	64
	47	BCT	68.6	3	2	63
	48	BCT	38.8	3	3	48
	49	Mx	59.6	3	3	32
	50	BCT	55.8	2	2	24
	51	BCT	51.8	3	2	22
	52	BCT	53.3	2	2	13

	53	BCT	41.7	4	4	16
	54	BCT	60.7	2.	2	13
	55	BCT	44.1	3	3	31
	56	BCT	33.0	1	2	24
	57	BCT	44.2	2	1	14
	58	BCT	58.2	3	2	22
	59	BCT	60.1	3	2	13
	60	BCT	57.6	2	2	25
	61	BCT	55.1	3	4	45
	62	BCT	44.6	3	5	30
	63	BCT	59.9	3	5	48
	64	BCT	59.8	3	3	29
	65	Mx	44.4	4	2	21
<b>OP = operation; Mx = mastectomy, BCT = breast conservation therapy</b> <b>DMS: 1= most active, 2= shared active, 3=collaborative, 4=shared passive, 5= most passive</b>						

## Data

The interview schedule was designed to provide a description of the patient's surgical treatment decision-making experience. Gathering information about consultations with multi-disciplinary breast team members; focussing on the content and style of consultations, patients' understanding of the information provided, and how these influenced treatment decisions. Contextualising information was sought on patients' treatment, their preconceptions, and pre-existing information and experiences of breast cancer, information from other sources and other factors influencing their treatment decisions. The interview schedule is found in Appendix 7, along with patient letters. Interviews took place between 23/03/2004 and 19/11/2004. All except one interview was conducted in the patients' home. Interviews were digitally recorded and transcribed verbatim. An example of a verbatim patient interview transcript is found in Appendix 10. Field notes were also kept.

## Data analysis (the Framework approach)

As described more fully in chapter 5, verbatim transcripts and the interviewer's field notes were analysed using the Framework approach, which provides a rigorous, comprehensive, systematic approach to manage and analyse the large volumes of textual data generated by qualitative studies; but permits extensive data exploration within and across both themes and cases, while retaining the link between each comment and the source data. Initial thematic analysis was

conducted by one clinical researcher (LC), two non-clinician researchers (DW and KC), and the study's consumer representatives (HMC and GS). The majority of clinician interview analyses (79.9%, 20/26 patient interviews) were facilitated by listening to the particular interview audio recording while analysing the verbatim transcript. To minimise bias and optimise consistency of data analysis 12/65 (20%) interview transcripts were independently coded and charted by two researchers (LC and DW) and then discussed, as an on-going process throughout data analysis.

The development of the theme, sub-theme, and factor structure utilised the same process as described in chapter 5. The final Framework patient data analysis theme headings and code numbers are illustrated in figure 6.2. An example of a patient interview Framework matrix is found in appendix 9. The adopted charting conventions and abbreviations shown in chapter 5, figure 5.3. The transcription conventions are also found in chapter 5.

FIGURE 6.2 Final Framework patient data analysis theme headings & code numbers

1) UNIT ID CODE					
2) PATIENT ID					
3) OP TYPE					
4) DMS					
BACKGROUND	5) <u>GENERAL</u> I.e. age, marital status, ethnicity employment, PHMx	6) <u>PRIOR EXPECTATIONS &amp; EXPERIENCE</u> Inc. sources of these.	7) <u>PATIENT JOURNEY</u> Thumbnail sketch of journey through clinic, who they saw, when, etc.		
DECISION-MAKING & CLINICIAN STYLE	8) <u>DOCTORS</u> Communication & interpersonal skills, perceptions of doctors.	9) <u>NURSES</u> Communication & interpersonal skills, perceptions of nurses.			
DECISION-MAKING RELATED TO INFORMATION	10) <u>INFO SEEKING BEHAVIOR</u> How, when and in what ways did patients look for (or were given info (not info from clinic).	11) <u>ACCESSIBILITY</u> General perception of team vs. other (who and what info).	12) <u>INFORMATION RELAYED &amp; GIVEN BY TEAM</u> Manner in which information was delivered, what tools / strategies used in delivery, inviting questions.	13) <u>INFORMATION CONTENT</u> What was actually said to the patient, questions asked to patient?	14) <u>PRIORITY INFORMATION NEEDS</u> What patients wanted or needed to know about their cancer and its treatment, what they actually asked about.
DECISION-MAKING PROCESS	15) <u>UNDERSTANDING</u> Patients perception of clinicians information & ID who.	16) <u>OPTIONS</u> Options given & implications of options.	17) <u>TIME</u> Patient perceptions of how much time they had to make decision & feelings about the amount of time.		
CHOICE	18) <u>FEELINGS ABOUT HAVING A CHOICE</u>	19) <u>CLINICIAN ADVICE</u> What did clinicians advise if or when asked for their preference?			
20) GREATEST INFLUENCE OVER DECISION-MAKING					
21) FACTORS ASSOCIATED WITH SATISFACTION / DISSATISFACTION					
22) ONE THING TO CHANGE					
FEELINGS	23) <u>FEELINGS ABOUT CANCER DIAGNOSIS</u> How did patient feel about being diagnosed & living with cancer, family / social aspects of having cancer, etc.	24) <u>FEELINGS ABOUT OPERATIONS</u>	25) <u>FEELINGS ABOUT ADJUVANT Treatment's</u> Chemotherapy, Radiotherapy & endocrine.		
26) COPING MECHANISMS					
27) EXTRA INFORMATION (Anything interesting, but which doesn't fit elsewhere)					
28) FIELD NOTE INFORMATION					

## FINDINGS

There was heterogeneity of women's experiences within the units. However, the decision-making experiences of women from the medium and high MR units were similar, and were

dissimilar to those of the women treated by the low MR breast unit. The themes identified were clustered into two main groups; patient-specific themes and breast unit-specific themes. Table 6.4 summarises the themes and sub-themes associated with variation in patients' treatment decisions.

TABLE 6.4 Themes and sub-themes associated with variation in patients' treatment decisions.

Patient-specific themes
<ul style="list-style-type: none"> <li>• Most reassuring treatment option</li> </ul>
<ul style="list-style-type: none"> <li>• Least disruptive treatment option</li> </ul>
Breast unit-specific themes
<ul style="list-style-type: none"> <li>• Information content</li> </ul>
<ul style="list-style-type: none"> <li>• Information content style</li> </ul>
<ul style="list-style-type: none"> <li>• Time and decision-making process</li> </ul>
<ul style="list-style-type: none"> <li>• Patient autonomy in decision-making</li> </ul>

## PATIENT-SPECIFIC THEMES

The patient-specific themes were heterogeneous within and across the breast units, and most seemed innate to patients; and predominantly independent of the breast teams' influence. However, two sub-themes were more influenced by patients' interactions with their breast clinicians and were associated with variation in patients' treatment choices. These were patients' perception of the most reassuring treatment option, and their perception of the least disruptive treatment option. Table 6.5 summarises the patient-specific sub-themes and factors.

## Most reassuring treatment option

Although patients were aware of and accepted the equivalence of survival with BCT and mastectomy and seemed to accept this, the extensiveness of surgery often influenced their perception of the safety of the treatment option. Many choosing mastectomy said this more surgically extensive treatment option reduced their anxiety about the completeness of cancer excision.

...[I could] never have...had as much peace of mind if I'd just had the lump removed, ...what if they've missed a little bit round it... [Patient 1, mastectomy, age 42, medium MR unit, p5]

Many of this group also talked about minimising the local recurrence risk. This was expressed as important in reducing patients' anxiety about the need for further treatment at a later date. Some also felt it must confer a better long-term outcome.

...I didn't contemplate just [BCT]...when you have the lumpectomy [BCT] you're worried all the time, every time it's your appointment at the breast clinic you...get anxious...worry all the time. ...at least having a mastectomy a good part of the worry is gone. I know you can still get it [recurrence], this has been explained...but...it gives me a greater chance... [Patient 23, mastectomy, age 62, high MR unit, p6]

Reassurance regarding their surgery was expressed in a different way by many of those choosing BCT. Some of this group felt because they were offered BCT, their cancer was not as bad or harmful as it might have been. A few also believed this inferred they were more likely to be cured. This was particularly predominant among patients of the low MR Unit who described the provision of a treatment plan or strong recommendations, rather than a more open choice of treatment.

Total mastectomy...conjures up...you are riddled with cancer. ...wide local excision...contains your thoughts that it's not as bad as your brain's telling you. [Patient 27, BCT, age 61, high MR unit, p9]

...[I] realised with having the choice, it must be small, because...I know there are instances where you're not given the choice, you've got to have the mastectomy, so I thought, "Well, it won't be very big, it hasn't spread much" [Patient 35, mastectomy, age 65, high MR unit, p5]

While most patients in this group based their decisions on correct information, some expressed the incorrect beliefs about the safety of the option they had chosen.

Mastectomy...much bigger operation, but feel that the problem's gone, it's not going to recur in the breast tissue because it's not there anymore. [Patient 31, mastectomy, age 64, high MR unit, p11]

I was told if you'd had the mastectomy...the cancer could still have come back on that side. ...and then I thought...if you had a mastectomy you don't [have] radiotherapy do you, so...if there had been any [cancer] cells possibly then in the tissue [left] that could have come back, I don't know whether they would have been cleaned up. [Patient 42, BCT, age 60, high MR unit, p17]

While most patients based their decisions on information provided by the clinicians, some utilised anecdotal experiences to decide their treatment and based their decisions on health beliefs within their family or community, as to which treatment was more reassuring or safer.

I do know several people who've had just the lump removed and in a year or two they've had to go back and have a mastectomy. [Patient 35, mastectomy, age 65, high MR unit, p9]

My best friend that had it [BCT] ...she'd been given 't choice and she said ..."I'm having 't lump out ...because if it comes back and you've had your breast off ...where's it gonna go?" ...and that's always stuck in my mind. [Patient 19, BCT, age 58, medium MR unit, p39-40]

### **Least disruptive treatment option**

Patients also chose their surgery based on what seemed the least disruptive treatment option. For some it meant choosing the option which they felt would cause least disruption to their wider life and commitments during treatment. For those choosing BCT this often meant the treatment associated with a shorter hospital inpatient stay for surgery. While many of those choosing mastectomy talked about wishing to minimise the overall treatment process and the potential need for further treatment, which might include further surgery or radiotherapy.

...I didn't fancy the radiotherapy...I just didn't want the hassle of going through that and I know a few people who've had the lump and had to go back. So I thought if I've got to have one or the other I might as well get it all done at once. ...I think that was probably my fear of operations as much as anything. [Patient 7, mastectomy, age 46, medium MR unit, p22]

I don't want to be coming back every day for radiotherapy for six week...I had got...my son and his two children here...And...I take my duty as a surrogate parent seriously and I thought, it's time-consuming, I've got to give the time up to go down to the hospital every day, [and I]...knew people that had had it and they said how tired and how weary [it makes them feel]...you've got to weigh up what your lifestyle is like. I didn't want to run



the risk of having to have two operations, that was the major, major issue for me...if I'd had a lumpectomy and for whatever reason it didn't have a clear margin and then I had to go back for a further lumpectomy or a mastectomy... [Patient 25, mastectomy, age 60, high MR unit, p7-8]

For others, the least disruptive treatment option was determined by the potential impact of surgery on their body image or sexual relationships. For some the preservation of their breast per se was extremely important either to themselves or to their partner.

When she said...that there really was a choice and that either way just as good, then my next thought was my husband, that it would be so much easier for him physically, to look at.. [Patient 25, BCT, age 60, high MR unit, p8]

I didn't get upset until the point where it was losing the whole breast...I hadn't had a sexual partner for three years...but I'm not on the shelf, I've not given up hope, [i thought] do I have to lose my full breast, is there any way you can just keep part of it. [Patient 48, BCT, age 38, low MR unit, p16]

My tits are precious...they've always been my asset, even though they're...a bit saggy now...it's a feminine thing. [Patient 50, BCT, age 55, low MR unit, p7]

While for others having a mastectomy would act as a constant physical reminder that they had had cancer.

If you're disfigured...it's a constant reminder that you've got, had or in remission of cancer...every time you look at yourself...it's never going to be anything you can forget because every time you take your clothes of it shouts at you. [That's] how I would have felt had I now had a full mastectomy... I can dress and it wouldn't be noticeable to the outside world but... [Patient 42, BCT, age 60, high MR unit, p23]

A small number had witnessed the result of surgery of relatives and wished to avoid a similar physical appearance.

...[all] I could see was my Mum's scar, all gathered up, and I thought, 'I don't want to look like that. ...I thought...[a mastectomy] will ruin my life. [Patient 12, BCT, age 69, high MR unit, p2]

Although body image concerns predominated among those choosing BCT and fear of recurrence predominated among those choosing mastectomy, when considering their options many vacillated between the two; trading between their concerns regarding safety and recurrence, and the disruption of normality and body image.

I thought I'm going to have to have a serious think about whether I'll cope with losing it [her breast]. ...I listened to both and I didn't fancy the radiotherapy... [Patient 7, mastectomy, age 46, medium MR unit, p22]

There was also a small highly specific group of patients who expressed their safety concerns and body image considerations in a different way. This particular group were younger women with breast cancer and a co-existing family history of breast cancer who were considering genetic testing and the possibility of risk reducing surgery in the future. This group also incorporated these issues into their consideration of the treatment options.

... [I knew the radiotherapy part of BCT would be] automatically lessening my chances to have reconstruction surgery if I feel like I need it ...I still don't know whether I would go through that [risk reducing mastectomy and reconstruction] or not but [as I chose mastectomy] my chance now is still there. [Patient 45, mastectomy, age 46, high MR unit, p10,16,26]

Although these themes have been classified as patient-specific themes, some of the sub-themes were influenced by the information provided by the patients' breast team. For example, the decision-making considerations of those undergoing BCT from the low MR unit were less likely to include the possibility of post-operative re-excision or the need for radiotherapy. In some instances patients described this information as being down-played, while others implied it was only provided in conjunction with the results of their therapeutic surgery.

