
Appendix 1

Funding, Insurance, NCRN trial acceptance



Cancer Research UK
PO Box 123
London WC2A 3PX
United Kingdom

T 020 7242 0200
www.cancerresearchuk.org

EDUCATION

15 May, 2002

Miss Lisa Caldon
288 Dobbin Hill
Sheffield
S11 7JG

Dear Lisa

Cancer Research UK Training Fellowship

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

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

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

Congratulations and very best wishes for a successful Fellowship.

With best wishes.

Yours sincerely

A handwritten signature in dark ink, appearing to read "Jean".

Ms Jean King
Director of Education Funding

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

Cancer Research UK is a registered charity No. 1069464. Registered as a company limited by guarantee in England and Wales No. 4323231.
Registered address: 61, Lincoln's Inn Fields, London WC2A 3PX. Patron Her Majesty The Queen
Presidents HRH The Duke of Gloucester KG GCMG and HRH Princess Alexandra, the Hon. Lady Ogilvy GCMG
Interim Chief Executive Professor Andrew Miller CBE PhD FRSE Director General (Science) Sir Paul Nurse FRS
Director General (Fundraising & Communications) Professor JG McVie MD FRCP



The Royal College of Surgeons of England

35-43 Lincoln's Inn Fields, London WC2A 3PE
T: 020 7405 3474 W: www.rcseng.ac.uk

Research Board

Chairman: Professor Peter Bell FRCS
Secretary: Martyn Coomer
tel 0207 869 6612
fax 0207 869 6644
e-mail: mcoomer@rcseng.ac.uk

13 June 2002

Miss Lisa Caldon
288 Dobbin Hill
Sheffield
S11 7JG

Dear Miss Caldon,

The Royal College of Surgeons of England Research Fellowship

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

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

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

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

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

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

Advancing Surgical Standards

Registered Charity No. 212808

To assist in advertising the Research Fellowship Scheme it would be much appreciated if you would kindly show the enclosed slide at any presentation you may give relating to this award and please also acknowledge the College on any posters you may be producing from the work. If you would prefer the slide sent to you via email in a Powerpoint format please ring ✓ 21/6/02 .
Bumbi Singh, Research, on 0207 869 6611 or email research@rcseng.ac.uk.


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

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

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

Every good wish.

Yours sincerely



Martyn Coomer
Secretary
Research Board

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

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

APPENDIX 1.2 Certificate of insurance

UNIVERSITY OF SHEFFIELD

DEPARTMENT OF FINANCE

To Lisa Caldon Date 26-Jun-03

Department Academic Palliative Medicine Unit

Certificate of Insurances (non clinical trial)

Trial Number NCT02/433

Department Academic Surgical Oncology Unit &
Academic Palliative Medicine Unit

Title of Trial Patient and Professional factors influencing the choice of surgery
in the management of Breast Cancer

Name of Investigators Prof M W R Reed, Lisa Caldon
Mr David Wilde, Prof S H Ahmedzai

Commencement Date Jun-03

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



C.F. Jackson, Financial Accountant (Insurances)

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

NCT

APPENDIX 1.3 Non-NCTI Clinical Trial registration acceptance

Received
21/10/03

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

Tel: 0113 3924083
Fax: 0113 3924092
www.ncrn.org.uk

Email: ncrn@canccrmed.leeds.ac.uk



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

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

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

17 October 2003

Dear Miss Caldton

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

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

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

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

Yours sincerely

A handwritten signature in black ink, appearing to be 'M Stead'.

Maxine Stead PhD
Principal Fellow (Clinical Trials)

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

Director:
Prof Peter Selby

Assistant Director:
Ms Nancy Lester

Associate Directors:
Prof Bob Haward
Prof Max Palmer

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

Appendix 2

Ethics and governance documents



Trent Multi-centre Research Ethics Committee

Derwent Shared Services
Laurie House
Colyear Street
Derby
DE1 1LJ

Chairman: Dr Robert Bing
Administrator: Jill Marshall

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

Your Ref:

18 March 2003

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

Dear Miss Caldon

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

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

Documents considered for Part 1 were as follows:

Applicable to whole study:

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

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

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

MREC/02/4/114

The Central Office for Research Ethics Committees is responsible for the operational management of Multi-centre Research Ethics Committees

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

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

MREC Conditions of Approval

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

Legal and Regulatory Requirements

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

ICH GCP Compliance

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

Yours sincerely



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

MREC/02/4/114



Trent Multi-centre Research Ethics Committee

Derwent Shared Services

Laurie House
Colyear Street
Derby
DE1 1LJ

Chairman: Dr Robert Bing
Administrator: Jill Marshall

Telephone: 01332 868905
Fax: 01332 868930

Your Ref:

Email: Jill.Marshall@derwentsharedservices.nhs.uk

28 May 2003

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

Dear Ms Caldon

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

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

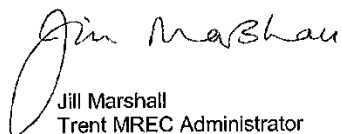
The members of the Committee present agreed that there is no ethical objection to the proposed amendment to the study. I am, therefore, happy to give you our approval on the understanding that you will follow the protocol and conditions of approval, as agreed.

Documents approved for this amendment:

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

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

Yours sincerely



Jill Marshall
Trent MREC Administrator

MREC/02/4/114

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Trent Multi-centre Research Ethics Committee

Derwent Shared Services

Laurie House
Colyear Street
Derby
DE1 1LJ

Chairman: Dr Robert Bing
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Telephone: 01332 868905
Fax: 01332 868930

Email: Jill.Marshall@derwentsharedservices.nhs.uk

18 March 2003

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

Dear Miss Caldon

MREC/02/4/114 - please quote this number on all correspondence

Patient and professional factors influencing choice of surgery in the management of breast cancer: A qualitative and quantitative study – PART 2

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

The documents considered for Part 2 were as follows:

Applicable to whole study:

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

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

- GP letter Version 1 dated 22 January 2003

2a Discussion Groups

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

MREC/02/4/114

The Central Office for Research Ethics Committees is responsible for the operational management of Multi-centre Research Ethics Committees

2b Postal questionnaire of patients

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

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

- Cover Sheet (Prompt Sheet) for Interview Version 2 dated 28/1/02
- Patient Interview Schedule Version 4 dated 27/1/02
- Surgeon Interview Schedule Version 4 dated 27/1/02
- Specialist Nurse Interview Schedule Version 4 dated 27/1/02
- Patient Consent Form for semi-structured interview Version 3 dated 24 January 2003
- Letter to Patient not being interviewed Version 2 dated 17 January 2003
- Sampling Frame for Interview Recruitment

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

Conditions of Approval

- No research subject is to be admitted into the trial until agreement has been obtained from the appropriate local research ethics committees.
- You must follow the protocol agreed and any changes to the protocol will require prior MREC approval.
- The MREC would expect to see a copy of any finalised questionnaires before they are used.
- You must promptly inform the MREC and appropriate LRECs of :
 - (i) deviations from or changes to the protocol which are made to eliminate immediate hazards to the research subjects;
 - (ii) any changes that increase the risk to subjects and/or affect significantly the conduct of the research;
 - (iii) all adverse drug reactions that are both serious and unexpected;
 - (iv) new information that may affect adversely the safety of the subjects or the conduct of the trial.
- You must complete and return the standard progress report form to the MREC one year from the date on this letter and thereafter on an annual basis. This form should also be used to notify the MREC when your research is completed.

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

Local Submissions

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

MREC/02/4/114

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

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

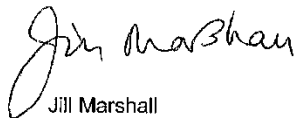
Local Sites

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

ICH GCP Compliance

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

Yours sincerely



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

Enc: MREC Response Form

MREC/02/4/114



Trent Multi-centre Research Ethics Committee

Derwent Shared Services

Laurie House
Colyear Street
Derby
DE1 1LJ

Chairman: Dr Robert Bing
Administrator: Jill Marshall

Telephone: 01332 868905
Fax: 01332 868930

Your Ref:

Email: Jill.Marshall@derwentsharedservices.nhs.uk

28 May 2003

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

Dear Ms Caldon

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

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

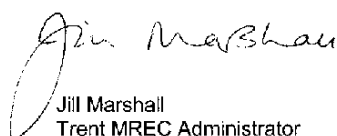
The members of the Committee present agreed that there is no ethical objection to the proposed amendment to the study. I am, therefore, happy to give you our approval on the understanding that you will follow the protocol and conditions of approval, as agreed.

Documents approved for this amendment:

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

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

Yours sincerely



Jill Marshall
Trent MREC Administrator

MREC/02/4/114

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Trent Multi-centre Research Ethics Committee

Derwent Shared Services
Laurie House
Colyear Street
Derby
DE1 1LJ

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Fax: 01332 868930

Email: Jill.Marshall@derwentsharedservices.nhs.uk

28 May 2003

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

Dear Ms Caldon

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

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

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

Documents approved for this amendment:

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

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

Yours sincerely

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

MREC/02/4/114

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Trent Multi-centre Research Ethics Committee

Derwent Shared Services
Laurie House
Colyear Street
Derby
DE1 1LJ

Chairman: Dr Robert Bing
Administrator: Jill Marshall

Telephone: 01332 868905
Fax: 01332 868930

Your Ref:

Email: Jill.Marshall@derwentsharedservices.nhs.uk

8 September 2003

received 11/9/03

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

Dear Ms Caldon

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

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

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

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

Documents approved for this amendment:

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

2a – Discussion groups:

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

2b Postal Questionnaire of Patients:

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

MREC/02/4/114

The Central Office for Research Ethics Committees is responsible for the operational management of Multi-centre Research Ethics Committees

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

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

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

Yours sincerely



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

MREC/02/4/114



Trent Multi-centre Research Ethics Committee

Chairman: Dr Robert Bing
Administrator: Jill Marshall

Derwent Shared Services
Laurie House
Colyere Street
Derby
DE1 1LJ

Your Ref:

1 October 2004

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

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

Dear Lisa

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

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

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

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

I hope this is helpful to you.

Yours sincerely

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

cc Jenny Hancock, Administrator, Derbyshire LREC

MREC/02/4/114

The Central Office for Research Ethics Committees is responsible for the operational management of Multi-centre Research Ethics Committees

APPENDIX 2.2 LREC & Research governance reference numbers and approval dates

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

Appendix 3

Consumer reviews

Project Review for NTCRN Consumer Research Panel

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

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

Name of reviewer: Hazel Marshall Cork

Date reviewed: 28. VII. 02

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

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

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

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

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

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

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

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

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

5 Are the timescales for the project realistic?

Yes.

6 Does the project represent value for money?

Yes.

7 Any other comments about this project.

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

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

☒ Strongly support this project

☐ Support this project with reservations

☐ Need more information

☐ Reject

Project Review for NTCRN Consumer Research Panel

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

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

Name of reviewer: Gillian Speed

Date reviewed: 26 September 2002.

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

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

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

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

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

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

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

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

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

5 Are the timescales for the project realistic?

The timescales seem adequate and realisable.