...he [surgeon] told me that it was actually a small cancer [2cm invasive cancer] and...he went on to explain how best to deal with it, explained the lumpectomy...the fact that I'd probably need a bit of radiotherapy...depending on what they found.." [Patient 55, BCT, age 44, low MR unit, p6]

One of my biggest fears in life for some reason...is having a mastectomy. On the other hand, if it's gonna save my life...then it wouldn't bother me...I wouldn't have hesitated – or even if I'd been told, "You can have [BCT]...but there was a possibility...it can recur"...I would have then gone for the mastectomy. [Patient 54, BCT, age 60, low MR unit, p17]

In contrast, medium and high MR unit patients voiced such information readily and described utilising it when making their treatment decisions.

He [surgeon] sat and drew diagrams and said that it was a lump, it was cancer. He went through the various options that I could take. He also had the mammogram up on the board so he was showing me that. He...gave me the options of either having the lump removed and going for follow-up treatment radiotherapy at \_\_\_\_, and which would be a five-week [course]...or the mastectomy. [Patient 9, mastectomy, age 50, medium MR unit, p4]

TABLE 6.5 Patient-specific sub-themes associated with variation in patients' treatment choice

Most reassuring option
<p><b>Safety and fears</b></p> <ul style="list-style-type: none"> <li>• Cancer fully removed</li> <li>• Survival</li> <li>• Local recurrence</li> <li>• Minimise the psycho-physical impact of diagnosis (implication of better prognosis with less extensive surgery)</li> </ul>
<p><b>Anecdotal information/experiences</b></p> <ul style="list-style-type: none"> <li>• Positive or negative anecdotal experiences of others</li> </ul>
Least disruptive option
<p><b>Minimise impact on life, relationships and social commitments</b></p> <ul style="list-style-type: none"> <li>• Social commitments</li> <li>• Family (especially partners and dependants)</li> </ul>
<p><b>Minimise hospital treatment experience</b></p> <ul style="list-style-type: none"> <li>• BCT - shorter in-patient stay</li> <li>• Mastectomy - shorter overall treatment (minimise need for radiotherapy and re-excision)</li> </ul>
<p><b>Minimise the psycho-physical impact of surgery</b></p> <ul style="list-style-type: none"> <li>• Body image disruption minimised with BCT</li> <li>• Potential impact on partners and relationships</li> <li>• Mastectomy as a constant reminder of cancer</li> </ul>

## BREAST UNIT-SPECIFIC THEMES

The experiences of patients from the medium and high MR units were similar, and dissimilar to those of the low MR unit. The breast unit-specific sub-themes related to treatment variation were; information content, information style; time and decision-making process; and patient autonomy in decision-making. These are summarised in table 6.6.

### Information content

The content and style of information patients received from their breast units influenced the treatment choices they made. Table 6.6 summarises the information content sub-themes and factors emerging from the data.

Patient accounts from the low MR unit focussed on their clinicians' reassurance regarding their cancer and its treatment, along with treatment recommendations. Patients from the low MR unit were also more frequently only openly offered BCT, even when they requested information about mastectomy or expressed a preference for it.

I went in and...[the consultant] said what they wanted to do, this operation and take it away [BCT] ...And I just said to her "Well why don't you just take the whole lot off...and she said...she didn't think there was any need whatsoever to go to those extremes. [Patient 60, BCT, age 57, low MR unit, p13]

In contrast patients from the medium and high MR units typically recounted much more detailed descriptions of the information about both BCT and mastectomy as treatment options available to them, what undergoing each would involve, the potential consequences and the amount of time they had for decision-making.

He went through the various options that I could take. ...having the lump removed and going for follow-up treatment radiotherapy, and which would be a five-week [course]...or the mastectomy. He also went through the pros and cons of each one...and wrote this down. [Patient 9, mastectomy, age 50, medium MR unit, p4]

Patients described different roles clinicians played in providing information for making decisions. Doctors were viewed as primary information providers, while BCNs reiterated, reinforced, and explored information needs. Patients of the high MR unit described discussions with their BCN and the extensive process of checking understanding. The low MR unit patients felt BCNs were happy discussing the topics covered by the consultant's consultation, but were generally

uncomfortable extending the scope of the consultant's consultation. This was most notable when patients expressed a preference in conflict with doctors' recommendations' or requested information and a discussion regarding alternative surgical options. In instances where patients' desire for such information was persistent, BCNs tended to refer patients back to the consultant for further discussion.

I said, "Well what happens if I just have the whole breast off," and she [BCN] said, "Well that's something you'll have to discuss with your surgeon, I can't tell you that. [Patient 60, BCT, age 57, low MR unit, p7]

## Information style

Within the information style sub-theme, four factors were associated with patients' choices; contextualising information; emphasis and minimisation; accessibility of information; and treatment recommendations. Table 6.6 summarises the information style sub-themes and factors.

### Contextualising information

Patients being involved in the choice of their surgery were contextualised differently. The medium and high MR units tended to introduce the concept and explain the rationale for providing options early within the consultation, leading patients to expect involvement in decision-making.

He was saying...some women like the choice. ...some...prefer one to the other...they're equal, there is no better option. The choice is yours. [Patient 42, BCT, age 60, high MR unit, p5]

Most patients at the low MR unit did not describe the provision of such information.

He said, "I'm sorry, it is malignant, but it is very, very small, you will need to have an operation. I think it would be appropriate for you to have a lumpectomy... [Patient 63, BCT, age 59, low MR unit, p7]

The other type of contextualisation observed was how individual treatment options were framed; whether this was in an open, directive or dismissive manner.

They were very clear that this was going to be my choice and that they wouldn't push one against the other. They just simply presented all the facts about the two. [Patient 33, BCT, age 57, high MR unit, p6]

[The surgeon] said, "Normally people with one that's as small as you have this incision [BCT], and at the end she mentioned mastectomy, but you got the impression she didn't think you should go along that line. [Patient 64, BCT, age 59, low MR unit, p16]

...a mastectomy would be like using a sledgehammer to open a nut. [Patient 43, BCT, age 61, high MR unit, p9-10]

Patients who receive a message framed in a directive manner, perceived the clinician to have a treatment preference or to be offering a treatment recommendation.

...he [surgeon] didn't actually say, 'Which would you prefer?' but I mean I, he's the professional, he knows...I didn't question it because...I thought, 'Well, he knows what he's doing,' and he of course was the second person who'd said what the course of action would be...so I was quite happy to take his word, I mean you've got to trust in them, haven't you? [Patient 63, BCT, age 59, low MR unit, p7]

#### Emphasis and minimisation

Clinicians often stressed certain cancer characteristics (small size and the early nature) which influenced patients' perceptions of the extent of their disease and which treatment they should undergo.

[The surgeon] said it was only a diddy [very small] one, that it hadn't grown very big and, it had started to invade slightly but they hoped it wasn't in the lymph nodes...the way [they]...explained the cancer made me feel a mastectomy wasn't necessary. [Patient 52, BCT, age 53, low MR unit, p6]

When patients received treatment recommendations which were emphasised they could also assume the recommended option was more likely to be successful in treating their disease, especially if the message was reiterated.

...that [BCT] was likely to be the most successful type of operation to have and that there was no need to have anything more drastic. [Patient 53, BCT, age 41, low MR unit, p15]

If a treatment option was emphasised, almost universally it was BCT. This option was generally the first to be mentioned and discussed, and in some instances it was the only option discussed. Some patients received information about BCT and had no recollection of a preliminary introduction of a choice of treatments being available. In this context they tended to assume it

was either the only option available, or the recommendation of the clinician or unit. If information about mastectomy was then subsequently introduced by the clinician, it could cause the patient surprise and alarm.

He [surgeon] said, "This is the size of the cancer." Then he drew a circle round it and said, "This'll be the area that we would remove." ...and you try to actually take in what he's saying as he's drawing this thing, and sort of except it and then the next thing he adds is, "This is what we'll do, or you can have a mastectomy." And at that point inside...you're screaming, "What? Why? Why?" I'm sort of just coming to terms with the whole thing and accepting that, I'm going to have this [BCT]...and then he said, "Or..." and you think, "Why?" if I need a mastectomy tell me I need one!" [Patient 42, BCT, age 60, high MR unit, p4-5]

### Accessibility of information

The language and consultation styles adopted by clinicians influenced the accessibility of information to patients. Language varied from every day to bio-medical. Those who received information in an easily understandable format, felt better able to understand and assimilate the information they were given.

She explained extremely well, quite a lot of detail and in simple terms which were quite easily understood ...and asked us if we had any questions to ask... [Patient 36, BCT, age 57, high MR unit, p5-6]

Clinicians' consultation styles also varied between an open, tailored, two-way dialogue which encouraged interaction between the patient and clinician, to a more prescriptive style.

He [the surgeon] accepted the fact that I had a brain, I'd been looking at things and...took my background into account [and]...we talked about things as a couple of adults. [Patient 6, BCT, age 56, medium MR unit, p7]

[The consultant] wasn't really listening to what I was saying. ...Rather than it be a discussion between us, I felt it was a one-sided discussion, that's the best way I can describe it. [Patient 62, BCT, age 44, low MR unit, p10-11]

The approach adopted influenced how patients felt about the consultation and their potential level of autonomy in the decision-making experience. These were often expressed more positively among those experiencing a more patient-centred consultation approach; where they were provided with clear, understandable, tailored information and the opportunity to express and explore their needs, concerns and preferences.

## Treatment recommendations

There was a tendency for low MR breast unit clinicians to volunteer a clear treatment plan containing recommendations based on what the clinician felt was most appropriate. These were often given early within the consultation.

I think it would be appropriate for you to have a lumpectomy ...So he didn't actually say, "Which would you prefer?"...and he of course was the second person who'd said what the course of action would be. [Patient 63, BCT, age 59, low MR unit, p7]

In contrast, the medium and high MR clinicians tended to provide patients with more open and comprehensive information and the opportunity to choose.

They were very clear that this was going to be my choice and that they wouldn't push one against the other. They just simply presented all the facts about the two. [Patient 33, BCT, age 57, high MR unit, p6]

Some patients, immediately after diagnosis, felt underprepared for a role in decision-making and asked their clinician's recommendation. At this point the medium and high MR clinicians usually spent more time discussing options and emphasising the time and support available; while low MR clinicians tended to recommend a treatment; if they had not done so already.

The force of clinicians' recommendations varied in a spectrum between encouragement to consider both options with a gentle steer toward a specific treatment option (almost invariably BCT), to a form of recommendation where patients felt they were denied their preferred treatment.

I was, "Get it off, cut it off." And she was ...very kind, very understanding but ...very gently steering me to the outcome that she wanted. [Patient 48, BCT, age 38, low MR unit, p16]

Mr \_\_\_ said to me..."I don't like doing mastectomies" ...So...there was no discussion really on having my whole breast off...And every time I brought up the subject...he wasn't really listening to what I was saying. [Patient 62, BCT, age 44, low MR unit, p12]

Patients from the medium and high MR breast units sometimes felt they were given treatment recommendations in some instances. However, when this occurred they tended to be more temperate and deferred to a later point in the decision-making journey; usually in response to patients expressing a consistent desire to be directed. These exceptions tended to occur among a



small subgroup of clinicians when cancers were described as particularly small in size. More often patients perceived a preference, based on the way information was portrayed, as although they were most often given information on both treatment options there was a strong emphasis on things like a small cancer size and safety of BCT, and occasionally mastectomy was described as a more extensive option than that required.

...I think he would have preferred me to have the lump removed. He said it was a very big operation having a full mastectomy,...I got the impression he thought I didn't need to have the whole mastectomy... [Patient 1, mastectomy, age 42, medium MR unit, p4]

TABLE 6.6 Information content and style sub-themes

Information content
<b>The facts</b> <ul style="list-style-type: none"> <li>• Options</li> <li>• Treatment details</li> <li>• Potential consequences</li> <li>• Comparison of treatments</li> <li>• Time for decision-making</li> </ul>
Information style: Spectrum from equipoise to forceful direction
<b>Contextualising information</b> <ul style="list-style-type: none"> <li>• Framing of involvement in decision-making</li> <li>• Framing of the options: Open/directive/dismissive</li> </ul>
<b>Emphasis and minimisation</b> <ul style="list-style-type: none"> <li>• Cancer size</li> <li>• Implication of 'early cancer'</li> <li>• Mastectomy as more a more extreme option</li> </ul>
<b>Accessibility</b> <ul style="list-style-type: none"> <li>• Language &amp; terminology: Everyday language vs. bio-medical</li> <li>• Consultation style: Two way dialogue vs. prescriptive; tailored vs. universal</li> </ul>
<b>Recommendations</b> <ul style="list-style-type: none"> <li>• Provided or not</li> <li>• Overt vs. perceived</li> <li>• Volunteered vs. provided on request</li> <li>• Timing of recommendation: Early vs. delayed</li> </ul>

### Time and process of decision-making

The decision-making experiences of patients from the breast units varied fairly consistently according to the breast unit they were treated by. The process was generally more rapid in the

low MR unit and patients fairly consistently reported pressure to make a decision immediately. This was reinforced by all but one consultant from the low MR unit consenting patients on the day of diagnosis, immediately after their initial discussion about their diagnosis and treatment.

I found it a very hard decision [I]...couldn't decide at all...I'd got to decide there and then whether I had a mastectomy or a lumpectomy...so I decided on the lumpectomy and within minutes all the paperwork was there. [Patient 51, BCT, age 51 low MR unit, p7]

It had to be a fairly quick decision; I wasn't allowed to go away and think about it. I could go back the next week,...and say 'I want to change my mind' if I want to. [Patient 46, BCT, age 59, low MR unit, p15]

Among this group, many recalled being told if they signed their consent form at this stage, they could 'rip up the consent form and sign another one' if they changed their mind before their surgery.

I was told all the way through that that could be ...ripped up half an hour before the operation. [Patient 62, BCT, age 44, low MR unit, p11-12]

In practice, a signed consent however sometimes seemed to be a barrier to further discussion or a subsequent alteration in decision, for a small minority who were uncertain about the treatment they had initially chosen and wanted to do re-discuss or alter their decision.