6 Does the project represent value for money?

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

7 Any other comments about this project.

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

Please tick the box that most closely indicates your strength of support for this project (cont. over)

☒ Strongly support this project

☐ Support this project with reservations

☐ Need more information

☐ Reject

Appendix 4

Clinician Survey 14 Breast Units

Surgical Management Preferences and Choices in Breast Cancer

Health Care Professional Information Leaflet

Please read this carefully

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

Please turn over

Why is this study being conducted?

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

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

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

Why have I been approached?

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

Who is organising the study?

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

Research Associate.

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

What does the study involve?

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

There are two main stages of the study.

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

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

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

1. Patient discussion/focus groups
Total 24 patients: 8 patients per group, 3 groups over 3 units
To inform the study and assist in refining the design of semi-structured interview schedules.
2. Patient postal questionnaire
Total 300 completed responses: 100 per unit.
600 to be distributed, assuming a 50% response rate

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

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

Total 180 interviews over the 3 units

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

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

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

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

Why are you doing an audit?

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

What would involvement in the audit involve?

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

What would involvement in the Professionals' survey involve?

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

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

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

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

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

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

How will patients be recruited?

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

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

What will happen to me if I take part?

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

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

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

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

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

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

Do I have to take part?

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

What are the possible risks of taking part?

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

What are the possible benefits of taking part?

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

How will this information be used?

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

What if I am harmed?

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

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

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

Who can I contact for more information?

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

What if I have other concerns?

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

Hospital, Sheffield S10 2JF.

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

Please keep this information leaflet for future reference

Useful contacts

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

Surgical Management Preferences and Choices in Breast Cancer

Breast Unit STUDY REPLY FORM

Please tick the appropriate boxes below

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

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

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

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

Name _____

Contact address _____

Telephone No _____

Email address _____

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

Signature

Name

Date

Please return the completed slip in the enclosed FREEPOST envelope.

Thank you

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

Dear «fname»,

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

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

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

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

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

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

Yours sincerely

<i>Unit/HCP Identifier</i>									
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Information Needs and Decision Making Preferences Specialist Breast Health Care Professional Questionnaire

Thank you for taking part in this study.

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

All information that you will provide will remain strictly confidential.

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

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

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

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

About this Questionnaire

This questionnaire is divided into two sections.

Section one

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

Section two

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

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

What will the results be used for?

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

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

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

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

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

Lisa Caldon Office: 0114 271 2225/3326

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

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

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

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

- 1. READ THE ACCOMPANYING HEALTH CARE PROFESSIONAL INFORMATION SHEET**
- 2. SIGN AND DATE THE CONSENT FORM (PAGE 4)**
- 3. HAVE SOMEONE WITNESS THE CONSENT FORM**

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

Study Number: MREC/02/4/114

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



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

Professor MWR Reed MBChB, BMed.Sci, MD, FRCS (Eng)

Professor SH Ahmedzai BSc, MB ChB, FRCP

Miss Lisa Caldon MB ChB, FRCS (Eng)

Mr David Wilde BSc, MSc

Tel: +44 (0)114 271 3326

Tel: +44 (0)114 271 3792

Tel: +44 (0)114 271 2225

Tel: +44 (0)114 271 1707

SPECIALIST HEALTH PROFESSIONAL QUESTIONNAIRE CONSENT FORM

(Version 1: 22/04/03)

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

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

To confirm agreement Please initial the box

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

☐☐☐

Name of respondent
(Print in BLOCK CAPITALS)

Date

Signature

Witnessed by
(Print in BLOCK CAPITALS)

Date

Signature

Breast Unit name
(Print in BLOCK CAPITALS)

Please turn over to Section One

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

Please tell us...

Your age

21 - 25 ☐₁

26 - 30 ☐₂

31 - 35 ☐₃

36 - 40 ☐₄

41 - 45 ☐₅

46 - 50 ☐₆

51 - 55 ☐₇

56 - 60 ☐₈

61 - 65 ☐₉

66 - 70 ☐₁₀

Your sex

Male ☐₁

Female ☐₂

Your profession

Nurse ☐₁

Staff Grade ☐₄

Consultant Surgeon ☐₂

GP Clinical Assistant ☐₅

Associate Specialist ☐₃

Trust Doctor ☐₆

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

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

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

Wide local excision ☐₁

Segmentectomy ☐₂

Quadrantectomy ☐₃

Other (please state below) ☐₄



Please turn over to Section One

Section One

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

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

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

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

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

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

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

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

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

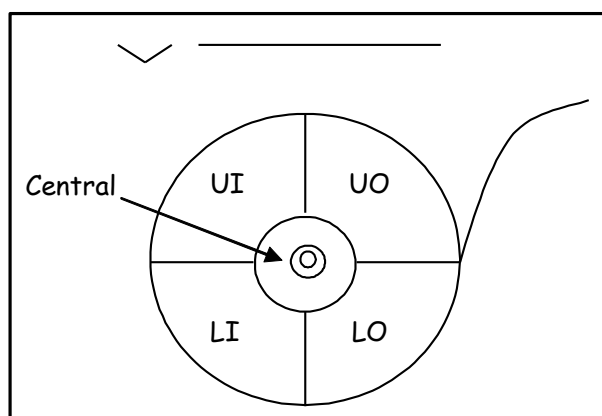
Bra Cup size

Divided into the following bra cup sizes:

A, B, C and $\geq D$

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

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



Tumour focality

Designated as being either:

Unifocal - a single area of tumour

Multi-focal, single-quadrant - greater than one area of tumour, lying, within a single quadrant of the breast.

NOTE: For the purposes of this study, the central site is also to be treated as a 'quadrant'.

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

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

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

Example of Clinical Scenario

This is how each scenario will be presented:

Scenario X

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

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

Mastectomy

☐ ₁

Breast Conservation Surgery

☐ ₂

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

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



Mastectomy

☐ ₁

Breast Conservation Surgery

☐ ₂

Please turn over to commence the scenarios

Scenario 1

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

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

Mastectomy

☐ ₁

Breast Conservation Surgery

☐ ₂

Scenario 2

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

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

Mastectomy

☐ ₁

Breast Conservation Surgery

☐ ₂

Scenario 3

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

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

Mastectomy

☐ ₁

Breast Conservation Surgery

☐ ₂

Scenario 4

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

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

Mastectomy

☐ ₁

Breast Conservation Surgery

☐ ₂

Scenario 5

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

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

Mastectomy

☐ ₁

Breast Conservation Surgery

☐ ₂

Scenario 6

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

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

Mastectomy

☐ ₁

Breast Conservation Surgery

☐ ₂

Scenario 7

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

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

Mastectomy

☐ ₁

Breast Conservation Surgery

☐ ₂

Scenario 8

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

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

Mastectomy

☐ ₁

Breast Conservation Surgery

☐ ₂

Scenario 9

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

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

Mastectomy☐ ₁**Breast Conservation Surgery**☐ ₂**Scenario 10**

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

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

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

Scenario 11

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

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

Mastectomy☐₁**Breast Conservation Surgery**☐₂**Scenario 12**

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

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

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

Scenario 13

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

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

Mastectomy

☐ ₁

Breast Conservation Surgery

☐ ₂

Scenario 14

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

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

Mastectomy

☐ ₁

Breast Conservation Surgery

☐ ₂

Scenario 15

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

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

Mastectomy

☐ ₁

Breast Conservation Surgery

☐ ₂

Scenario 16

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

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

Mastectomy

☐ ₁

Breast Conservation Surgery

☐ ₂

Scenario 17

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

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

Mastectomy☐ ₁**Breast Conservation Surgery**☐ ₂**Scenario 18**

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

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

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

Scenario 19

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

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

Mastectomy☐₁**Breast Conservation Surgery**☐₂**Scenario 20**

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

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

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

Scenario 21

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

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

Mastectomy

☐ ₁

Breast Conservation Surgery

☐ ₂

Scenario 22

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

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

Mastectomy

☐ ₁

Breast Conservation Surgery

☐ ₂

Scenario 23

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

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

Mastectomy

☐ ₁

Breast Conservation Surgery

☐ ₂

Scenario 24

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

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

Mastectomy

☐ ₁

Breast Conservation Surgery

☐ ₂

Scenario 25

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

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

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

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

Please turn over to commence Section Two

Section Two

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

Part One

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

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

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

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

Part Two

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

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

	+++	++	+	-	+	++	+++	
Not at all independent	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆	<input type="checkbox"/> ₇	Very independent
Not at all emotional	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆	<input type="checkbox"/> ₇	Very emotional
Very rough	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆	<input type="checkbox"/> ₇	Very gentle
Not at all competitive	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆	<input type="checkbox"/> ₇	Very competitive
Not at all kind	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆	<input type="checkbox"/> ₇	Very kind
Not at all aware of the feelings of others	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆	<input type="checkbox"/> ₇	Very aware of the feelings of others
Gives up easily	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆	<input type="checkbox"/> ₇	Never gives up easily
Not at all self confident	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅	<input type="checkbox"/> ₆	<input type="checkbox"/> ₇	Very self confident

Part Three

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

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

Part Four

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

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

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

Part Five

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

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

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

Part Six

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

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

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

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

Please continue on a separate sheet if necessary

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

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

Before returning the questionnaire, please ensure that...

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

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

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

THANK YOU AGAIN FOR YOUR HELP AND CO-OPERATION

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

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

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

Before returning the questionnaire, please ensure that...

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

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

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

THANK YOU AGAIN FOR YOUR HELP AND CO-OPERATION

APPENDIX 4.5 Clinician questionnaire covering letter

Dear

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

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

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

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

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

Yours sincerely

Appendix 5

Clinician correspondence and Interviews

(3 Breast units)

APPENDIX 5.1 Clinician interview consent form

Study Number: MREC/02/4/114

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



The University of Sheffield

Section of Surgical and Anaesthetic Sciences

Academic Surgical Oncology Unit

& Academic Palliative Medicine Unit

K Floor Royal Hallamshire Hospital

Sheffield S10 2JF

UK

Mr David Wilde BSc, MSc

Tel: +44 (0)114 271 1707

SPECIALIST HEALTH PROFESSIONAL SEMI-STRUCTURED INTERVIEW CONSENT FORM

Surgical Management Preferences and Choices in Breast Cancer:

A qualitative and quantitative study.

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

Please initial the box

3. I confirm that I have read and understand the information sheet dated 22nd January 2003 (Version 3) for the above study.

☐

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

☐

3. I agree to take part in the semi-structured interview section of the study.

☐

4. I agree to the discussion session being audio recorded.

☐

Name of respondent
(CAPITAL LETTERS PLEASE)

Date

Signature

Witnessed by
(CAPITAL LETTERS PLEASE)

Date

Signature

Breast Unit name _____

Unit/Surgeon Identifier

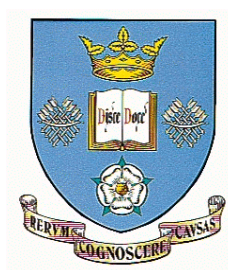
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
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Surgical Decision Making: Doctor's Interview

Thank you for taking part in this study.

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

All information that you will provide will remain strictly confidential.