At this point [one day before surgery] it might not be a good idea to change your mind. [Patient 57, BCT, age 44, low MR unit, p11]

So after thinking long and hard...I rang up the breast care nurses the week before my operation was due, and I made an appointment to go and speak to Mr\_\_\_...to talk through with him...because I'd decided by then I wanted the whole thing off. ...So I went to see him...and I felt I was talked out of the mastectomy...there was no discussion really on having my whole breast off... And every time I brought up the subject...I felt that, because Mr - didn't want to do it...he wasn't really listening to what I was saying. ...I feel that I...went with what he said, rather than what [I wanted] 'cos I'd gone in there to tell him I wanted a mastectomy and to rip up the consent form and sign another one. ...and even when I came out I still wasn't 100 one hundred per cent that I'd done the right thing. [Patient 62, BCT, age 44, low MR unit, p11-12]

In contrast, the medium and high MR unit's patients found the process of decision-making less rushed. They were almost universally provided with clear information early in the consultation about the date of their surgery and were told they had until then to make a decision. Patients who expressed an immediate preference for a specific option were often encouraged to spend time considering the options to ensure they were making the right choice for them. The amount of time patients had for exploring information and going through the decision-making process,

affected how prepared they felt for the task. Most felt they were given a sufficient and realistic timeframe and this knowledge provided a sense of security and reassurance that more autonomous decision-making was achievable.

I was thinking from one to the other...thinking "My God, what a decision..." but knowing I'd got this fortnight...and being told two or three times I didn't have to make a decision there and then, I could leave it right 'til the morning of the operation...helped. So I didn't panic. [Patient 31, mastectomy, age 64, high MR unit, p8]

When patients were given choices and were either only given a short time for decision-making or not given clear information on how much time was potentially available for the process, they tended to feel making a choice was unachievable. They often felt overwhelmed and underprepared for such a task, and were more likely to ask the opinion of their clinicians.

I found it a very hard decision...just couldn't decide, couldn't decide at all...I'd got to decide there and then. [Patient 51, BCT, age 51, low MR unit, p7]

Given only 24 hours to decide: "[It was] like...dropping you out of an airplane with no parachute." [Patient 38, BCT, age 57, high MR unit, p17]

Patients often expressed they needed to spend time away from the clinical environment following their diagnosis, to recover from shock of diagnosis before they could meaningfully engage in decision-making.

All that information...gets crammed in your head and you have everything just swinging round and...you're awash with it until you can come home and then you've got that time to relax and chill and just let your mind unwind and then think about everything that's been said. [Patient 48, BCT, age 38, low MR unit, p33]

I bet it was a good ten days before I actually calmed down and just thought, quite calmly...this is what I'm going to do. [Patient 42, BCT, age 60, high MR unit, p15]

### **Patient autonomy in decision-making**

A surprisingly large proportion of women had a preconception that they would be told what their treatment plan would be, and expressed surprise when offered choice of treatment.

Giving me this option...without giving me any advice as to which one he thought would be good...came as a real shock, I wasn't expecting it. [Patient 33, BCT, age 57, high MR unit, p4]

All my life if I've needed to go to a doctor, I've followed instructions: "Take these tablets" or "Do nothing" and whatever I've been advised I've always followed those directions.  
[Patient 57, BCT, age 44, low MR unit, p4-5]

Breast units had a substantial impact on the level of autonomy patients desired and were willing to assume in the selection of their treatment. This impacted on the extent to which women's decisions were clinician-opinion or patient choice-based. When patients received an explanation about why a choice was offered, most wanted to participate in making a treatment choice.

I think it's nice that you do have the choice. ...better than somebody just saying to you, "Right, we're going to do this," or "We're going to do that...I think it's important...  
[Patient 37, BCT, age 67, high MR unit, p21]

The level of autonomy patients felt it was possible for them to achieve in decision-making was influenced by the gap they perceived between their knowledge and experience, and that of their clinicians. It was also influenced by whether patients felt this gap could be narrowed or bridged. Feeling positive about participating in decision-making was more often expressed among those experiencing a more patient-centred consultation approach (especially by their consultant surgeons), and when patients described the provision of clear, understandable, tailored information and the opportunity to express and explore their needs, concerns and preferences. The amount of time patients believed they had for decision-making also exerted an effect. The availability of time and this approach often allowed patients feel they had sufficient knowledge and confidence to participate more autonomously in decision-making.

Patients also described benefitting from receiving an individualised description and diagram of their cancer's characteristics and a synopsis of pertinent treatment option information by their clinicians. If provided, such tools were utilised by patients as a method to simulate their recall of the consultation discussion during the decision-making process.

She drew diagrams to show me, she'd also got the callipers to show me how big the tumour was. She explained extremely well, quite a lot of detail and in simple terms which were quite easily understood...She then gave me options as to treatment. ...we spent quite a bit of time with [the BCN]...and she was explaining all sorts of things ...and asked us if we had any questions to ask.... nothing that we didn't already understand I don't think. It's hard to take in all at once... (Patient 36, age 57, high MR unit, BCTp5-6)

Most patients needed support and encouragement of their clinicians to more comfortably engage in more autonomous decision-making. This assisted in the acquisition of the knowledge necessary for decision-making and provided the confidence to undertake this role in an unfamiliar but supportive environment.

I felt a little bit...alone...Not qualified...to be making this decision myself. ...it was like stepping out into the unknown...it was a big thing to take on. ...But I was aware that everybody was there to help me. Everybody was on my side. [Patient 31, mastectomy, age 64, medium MR unit, p7-8]

When such a consultation approach was not adopted, many patients could feel there was such a gap in experience, knowledge and power between themselves and their clinicians, that the expert was the only person who could assume control of decision-making.

They were the people who had the knowledge, the information, the skill. It was my body...and...I really didn't know what was best for me, so whatever they led me to believe would be best, that's what I would go along with. [Patient 18, BCT, age 62, medium MR unit, p30]

The discrepancies in the power patients perceived between themselves and their clinicians were often more pronounced among the low MR breast unit patients, and were reinforced or moderated by clinicians' information provision and consultation skills.

[The consultant's] not intimidating in that way...but you do feel as though you're slightly walking on eggshells. ...the trouble is you're in a very, very vulnerable position...there are some questions you wouldn't ask because you don't want to upset people, because you feel they're in charge of your life. [Patient 49, Mastectomy, age 59, low MR unit, p17-18]

...we were on the same wavelength...always working together for my benefit. I didn't have to think, "Well he knows better than I do so I'll go with what he says,"...there was never any confrontation, never any 'Well I'm not quite sure, but he must know best...' [Patient 12, BCT, age 69, medium MR unit, p20]

Doctors seemed to have the capacity to exert the more disempowering influence within the situation and relationship, and the presence of a BCN within a consultation sometimes seemed to encourage greater patient involvement in the discussion of options and decision-making.

Because there was two doctors in the room and I didn't have a [Breast Care] nurse in with me...when I had a breast care nurse with me before, we were all involved in the conversation so I felt I had my support with me...I just felt a little bit, not intimidated, because he's not an intimidating man, I just.. [Patient 62, BCT, age 44, low MR unit, p11-12]

There was variability among patients' descriptions of their decision making considerations and the speed of their decision making journeys. Within all units, some made swift decisions based on specific strong preferences. However, the differences in information provision and consultation approach often meant that patients of the low MR unit seemed to experience simpler and more rapid decision-making than patients from the other units. They described the tendency of clinicians to provide a treatment plan or heavily direct their decision. In contrast, decision-making

at the medium and high MR units tended to be more complex, with patients often describing periods of reflection and deliberation. Although some patients of the medium and high MR units found the decision-making experience more challenging, on reflection these patients often expressed feeling proud of the achievement, often expressed their ownership of the decision, and confidence in the treatment chosen.

## CONCLUSION

This component of the study provides new information on the interface between clinicians and patients; exploring the clinical consultation and decision-making experiences from the perspective of women with breast cancer who are suitable for BCT. The findings may explain the reasons why continued variation in MRs is observed. It demonstrates both overt and more subtle influences of clinicians over decisions.

While decisions were influenced by patient-specific themes, breast clinicians exerted a substantial influence. Patients described differences in their experiences of decision making related to the treatment options offered and how this was communicated (information content and style; equipoise to directed). They described differences in the level of autonomy they were provided and the decision support given, along with differences in the time allocated for decision-making. Among the breast units studied, low MR unit patients tended to describe the provision of less comprehensive, more directive information by their clinicians, less autonomy and less time for decision-making. They also described the earlier consolidation of decision making by consenting (at diagnosis or a week later). Conversely, high and medium MR units' patients tended to describe receiving more comprehensive less directive information, alongside greater support and time for decision-making. They also often described a more complex consideration of the options and treatment facts in the context of their preferences; more consistent informed autonomous decision-making. The themes associated with differences in breast unit MRs are summarised in table 6.7.

This study adds to information available from others published since the onset of this programme of research, increasing the description of the interface between clinicians and patients. Providing

information on what is being communicated, how much actual choice patients are being given and what is influencing patient decisions. The evidence from this study and others demonstrate that although patients want to play increasingly autonomous roles in choosing their treatment,(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) there is' continued acquiescence to clinicians.(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) As mortality rates among this patient group falls (64% 20 year survival now, compared with 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) patients experiencing a positive decision making experience and undergoing a treatment that is right for them, becomes increasingly important in seeking to optimise QoL and psychological morbidity in survivorship.(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 findings suggest that if the focus remains on involving patients in medical decisions, clinicians must be encouraged to adopt a more open, tailored, informing and empowering approach in consultations, if any but the most active of decision-makers are to truly choose their treatment.



TABLE 6.7 Summary of themes associated with breast unit treatment variation.

Low MR unit	Medium and high MR units
Less comprehensive information	More comprehensive information
Active direction of choice: <ul style="list-style-type: none"> <li>• More directive information</li> <li>• More volunteering of opinion</li> </ul>	Reluctance to direct choice: <ul style="list-style-type: none"> <li>• Less directive information</li> <li>• Less volunteering of clinician opinion</li> </ul>
Less active support of autonomous patient decision-making	Active support of autonomous patient decision-making
Time pressure for decision-making <ul style="list-style-type: none"> <li>• Process factors</li> <li>• Consent early: At diagnosis or one week after diagnosis</li> </ul>	Lack of time pressure for decision-making <ul style="list-style-type: none"> <li>• Process factors</li> <li>• Consent later: At pre-assessment clinic or pre-operatively</li> </ul>

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## Chapter 7

### An emergent theme

**Women's views and experiences of choosing their breast  
cancer surgery**

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## ABSTRACT

**Background:** Patients' participation in decision-making is a field of increasing interest, as health services become focused on the provision of patient choice. This chapter explores patients' views and experiences of choosing their initial therapeutic treatment of primary breast cancer.

**Methods:** Semi-structured interviews were conducted with 65 patients as part of a study exploring variation in treatment rates among three specialist breast units of a UK region. All were identified by their clinicians as those offered a choice of therapeutic surgery for breast cancer. Interviews were transcribed verbatim and analysed using the Framework Approach.

**Results:** Patients' reactions to their involvement in treatment decision-making emerged as a key theme within the main study. Three sub-themes defined the theme; initial responses, later responses, and influence over responses. Many patients initially assumed they would be provided a specific treatment plan. Individual preferences and patients' perceptions following interactions with their clinicians, were key in shaping patients' responses and adaptation to treatment choice; specifically through the way information and decision-making were presented, encouraged and supported, and the time patients were given for the task.

**Conclusions:** Clinicians should be aware of patients' reactions to participation in treatment decisions. This chapter increases our understanding of how clinicians can influence patients' expectations and responses to treatment decision-making. These findings may be relevant to other healthcare contexts.

## BACKGROUND

There is increasing interest in patients' participation in healthcare decisions, and it is widely assumed patients want increasing autonomy in these. The evidence that patients with cancer want to be well informed is irrefutable,(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 this does not necessarily correlate with possessing an active PDMS.(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) Some adopt information acquisition as a coping strategy.(Blanchard, Labrecque, Ruckdeschel, & Blanchard 1988;Cassileth, Zupkis, Sutton-Smith, & March 1980;Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller 1997a;Hack, Degner, & Dyck 1994;Miller, Brody, & Summerton 1988) However, there is gathering evidence of a shift in patient PDMS toward the more active end of the spectrum.(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) The evidence points to the beneficial impact of more autonomous decision making on patient satisfaction, regret and psychological recovery.(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) But separating the contributions of good communication/information provision and participation in decision making toward the positive effect are difficult. Fallowfield proposed optimal communication/information was the enhancing factor.(Fallowfield 1997) However evidence from a prospective mixed methods study by Deadman et al. investigating the psychological effects of breast cancer treatment among women (n=114) suggest the decisional role itself provides the enhancing impact.(Deadman, Leinster, Owens, Dewey, & Slade 2001) Hack demonstrated similar findings.(Hack, Degner, Watson, & Sinha 2006) There remains limited understanding of what patients feel about engaging in decision making, and what can enhance or deteriorate their experiences.