Academic Surgical Oncology Unit, Division of Clinical Sciences (CSUHT),
Section of Surgical and Anaesthetic Sciences, K Floor, Royal Hallamshire

Checklist (Pre-Interview)

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

About you and the unit you work in

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

1. How long have you worked in this breast unit?
2. What is it like to work as a specialist in this breast service?

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

Before a consultation where a diagnosis is to be given

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

4. *When is your regular breast MDT meeting held in relation to the clinic where patients are given a diagnosis of breast cancer?*
5. *How do you usually feel after an MDT meeting?*
6. *If, at a prior consultation, it was suspected that a patient had a breast cancer, is there anything you, or anyone else in the team would do, or say to them, at that stage?*
7. *What way, if any, are patients themselves prepared for the news that they have breast cancer?*

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

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

During a consultation with a newly diagnosed patient

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

About patients' information needs

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

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

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

What a patient is offered

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

Interviewer Note:

Read out text in quotation marks

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

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

16. Thinking about your experiences with the patients you see **[SHOW CARD 1]** please look at the responses on the card and tell me, during consultations, who generally makes the final decision about what surgical treatment to have?

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

Communicating with patients who have breast cancer

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

Interviewer Note:

Read out text in quotation marks

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

Active decision makers

Collaborative decision makers

Passive decision makers

*In this final section of the interview, I would like to ask you a few questions about how you find communicating with each of these types of patient during the consultation process that leads to a final treatment decision. I would like to start with situations with **ACTIVE** decision makers.*

[SHOW CARD 2] *For the purposes of this study we define active decision makers as..."*

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

Definition adapted from:

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

17. *Firstly, I would like you to think about a situation you have had with a patient who was **ACTIVE** about making decisions. Without revealing any confidential details, please tell me about your experience with them up to the point when a treatment decision was made.*

Interviewer Note:

Read out text in quotation marks

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

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

Definition adapted from:

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

18. This time I would like you to think about a situation you have had with a patient who was **COLLABORATIVE** about making decisions. Again, without revealing any confidential details, please tell me about your experience with them up to the point when a treatment decision was made.

Interviewer Note:

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

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

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

Definition adapted from:

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

19. Finally in this section, I would like you to think about a situation you have with a patient who was **PASSIVE** about making decisions. Again, without revealing any confidential details, please tell me about your experience with them up to the point when a treatment decision was made.

Interviewer Note:

Read out text in quotation marks

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

20. Thinking first of all in a wider sense, who or what do you think has the greatest influence on patients' decisions about which surgical treatment to have?

21. And thinking within the context of the breast team here, who or what do you think has the greatest influence on patients' decisions about which surgical treatment to have?

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

Checklist (Post-Interview)

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

For office use only									
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Unit/Surgeon Identifier									
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	/	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Surgical Decision Making: Doctor's Interview

Recorder Interview ID Code

Thank you for taking part in this study.

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

All information that you will provide will remain strictly confidential.



Checklist (Pre-Interview)

Does the participant have any questions at this stage? (if YES, write down what they are)		
Talk the participant through the project and what will happen during the interview		
Take the participant through the Consent Form and have them sign it		
Interviewer:	Venue:	Date: / /2003

About you and the unit you work in

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

1. How long have you worked in this breast unit?
2. What is it like to work as a specialist in this breast service?

Prompts

Likes & dislikes

What is the unit philosophy?

Day to day running of the service

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

Constraints / facilitations

What is this place to work in compared to others?

How well do you get on with your colleagues?

Examples of these

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

Prompts

Impact on how consultations go and patient decision making / satisfaction

Before a consultation where a diagnosis is to be given

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

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

Prompts

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

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

Prompts

Heavy / light workloads

Bearing upon following consultations

6. If, at a prior consultation, it was suspected that a patient had a breast cancer, is there anything you, or anyone else in the team would do, or say to them, at that stage?

Prompts

Inklings

Bring a relative or friend

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

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

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

Prompts

Look for continuity / links from **Q5**

During a consultation with a newly diagnosed patient

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

Prompts

Person who breaks the news

Others in the room

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

If yes, please describe it?

How do previously discussed work styles manifest in consultations?

Examples of this...

Who does most of the talking / questions and when asked

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

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

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

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

About patients' information needs

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

Prompts

Harder / easier consultation process

Examples of this

Look for continuity / links from **Q7**

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

Prompts

Confirmation of cancer

Stage of disease

Prognosis

Survival

Types of treatment

Physical and psychological aspects of cancer

Family risk of disease

When discussing diagnosis, what do patients understand well about what is told to them?

...And what information is understood poorly?

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

Prompts

Likelihood of recurrence

Likelihood of cure

Stage of disease

Prognosis

Survival

Types of treatment

How to spot a potential recurrence

Family risk of disease

Coping with cancer

When discussing treatment options, what do patients understand well about what is told to them?

...And what information is understood poorly?

What a patient is offered

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

Prompts

Only Breast Conservation Surgery

Only a Mastectomy

A choice between Mastectomy & Breast Conservation Surgery

Other treatments - please state which

Interviewer Note:

Read out text in quotation marks

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

15. Do you think patients are getting the degree of choice they want?
16. Thinking about your experiences with the patients you see **[SHOW CARD 1]** please look at the responses on the card and tell me, during consultations, who generally makes the final decision about what surgical treatment to have?

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

Own description:

Communicating with patients who have breast cancer

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

Interviewer Note:

Read out text in quotation marks

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

***Active** decision makers*

***Collaborative** decision makers*

***Passive** decision makers*

*In this final section of the interview, I would like to ask you a few questions about how you find communicating with each of these types of patient during the consultation process that leads to a final treatment decision. I would like to start with situations with **ACTIVE** decision makers. **[SHOW CARD 2]** For the purposes of this study we define active decision makers as...”*

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

Definition adapted from:

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

17. Firstly, I would like you to think about a situation you have had with a patient who was **ACTIVE** about making decisions. Without revealing any confidential details, please tell me about your experience with them up to the point when a treatment decision was made.

Prompts

What happened – the story

How did you get on with the patient and nurse?

How did the nurse get on with the patient?

Specialist's feelings about how things went

How was the decision arrived at?

What influences were apparent?

Looking back, how satisfied were you with the experience?

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

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

Did this awareness change your approach to this person?

Interviewer Note:

Read out text in quotation marks

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

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

Definition adapted from:

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

18. This time I would like you to think about a situation you have had with a patient who was **COLLABORATIVE** about making decisions. Again, without revealing any confidential details, please tell me about your experience with them up to the point when a treatment decision was made.

Prompts

What happened – the story

How did you get on with the patient and nurse?

How did the nurse get on with the patient?

Specialist's feelings about how things went

How was the decision arrived at?

What influences were apparent?

Looking back, how satisfied were you with the experience?

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

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

Did this awareness change your approach to this person?

Interviewer Note:

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

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

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

Definition adapted from:

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

19. Finally in this section, I would like you to think about a situation you have with a patient who was **PASSIVE** about making decisions. Again, without revealing any confidential details, please tell me about your experience with them up to the point when a treatment decision was made.

Prompts

What happened – the story

How did you get on with the patient and nurse?

How did the nurse get on with the patient?

Specialist's feelings about how things went

How was the decision arrived at?

What influences were apparent?

Looking back, how satisfied were you with the experience?

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

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

Did this awareness change your approach to this person?

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

Interviewer Note:

Read out text in quotation marks

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

20. Thinking first of all in a wider sense, who or what do you think has the greatest influence on patients' decisions about which surgical treatment to have?

21. And thinking within the context of the breast team here, who or what do you think has the greatest influence on patients' decisions about which surgical treatment to have?

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

Prompts

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

Checklist (Post-Interview)

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

APPENDIX 5.4 *Clinician post interview letter*

<<insert professional's name and title>>

<<insert address>>

Dear <<insert professional's name>>

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

Healthcare Professional Survey

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

Interviews

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

Feedback

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

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

Once again thank you for your participation.

Yours sincerely

APPENDIX 5.5 *Clinician finalising patient recruitment information*

FINALIZING LETTER RE IN DEPTH STUDY 3 UNITS PATIENT RECRUITMENT PHASE

Dear,

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

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

To confirm:

- Inclusion criteria are: All women newly diagnosed with breast cancer who were/are eligible for a choice of surgical treatments (breast conservation surgery or mastectomy).
- The only exclusion criteria are: Women who were only eligible for mastectomy, and those with current diagnosed acute psychiatric illness, liable in the opinion of the patient's doctor to affect their ability to give fully informed consent.
- Information packs regarding the study should ideally be given to all eligible patients, as identified at the MDT, and recorded in the MDT notes by the data co-ordinator or clerk. We would like to be sent a list of those eligible for inclusion in the study and who has received a pack etc. This way we will be able to keep track of recruitment.
Please see the attached fax form which could be used for this purpose. The form could either be faxed to us or emailed, depending on your preference.
- The first phase of patient recruitment is to the discussion groups. We need to recruit 8 patients in total, ideally 4 who chose mastectomy and 4 who chose conservation surgery.
- When the required number of women have been recruited to this phase, we will provide you with the information packs for recruitment to the questionnaire/interview phase.
- The process of recruitment will be the same for both phases; only the patient information leaflets in the information packs will be different.
- We anticipate that there will be more expressions of interest in the study in those receiving information about the discussion groups, than we are able to include in the groups themselves. We anticipate this occurring due to the proportions of those undergoing the different surgical options at any point in time. These 'excess' individuals will be invited by us to participate in an interview instead of the discussion group, that way they can still be included in the study.
- If it becomes evident over the course of an interview that a patient has become distressed, David (with the patient's permission) will contact the appropriate unit team member to inform them of the event.
- Following an interview David will contact the participating patient to thank them for their involvement and ask whether they have any questions or comments. Would you like him to inform you as to who was interviewed and when?

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

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

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

As always, all the best.

Yours sincerely

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

Eligibility for approach for the study

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

Recruitment procedure

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

Thanks. Lisa and Dave

Patient and professional factors influencing choice of surgery in the

Appendix 6

Patient Information needs and decision making

Questionnaire

(3 Breast units)

APPENDIX 6.1 *Patient approach letter*

Treating breast unit letter head

/ / 2005

Dear

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

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

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

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

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

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

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

Thank you for your help.

Yours sincerely

Surgical Management Preferences and Choices in Breast Cancer

Please read this carefully

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

Please turn over

Why is this study being conducted?

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

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

Why have I been approached?

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

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

Who is organising the study?

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

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

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

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

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

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

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

We would ask you to complete the Consent Form and fill in the questionnaire

and return them to us. An envelope will be provided; you do not need a stamp.

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

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

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

Do I have to take part?

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

What are the possible risks of taking part?

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

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

your breast care nurse.

What are the possible benefits of taking part?

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

How will this information be used?

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

What if I am harmed?

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

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

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

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

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

Who can I contact for more information?

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

What do I need to do now?

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

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

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

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

What if I have other concerns?

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

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

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

Useful contacts

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

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

Please keep this information leaflet for future reference

Surgical Management Preferences and Choices in Breast Cancer

STUDY REPLY FORM **Questionnaire and/or interview**

Please tick the appropriate box

☐

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

☐

YES, I would like to take part in this study

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

☐

YES, to the short questionnaire part of this study

☐

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

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

Name _____

Contact address _____

Telephone No _____

Email address _____

Date _____

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

Thank you

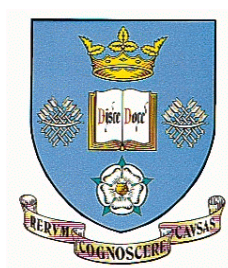
Unit/Patient Identifier <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	For office use only <input type="text"/>
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Information Needs and Decision Making Preferences Questionnaire

Thank you for taking part in this study.