Providing patients with choices has become a recognised priority,(Association of Breast Surgery at BASO 2009;Blichert-Toft, Smola, Cataliotti, & O'higgins 1998;Department of Health 2001a;Department of Health 2001c;Department of Health 2009;General Medical Council 2008;Kaufmann, Morrow, von, & Harris 2010;National Collaborating Centre for Cancer 2009;Nattinger, Hoffman, Shapiro, Gottlieb, & Goodwin 1996;Nayfield, Bongiovanni, Alciati, Fischer, & Bergner 1994;Royal College Of Surgeons Of England 2002;Scarth, Cantin, & Levine 2002a;Scarth, Cantin, & Levine 2002b) as the two main surgical options for cancers under 5cm diameter demonstrate equivalent survival(Blichert-Toft, Brincker, Andersen, Andersen, Axelsson, Mouridsen, Dombernowsky, Overgaard, Gadeberg, Knudsen, & . 1988;Clarke, Collins, Darby, Davies, Elphinstone, Evans, Godwin, Gray, Hicks, James, MacKinnon, McGale, McHugh, Peto, Taylor, & Wang 2005;Fisher, Anderson, Bryant, Margolese, Deutsch, Fisher, Jeong, & Wolmark 2002;Jacobson, Danforth, Cowan, d'Angelo, Steinberg, Pierce, Lippman, Lichter, Glatstein, & Okunieff 1995;Lichter, Lippman, Danforth, Jr., d'Angelo, Steinberg, deMoss, MacDonald, Reichert, Merino, Swain, & . 1992;Poggi, Danforth, Sciuto, Smith, Steinberg, Liewehr, Menard, Lippman, Lichter, & Altemus 2003;Sarrazin, Le, Arriagada, Contesso, Fontaine, Spielmann, Rochard, Le, & Lacour 1989;van Dongen, Voogd, Fentiman, Legrand, Sylvester, Tong, van der, Helle, van Zijl, & Bartelink 2000;Veronesi, Cascinelli, Mariani, Greco, Saccozzi, Luini, Aguilar, & Marubini 2002) and morbidity;(Carlsson & Hamrin 1994;Dorval, Maunsell, Deschenes, & Brisson 1998;Fallowfield, Baum, & Maguire 1986;Ganz, Desmond, Leedham, Rowland, Meyerowitz, & Belin 2002;Irwig & Bennetts 1997;McCready, Holloway, Shelley, Down, Robinson, Sinclair, & Mirsky 2005;Moyer 1997;Sanger & Reznikoff 1981;Schain, Edwards, Gorrell, de Moss, Lippman, Gerber, & Lichter 1983;Stefanek 1993) with the exception of 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) and recurrence.(Clarke, Collins, Darby, Davies, Elphinstone, Evans, Godwin, Gray, Hicks, James, MacKinnon, McGale, McHugh, Peto, Taylor, & Wang 2005;Early Breast Cancer Trialists' Collaborative Group 2002;Jatoi & Proschan 2005;van Dongen, Voogd, Fentiman, Legrand, Sylvester, Tong, van der, Helle, van Zijl, & Bartelink 2000;Veronesi, Cascinelli, Mariani, Greco, Saccozzi, Luini, Aguilar, & Marubini 2002) Also patients with breast cancer are known to possess varying attitudes to these treatments and place different significance on factors which might differentiate between the two in patient decision making.(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 & Margoese 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, & Karsen 2002;Smitt & Heltzel 1997;Wei, Sherry, Baisden, Peckel, & Lala 1995;Wilson, Hart, & Dawes 1988)

However it is also recognised that patients possess different preferences for being involved in decision making.(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, & Porzolt 1997) Not all want to play an active role in choosing their treatment. This chapter explores a strong emergent theme; patients' reactions to being involved in choosing their treatment, and the factors influencing these. The theme arose from the patient interviews conducted among women with breast cancer, as part of the research study exploring surgical treatment variation. All patients were identified by their clinicians as having been offered a choice of surgery (BCT and mastectomy).

Breast cancer surgical decision making is an ideal context in which to explore patients' experiences of healthcare decision-making for the reasons outlined above. It is also likely to become increasingly complex, as the range of potential treatment options and proportion of patients eligible for treatment choices increases with the advent and wider adoption of newer

treatments such as neo-adjuvant chemotherapy to down-size cancers extending the scope of BCT, and the more routine incorporation of oncoplastic surgical techniques.

## **METHODS**

The study design, setting and sample and data analysis are presented in chapter 6

## **FINDINGS**

Patients' subjective views, feelings and experiences of being involved in choosing their treatment emerged as a prominent theme from the patient interviews. Three sub-themes encapsulate the theme: initial responses to involvement in decision-making; later responses; and influences over patients' responses to being given a choice of treatment. These subthemes and factors are summarised below and in tables 7.1 and 7.2.

### **INITIAL RESPONSES TO INVOLVEMENT IN DECISION-MAKING**

Patients described a range of initial responses to the invitation to participate in treatment decisions; which are defined by six factors; expected involvement, unexpected involvement, overwhelmed by the need to make a decision, acceptance of decision-making role, acceptance of clinician's recommendation and decision making role unwelcome. Table 7.1 summarises these.

#### **Expected involvement**

At diagnosis, a small number of patients had anticipated being involved in treatment decision-making. Those who did often expressed the opinion that they should be provided with such an opportunity.

I have the right to choose what happens to me. [Patient 42, BCT, age 60, high MR unit, p18]

### **Unexpected involvement**

The majority however, assumed that they would be given a clear treatment plan by their specialist clinicians, rather than offered a choice.

Giving me this option...without giving me any advice as to which one he thought would be good...it came as a real shock, I wasn't expecting it. [Patient 33, BCT, high MR unit, age 57, p4]

### **Overwhelmed by the need to make a decision**

Patients often described feeling initially 'shocked' on receiving confirmation of their potentially life threatening disease, and some felt this impeded their capacity to absorb information provided within their consultations. When invited to select their own treatment at this specific time point, a number of this group felt overwhelmed.

I got a mental shutdown ...swamped. [Patient 48, BCT, age 38, low MR unit, p6]

This was particularly marked among those whose diagnosis was unexpected.

You're sitting there and the doctor's talking to you, you don't take it all in. Most of it goes straight over your head, and you come out afterwards thinking, 'What did he say?' ...I think all I heard at the time was cancer...that was the only thing that sunk in. [Patient 16, mastectomy, age 73, medium MR unit, p7]

The acuteness of their diagnosis, awareness of their lack of knowledge, and the synchronous provision of seemingly large volumes of information on both diagnosis and treatment could exacerbate this perception.

...I didn't want to be overloaded with too much information...didn't want to know about everything all in one go,...that was just too much. [Patient 41, BCT, age 42, high MR unit, p6].

This could result in patients having difficulty envisaging their assumption of a decision-making role and feeling overwhelmed at the prospect; especially initially.



They were the people who had the knowledge, the information, the skill. It was my body...&...I really didn't know what was best for me. [Patient 18, BCT, age 62, medium MR unit, p30]

This group sometimes felt isolated and fearful.

It was unknown territory, and I don't like being on unknown territory, I like to be in control, and I wasn't going to be control, and what was more I'd got to make this decision for myself. ...I felt...I was alone...not qualified...it was like stepping out into the unknown because you're here with this disease, and you don't know which way it's gonna go until after the surgery...it was a big thing to take on... [Patient 31, mastectomy, age 64, high MR unit, p7-8]

## Acceptance

Some patients immediately accepted a more autonomous role in decision-making.

...it surprised me that I'd got to choose...I don't like having to choose...but...when he told me I didn't find it difficult. [Patient 39, BCT, age 71, high MR unit, p26-27]

This group often anticipated participating in the selection of their treatment, and tended to describe a form of uncomplicated and instinctive decision-making upon presentation of the available options. Decisions among this group were inclined to be based on either pre-existing information or strong treatment preferences, and were therefore often swift; occurring immediately or within a few days.

From when he first told me that he was suspicious, I'd already made my mind up that, if I was offered the lump [BCT] or the full mastectomy, it would be the whole...I could never have...had as much peace of mind if I'd just had the lump removed. [Patient 1, mastectomy, age 42, medium MR unit, p4-5]

Many of these did so recognising the personal nature of such a decision and the importance of the individual patients' preferences in this particular context.

It's nice that you do have the choice...better than somebody just saying to you, "Right, we're going to do this," or "We're going to do that...I think it's important.....it's a very personal decision, isn't it. [Patient 37, BCT, age 67, high MR unit, p23]

Although many described accepting this role in decision-making, this could co-exist with a degree of anxiety. Such anxiety chiefly arose from difficulty conceptualising their role in decision-making; patients often felt lacking in knowledge (especially initially), and the timing of making

such a major decision around the time of their diagnosis could exacerbate their sense of vulnerability.

I've found [decision-making] ....really hard. It was nice to have the choice but not knowing much about it and wondering which one will be the best for me... [Patient 41, BCT, age 42, p9,11]

This was especially evident among those for whom the role or diagnosis was unexpected.

### **Acceptance of clinician's recommendation**

Another group who experienced an uncomplicated decision-making process articulated their acceptance of the clinicians' clear and specific treatment recommendations or treatment plan. Some described an element of participation in the process, while others did not.

[They] gave me the information I needed...and advised, which you expect a doctor...to do, but I never felt as if I was told what to do. I always felt I had that choice. [Patient 42, BCT, age 59, high MR unit, p29]

He didn't actually say, 'Which would you prefer?' But...he's the professional...and he...was the second person who'd said what the course of action would be...so I was quite happy to take his word, I mean you've got to trust in them, haven't you? [Patient 63, BCT, age 59, low MR unit, p8]

### **Decision making role unwelcome**

A minority understood they could choose their treatment, but it was an unwanted role. This group wanted their clinicians to issue them with a treatment plan or direct them towards a specific treatment the clinician felt was best, rather than involve them in the decision-making process.

I didn't want any choice...I just wanted them to tell me what was the right thing for me. ...whatever they led me to believe would be best, that's what I would go along with. [Patient 18, BCT, age 62, medium MR unit, p30]

## LATER RESPONSES TO INVOLVEMENT IN DECISION-MAKING

For many patients, their responses to involvement in decision making changed over time. These often seemed adaptive; occurring as a consequence of patients' recovery from the initial shock of their diagnosis, the acquisition of knowledge, and the provision of reassurance and decision support by their clinicians. A range of later responses were described, which are categorised by four factors; positive adjustment to the decision-making role, reluctance to accept the decision-making role, desire for greater participation in the decision-making process, why choices are offered. Table 7.1 summarises these.

### **Positive adjustment to the decision-making role**

By the time of interview most patients exhibited a good understanding of the information on which to base an informed decision, and while a lack of confidence or a reluctance to participate in decision-making could persist, this was not the case for the majority. Patients could find the experience of decision-making challenging, but most adjusted.

I kept thinking I've got this decision to make and I can't do it. But...we did it [patient and husband] and we made the right decision. [Patient 37, BCT, age 67, high MR unit, p14]

For some undertaking this role became empowering; they expressed the view that the opportunity had helped to restore a sense of control, and ameliorated the feelings of power loss experienced at diagnosis.

The most important thing...was that I had got the choice. ...I think more women'd perhaps...feel a bit better able to cope if they realised that there was more of a choice. [Patient 24, BCT, age 43, high MR unit, p23]

Some experienced an amplified sense of achievement born from the challenge they experienced coming to a decision.

I've changed my mind as things have progressed...initially I was angry that I was given a choice, I felt let down by the service, I thought they should make the choice, they're the experts. But now I'm glad that I had the choice." "I wanted to be in control of something. I felt that everything was spinning out of my control. [Patient 25, mastectomy, age 60, high MR unit, p27-28 and p16]

They also expressed positivity that the role confirmed the importance of their own opinion, and permitted them to undergo a treatment which felt right for them as an individual.

I'm glad that I had the choice, because I've made the choice and I've got to live with it. And I am quite sure that I made the right choice...for me. [Patient 25, mastectomy, age 60, high MR unit, p28]

### **Reluctance to accept the decision-making role**

By the time of interview only a small minority of patients expressed persistent dissatisfaction with being asked to choose their treatment. This group often described feeling oppressed by the enormity of their diagnosis, or unqualified and ill-equipped to undertake the role. Some attributed this to an inability to either absorb the information required for decision-making, or evaluate the pros and cons of the options.

I'd got all the information, it was just my head that wouldn't work it out...my brain...wouldn't make a decision...weighing up the pros and cons. [Patient 28, BCT, age 60, high MR unit, p17]

Others feared making the *wrong* decision. These patients articulated being convinced that their expert specialist clinicians must know which treatment would be best for them. They were therefore adamant the clinician should determine the most appropriate treatment course.

How can I make this decision? This is my life we're deciding about and I'm not qualified. ...they're the experts...I...couldn't cope with making that decision. It's so important. [Patient 42, BCT, age 60, high MR unit, p4-5]

If their clinicians retained a non-directive stance, these patients expressed dissatisfaction, and described seeking indications of their clinicians' treatment preferences from the way information and options were portrayed. A very small minority of this group, felt that undertaking a role in choosing their treatment was a worse experience than being diagnosed with cancer.

I think I spent the next week or ten days [after diagnosis with]...it causing more grief and stress...trying to come to terms with having to make this decision, than accepting I'd got the cancer in the first place. My mind was just like a rat in a trap. Didn't know which way to turn, no escape,...on the really bad days I really thought I was going mad. [Patient 42, BCT, age 60, high MR unit, p5]

## **Desire for greater participation in the decision-making process**

Some patients however desired more autonomous decision-making experiences than their clinicians seemed willing to permit.

I'd have liked them to have said...we've found a lump, it's malignant, it's a grade three which means it's fast-growing, these are your options. [Patient 62, BCT, age 44, low MR unit, p18]

This group often expressed treatment preferences which conflicted with those of their clinicians. When patients felt their clinicians failed to respect or take into consideration their preferences, they described a loss of trust and in some cases, frustration and anger. This was particularly marked among those who felt their clinicians ignored both their treatment preference and desire for active participation in decision-making.

The way he was talking...there was no discussion...I feel that I went with what he said, rather than what [I wanted]...I was really angry, ...I really wished I'd have stuck to my guns. If I could give any doctor any feedback, it's "Listen to what your patient's saying...you might think, well, the best thing is this," but listen to why they don't want to go with that... [Patient 62, BCT, age 44, low MR unit, pg-11]

## **Why choices are offered**

A very small minority doubted their clinicians' motivation for involving patients in treatment decisions; assuming they provided the role to minimise blame or litigation should something go wrong.

...my first thoughts when they ...[gave] the option of the lumpectomy and the mastectomy ...[were] "Oh that's because of litigation." ...These days everybody has to be so careful...if you decide that they've pointed you in the wrong direction they're going to litigate...I thought, is that why they're giving you a choice... [Patient 42, BCT, age 60, high MR unit, p12]

TABLE 7.1 Patients' responses to being given a choice of treatment for breast cancer

Initial responses
<b>Expected involvement</b> <ul style="list-style-type: none"> <li>Anticipated choosing their treatment</li> </ul>
<b>Unexpected involvement</b> <ul style="list-style-type: none"> <li>Anticipated would be given a treatment plan</li> </ul>
<b>Overwhelmed by the need to make a decision</b> <ul style="list-style-type: none"> <li>Overwhelmed by diagnosis &amp; volume of information provided</li> <li>Perceived inadequacy of knowledge/capacity for decision-making</li> </ul>
<b>Acceptance of decision-making role</b> <ul style="list-style-type: none"> <li>Early acceptance &amp;/or a pleasant surprise</li> <li>Decisions tended to be made quickly</li> <li>Pre-existing preferences for a treatment</li> </ul>
<b>Acceptance of clinician's recommendation</b> <ul style="list-style-type: none"> <li>Given a clear recommendation by clinicians which agree with</li> <li>Options mentioned, but not perceived given a real choice by clinicians</li> </ul>
<b>Decision making role unwelcome</b> <ul style="list-style-type: none"> <li>Preference for clinician directed treatment (passive PDMS)</li> <li>Perceived lack of knowledge to undertake the role</li> </ul>
Later responses
<b>Positive adjustment to the decision-making role</b> <ul style="list-style-type: none"> <li>Transient sense of being overwhelmed overcome by clinicians empowerment strategies</li> <li>Varying degrees of challenge experienced</li> <li>Some experience empowerment through involvement in the decision-making process</li> </ul>
<b>Reluctance to accept the decision-making role</b> <ul style="list-style-type: none"> <li>Perceived insufficient knowledge or experience to make a choice</li> <li>Perceived extensive clinician-patient power gap</li> <li>Persistently fearful and ill-equipped or overwhelmed</li> </ul>
<b>Desire for greater participation in the decision-making process</b> <ul style="list-style-type: none"> <li>Perception of denial of preferred role in decision-making</li> </ul>
<b>Why choices are offered</b> <ul style="list-style-type: none"> <li>Perceived as a get out clause if 'something goes <i>wrong</i>'</li> <li>Avoidance of litigation</li> </ul>

## INFLUENCES OVER PATIENTS' RESPONSES TO BEING GIVEN A CHOICE OF TREATMENTS

There were numerous influences over the way patients responded to being given a choice of treatment. These were defined by five factors; personal factors; clinicians' consultation style; exploration of information needs, treatment preferences and concerns; patients' perception of their role in decision-making; and time given for consideration. These are summarised in table 7.2.