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

All information that you will provide will remain strictly confidential.



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

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

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

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

Unit/Patient ID number: _ _ _ _

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

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

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

Please initial box

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

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

Date

Signature

For office use only

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

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

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

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

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

Your Information Needs

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

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

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

Please turn over

CXX

Your Decision Making Choices

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

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

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

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

- | | |
|--|---------------------------------------|
| I made the final selection about which treatment I had. | <input type="checkbox"/> ₁ |
| I made the final selection of my treatment after I had seriously considered my doctor's opinion. | <input type="checkbox"/> ₂ |
| My doctor and I shared the responsibility for deciding which treatment was best for me. | <input type="checkbox"/> ₃ |
| My doctor made the final decision about which treatment was used, but seriously considered my opinion. | <input type="checkbox"/> ₄ |
| My doctor made all the decisions regarding my treatment. | <input type="checkbox"/> ₅ |

Please turn over

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

Consultant ☐ ₁

Specialist Registrar ☐ ₄

Associate Specialist ☐ ₂

Basic Surgical Trainee ☐ ₅

Staff Grade ☐ ₃

Other (please state) ☐ ₆

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

Please write in BLOCK CAPITALS

What operation did you have for your breast cancer?

None ☐ ₁

Wide Local Excision / Breast
Conservation Surgery ☐ ₄

Mastectomy ☐ ₂

Other (please state) ☐ ₅

Mastectomy + Breast Reconstruction ☐ ₃

Feedback of results

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

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

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

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

Appendix 7

Patient correspondence and Interviews

(3 Breast units)

APPENDIX 7.1 Patient Pre Interview Letter

Interview: atam

Dear

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

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

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

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

Yours sincerely

David Wilde

Research Associate

A handwritten signature in black ink, appearing to read 'D.S. Webb', is written over a horizontal line.

Patient Satisfaction with Surgical Decision Making Interview

Thank you for taking part in this study.

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

All information that you will provide will remain strictly confidential.



Checklist (Pre-Interview)

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

1. Can you tell me a bit about what you knew or understood about breast cancer before you realised something was wrong with your breast?
2. Please tell me about the time from when you first realised there was something wrong with your breast to the time you went to hear about your results.
3. And what happened when you went to the clinic and were told you had breast cancer?
4. What were you told about your diagnosis?
5. How much did you understand about what you were told about the cancer?
6. Did you spend any time alone with the BCN after seeing the doctor?

7. And what happened while you were talking about what operation you could have?
8. Can you tell me more about the times you were talking with the **DOCTOR**?
9. Can you tell me more about the times you were talking with the **NURSE**?
10. Did the breast team give you any cancer / treatment / support information?
11. So, please tell me what operation(s) you had for your breast cancer?
12. Looking back, from when you were first diagnosed until now, what do you feel about the care you have received?
13. Now that you have been through this experience, what do you think are the most important things someone with breast cancer needs to know...
14. ...About diagnosis?
15. ...About the operation(s) they can have?
16. Is there anything else you would like to add to what we have been talking about today?

Patient Identifier

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
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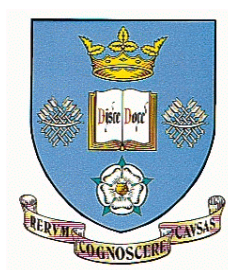
Recorder Interview ID Code

Patient Satisfaction with Surgical Decision Making Interview

Thank you for taking part in this study.

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

**All information that you will provide will remain strictly
confidential.**



Checklist (Pre-Interview)

Has the participant read the Information Sheet ?		
Has the participant read through the Interview Schedule ?		
Does the participant have any questions at this stage? (if YES, write down what they are)		
Talk the participant through the project and what will happen during the interview		
Take the participant through the Consent Form and have them sign it		
Interviewer:	Venue:	Date: / /2003

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

Prompts:

Patient's own medical history

Patient's family's history of breast cancer

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

What was going through your mind?

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

Prompts:

Timeline from start to clinic

What was going through your mind?

Feelings / fears / anxieties

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

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

If YES, who was that?

Talking to a male doctor / change of doctor?

Had you thought that it might be breast cancer?

Any thoughts about what you might do about it?

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

Prompts:

Anyone else went with you?

Feelings immediately before clinic

Expectations about what you might be told / happen next?

4. What were you told about your diagnosis?

Prompts:

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

Hearing about the results / diagnosis

Was the patient in normal clothes or a gown?

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

Was there anyone else in the room at time?

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

What were your feelings knowing you had breast cancer?

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

Prompts:

What did you understand about what was said to you?

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

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

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

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

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

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

Prompts:

What did you talk about?

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

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

Prompts:

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

What aids / tools were used?

What did you know about breast cancer operations before this?

Throughout the consultation, who asked most of the questions?

Who did most of the talking?

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

Prompts:

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

Do you feel the doctor understood your needs?

Do you feel the doctor understood your concerns?

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

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

Prompts:

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

Do you feel the nurse understood your needs?

Do you feel the nurse understood your concerns?

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

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

Prompts:

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

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

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

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

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

Prompts:

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

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

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

GP

Relatives

Friends / Neighbours

Support groups

Books

Magazines

Video(s)

Internet

Telephone help line

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

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

ASK BEFORE CONTINUING INTERVIEW ABOUT ANY FURTHER OPERATIONS / TREATMENTS

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

Prompts

Has it met your expectations?

In what way did it not meet your expectations?

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

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

Prompts

...About their diagnosis?

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

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

Checklist (Post-Interview)

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

CONSENT FORM (patient interview)

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

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

Please initial box

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

Name of respondent

Date

Signature

Researcher

Date

Signature

Appendix 8

Framework Example Patients

Framework Matrix example two patients from medium MR unit

REF NO FOR WRIT E UPS	Op	Age (yrs)	time 1st therapeutic OP to interview (days)	DMS	Background	Prior expectations & experience. Re disease, own symptoms, Rx(Inc. source).	Patient Journey (how long and who saw)	DM & HCP style	Communication & interpersonal skills NURSE
				4	5	6	7	8	9
1	Mx	42.9	28	Pt ideal= 2 Pt actual= 2 Coder DMS imp = 1 Coder info seeking imp = ACTIVE	MARRIED(3). Daughter(12), FHx: Mum, 42, 2 of mum's aunts & 3 cousins(1). PATIENT DETERMINED RE OP CHOICE FROM OUTSET(4,7).	Lot of prior experience: FHx: mum, 2 aunts & 3 cousins(1). Mum Mx @ 42, didn't need chemo, recurrence @ 63 'with a vengeance', deceased shortly after(1). No friends have it(1). Br Ca aware 'big style', can't take HRT, regular checks(1). Abscess in other breast 2/12 prev, checked 'every day...obsessed with it'(1). Knew not just and abscess sticking through, quite hard, 'hoped I'd broke a rib'(2). Read stories in media(9). AWARENESS OF CHOICE, OPS & Rx's(1,4).	SYMPTOMATIC lump(2), GP next day(2). OPA 10/7 later(2), H'band present(3). DC, voiced suspicions(3). Pt knew wanted Mx(4). Saw BCN(3). Results 1/52(3). H'band, BCN, & clinic nurse present(5). DC confirmed Ca(4), pt chose Mx(4,7,8). In hospital 45 hours post op(7). Uneventful recovery(7). Grade 3, Ln clear(8). DX(8). Seen oncologist, v. aggressive Ca, having chemo(9). Awaiting appt for 'gene test'(12).	DC: Pt 'got on fine', 'lovely man', 'v. caring', 'v. sincere'(6). DIRECT LANGUAGE USED(5). THOROUGH(4,5,6,7,8). SUGGESTED Mx was a 'v. big op'(5). 'definitely' LISTENED TO NEEDS & CONCERNS(8). Everyone was reassuring(6).	Saw both BCNs(6). Got on 'great' with both(6). DA came to see pt at admission(7). BCNS LISTENED TO NEEDS & CONCERNS, 'v. much so'(8). Everyone was reassuring(6).
2	Mx	59.7	34	Pt ideal= 3 Pt actual= 2 Coder DMS imp = 1 Coder info seeking imp = ACTIVE	MARRIED(1). TEACHER(8). Regular mammograms(1). FHx: Aunt(1). Neighbour = a confident(2).	Br Ca = a lump, something abnormal(1). Try on 2ndry(1). If I try expected a Mx(1). 'More difficult' if a 2ndry(1). GENETIC & NON-GENETIC FHx Ca 'So we were very...alert'(1): Aunt (Br Ca & Lung)(1). Husband's sister Br Ca (Mx, tamoxifen, died 7 yrs later from bone mets)(1). Husband - 1 cousin, Br Ca, had Mx, gave pt info(5), another cousin in bowel Ca(1). EXPECTED CONS WOULD TELL HER WHAT TO HAVE (Mx)(4) & PREPARED SELF FOR IT(4).	Regular mammo(1). Xmas 03 noticed dimpling, no lump(1). Showed h'band(1), thought it was a muscle as large breast(1), didn't think it was much(10). March 04, larger, GP REFERRED(1). OPA: DC(1,2). RESULTS IN 1/52(2) + H'band(2,3) & BCN (M8)(3). CHOSE Mx(4). IP 4/7(10). BCN visited pre & post op, brought info(5). Post op: bit painful under arm(7). OP RESULTS 2/52 (DC)(8): tests clear initially, but oncologist said 'something at top of femur'(10). MRI scan, awaiting results(10). SHFOR follow up(3).	DC: OPEN, THOROUGH(2-3,6,7,8,9,10). SIMPLE LANGUAGE(3,9): 'precise'(3) & clear'(3,9). OPEN CHOICE GIVER, NO PREFERENCE(2,8). 'v. nice. Kind, good bedside manner'(2,6,9). 'gentle...helpful'(4). GOT ON WELL, 'could talk to him', 'DIDN'T feel intimidated(4) & UNDERSTOOD NEEDS & CONCERNS(8). SH: '...just as nice'(3) 'I felt really confident(3). ONCOLOGIST: no bedside manner, didn't mince words, felt 'shell-shocked' afterwards(4).	Both: v. good & v. kind(3). Really helpful, 'I give them 10 out of 10'(3). 'I felt really confident'(3). UNDERSTOOD NEEDS & CONCERNS(8). MB KIND(6) & REASSURING(5,9). Calmed us down, soothing, helpful(5). DA, 'did the same thing'(5,6). KIND '...gave me other things for my bath...really appreciated that'(6). BOTH EXPRESSED NO OP PREFERENCE(8).