### Personal factors

Patients arrived at diagnosis either with an expectation of being provided with a treatment plan by the doctor (most patients) or with a sense of entitlement about choosing their treatment (minority). Their expectations were often associated with patient factors, in particular, prior knowledge and healthcare experiences; both generally and those specific to breast cancer.

All my life if I've needed to go to a doctor, I've followed instructions: "Take these tablets" or "Do nothing" and whatever I've been advised I've always followed those directions. [Patient 57, BCT, age 44, low MR unit, p4-5]

Some assigned their expectations to their age or generation; older patients being less likely to anticipate involvement in treatment selection.

Maybe it's my generation, but you just think, "Well the doctors know best"...I didn't particularly want to know worst case scenarios...statistics...I just wanted to go and have it done and...move on from there. [Patient 43, BCT, age 61, high MR unit, p10-11]

This was especially relevant among a small minority for whom this was the second experience of finding a breast lump.

Twenty years ago, I found a lump...all I was told was that if it was found to be cancerous...that I had to sign this consent form and whilst I was under the operation, they were doing this frozen section, they would take the breast off, there and then. That was the only information I was given. ...as it was it was just a benign lump ...all the information I was given this time is absolutely phenomenal...I just thought it was going to be the same procedure as then. [Patient 22, BCT, age 58, high MR unit, p1]

## Clinicians' consultation style

Without exception the patients interviewed wanted to feel secure in the care of their expert clinicians, who had the knowledge and experience to optimally manage their cancer. However, clinicians' provision of information, consultation and communication skills also profoundly influenced how patients felt about being involved in decision-making. Participating in treatment decisions was expressed more positively among patients describing a more patient-centred consultation approach; where clear, understandable, tailored information was provided, along with the opportunity to express and explore their needs, concerns and preferences.

He accepted the fact that I had a brain, I'd been looking at things and...took my background into account...we talked about things as a couple of adults. [Patient 6, BCT, age 56, medium MR unit, p7]

Most needed support and encouragement of their clinicians to gain the confidence for engaging in more autonomous decision-making

I felt a little bit...alone...Not qualified...to be making this decision myself...it was like stepping out into the unknown...it was a big thing to take on. ...But I was aware that everybody was there to help me. Everybody was on my side. [Patient 31, mastectomy, age 64, high MR unit, p7-8]

Patients benefited from receiving an explanation of why they were being offered a choice of treatments. If this style of consultation was not adopted, patients sometimes felt there was such a gap in experience, knowledge and power between themselves and their clinicians, that the expert was the only person who could assume control of treatment selection. Doctors seemed to have the capacity to exert the more disempowering influence within the situation and relationship, and BCNs sometimes facilitated greater patient involvement in the discussion of options and decision-making.

Rather than it be a discussion between us, I felt it was a one-sided discussion, ...there was two doctors in the room and I didn't have a nurse in with me...when I had a breast care nurse with me before, we were all involved in the conversation...I felt I had my support with me.. [Patient 62, BCT, age 44, low MR unit, p11-12]

The consultation style of clinicians seen earlier in their journey to cancer diagnosis of could also influence patients' expectations.

Having not expected to have a choice [it]...did throw me." [p10] "...because [the doctor] previously...had said usually [they usually]...recommend...mastectomy [in cases like mine]... [Patient 65, mastectomy, age 44, low MR unit, p7]



## Exploration of information needs, treatment preferences and concerns

Although some patients preferred a less autonomous decision-making experience, they still often wanted their treatment plan to take into consideration their individual preferences, needs and concerns. Some vocalised the conundrum that, within the timeframe available, clinicians could not be expected to get to know their patients sufficiently well to make individualised treatment decisions.

“Everything considered, I think that’s what you should do.” ...I think...I wanted the consultant to say that to me. ...[But] a consultant has never seen me before and doesn’t have a detailed understanding of my medical history or my psychological state...so I suppose I couldn’t reasonably expect him to make that decision.’ [Patient 29, mastectomy, age 48, high MR unit, p23]

This realisation of this, could lead naturally passive patients to become more willing to assume a more autonomous role.

I would say it would be nice for the experts to make a decision and tell you what they think you should have, and not give you a choice. Having said that, in hindsight, if I had been told that I was to have the lumpectomy I would have had a lumpectomy and...radiotherapy and I wouldn’t have questioned it...I would have been none the wiser about...how quick and easy mastectomy is compared to it.’ [p21-22] ‘...[and] I don’t want to be coming back every day for radiotherapy for six week’ because I had got...my son and his two children here...And...I take my duty as a surrogate parent seriously and I thought [radiotherapy] it’s [very] time-consuming. [Patient 25, mastectomy, age 60, high MR unit, p7-8]

The language style clinicians adopted affected patients’ impression of their knowledge-base. Patients also described benefiting from clinicians’ proactively checking their understanding of the information provided. Patients who felt they had sufficient time with their clinicians to gather information and gain confidence, described feeling more positive about their participation in decision-making. Many patients found the repetition and re-exploration of information, an opportunity to both consolidate and optimise their knowledge-base, and endow sufficient confidence for engaging in decision-making.

There always...somebody to follow up, to...ensure...you’ve understood. And if you haven’t, they...go through it...again...until you do. [Patient 17, BCT, age 50, medium MR unit, p23]

Most patients interviewed found the time they spent with their BCN following their initial consultation with the surgeon invaluable. This extra consultation provided patients with much needed psychological support, as well as providing an opportunity to further explore the available treatment options and their information needs. This aided their absorption of information through reiteration and reinforcement, and provided an opportunity to explore their personal preferences.

I tried to research it a bit...had a look on the internet...discussed it with breast care nurse at various points on the telephone. [Patient 57, BCT, age 44, low MR unit, p4-5]

Patients' challenge regarding decision making was often associated with their feeling of possessing insufficient information, decision support and time to comfortably make a choice. Some felt their clinicians' supply was inadequate.

I was floundering...there was no information on which to make a choice. I wasn't being forced to make a choice on the spot...So...I tried to research it a bit. [Patient 57, BCT, age 44, low MR unit, p4-5]

They felt the solution was to spend more time with their clinicians to gather information and gain decision making confidence.

I would have liked more time to have been able to absorb what I was being told and not just that hour slot...if I could've had perhaps a couple of hours where I could have sat with somebody and they could have explained the operations in, more detail. [Patient 38, BCT, age 57, high MR unit, p24]

Others felt the issue was purely their inability to absorb and process information at the time.

It was limited information but ...I don't think I could have taken much more in anyway.' [Patient 65, mastectomy, age 44, low MR unit, p12]

While some absorbed the information, but found weighing up the pros and cons especially difficult, due to the high stakes but equal survival associated with the options.

I don't consider me a person who...has problems making decisions and yet this was...an impossible decision...I wasn't educated to do it...I wasn't experienced...[and] I couldn't even make it on psychological grounds as...I didn't know at the time of making the decision how I would feel...if there had been a benefit of one over the other...there wouldn't have been the choice. [Patient 42, BCT, age 60, high MR unit, p23-24]

Many who received an individualised diagram with synopsis of pertinent cancer and treatment information from their clinicians, described benefit from its provision; they used it to simulate their recall of the consultation information and consideration during decision-making.

...my mind was...not terribly clear at the time [of diagnosis appointment, so]...it was useful to have it [diagram] when I came back [home] to look at it... [Patient 9, mastectomy, age 50, medium MR unit, p6]

They also described benefitting from having someone with them in the consultation who was not part of the clinical team. This allowed them to effectively extend the consultation through later re-discussion, which facilitated their absorption of information.

That's why you need somebody with you because I'll say something to [husband] and he'll say, "Well you haven't understood what they've said" because he has obviously taken more in than I have, because I think you are in...shock. [Patient 21, BCT, age 54, high MR unit, p10]

### **Patients' perception of their role in decision-making**

Patients' responses to decision-making were also influenced by whether or not they perceived they were being offered a *genuine* opportunity to choose their treatment. When clinicians presented options in a non-directed manner, patients were more likely to feel a genuine choice was available.

They were very clear that this was going to be my choice and that they wouldn't push one against the other. They just simply presented all the facts about the two. [Patient 33, BCT, age 57, p6]

In contrast, if patients were presented with a recommendation or treatment plan rather than options, they generally assumed they were not being offered a role in choosing their treatment.

...at the end of the day you...listen to what they say and you think 'well he's the one that knows what he's doing' and you sort of go with him...unless you're dead set against it. [Patient 21, BCT, age 54, High MR unit, p6]

When patients participated in decision making but felt their decisions were not accepted by their clinicians, they could feel insecure, frustrated or angry.

[The] nurse on the ward...kept saying "Well, [consultant]'s also mentioned...wide local excision [BCT]"...then...2 or 3 hrs later one of the Breast Care Nurses came up and started going through the same thing again. ...[and I] started to get a bit wound up..."What do you think I've spent the last two weeks deciding?" [Patient 65, mastectomy, age 44, low MR unit, p18-19]

## Time given for consideration

Patients often articulated that before they were able to meaningfully engage in treatment decision-making, they need time away from the clinical environment to recover from shock of their diagnosis.

I bet it was a good ten days before I actually calmed down and just thought, quite calmly...this is what I'm going to do. [Patient 42, BCT, age 60, high MR unit, p15]

They needed time assimilate and explore the information they had received.

All that information...gets crammed in your head...you're awash with it until you can come home and then you've got that time to relax and chill and just let your mind unwind and then think about everything that's been said. [Patient 48, BCT, age 38, p33]

They also required a realistic timeframe in which to make a decision; given this they could believe more autonomous decision-making was achievable.

I was thinking from one to the other...thinking "My God, what a decision..." but knowing I'd got this fortnight...and being told two or three times I didn't have to make a decision there and then, I could leave it right 'til the morning of the operation...helped. So I didn't panic. [Patient 31, mastectomy, age 64, high MR unit, p8]

However, if not provided with a clearly defined time frame in which to make their treatment decision, they tended to assume the decision was required immediately and that this was not an unachievable objective.

I found it a very hard decision...just couldn't decide, couldn't decide at all...I'd got to decide there and then. [Patient 51, BCT, age 51, low MR unit, p7]

TABLE 7.2 Influences over patient responses to breast cancer treatment choices

<b>Personal factors</b>
<ul style="list-style-type: none"> <li>• Prior knowledge and healthcare experiences (general or specific to breast services)</li> <li>• Decision-making preferences; active, collaborative or passive</li> <li>• Specific personal treatment option preferences</li> </ul>
<b>Clinicians' consultation style</b>
<ul style="list-style-type: none"> <li>• Accessibility of clinician and information</li> <li>• Tailored dialogue vs. prescriptive approach</li> </ul>
<b>Exploration of information needs, treatment preferences and concerns</b>
<ul style="list-style-type: none"> <li>• Opportunity to optimally explore information needs and reinforce knowledge</li> <li>• Sufficient clear, understandable, unambiguous information for informed decision-making</li> <li>• Time to explore information and preferences</li> </ul>
<b>Patients' perception of their role in decision-making</b>
<ul style="list-style-type: none"> <li>• Provision of a genuine choice</li> <li>• Provision of a clear explanation of the rationale for treatment choices</li> <li>• Invitation, encouragement and support of patient decision-making</li> <li>• Patient feels decision-making is achievable (information, support, time)</li> <li>• Support and encouragement of more autonomous decision-making by clinicians</li> </ul>
<b>Time given for consideration</b>
<ul style="list-style-type: none"> <li>• Sufficient time for reflection and consolidation</li> <li>• Clearly defined timeframe for decision-making provided or not</li> </ul>

## WHAT PATIENTS NEED FOR A POSITIVE DECISION-MAKING EXPERIENCE

The three subthemes above generated eight factors which encompassed patients' requirements for a positive decision-making experience. These are summarised in table 7.3 and the following quote highlights many of them.

The choice...to have it explained to you and to make sure that the patient knows at any time they can change the mind. ...And... open communication...being able to ring up the breast care nurses and ask anything about the operation because it is so much to take on board in what is possibly half an hour to an hour's appointment. ...and then...time to...let your mind unwind and...think about everything that's been said. ...[and] having clear and precise information at all times. [Patient 48, BCT, age 38, low MR unit, p33]

Across the interviews patients wanted to be prepared for their decision-making and cancer journey. They viewed the information, advice and guidance they received from their clinicians as a means of equipping them for this, and as a method to empower and take care of themselves physically and psychologically. This view was expressed independent of the treatment options they chose. Despite the fact that patients sometimes felt overwhelmed by the volume of information they were given and at times felt unable to absorb it all, most expressed the desire to be fully informed about their cancer and treatment.

The key to a positive experience of decision making among the minority who were steadfastly passive, was the security of being issued with a specific treatment plan by the expert clinician. This group's needs were focussed on the clinician relaying a sense of caring, reassurance and empathy, rather than knowing the details of options. However, they still expressed the desire for information. The retrospective nature of the interviews permitted some to reflect that although they were happy to undergo BCT (which their clinicians usually recommended), some possessed quite crippling anxiety and concerns about local recurrence. With hindsight, this group talked about the desire for their clinicians to tailor their treatment plan or guidance to their individual needs and concerns. Some recognised this could be difficult.