REF NO FOR WRITE UPS	Factors associated with sat/dissatisfaction	1 thing to change	Feelings			Coping Mechanisms	Extra information	Field note info	Coder
1	Process, individual HCP contact & outcome		About Cancer diagnosis, living with cancer, family / social aspects of having cancer, etc.	About operations for cancer	About adjuvant Rx, chemo, DXT & endocrine		Anything interesting, but which doesn't fit elsewhere!		
								28	
2	1 SATISFACTION: STAFF(6-7). OVERALL CARE: quicker than I expected(11), couldn't have been better if I'd gone private(10). DISSATISFACTION: Hospital food(10 11).	Every woman should have a mammo 2 x a yr, esp high risk women(11), coz 'a lot can happen in 23 months' (11).	When found lump, realised why she felt unwell for 2 months(10). AT DIAGNOSIS: '...it was like history repeating itself ...I was ...20 when my Mum had breast cancer, it was like I remembered everything...but...I don't think I had fit...crying and sobbing and, I was positive and I knew I'd get through it. I was more worried about being put to sleep, the anaesthetic, than actually the cancer.' (4). Husband's main concern was I was still here(3). Didn't have any feelings, numb v. quiet(6 7), thoughts RE practical matters, adj Rx, hair loss(6). Concerned RE daughter, thinking of taking out ins policy(12).	More worried RE anaesthetic than the cancer: 'terrifies me', friends num died in theatre FOR MINOR OP(4). As soon as DC said he was suspicious, pt knew she wanted Mx'. 'I wasn't playing at it, it's be all gone' (4). Could never have peace of mind if WLE, what if missed a bit(4-5,8,10).	Thoughts RE practical matters, adj Rx(6), hair loss(6,13). 'you can disguise the fact you have had an op (6). Don't want a wig, cap/bandana instead(13). That will be most distressing part, though told it will come back thicker & curly. 'I think he(onc) is telling me fairytales' (13). Concerned RE being sick, not worried, I'll have 4/12s sleep(13). 5/52 RXT: have to go to WPH every day, 'little bit off putting' (8).	positive attitude(4). Practically minded(6). Sense of humour(13,14)			DW 15/10/04
	2 SATISFACTION: Screening unit(2). TEAM COMMUNICATION & INFO GIVING STYLE CONS(2,3,4,6,8,9). BCNS(3,5,6,8,9). TEAM AS A WHOLE: 'I felt really confident' (3). SPEED OF JOURNEY(8). Wrt then info useful(9). OVERALL CARE(9). DISSATISFACTION: Oncologist COMMUNICATION STYLE(4). Busy hospital ward, didn't sleep(9). MRI scanner 'claustrophobic' (10).	NO CHANGE TO CONSULTATIONS(9). HOSPITAL: busy ward, didn't sleep(9).	AT HEARING NEWS 'shattered' (2). Husband has COPEd worse THAN PT THOUGHOUT EXPERIENCE(6,7): They suffer 1/2 the pain(7). V. difficult to tell friends & kids teach(8). (friends) thought I was on the death list...As soon as they hear big 'C' they think that's the end' (8).	FEAR OF RECURRENCE WITH BC5(8,9): 'I don't see any other option... (9) '...wanted to be 100% certain ...rid of it'(8). AESTHETICS = 2NDRY '...what's the point of vanity' (8).	NO COMMENTS.	TRUST IN TEAM & BEING INFORMED(2,3,4,5,6,8,9). SUPPORT H/BAND.	Bedside manner' is important(11).		DW 1/10/04 & Joint check 27/10/04

Appendix 9

Framework Example Clinicians

Framework Matrix example three clinicians from medium MR unit

HCP no.	HCP ID	Background				DM & HCP style	
		general i.e age, time in unit, other units etc.			Perception of team (Colleagues & environment)	Communication & interpersonal skills SELF	communication & interpersonal skills other DOCTOR
			1	2	3	4	5
1	BS013	Male, 12yrs in breast unit. Job not too stressful except meeting targets. ...there's a sort of excitement about getting bad news'(8). It's really bad news may be apprehensive (esp if late/missed diagnosis) but not personally upset. Finds DCIS easier to talk about coz 'its bad, but...'. (4)	DISTANCE Don't get too involved/close(4). DISCUSSES WITH Nursing Assistant (NA) & gets them to give POSITIVE feedback (reconsultation) ...say something you want to hear... (6). RESIGNATION if went badly ...oh well that's 1 in... (6). RELIANCE ON BCNS(1,4,5,15) TO FILL IN THE GAPS & 'pick up the pieces' QQQ(1).	Very busy unit. Teamworking, cross cover, no hierarchy, good bunch, like-minded, relaxed(1). MDT makes feel 'confident' 'organised'(2). 'we're...much the same age group but there's probably a 15-year spread with me being the oldest and I think the way they have developed...means that they do spend more time talking to patients whereas I try and judge how the patient's taking things or accepting things and go on as appropriately I think, with sympathy or fact, to a certain point and then I think I can go no further really and...that's when I move them on to the breast care nurses to pick up the pieces, so there are different styles certainly - I haven't observed them...but they do spend twice as long with them as I do so I assume they're saying more. (1)	RECOGNISES SELF-LIMITATIONS "...a bit 'pragmatic' (7), 'dogmatic' (15). '...doctor knows best...' (hopes not that bad)(7). 'probably biased... talking down to them in...patient's eyes...' get to a certain point (in consultation) then can 'go no further' QQQ(1,4)(15) SEEMS RESIGNED: 'if went badly' ...oh well that's 1 in... (6) & RELIES ON BCNS to 'pick up the pieces' QQQ(1,4) & I'm only the start of the information, don't leave with my last comment(4,5) they're (BCNs) the 'let out clause' QQQ(1,4)-(4,5,15) unlucky for us both to be having a bad day(6). Some excitement before a consultation coz have 'privileged information' (4) & there's a sort of excitement about getting bad news' (8). DISCOMFORT WITH CANCER easier to talk about DCIS coz its more positive(3,4). No expectations of how consultation will go: 'often can't remember them' 'I'll see their face, then 'it might come back to me...' (3).		Recognises generation gap in consulting style between self and other consultants (1). Never observed them but they spend ~2x as long with patients, so presume they say more(1)
2	BS015	Male, 6 yrs in unit. Trainee @ NCH. THE ULTIMATE PROFESSIONAL. CONSISTENT MESSAGE balanced views, counselling skills, thorough, prepares ++ beforehand. COMFORTABLE IN ROLE.	PREPARATION: pre-clinic read notes, plan OP slots, even if it means starting clinic later(2,10). EXPERIENCE 'You learn' (emotional side of breaking bad news). COMFORTABLE IN ROLE & confident of team standards(10).	Fantastic. PROUD of very good team, comfortable(1). '...one of my colleagues very good with his patients, but...more matter-of-fact gives...basic information and might spend less time...has a way of working that a lot of the...extra...filled in by the bcns. (1) ENCOMPASSING DEFINITION OF TEAM. 'Can do people' do extra to achieve the targets(1). ETHOS: CONSISTENT MESSAGE, protocol driven(2,27) - can cramp individual style(2) = reason why thinks the BCNs minimally affect pre DM(2). '...that's a different style. I personally spend probably longer'. If a patient needs five minutes, 45 minutes that's fine...they'll get the individual amount of time they need. I think we've developed a style in ____ the guidelines and protocols of the unit tend to be what we tend to say and we all try to sing from the same hymn sheet. ...in some ways that cramps style, as it doesn't allow individuality, and I think probably across the board the breast care nurses are very good at reinforcing our team message and I personally don't think that they make a great deal of difference to decisions because I think they just sing with the same hymn sheet as we do'. (BS015; high MR unit, pt-2 BCNs REITERATE MESSAGE @ VARIOUS POINTS = where teamwork is important(11). shared care with consultants...so careful to document accurately what discussed with pt(6).	CONSISTENT MESSAGE. CONFIDENT, BALANCED(25+ gen obs). THOROUGH prepares ++ beforehand(2,10,11). PERFECTIONIST: go through things to my satisfaction(11). DON'T ASSUME pt info/reaction(5)/info giving by colleagues(11). OPEN, HONES T(4,5); if asked direct question(4), but sometimes fudges answer - i.e. am I going to die? I certainly hope not' (12). GOOD COMMUNICATION SKILLS(3,4,7,8,9,10,12,14). KIND, SENSITIVE, EMPATHIC & HOLISTIC (DESPITE TIME IN JOB) BUT KEEPS BOUNDARIES, RESPECTFUL OF PPS, COMFORTABLE IN ROLE & COUNSELLING SKILLS (learnt from courses)(7). GIVES TIME The 'clock is irrelevant to me' spend as long as the individual pt needs, even if it means overrunning(2).	BS013 very good with pps, but more matter of fact gives the basic info, rest filled in by the nurses(2).	
3	BS014	Female, 2 1/2 yrs as consultant, 1 yr as SpR in DCGH. Worked in Notts beforehand(5). MDT: Mon. lunch & Thurs. aft.(3). WORKLOAD increasing: no. Ca 5, extended screen age, xgp referrals(3). BCNNOT ALWAYS PRESENT 'nuns are two few'(5). PROFESSIONAL(4,12), SENSITIVE & TRIEDS NOT TO, BUT GETS EMOTIONALLY INVOLVED: gets emotionally & mentally exhausted @ end of a results clinic coz trying to keep it very professional & give them hope(4). PERCEIVES SELF AS OPEN INFO GIVER(6,12,13,14,15) QQQ(15). CONFIDENT IN SELF & UNIT(3,4) HMC & LC ANALYSED - DISPARITY IN OPINION: LC - THOUGHT CENTRAL, ACH, OF INSTEAD AND MORE	SUPPORTIVE TEAM(1). DM DEVOLVED TO TEAM LEVEL: 'consensus of opinions' - esp useful with complex cases(3). PROFESSIONALISM(4,12). EXPERIENCE '...keep it under control' personal but to a limit, no point in me breaking down, can't take it all home with you(12). USES SMALL BREAKS IN CLINIC (take time dictating & nurse bring a cup of tea) if a really difficult consultation, but otherwise RE SOLUTION 'next' (as no time)(6) - SEEMS CONTRADICTORY WITH SENSITIVE, INVOLVED.	Very well organised, work as a team, supportive, flexibility & shared care(1). BUT TRY TO MAINTAIN CONTINUITY WHERE POSSIBLE(1). TARGET DRIVEN & PT FOCUSED. Work hard (extra clinics etc)(1,2) TEAM AVAILABILITY (BCNs & Sx) Q(2). Adhere to BASO guidelines(2). Surgeons have individual style(2). BCNs role is to reiterate exactly what I have said(8) - BUT BCNs not in the consultation(5). UNIT/LAYOUT NOT IDEAL, corridor walk 'probably not the best' (5).	THOUGHTFUL & CONSCIENTIOUS; doing my job to the best of my ability(2) & work hard to keep it very professional(4) & give them hope(4,5). BUT CONTROLLING (general obs, over int) NO NONSENSE APPROACH & LANGUAGE(4,5,6,11). HONEST(8). CARING(11). ?TAILORS CONSULTATION(4,5) & APPROACH, OR NOT: 'its my job to give you information (pt complains too much info) if you want to take it, its up to you' (6) & CAN MAKE ASSUMPTIONS RE PPS RATHER THAN INQUIRING i.e elderly, 'social problem' / illness (arthritis) & Mx direction(13). USES BODY LANGUAGE: eye contact(5) & COUNSELLING SKILLS(5). Reconcile those with incorrect preconceived ideas (Mx & no recurrence)(13). RECRUITS PT'S PARTNER To get the patient to make '...the right decision'. QQQ(14).	DIFFERENT PERSONALITIES/STYLES(2), some talk a lot, give lot of info(2), and others give minimum info, leave rest to BCNs(2) (= H4), some develop 'good rapport' & 'empathise' (2), others 'keep it on a very professional basis' (2).	