Although decision-making experiences varied, the majority of patients seemed satisfied. The reasons for satisfaction however varied. Those who participated more fully in decision-making and whose clinicians provided comprehensive information and supported their patients' decision-making, often expressed satisfaction related to their assumption of a role in choosing a treatment that felt appropriate for them as an individual, which also often increased their sense of control and empowerment. Those who were treated by clinicians who offered less choice and more

treatment direction, often expressed satisfaction about the security they felt as a result of the expert guiding them or providing them with a treatment plan.

He didn't...say, "Which would you prefer?" but...he's the professional, he knows...I was quite happy to take his word, I mean you've got to trust in them, haven't you? [Patient 63, BCT, age 59, low MR unit, p19-20]

While those who expressed dissatisfaction with their decision-making experiences, were often those who felt they were forced to assume a greater or lesser role in decision-making than they desired, and whose clinicians adopted a prescriptive approach, only offering treatments which were incongruent with their patients' preferences.

If I could give any doctor any feedback, it's...listen to what your patient's saying...you might think, "Well, the best thing is this," but listen to why they don't want to go with that. [Patient 62, BCT, age 44, low MR unit, p11]

The provision of patient-centred care was often central to how comfortable patients felt in their consultations, the decision-making process and their treatment.

I was dealt with compassion and efficiency...treated as a person, not as a walking disease. [Patient 14, BCT, age 60, medium MR unit, p16]

They appreciated being provided with honest, tailored understandable information, and experiencing a supported decision-making process, and the sense of not being rushed.

He went to great care to explain and...you didn't feel he was rushing you. [Patient 20, BCT, age 58, medium MR unit, p14]

We were on the same wavelength...we were always working together for my benefit. I didn't have to think, "Well he knows better than I do so I'll go with what he says"...there was never any confrontation, never any "Well I'm not quite sure, but he must know best. [Patient 12, BCT, age 69, medium MR unit, p20]

TABLE 7.3 Summary: What patients need for a positive shared decision-making experience

<b>Tailored Decision-making experience</b>
<ul style="list-style-type: none"> <li>Patients permitted to play the role they desire in decision-making*</li> </ul> <p>* but some are initially ignorant of a possible role, PDMS can change in response to information and support and some described benefiting from choices even though they initially held more passive preferences.</p>
<b>Perception of a genuine role in decision-making</b>
<ul style="list-style-type: none"> <li>Provision of a genuine choice</li> <li>Provision of a clear explanation the rationale for treatment choice</li> <li>Permission or invitation to participate in decision-making</li> <li>Encouragement and support to participate in decision-making</li> <li>Perception that decision-making is achievable (information/knowledge, support, time)</li> <li>Negative responses when choices which did not feel genuine</li> </ul>
<b>Knowledge</b>
<ul style="list-style-type: none"> <li>Clear comprehensive, unambiguous information necessary for decision-making</li> <li>Opportunity to explore information needs</li> <li>Opportunity to build on knowledge (reiteration, reinforcement, re-exploration)</li> </ul>
<b>Tailored patient-centred communication</b>
<ul style="list-style-type: none"> <li>With doctors and BCNs</li> <li>Freedom to explore information, preferences and barriers to shared decision-making/options</li> </ul>
<b>Accessibility of clinicians and decision support</b>
<ul style="list-style-type: none"> <li>Accessibility for multiple consultations if necessary</li> <li>Accessibility of clinicians within consultations; unrushed time, open tailored discussions</li> </ul>
<b>Time to work through the decision-making process</b>
<ul style="list-style-type: none"> <li>To explore information needs and preferences and consider options in the light of these and their personal preferences</li> </ul>
<b>Empowerment</b>
<ul style="list-style-type: none"> <li>Appropriate tailored decision-making support</li> <li>Knowledge</li> </ul>
<b>Reassurance</b>
<ul style="list-style-type: none"> <li>Safety and acceptability of the option preferred or chosen</li> <li>Reassurance regarding support for decision-making</li> <li>Endorsement of option preferred or chosen by patient</li> </ul>



## CONCLUSION

This chapter describes a very strong emergent theme from the interviews with women identified by their breast team clinicians as given choices of breast cancer surgery, and increases our understanding of what patients feel about being asked to make treatment choices. In an era of change where patients are increasingly viewed as partners in healthcare decision-making, this information is crucial to optimising the quality of patients' healthcare decision-making experiences.

Patients interviewed expressed varying desires for participation in decision-making, consistent with the active, collaborative and passive decision-making preferences described in the literature.(Degner et al. 1997b) These qualitative findings support the findings of recent questionnaire-based studies; and confirm that the DMS of patients has changed with time, the majority of patients now happy adopting more active or autonomous roles in healthcare decisions.(Beaver, Luker, Owens, Leinster, Degner, & Sloan 1996;Bilodeau & Degner 1996;Degner, Sloan, & Venkatesh 1997b;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) However, the findings also highlight that certain contingencies exist to the way patients perceive treatment decision making and they provide additional detail to that possible from questionnaires; highlighting some subtleties involved. These include how preconceptions and initial responses are substantially modified by information, consultation styles and decision making support provided by clinicians, and how involvement in decision-making was presented to them.

Most patients found being involved in breast cancer treatment decisions, either novel or a challenge. An unexpected majority had no expectation of being involved in choosing their treatment. They anticipated the provision of a treatment plan at diagnosis instead. This meant they were often initially surprised by the offer of this role. Patients often described experiencing a number of personal responses they as they progressed through the decision making experience and had the opportunity to reflect on it. These often changed over time; initial responses often giving way to later responses.

Clinicians had a substantial influence over how patients felt about involvement in this healthcare decision; patients' adaption seeming to result from their interactions with their clinicians and the

passage of time from the acuteness of their diagnosis. The process of adaption was described more fully and specifically among those experiencing more facilitative/less directive consultations and decision making.

Many patients described needing time and the support of their clinicians to adjust, become sufficiently informed and feel appropriately supported to operate more comfortably in this role. They often described requiring and desiring the opportunity to receive information at multiple time points within and away from the clinical environment. This was necessary to absorb and process information, and reach a decision. This is where an additional consultation with BCNs was of great potential benefit.

Patients' views were influenced by prior expectations and experiences, together with the acuteness of their diagnosis and awareness of their knowledge deficiency. Most patients' initial conceptions and responses adapted and the majority seem to accept and even embrace this role, once provided with the rationale for their involvement by their specialist clinicians, and provided with patient-centred explanations, information, time and support. For many, choosing their treatment became a positive aspect of their cancer experience and a chance to re-establish a sense of power and control denied at their cancer diagnosis. This was true for both many who found decision-making relatively uncomplicated, and those finding it more challenging.

While decision-making experiences varied, most of the women interviewed expressed satisfaction with their particular decision-making experience. The reasons for their satisfaction were expressed irrespective of their treatment type, but differed according to their experience of consultation and decision-making. The provision of individualised patient-centred care, accessible information, tailored consultations and decision-making experiences, and the provision of appropriate decision support were often central to patients' satisfaction with their decision-making experiences. Those describing the provision of more comprehensive information and autonomous but supported roles in choosing their treatment often expressed satisfaction that they had received patient-centred care. They often ascribed their satisfaction to their clinicians treating them as partners in the process and frequently described how such engagement provided, not only the opportunity to select the treatment that was right for them as an individual, but also the opportunity to re-establish a sense of control and empowerment at a time of vulnerability. However, patients could equally be satisfied by the provision of a more directed approach from their clinical specialist or expert; provided they felt their opinions and needs were respected, and the option suggested was acceptable to them. This group often expressed their

satisfaction residing in the reassurance and sense of security they gained from being under the care of an expert and receiving an expert's opinion.

A powerful method of providing patients with reassurance, and optimising their satisfaction with decision-making was the clinician's endorsement of the operation patients decided to undergo; whether this was articulated by the clinician or perceived by the patient. This was evident even amongst patients who had a fairly clear idea of their preferred treatment. Patients wanted reassurance they were making the *right* choice, a choice that was *safe* and acceptable to their clinicians.

Dissatisfaction was expressed most markedly among those whose decision-making experiences and treatment were discordant with what they wanted: Those who felt forced to assume a more or less autonomous role in decision-making than they desired, and whose clinicians adopted a prescriptive approach, only offering treatments incongruent with their patients' preferences.

A potential limitation of the study is that participants were interviewed following the completion of the decision-making experience. This raises the possibility of recall bias and post hoc justification influencing the findings. This is explored in the general discussion. The interviews however took place within a similar timeframe to other qualitative studies exploring decision-making, and had the interviews had been conducted earlier, the information about how perceptions adapted over time and what influenced this would have been absent.

All participants were identified by their own specialist clinicians as having been offered treatment choices. Despite this, some patients' descriptions of their experiences seemed inconsistent with the provision of options and a role in choosing their treatments. This might represent the belief of some clinicians that they are providing their patients with choices, when they are in fact offering much less autonomy.

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## Chapter 8

### Review of findings

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<b>Aim</b>	To identify whether variation in the initial therapeutic treatment of breast cancer, suggested by UK NHSBSP reports, persists following correction for case-mix and caseload; and identify whether specialist breast clinicians (doctors and nurses) possess particular treatment preferences which impact on patient consultations, treatment decisions and therefore MRs
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This study investigates variation in hospital breast unit MRs from key stakeholder perspectives (patient, specialist doctor and BCN). It provides new information and a fuller understanding of the prelude to and interface between patients and clinicians, in situations where patients can be provided choices and treatment varies.

Employing a mixed methodology multi-perspective study, we demonstrate variation MRs is not due to units' case-mix, but largely due to the impact of clinicians' beliefs and preferences over decision making. These dictated which patient groups received genuine options, clinicians' consultations and approach to decision making, and patients' decision making experiences. The breast units studied possessed different decision making cultures with a central ethos which was either focussed on a more facilitative or directive approach toward decision making. These were based on the central belief of what comprises optimum patient management; patients undergoing the treatment their expert clinicians deem preferable or patients deciding this for themselves, having been provided with the tools (knowledge and support) and time to do so. The differences between units with varying practice patterns are summarised in table 8.1 and 8.2.

## OBJECTIVES AND FINDINGS

<b>Objective</b>	Identify whether inter-unit variation in the surgical treatment of breast cancer persists after correction for case-mix
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<b>Finding</b>	Significant variation in breast cancer MRs persists when case-mix is excluded.
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5109 primary breast cancers detected over a six-year period (1997-2003) by the Trent region's 11 breast screening units, were analysed at individual case level to identify whether case-mix and case-load explained variation MRs observed at aggregate level.

Expected case-mix adjusted MRs were derived by logistic regression using the variables cancer size, site and grade, patient age and year of presentation (representing changes in evidence-based practice). The region's overall case-mix adjusted practice was employed as the reference population. Significant variation existed in breast unit MRs (range 25%-45%,  $p < 0.0001$ ), which persisted following case-mix adjustment ( $p < 0.0001$ ). Two-fold variation was demonstrated overall (observed to expected unit MR coefficient range 0.66-1.36). Variation increased to almost four-fold among the small diameter subgroup (observed to expected unit MR coefficient range 0.55-1.95, among less than 15mm diameter cancers).

Neither case-mix correction nor the available literature explains wide variation in MRs. Further research is required to investigate the other potential patient and clinician causative factors.

**Objectives** Identify whether clinicians possess preferences which influence patients' decision-making in breast cancer, and in what way

Identify how clinicians influence patients' treatment decisions in the light of treatment guidelines

**Finding** Clinicians possessed treatment preferences which despite agreed treatment guidelines, were also influenced by patient age and clinicians' gender and occupational role.

A quantitative cross-sectional postal survey utilising DCE methodology examined whether clinicians possessed preferences for breast cancer surgical options. All permanent specialist breast team clinicians (doctors and nurses) from the 14 Trent breast units were invited to indicate their preference for surgery (mastectomy, BCT or patient choice) over a series of hypothetical

scenarios randomly generated from a group of preoperatively available variables; patient age, bra cup size, cancer size, site and cancer centrality. 68/93 clinicians completed the survey (73% response rate) and data were analysed across the 25 scenarios (n=1,695) using multinomial logistic regression with allowance for response clustering, comparing preference for choice, with preference for mastectomy or preference for BCT.

Clinicians' treatment preferences were predominantly consistent with evidence-based breast cancer treatment guidelines, which recognise the boundaries of survival equivalence and acceptable recurrence risks, while being flexible to patient preferences and therefore contain few absolute indications or contraindications to specific treatment options. Clinicians' preference for mastectomy, over choice, over BCT, was positively correlated with increasing cancer size, reducing breast size, central cancer position and multi-centricity ( $p < 0.001$ ). However contrary to guidelines, clinician preferences were also significantly influenced by patient age; increasing patient age correlated with increased preference for mastectomy ( $p < 0.001$ ). The age impact was less marked among those preferring BCT and in the oldest patient age groups. The DCE also demonstrated, clinicians preferring BCT or mastectomy had different thresholds for altering their preferences. Those preferring BCT shifted toward choice when cancers exceeded 20mm diameter and those preferring mastectomy shifted toward choice in cancers under 30mm diameter.

Despite the clear demonstration of the impact of the patient and cancer characteristics over clinician preferences, the low pseudo  $R^2$  (0.29) indicates the factors examined within the DCE only account for 29% of the clinicians' responses. Something else is responsible for the majority.

Clinician gender and occupation were also associated with their preferences: Female clinicians and nurses tended to prefer choice rather than mastectomy ( $p = 0.015$  and  $p < 0.001$  respectively). Nurses were more likely to prefer choice than specific treatment options ( $p < 0.001$ ), and doctors were more likely to demonstrate specific treatment preferences (mastectomy or BCT) than prefer choice.

<b>Finding</b>	<b>Breast teams/clinicians differed in who they provided with options.</b>
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Qualitative methodology comprising semi-structured interviews, highlighted that variation in MRs was associated with differences in breast unit teams/clinicians identification of patients provided with options/choices, and how much direction and genuine choice patients were provided. Descriptions from the low MR unit differed from the more similar medium and high MR units. Among the units studied, lower MRs were associated with the offer of BCT rather than options to women with smaller cancers, and the provision of more directive information regarding BCT to those given options.