HCP no.	HCP ID	Communication & interpersonal skills other NURSE	DM related to information	Patients' prior information	Info relayed & given by team (how said) - inc tools & inviting questions etc.	consistency/inconsistency of info relayed & given by team (how said) - HCP description over the interview
1	BS013	not observed. The 'girls' (BCNs)(2) get more 'emotionally tied up' in their own and patient's emotions(4). TRUSTS BCNs SKILLS: INFO GIVING, SUPPORT(1,4,5,6). ENSURE PT UNDERSTANDING: they will 'suss them' (patient needing more help) & probably have conversation on a more similar 'level'(15) & patient may better express themselves/ask more questions etc.(6)	virtually nothing'. ...unless had a relative (with Ca)(7). They use the word 'Mesothecomy' makes me think they don't know a lot(7). SOURCE: 'magazines, friends and old wives tales', some inaccuracies (younger ones know more) - so i tend to 'nip it in the bud' 'sweep the 'state clean' ...forget that, that's not really the case, what really happens is... (7)		DISCOMFORT AT USING THE TERM CANCER(4). Need to hit the right level of 'gravitas' - it's bad & I'm sorry but... (4). try to give news in a nice way(4). BLUNT: just forget that... (7) there it is we can't change it we'll get on and deal with it for you(4) ...I'll go straight to the point (if questioned directly)(3). TRY TO BE HONEST 'try not to make promises I can't keep(4). TRY TO INTERPRET PATIENT REACTION & TAILOR...go on with sympathy or fact'. CONTROLLING: sweep the state clean(7) & CONFINES PT TO OWN (INFO GIVING) AGENDA: "...just forget that (prior info)... (7) get them back to the bit in question if they're racing off (asking ques)(6) - SEE PRIOR INFO COLUMN. Focus on pt unless 'too distressed', then turn to h band(5). Keep checking they understand(5) BUT FOCUS QUESTIONS on others in the room(6). REACTION TO OWN LIMITATIONS (PT EMOTION & NEEDS): can 'go no further' and move them on to the BCNs to 'pick up the pieces' QQQ (1,4). TOOLS: pen thing(5,6).	FULL OF INCONSISTENCY: DISCLOSURE: 'honesty's best' 'openness'(3) VS DISCOMFORT AT USING THE TERM CANCER(4). Keep checking they understand VS focus mainly on others in room (if pt distressed) & redirects if racing off with Qus. DIRECTIVE VS ACCEPTING OF PT CHOICE: DIRECTIVE: 'ageist' with older women (if finding choice difficult steer them to what is 'easier for me' - Mx) & if Pterring to Mx, 'encourage them' by mentioning reconstruction. ACCEPTING OF ACTIVE DMS DECISIONS EVEN IF FOR NON-STANDARD Rx. (12,13) & it's not what i think, it's what you want that's important(5).
2	BS015	good @ reinforcing the 'teams' message - sing from the same hymn sheet(2,27).	Variable: 'nothing' to 'everything'. Can be age related: older women own or others' experiences, younger may have been on the net & 'know' or think they know everything (11). Info more accurate if have a friend or relative treated for br ca(11,26). esp if recently treated(11). Most know they won't need necc need Mx(13)		Give pt time they need(3,8). "...give a very balanced view (options info)...(25). If suspicious 'hints at' & asks 'anything else you'd like to ask me?'(4). GENTLE APPROACH Standard 'pattern'(12,20) THOROUGH EXPLANATION IN SIMPLE, CLEAR LANGUAGE & USES REITERATION(3,4,7,8,9,10,11,12,14). TAILORED TO PT RESPONSE & QUESTIONING(3,4,7). Explains what about to explain in next(7,8,10) & first 'any questions?'(7). brief summary 1st, then builds on. Orders info (process & BCs 1st)(3,25). USES PAUSES (to absorb) & BREAKS (too upset)(7). COMFORTABLE WITH PT LED CONSULTATIONS (sometimes down ++theoretical pathways)(4). on rare occasions: if v small ca and v large breast or unfit and need quick Op under LA (16,22), 'steer them (BCs)' Q(16) TOOLS: explains via detailed drawings & refers back/shows @ results' ...remember what we ... (9). Invites qus @ start and end(3,8). Tries to keep 'loose canon' relative's in check (checks pt wants answer)(9,10). IF PROBS DM: use examples & personalises(23,24).	CONSISTENT
3	BS014	good rapport, empathy, some keep it 'professional'(2). BCNS SUPPORTIVE(4).	varies depending on age(6), PT INTERPRETATION OF INFO(7) & geography - NCH vs DGBH & no. internet pages (& @ NCH)(6). Elderly 'pre-conceived notions' (6) & 'I have to 'brain-wash' them into forgetting the way thing were done in the past(6,7). Info from friends, family, personal experience, net(6). MEDIA CAN 'distort things' (7). COMPARES correct Vs incorrect info(6,7). MYTHS: DXT & hair loss(8). TIME/ENERGY CONSUMING IF 'KNOW' LOTS, easier to deal with those who know a little(7). Takes time to check correctness and re-educate & explain why certain things not feasible (esp net surfers)(7)		USES BODY LANGUAGE eye contact(5). DRIP FEED INFO UNTIL SURE OF DIAGNOSIS(3,4,7). DON'T VERBALISE OUTRIGHT UNLESS PT AKS DIRECTLY COZ TIME CONSUMING & busy clinic & they will need > time(3,4). NO NONSENSE APPROACH & LANGUAGE(4,5,11). never directly disagree with Rx don't agree with(11). ?TAILORS CONS/INFO(4,5,12) OR NOT: ...my job to give you info (if complains too much) if 'you want to take it, it's up to you' (6). HONEST(8). Recap story, GIVE TIME(5,11) (COMPOSURE & QUS) wait for them to make the 1st move(5) OUTLINES CONSULTATION & Rx(5). GIVES REASSURANCE (prognosis & diagnosis)(4,5). USES REITERATION(5,8) & EMPHASIS: - vs side (to give hope)(5). choice(9,14) & time for DM(13,14). OFFERS CHOICE (IF APPROP)(9). OUTLINES Rx op(4,5). WANTS TO BE NON-DIRECTIVE, BUT CAN DIRECT DM BY: INFO RELAY/RESTRICTION(6,11,13). SCENARIOS(9,11,13)	INCONSISTENT/CONFLICT: COUNSELLING SKILL APPROACH Vs CONTROLLING CHOICE GIVING VS DIRECTIVE: PERCEIVES SELF AS OPEN INFO GIVER(6,12,13,14,15) QQQ(15) 'hope that I leave it to them Q(12). BUT SEEMS TO GUIDE PATIENTS TO BCs WHERE POSSIBLE(9,11,13,14) - 'I probably guided them...the majority (to BCs)' QQQ(13)(9,11) & THE PASSIVE WOMAN who 'wanted' a Mx, whose husband wanted her to have BCs(13) 'I and to convince her that the Mx wasn't necessary & probably the husband's presence helped' Q(14), & collaborative patient who in the 1st instance says 'what a Mx. i say' ...no, no, lets just go through this' & re-educate them if they have a preconceived idea Mx means it will never come back and give them the 3 years scenario(13). & i.e young woman wanting Mx QQQ(9).

HCP no.	HCP ID	Info content (What said), incl. asking quest	10	11	12	13
			Priority info needs (what need/want to know)	Active DM	Collaborative DM	
1	BS013	Give a 'bit of insight'(stvisit), more 'if they involve me in conversation (3). DISCOMFORT WITH WORD CANCER, USES EUPHATISMS WHICH CREATE CONFUSION 'lump, shadow...things have come back positive'(4)...they often reply 'does that mean I've got a growth doctor?' so...at some point I feel I've got to mention the word cancer'...(4). PATERNALISTIC LANGUAGE/STYLE. RESTRICTED INFO GIVING(6) & DIRECTIVE WITH OPTIONS: might say '...perfectly reasonable' to 'take away the bad bit...' (WLE)(5)...don't have to lose your breast/can keep your shape...and not mention Mx again...unless they (pt) bring up the topic...' QQ(9). DXT to 'sterilise' rest of breast(5,8). WL-as good as mx or wouldn't give a choice(8). Mention 'all the facts' including 'the negative' (13): 'surveillance thereafter' & recurrence(13) = 'tricky coz you're sort of saying...it might not work (BCS)(8). TRY TO REINFORCE PERCEIVED PREFERENCE if pt edging to Mx' '...might encourage them by mentioning reconstruction'. QQ(13). Info given 'depends on how much they keep questioning' (5). Encourage time to decide & to discuss/question with BCN(5,6). TOOLS: 'my own way' '...pen-thing'.	varies' have to 'tease it out' rather than having a 'hit list'(7). Safe environment(unit) (7). RELY ON BCNS TO IDENTIFY AND DEAL WITH Nurses will 'suss it'(6)	Patient wants herbal Rx. Its my job to make sure she understands what she is doing(12) not to force people(12). No evidence that non-conventional Rxs work better, but a positive attitude may give her a chance(immunity & cancer) so cant discount(12,13). If there's something they want me to do 'that's reasonable, that's their way of dealing with their illness, then I'll do that.' (12)	so common, no one stands out. 'they're 'more straightforward'(13). They just want to know the facts, both sides, pros-cons, where things might go wrong/further surgery(13). If they're erring I way I might encourage them (Mx with reconstruction)(13).	
2	BS015	Brief summary then '...its a breast cancer'. (7,12) NO EUPHATISMS (avoid confusion)(12). 'I will give you all the information i can to try and make that choice (7). Explain what about to explain next, but first' any questions? (7). Ca info (size, site)(3,8). need and Op(8). choices & explain why(8,14): the 1st option is... (BCS)(3,8,25) '...the alternative...(Mx) QQ(8). The 2 ops = survival, 1 not superior or wouldn't give a choice'. QQ(8). EXPLAINS re margins, pass 2nd op. DXT & why, +talks re lymph nodes, drains, arm exercises, acc need DXT with Mx(8,10), discuss surgery date(3). Always recommend write their Qus down so don't forget(8). Adj. Rx. depends on results & why(8,10). BCNs will see next(8,10)	Ca INFO Are you sure its Ca? How long has it been there?(12) is it growing fast?(9,12). TREATMENT am I going to loose my breast/hair? Will i need Chemo? PROCESS When will my Op be?(9). PROGNOSIS(9,12) Am I going to die?(12) WIDER ISSUES HRT? Daughter's risks?(9)	CLEAR EG65. One congruent with opinion (had a choice) -Previous br Ca wanted Mx '...before' '...I'd even go the word Mx out'(17). Other eg. Incongruent had BCS then refused DXT (cosmetic fears). COMFORTABLE WHEN DM CONGRUENT WITH SAFETY '...there's no reason for me to try and talk them out of it...' coz choice, DISCOMFORT WHEN INCONG WITH SAFETY no choice(23)/complementary therapies(18). Tend to be highly educated, too much information(18). Aware of DMS straight away; they say 'I want...I've decided...' early in my standard patter(20).	EG & SPOKE GENERALLY. 'they're the easiest(21), most satisfying(22): shared discussion & you can take them to a different level - they weigh up what is said and may seek your approval for their choice(21) '...you give the information and it's acted upon and sensible questions are asked..' DRAWS COMPARISON WITH PASSIVE & ACTIVE QQ(22). May not be aware of DMS (passive or collaborative) at the time, as take time to make a decision(22). Stress there is time(21).	
3	BS014	IF SUSPICIOUS dont volunteer unless pt asks directly; then say 'my suspicions are quite high (3). PRIOR TO CONS: PREPARES PT 'bring someone' to next cons(7). @ DIAGNOSIS: 'its a cancer' (4,5) & 'tell them the options(5), pros & cons(14), BUT give +ve side, not -ve(5). EXPLAIN aim of Op to rid Ca & adj. Rx is prevent coming back(5,7). Talk re adj side effects(7). IF CAN'T MAKE DECISION tell them not to worry, PLENTY OF TIME. TILL morning of surg(5). WON'T 'convey my choice' (9,10) BUT SEEMS DIRECTIVE TO BCS IF POSSIBLE OPTION (SEE INCONSISTENCY COLUMN). IF ASKED say 'your choice'. 'I don't know...' (9) '...you have to choose what's right for you', so have no regrets(9). If a young woman says I'll have a Mx (for peace of mind) ...right, its a choice, but 2 choices from a choice, its a choice.	CURE / PROGNOSIS(7,8). HAIR LOSS(8) - seem preoccupied with hair loss & chemo(8)	Clear eg. Surfaced net, brought papers. Locally advanced ca needed chemo and refused, pt had own business - no time for our Rx. uncooperative with team(11). Really difficult(11,12) nothing I said was right unless it sounded right to her(11). Compromised what did but told her (the patient) 'I don't like to treat a patient with my hands tied behind my back... (11). ACTIVE DM'S: FELT HELPLESS WHEN PT DOESN'T FOLLOW ADVICE(11). RECOGNISE early on this person is '...going to give you a hard time...' (12). ARE ADAMANT(12). VERBAL(12), not very open(11). Can spend > time 'convincing' them if wrong info or want Rx that's not right for them(15) & need time to go through everything(12,15). Try & get them to see that there's a choice & THEN still listen to what they say.	no eg. Easier situation(13) some make decision there and then(13). or take longer (if 2 minded)(13). RECOGNISE early; make decision after results and explained pros & cons(14).	

HCP no.	HCP ID	DM process	understanding (HCP's perception of Pt understanding of info)	Options - factors underlying options given	Time to make decision & feelings about amount of time
		Passive DM			
		14	15	16	17
1	BS013	can't think of any. Try to move them from passive to collaborative.. Think I convert most(14), if not try to involve their relatives(14). If they leave the decision to me, got to be sure they understand what they are doing. (13). Don't like it when its my choice 'hangs over me' (14) if recurs(BCS) or if regret(Mx). 'I try & sense what they would like QQQ(14) i.e. old folks - simplest (Mx) over & done with(14)...but may be what it simplest for me SEE WHAT WOULD YOU ADVISE COLUMN.	limited amount can 'absorb & understand' (5). Sometimes they're 'totally vacant' other times 'right there with you' (6). AWARE THAT EUPHAMISMS CREATE CONFUSION 'lump_shadow, things have come back positive' (4) ...they often reply 'does that mean I've got a growth doctor?' Pts don't understand choice well, esp those with an 'old-fashioned frame of mind' (8). Keep checking they understand(Pt & rels)(6). Confers with NA 'do you think she understood?' (6). Hope they pick that up with the nurse (poor understanding)(9).	Never tell them about WLE without mentioning Mx in case of a nervous disposition & ...want to be rid of it doctor...(9). BUT CAN GIVE LIMITED INFO RE OPTIONS, ONLY MENTIONS AS you don't have to lose your breast....unless they (pt) 'bring up the topic...' QQQ(9). Age might come into it, but doesn't exclude them from WLE(9). Guidelines: standard reasons: acceptable cosmetic result with reasonable margins, prox to nipple etc.(9)	a lot decide that morning' 2-3hrs min I hope. may go home & think about it. At end of clinic BCN tell him 'she's decided..' (15)
2	BS015	NO EG. No matter what you say they reply '...what do you suggest?(23) & keep bouncing back (BCN & Dr)(22). May not be aware of DMS (passive or collaborative) at the time, know when OP day & still no decision(22) - then go through again & get nurse involved again(23,24). Stress there is time(21, 23,24), one not better than other, use examples ...some women choose...because...(23,24). Try to personalise & pick up reasons why they might choose one or the other(24). Tend to be older, not very confident(24).	Understands why at times don't listen well (stressful situation)(5). The 'red mist' can come in / 'shutters come down' when the word cancer is mentioned know not going to get much in(11). Even if not taken much in, BCNs REITERATE INFO @ VARIOUS POINTS(11). Most understand 'breast cancer' & will need an OP: sometimes need to clarify cancer is always malignant(13). Poor understanding that have a choice and I won't direct(14).	Team decision @ MDT based on guidelines & initial clinical & rad. assess(box 'suitable for choice')(6). Everybody who doesn't need a Mx ...gets a choice Q(15,16) & if they really want one (& its not offered) team will look really hard to see if can change that Q(16). ONLY Mx: >5cm independent of Ca;Br=Mx. BCS only - anecdotal cases only: old unfi it with small Ca & woman with enormous breast and very small UOQ Ca(14,15). I wouldn't say (to a patient) '...you shouldn't have a Mx because its too small (the Ca)'. Q(15) BUT MIGHT 'steer them (BCS)' Q(16) by stressing smallness(22).	70% (Active & collaborative DMS) have probably decided before they leave the room(25). A small proportion undecided - esp if not got partner there(25). Even most passives made a decision by end of PAC after extra time with BCN(24)
3	BS014	EXAMPLES USES ARE WHERE PARTNER MORE ACTIVE IN DM THAN PATIENT RATHER THAN PATIENT NECESSARILY PASSIVE(14,15). 2 examples. Partner can either be a help or hinderance(14): Corrects family if feels they are trying to take the upper hand(14) UNLESS AGREES WITH THEM - one eg. here). one eg. 'passive' patient(suitable for BCS) who 'wanted a mastectomy', husband wanted her to have a WLE '...I had to convince her that the the Mx was not necessary & probably the husbands presence there helped for her to decide in favour of the WLE'. QQQ(14) in this case the husband helped the patient make the decision. (14) (15) (16) (17) (18) (19) (20) (21) (22) (23) (24) (25) (26) (27) (28) (29) (30) (31) (32) (33) (34) (35) (36) (37) (38) (39) (40) (41) (42) (43) (44) (45) (46) (47) (48) (49) (50) (51) (52) (53) (54) (55) (56) (57) (58) (59) (60) (61) (62) (63) (64) (65) (66) (67) (68) (69) (70) (71) (72) (73) (74) (75) (76) (77) (78) (79) (80) (81) (82) (83) (84) (85) (86) (87) (88) (89) (90) (91) (92) (93) (94) (95) (96) (97) (98) (99) (100) (101) (102) (103) (104) (105) (106) (107) (108) (109) (110) (111) (112) (113) (114) (115) (116) (117) (118) (119) (120) (121) (122) (123) (124) (125) (126) (127) (128) (129) (130) (131) (132) (133) (134) (135) (136) (137) (138) (139) (140) (141) (142) (143) (144) (145) (146) (147) (148) (149) (150) (151) (152) (153) (154) (155) (156) (157) (158) (159) (160) (161) (162) (163) (164) (165) (166) (167) (168) (169) (170) (171) (172) (173) (174) (175) (176) (177) (178) (179) (180) (181) (182) (183) (184) (185) (186) (187) (188) (189) (190) (191) (192) (193) (194) 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Where there is choice, offer it(9). CHOICE: to all except Mx on clinical grounds: ONLY Mx: >3cm 'I think', close to the nipple, Ca;Br-size ratio, cosmetically unacceptable' result(9).	Some give the decision there and then (@ diagnosis)(13). esp collaborative(15) & will go through the consent form @ then(5). BUT encourage the active and collaborative to really consider(15). The '2-minded' may wait till the OP day(13). 'I do give them that time and I give them the choice ...[if] they've decided on a particular operation, doesn't mean that I will hold them to it. They could still the operation or what they want right up 'til the morning of the surgery so they know that they have that time to decide.' [BS014, high MR unit, pt13](13).	

HCP no.	HCP ID	Choice	What would you advise? - Reply & reaction when asked for their preference		Greatest influence over DM
		feelings about choice giving			
1	BS013	More difficult ones: explaining why they have a choice, will often say 'what do you think' (5). Like to think we offer a choice where appropriate (10) its a team decision (what to offer) which takes the pragmatic, biased approach. 'I might have as an individual out of it' QQQ(10). AMENABLE TO CHANGE patients can 'reverse our decision (MDT) (10) would not do anything would not condone (12), but do anything thats reasonable, thats their way of dealing with it(12) & not refuse/preside too hard (Mx) as long as understands the risks & takes responsibility for the decision(10).	No it isn't what I think, its what you want.. Got a choice, don't have to decide now(5). We wouldn't give a choice if one was better(6). 'I try & sense what they would like' QQQ(14) Get the feeling that old folks want simplest (Mx) done & dusted(14) & dont like doing Mx in younger women QQQ(14). that probably makes me ageist(14). But I may do what it easiest for me (Op/Follow up/DXT), and not what will suit them best(14). Dont like it ' (14) but willing to make the decision but 'got to be sure they understand what they are doing. (13).	2 (11) VS collaborative...they're so common no one really stands out.	21 1. Family history (prior knowledge). 2. Surgeon. 3. BGN (14) - 'their bias if there is one, could be tipping the balance' (15)
2	BS015	No problem(17) & if no real choice but Pt wants BCS will reevaluate (as a team) Q(16).	Sometimes is age related (older pts more trusting of doctors & go along with you). STEPWISE GUIDANCE: 1. Stress there is time(21, 23, 24) & explain why a choice: equal Bx's, & people have personal preferences etc.(14) 2. if stuck use examples...some women choose...& what might influence their 'feelings' QQQ(14)(14,23,24) & try to personalise & pick up reasons why they might choose one or the other(24). 3. I cant remember when i had to say '...OK then i'll decide, we'll do blah-blah...'. QQ(24). if I had to i would err toward BCS(24) but try +-to avoid directing(23,24)	2 VS Collaborative	Breast team (UNIT + NATIONAL LEVEL), coz 'they decide the proportion of women who aren't... suitable for a choice... (25) (+26) & it's "...the way you tell it & how you sell it..." (balanced Vs. unbalanced info). 'I suppose we all do it subconsciously, we always mention BCS first'. QQ(25). in cases where small screen-detected concerns think 'by stressing smallness' pts feel happy having BCT (22). NON-TEAM INFLUENCES: Personal experiences of friends and family(26)
3	BS014	As a team, and self individually offer choice where suitable(9,10). coz patients have different reasons for choices make(9). PERCEIVES SELF AS OPEN INFO GIVER(6,12,13,14,15) QQQ(15). BUT CAN BE DIRECTIVE(13,14): (if not suitable for WLE, guides to Mx)(13). Hope the BCNs allow the patient to make their decision'.	I will help them to come to a decision, EMPHASISE 'your choice', not sure how I would react if sitting on that side... (9) & WON'T convey my choice (9,10) OR make DECISION for them(10,13). Emphasises time to choose(5,11). BUT CONFLICTING PICTURE OVER INTERVIEW - COMPARE WITH WHAT SAID - INCONISTENCY WITH HOW ADVISES THOSE WITH A CHOICE WHO DO NOT ASK FOR OPINION: CAN BE DIRECTIVE(13,14) BY: INFO RELAY/RESTRICTION(6,11,13), SCENARIOS(9,11,13) i.e. young woman warning Mx QQQ(9) & USE	1 VS. NOT STATED DIRECTLY ?? collaborative: the majority (IMPLIED BY DMS & TIEIN TO MAKE DECISION).	OVERALL MAIN INFLUENCE 'the surgeon' (IMMEDIATE STRONG REPLY): 'I hope that I leave it to them to make the decision, I hope that I don't push them in any particular direction. [but]...I think the majority do tend to be ...guided by what is told to them...' (16). Feels sometimes those who are biased toward Mx give one-sided information(16) rather than the '2 sides of the coin' (16). NON-TEAM: families & partners, children(16).