<b>Finding</b>	<b>Breast teams within units possessed a decision making culture with a central ethos, based on the possession of particular beliefs. These influenced the information provided to patients; and their consultation and decision making approaches.</b>
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Semi-structured interviews with 26 clinicians from the three breast units representing the spectrum of case-mix adjusted MRs from the region, demonstrated clinicians possessed treatment preferences and beliefs which were predominantly clustered by their breast unit. These consolidated within a unit ethos and were associated with the description of a particular unit decision making culture. The decision making cultures seemed self-perpetuating and were reinforced by the processes and practice adopted by individual clinicians and as a team. The low MR unit ethos and culture differed from that of the other units.

Despite the possession of a differing ethos, the primary underlying motivation was similar within all units. They wanted to provide optimum management to their breast cancer patients and minimise the negative impact of the diagnosis. They diverged in their possession of a different set of beliefs about what the optimum management comprised. This was perceived to be informed patient decision making or a specific treatment.

The ethos and practice of the low MR unit are termed outcome-based practice. Their focus was on a particular treatment goal. They described the possession of the central belief that BCT was optimum and mastectomy should be avoided where possible. They concurrently possessed the



predominant belief that most patients possessed a passive PDMS, and were unable to assimilate and contemplate the volume of new information required to engage in informed decision making. They therefore expressed the trained expert, the clinician, was the most appropriate individual to determine the optimum treatment for their patients. Therefore BCT was universally recommended where not absolutely contraindicated.

In contrast the medium and high MR unit clinicians' ethos and practice are termed process-based. Their focus was on a particular process of treatment decision-making; more autonomous patient decision making. These clinicians described core beliefs that only individual patient could judge which particular treatment was right for them, and that patients were capable of making such decisions if provided with suitably understandable information, support and time. They described a reluctance to provide recommendations; stating the desire to avoid their personal preferences exerting undue influence over patients' decisions.

Despite the presence of a central ethos and particular decision making culture within breast units, some heterogeneity was described within them. There was some diversity in individual clinicians' beliefs and strength of adherence to them. However, clinicians' perception of the norm and the extent of diversity described were embedded within and dominated by the culture of their breast unit. Although some clinicians' beliefs seemed to have more in common with those from other units and they were outliers in the context of their unit norm, only small a few were true outliers.

<b>Finding</b>	<b>UK women want &amp; achieve more autonomy in choosing their treatment than previously realised and this influences the choices women make</b>
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A quantitative patient survey utilising validated instruments, was conducted within the same three specialist breast units representing practice variation. Completed questionnaires were received from 356/697 consecutive eligible patients offered a choice between BCT and mastectomy (51% response rate) Respondents had a mean age of 58.5 years (range 30.4-89.0) and completed the questionnaires a mean 6.9 weeks after their surgery (range 1.3-48.6). 74% underwent BCT (n=262) and 26% mastectomy (n=94).

High proportions of active decision-making (PDMS and ADMS) were demonstrated; particularly among those choosing mastectomy (active ADMS 83% vs. 58%,  $p < 0.001$ ) and those treated by

the high MR unit (active ADMS 80% vs. 54% and 52%,  $p<0.001$ ). Higher concordance of PDMS and ADMS was noted among active decision makers (91%,  $p<0.001$ ) and there was a non-significant trend for greater concordance among those choosing mastectomy (67% vs. 59%,  $p=0.070$ ).

<b>Finding</b>	<b>Patients' treatment choices are substantially influenced by breast-team influences; the options provided; content and portrayal of information; time given for decision-making; and degree of patient autonomy in decision making promoted and supported</b>
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Qualitative interviews were conducted among a subgroup of 65 patients completing the DMS questionnaire phase of the programme of research. The women articulated different preferences for specific treatment options based on innate patient-specific factors consistent with known influences over breast cancer patients' decisions from existing literature; body image, recurrence fears, radiotherapy concerns, social commitments etc. Women from the different breast units did not possess fundamentally different preferences for treatment. However their treatment choices were influenced by three clinician/unit factors impacting these more innate patient factors associated the information provided by clinicians; patients' perception of their options, the most reassuring treatment option and least disruptive treatment option.

Patients' interactions with their clinicians impacted their decisions in other ways. Clinicians' preferences (either for BCT or more autonomous decision making) were clearly communicated to their patients. These and the breast units' environment for decision making established by the decision making culture and reinforced by the units' processes, had a substantial influence over patients' decisions. Differences were described in the information provided (content and portrayal) to women were about their cancer, the treatment options offered (choice of surgery or BCT), the level of promotion and support of more autonomous patient decision-making, and the time provided for the process.

The ethos of the low MR unit meant that some clinicians deemed patients so clearly suitable for BCT, they did not consider providing options. While others considered suitable for choices they often readily volunteered treatment recommendations. Correspondingly, predominant

descriptions of decision making among these patients were those guided by clinicians' recommendations rather than those based on more comprehensive information and personal deliberation. Experiences among the other units contrasted with this. These were described as more deliberative and comprehensive; based on the consideration of patients' preferences in the context of more extensive expressed knowledge. This was consistent with the medium and high MR units' descriptions of a process-based ethos focussed on facilitating shared decision making.

**Objective** Identify how patient satisfaction with the decision-making experience is influenced by the above

**Finding** Patient satisfaction was influenced by patient-centred care; the provision of tailored, clear information and time; the receipt of reassurance; and involvement in decision-making with individualised support

Patient satisfaction was influenced by the perception of the provision of patient-centred care. This encompassed the provision of clear tailored information, involvement in the decision-making process to the individual's level of preference, unrushed time within consultations and adequate time for decision-making. Despite the predominance of the active PDMS and ADMS among the patients, at diagnosis only a minority of those interviewed anticipated involvement in choosing their treatment. Satisfaction was influenced by patients' involvement in the decision-making process even if they did not possess an active PDMS. However, describing benefit and satisfaction from engaging in decision making was for most, contingent on patients feeling adequately informed, confident and supported in undertaking a more autonomous role.

However a minority with a passive PDMS, viewed more autonomous engagement in decision making as a cause of sometimes extreme dissatisfaction; even with the above prerequisites met.

Patients' satisfaction was also increased by the receipt of reassurance regarding their treatment; especially if this was readily volunteered by clinicians. This included many of those describing more directed and paternalistic experiences. Reassurances and a strong direction toward BCT

could be viewed as sources of satisfaction, providing patients did not possess conflicting preferences for mastectomy and/or a more active DMS.

## THE BENEFITS OF ADOPTING A MIXED METHODOLOGY APPROACH

The study design reflects the complexity of communication and decision making in healthcare. The adoption of a multi-perspective mixed methodology approach enhanced the findings of the overall study. Utilising both qualitative and quantitative methods, enabled issues raised within one section of the study to be explored from a different aspect in other sections of the study. The adoption of this more complex approach was considered important in permitting the generation of a more coherent picture of decision-making and the factors associated with variation in the surgical treatment of breast cancer.

## MISMATCHES IN RESULTS

There are a few possible mismatches between the results of the DCE and clinician interviews.

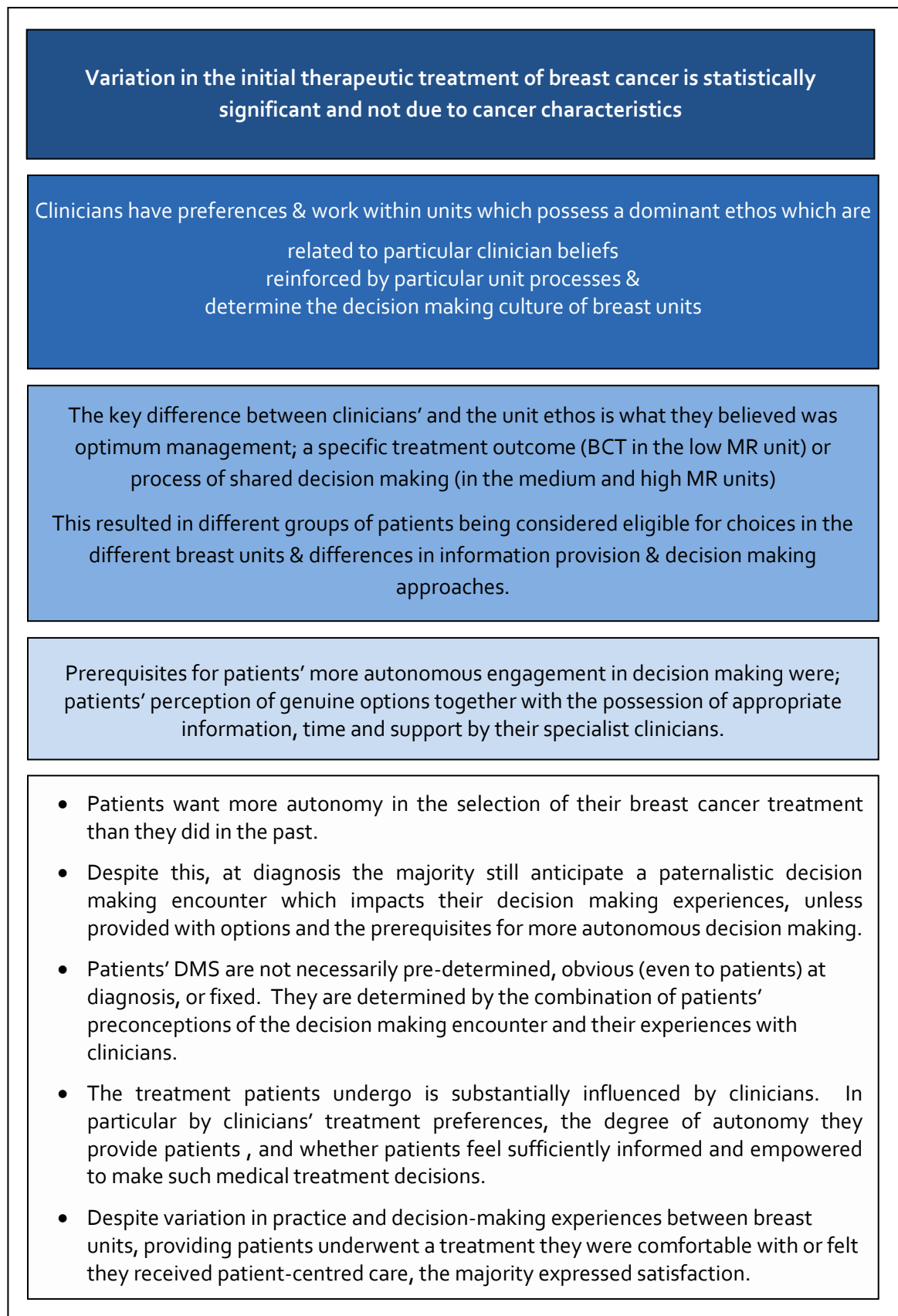
At a regional level, clinicians' responses to the hypothetical DCE scenarios indicated different thresholds for the transference of their preferences from BCT and mastectomy to patient choice. Those preferring BCT shifted toward choice when cancers exceeded 20mm diameter and those preferring mastectomy shifted toward choice in cancers below 30mm. Interviews with the subgroup of clinicians from the three breast units reflecting practice variation were consistent with the possession of different thresholds for clinicians' preferences. But the cancer diameter thresholds for the preference shift indicated by the DCE were less well clarified within the interviews. Most clinicians would consider cancers of these sizes small; unless breast volume is also small. The specific thresholds demonstrated by the DCE may be the product of a dominant influence by one of the other variables. The DCE requires that ideally variables be independent. But breast volume and cancer size are not truly independent when the breast volume is smaller, as the aesthetic outcome of BCT is compromised when over 20% of the breast volume is excised without volume replacement.

This could represent a potential mismatch in the results of the different methodologies or residual gap in understanding clinician preferences. Specifically, the clarification of the threshold for clinicians from the different breast units shifting from offering options to promoting mastectomy. As a group, medium and high MR clinicians described providing options to those not requiring mastectomy on clinical grounds. Theoretically they offered options to a much wider group than the low MR clinicians, who viewed small cancer size as a relative contraindication to choices. Some considered cancers up to 40mm diameter 'small'; especially if they were also located peripherally. However the specifics of clinicians from the different units believing mastectomy was indicated on clinical grounds, was not fully explored.

TABLE 8.1 Summary of themes associated with breast unit treatment variation.

	Low MR unit	Medium and high MR units
<b>Ethos</b>	Avoidance of mastectomy where possible	Promotion of more autonomous patient decision making where possible
<b>Options</b>	Choice for 'borderline' or larger cancers. BCT for smaller (especially peripheral) cancers	Choice for those suitable for BCT
<b>Information</b>	Less comprehensive, more directive	More comprehensive, less directive
<b>Communication</b>	More closed/clinician-centred consultation style	More open/patient-centred consultation style with active promotion of wider more extensive discussion (especially high MR unit)
<b>Recommendations</b>	More active direction of choices & volunteering of clinician opinion	Reluctance to direct choice & less volunteering of clinician opinion
<b>Checking patient understanding</b>	Less extensive	More extensive (especially high MR unit)
<b>Patient knowledge</b>	Narrower and less complete descriptions	Broader and more complete descriptions (margins, & inevitability & details regarding radiotherapy with BCT)
<b>Patient autonomy</b>	Support of autonomous patient decision making in selected subgroups; overtly active decision-makers & some cancers borderline for BCT.	Routinely pro-active support and encouragement of autonomous patient decision making in all from early in the decision making process.
<b>Decision making culture</b>	Encourages acquiescence	Encourages autonomy
<b>Time for decision making</b>	Short timescales and time-pressure for decision making	Longer timescales and attempt to lessen time-pressure in decision making
<b>Consent</b>	Consent early: At diagnosis or one week after diagnosis	Consent later: At pre-assessment clinic or pre-operatively
<b>Overall impression</b>	('Informed') compliance	Informed consent

FIGURE 8.1 Summary study findings.



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## Chapter 9

### Discussion

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## 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 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 patients' 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;Monypenny 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 centrality) 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, Collimediaglia, & 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 centrality 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 primary 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 patients' 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 (particularly 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.

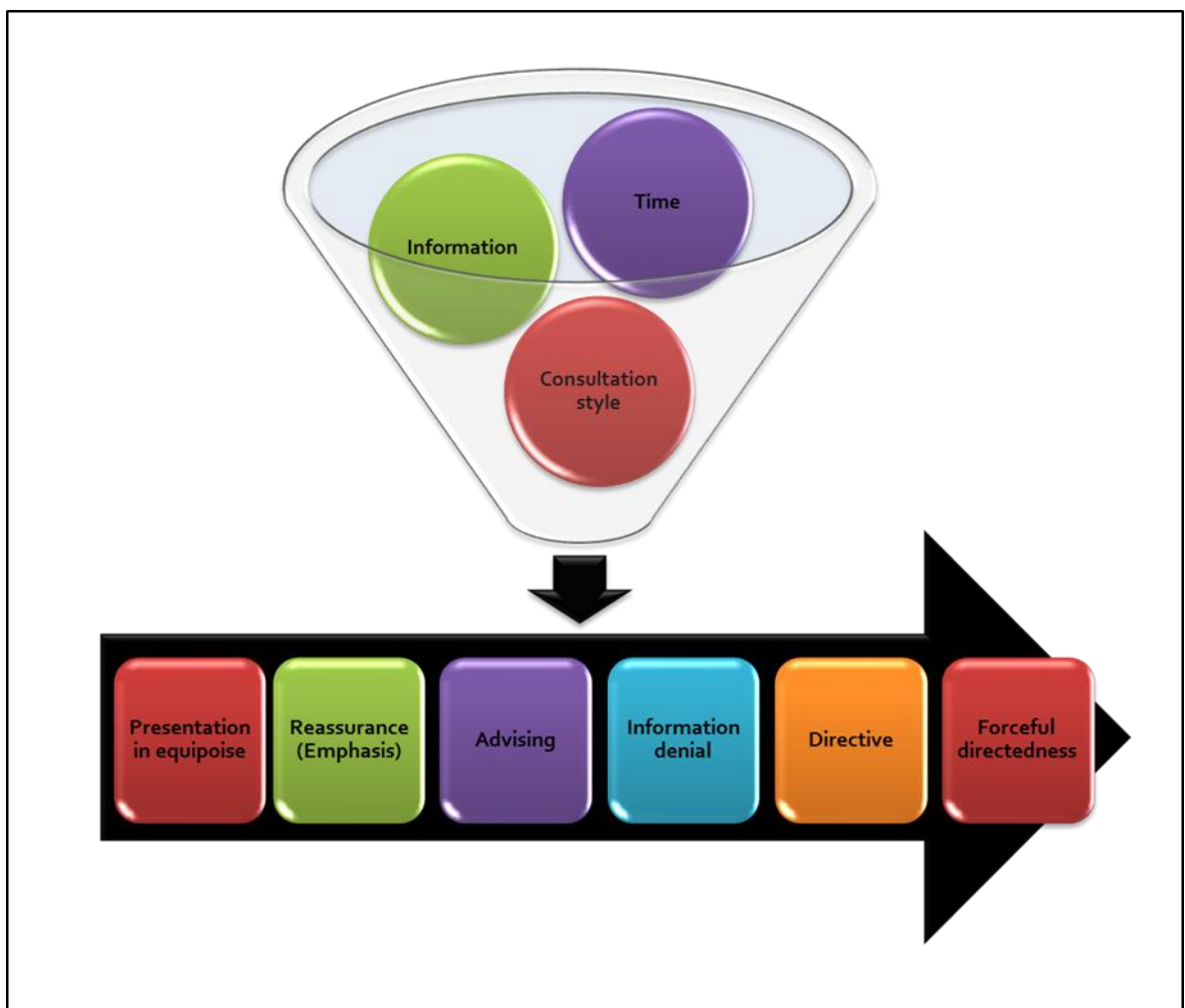


The evidence from the literature is unclear about whether surgeons' years of experience (Grilli, Scorpiglione, Nicolucci, Mainini, Penna, Mari, Belfiglio, & Liberati 1994; Liberati, Patterson, Biener, & McNeil 1987; McKinlay, Burns, Durante, Feldman, Freund, Harrow, Irish, Kasten, & Moskowitz 1997) and 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, & Karsen

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; 1<sup>st</sup> dimension power. Clinicians controlled the consultation/decision making

agenda; some directed and subjugated patients by failing to provide time and demonstrating poor listening skills; 2<sup>nd</sup> 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); 3<sup>rd</sup> 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 of 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 cited 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, Trichter, & 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

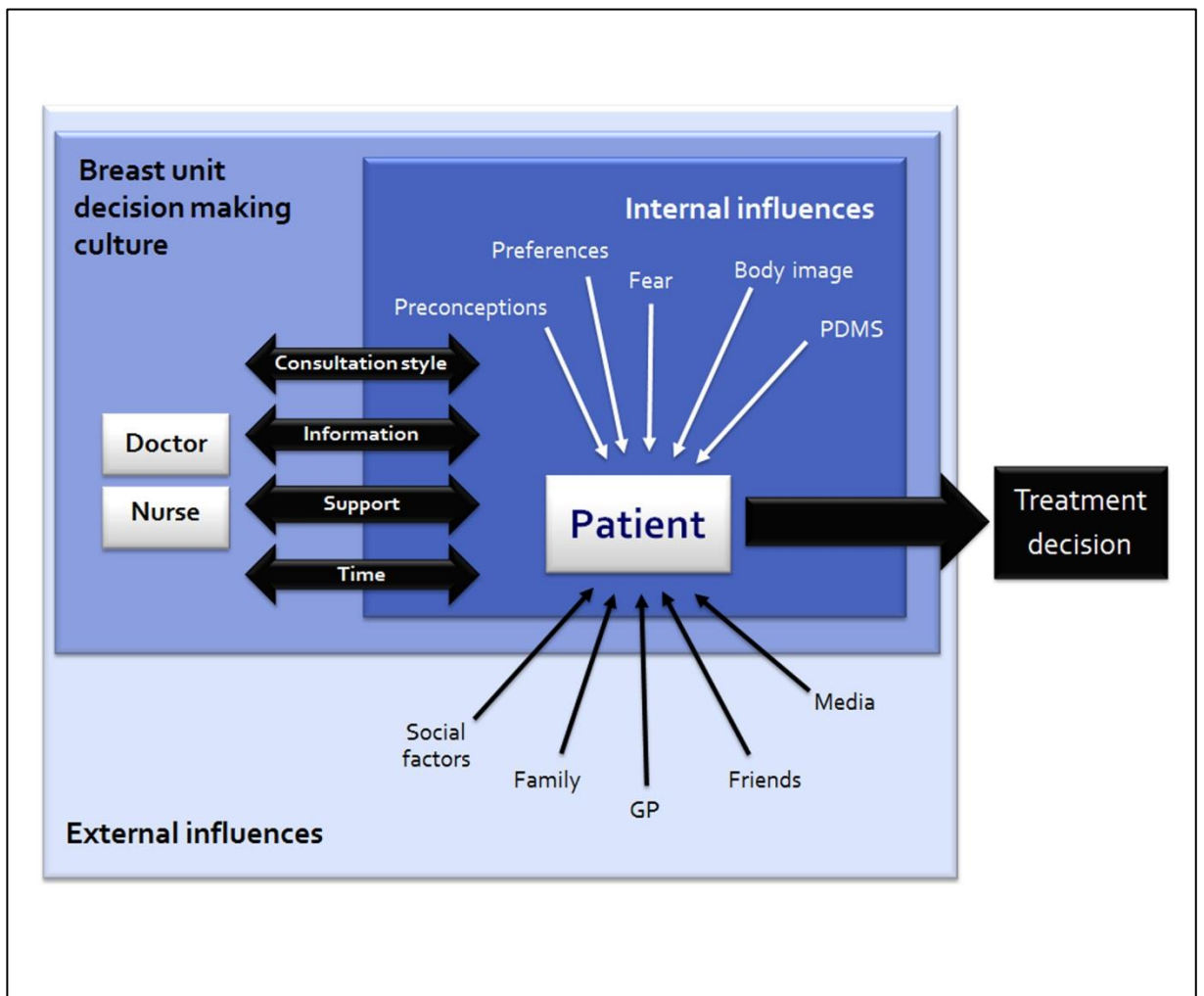


FIGURE 9.3 Proposed model the decision making approach for the surgical treatment of breast cancer

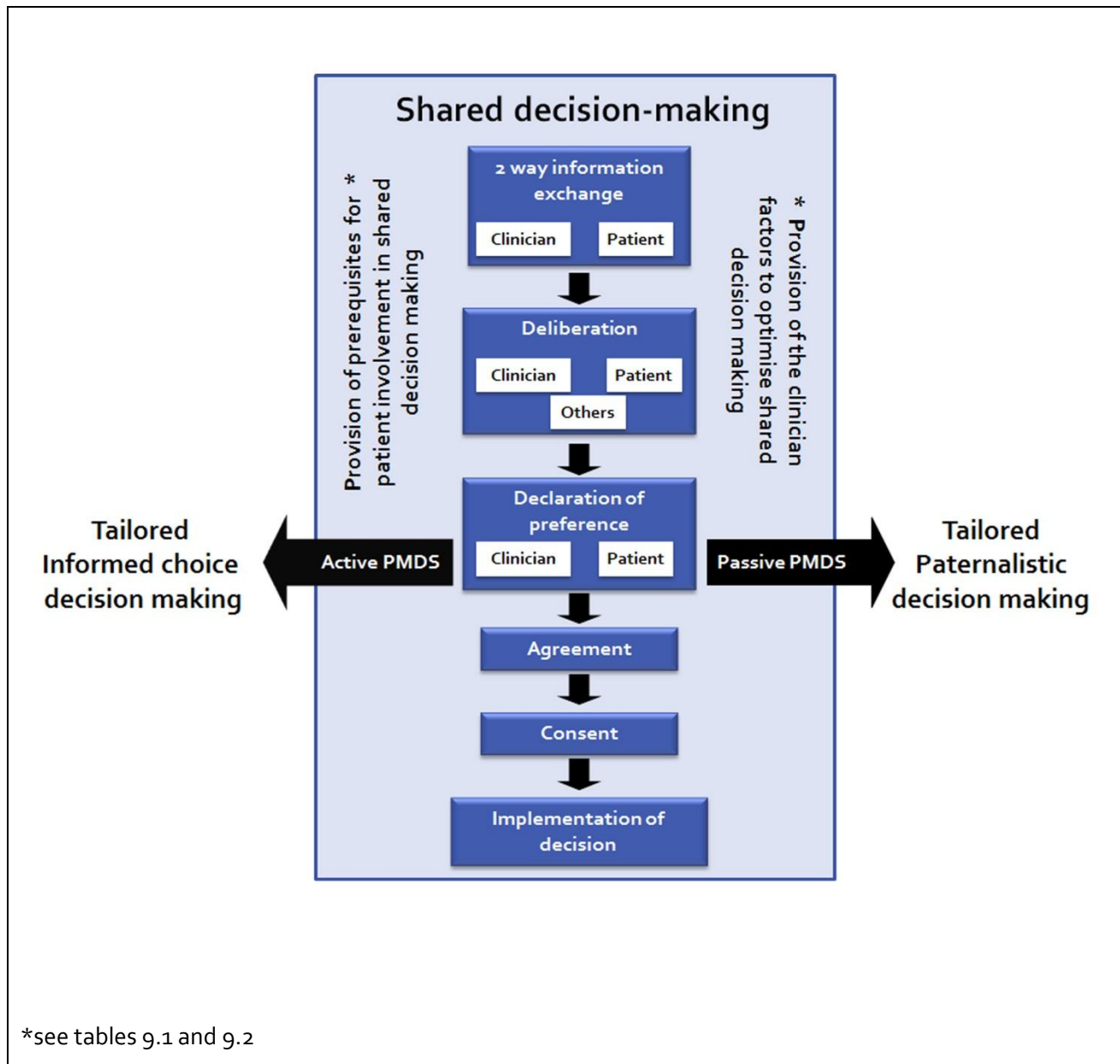


TABLE 9.1 Summary of the prerequisites for patient involvement in shared decision making

Awareness of the availability of patient involvement in decision making & the options	
<b>Perceive provided a genuine choice</b>	
<b>Understand why there is a choice</b>	<ul style="list-style-type: none"> <li>• Rationale for a more autonomous role in the process</li> </ul>
<b>Possess tools for informed decision making</b>	<ul style="list-style-type: none"> <li>• Information/knowledge</li> <li>• Time</li> <li>• Support</li> </ul>
<b>Decision making &amp; psychological support</b>	<ul style="list-style-type: none"> <li>• Clinicians, especially BCNs</li> </ul>
<b>Time</b>	<ul style="list-style-type: none"> <li>• Realistic timeframe for decision making</li> <li>• Unrushed consultations &amp; accessibility</li> <li>• Time away from the clinical environment</li> </ul>
<b>Safety</b>	<ul style="list-style-type: none"> <li>• Of the options</li> <li>• Of the decision making environment</li> <li>• What will happen if unable make decision</li> </ul>
<b>Confidence</b>	<ul style="list-style-type: none"> <li>• For decision making in a supported environment</li> </ul>

TABLE 9.2 Summary clinician factors to optimise shared decision making

Minimise skewed power-relationship	
<b>Provide prerequisites for patient decision making</b>	
<b>Communication skills</b>	<ul style="list-style-type: none"> <li>• Good communication skills; active listening etc.</li> <li>• Patient-centred approach</li> <li>• Tailor communication &amp; information</li> </ul>
<b>Portray</b>	<ul style="list-style-type: none"> <li>• Caring</li> <li>• Traditional expert abilities</li> </ul>
<b>Accurately identify PDMS</b>	<ul style="list-style-type: none"> <li>• Differentiate between initial reactions &amp; passive PDMS</li> </ul>
<b>Information</b>	<ul style="list-style-type: none"> <li>• Clear</li> <li>• Plain English</li> <li>• Non-biased full information</li> <li>• Reiterate (within &amp; over consultations)</li> </ul>
<b>Check understanding</b>	
<b>Provide tools to reiterate pertinent points of tailored information</b>	
<b>Defer direction/recommendations till later in the decision making process</b>	

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## **Chapter 10**

### **Implications**

**Suggestions in response to the study findings**

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## 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 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 mastoplasty, 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.

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## Chapter 11

## Conclusions

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## 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.

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## Chapter 12

### Future research

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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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