HCP no.	HCP ID	Factors associated with sat/dissatisfaction	1 thing to change	Extra information	Field note info	coder
		Process contact & outcome				
		22	23	24	25	
1	BS013	<p>SATISFACTION: team work, team runs well. If feel patient understands & takes responsibility for decision. If given information well BUT??HOW BOTHERED AS if bad one ...oh 1 in a...'</p> <p>DISSATISFACTION targets +++ =some stress.</p>	<p>1. Brand new customised clinic (compared with higgledy-piggledy one) Personally likes ('quaintness') BUT recognises not so good for patients(19). 2. Luxury of having the BCN in at consultation - BUT likes fact can ask NA FOR NON-THREATENING opinion & patient would have less time to make decision & not ge the chance to talk on a different level</p>			LC
2	BS015	<p>SATISFACTION: PROFESSIONISM (OWN & TEAM) & TEAM ETHOS, FUNCTIONING. DISSATISFACTION: workload, resources, targets (but achieve) & LACK OF CONTINUITY (INDIVID CASES).</p>	<p>The ability to offer all women who require a Mx immediate reconstruction without it affecting their Op date(27)</p>	<p>Odd case will play on your mind: the very young(3). Patients reactions: nothing surprises me - seen every reaction and not always expected, even if seen woman before(5)</p>		LC 1st code. Edited & amended LC&DW
3	BS014	<p>SATISFACTION: Team(1,2). OWN PROFESSIONALISM(4,12). DISSATISFACTION: inadequate time slots for pt consultation(16). Prefer to have BCN in with her(5). UNIT LAYOUT (distressed patients having to walk down the corridor)(5). WHEN PT DOESN'T FOLLOW ADVICE(11).</p>	<p>Workload - inadequate time to see each pt for as long as want, coz of the volume for work(given a 5 min slot for 2 new pts and 15 minutes for a results pt)(16)</p>	<p>PERCEIVES NON CHOICE SURGEONS AS THOSE WHO DIRECT TO Mx, NOT NECC THOSE WHO DIRECT TO BCS(16+ GEN IMP). feel surgeons who want patients to go down 1 route give very restricted information(13). DIAGNOSIS = 'bombshell' to screening pt(4). ABRUPT IN MANNER IN PARTS OF THE INTERVIEW. ? LANGUAGE BARRIER OR MEANING AS SAID.</p>		LC & DW SEPARATE CODES. + HMC REVIEW. COMPARED BY LC & DW. RE- SENT TO HMC FOR CONSENS

Appendix 10

Coded interview transcript example

*SURGICAL MANAGEMENT PREFERENCES STUDY: Interview (Patient)

*VENUE: [REDACTED]

*DATE: 11/06/2004

*ID: Patient [REDACTED]

*INTERVIEWER: DJW

1:00:45.
Coded + Coded 24-25
NB: 100
Inputted as 1004.

INT: Right, OK. Start, thanks for being interviewed. I want to start with question one. If you could tell me a little bit about what you knew or understood about breast cancer before you realised there was something wrong with your breast?

RESP: Well, as I said, the erm, thing I understood that if I did find something wrong, they did the initial biopsy and then if needs be, a full mastectomy. I haven't, I mean I do know people that's had breast cancer. My daughter-in-law's mum had it and she's fine. Erm, but not knowing an awful lot about it. (6)

INT: Right.

RESP: And of course I didn't realise there was anything wrong anyway.

INT: Right, were you picked up on screening?

RESP: It was picked up on the mammogram, yeah. (7)

INT: Right, OK.

RESP: There was no lump, I'd got no lump or anything and it was, I thought actually I'd finished going for screening at sixty-five. (8) (6)

INT: Right, yeah.

RESP: Not realising it they've now taken it to seventy.

INT: That's right, yeah.

RESP: So, of course I went and had it done and I thought, "Oh that's fine, now, I may get another one before I'm seventy, I might not." Erm, and then of course ten days later they sent for me to go to the City because I'd bee to the mobile one at the GRI.

INT: Oh right, yeah.

RESP: The screening.

INT: Uh-huh.

RESP: And they sent for me back and as I say, I went into see Dr Turnbull and she showed me the plates, the left side, the old plates and the new plates and then the same with the right side and on the middle plate there was, you could see this sort of white, just a white mass and she said, "That is what we're looking at." (9)

INT: Right, hmm.

Radio - Mamm
Tools =

RESP: She then did a scan and erm, picked I up on the scan so she knew where she was going in to take the cells from. As I say, she took the cells off and then they went to be analysed. (12) (13) P.H.
23/01/00

INT: Right, OK. Dr Turnbull, is she the radiologist?

RESP: She's a, a consultant radiologist, yeah.

INT: That's right, yeah. So is there, has anybody in your own family, immediate family had breast cancer? X.H. (5)

RESP: No.

INT: No, OK. And you said, have you had any friends or..?

RESP: As I say, my daughter-in-law's mum, she had breast cancer and my daughter-in-law's had two lumps removed but they were benign. And my sister did, my eldest sister years ago, years and years now, I think she had two lumps removed but they were benign.

INT: Right, OK.

RESP: So there's nobody really in the family.

INT: Your daughter-in-law's erm, mum had it, you said?

RESP: Yeah.

INT: Yeah, and what did she have, did she have a mastectomy or..? (6)

RESP: No, I think she had the wide local. (7)

INT: Right, OK.

RESP: As well. And then, radiotherapy. (8)

INT: Afterwards, yeah.

RESP: Afterwards.

*Q1. PLEASE TELL ME ABOUT THE TIME FROM WHEN YOU FIRST REALISED THERE WAS SOMETHING WRONG WITH YOUR BREAST TO THE TIME YOU WENT TO HEAR ABOUT YOUR RESULTS?

INT: And erm, so when, when you got the letter back from the, the erm, the mammography, the mobile unit to go and, to go to the hospital, what went through your mind then?

RESP: I thought, you know. I don't really think I thought there was anything wrong, but I know when I was having it done the girl had a bit of a job one side to just get it right and I suppose in my own mind I thought, "Well, probably the plates hadn't taken properly." Because normally if you go to the City breast screening you, you wait until you know that the plates are OK, well of course in the mobile one. (23)

INT: You don't.

RESP: They, you don't know.

INT: No, course.

RESP: So, I sort of thought, "Well," you know, "It's erm, it's probably nothing, it's probably just that something's not taken right or something."

INT: Right.

RESP: That was what I was thinking in my own mind.

INT: Hmm.

RESP: And then when I went to see Dr Turnbull, I think I thought, "Well, there's no lump." You know, and she said more or less straight away, "Well, it's not a cyst." And I just thought, "It's probably tissue or something."

linked (12)

INT: Right.

RESP: Ever the optimistic! I think, well you do, I think you've got to, you know, "It can't be anything."

INT: Hmm-hm.

RESP: So, when I went back...

INT: Is this, is this, did she say this before she'd done the tests and things?

RESP: She did say when she'd done the erm, scan, she did say, "It's not a cyst."

INT: The scan, right.

RESP: But she didn't sort of say anymore. Erm, she just said, "I can't," well she was going to, she said, "I'm going to give you a local anaesthetic and no the needle biopsy." But then she said, "Are you on any medication." And I said, "Yes, I'm on Warfarin." [?] "Ah, that squashes that idea, I can't do that because you'll bleed too much."

(5)

INT: Right, OK.

FNA

RESP: Erm, but she said, "I can take some cells off." So she then looked again on the scan to know just where she was going in. Erm, and she drew the cells off. A mean that was, that was really, didn't really hurt, no more than having a blood test. Erm, and she just, you know, said, "Right, they'll give you an appointment for when you come back to see the consultant to get your results." Which was only a week afterwards.

(7)

INT: Yeah, hmm-hm.

RESP: So err.

INT: So, erm, and this point had you spoke to anyone about what your thoughts might be or..?

RESP: No, I don't think I did.

INT: No.

RESP: You know, I just thought, "Ooh well," you know, "Hope against hope everything's going to be alright."

23

INT: And so when you came home from that, that consultation with Dr Turnball, had you started to think anything else, that might be something a bit more serious or..?

RESP: Well I suppose it's crossed the back of your mind, erm, I think, because Norman went with me to that one, but he didn't go in with me of course, he just waited. Erm, and we just said, well, you know, we'd just got to wait and see, it's only a week, it's not going to be that long.

7

INT: Yeah.

RESP: you know, it, just hope for the best and you know, we discussed it, naturally it's on your mind, you're thinking about it, sort of at the back of your mind, you try to do everything that will take it away.

INT: Yeah.

*Q2. AND WHAT HAPPENED WHEN YOU WENT TO THE CLINIC AND WERE TOLD YOU HAD BREAST CANCER?

RESP: So I didn't, because I know on the morning we went, went back to see, for the results, my daughter said to me, she went with me then and she conned her dad into doing some wallpapering for us so as she could come with me. And erm, she says, "Oh, well knowing you it'll be a cyst, Mum, or something." Because some years ago I had problems with abscesses in my groin but, touch wood, they all cleared up.

INT: Yeah.

RESP: Erm, I said, "Well it might just be tissue, Karen." I mean, this was a discussion that was going as we walked up the breast care unit. And then sat, we went in and we just sat and then they came and called me and she said, "Shall I come in with you?" I said, "No, I'll be alright." And the nurse said to her, "Yes, you can do if you'd like to." And I said well, "It's my daughter." She said, "Ooh, that's fine." So of course she came in with me and she sat and she listened because...

7

INT: Is this when you saw Mr Sibering?

RESP: No, I saw Dr Wheheadner.

INT: Dr Wheheadner sorry.

RESP: Then, because he was on holiday. I didn't actually see Mr Sibering until I was in hospital.

7

INT: Oh, I see, til the day of the operation.

RESP: Til I'd gone in. (2)

INT: OK. So when you saw Miss Wheheadner what happened then? When you went in to see her?

(13) RESP: She said, erm, "we've got your results from the cells that were taken off and I'm afraid they are cancer." So, that's when I went blank then. Erm, and she said, she sort of went on quite quickly because if I suppose if I wasn't her patient in a way, but she said, she sort of got a piece of paper and she said, "You've got two options. There's the full mastectomy or the we can do the wide wide local which we will take off a wide area round it. And we shall also take some from the lymph nodes." And then she sent on, you know, sort of carried on a bit more and Veronica, the breast care nurse... (12) (13)

INT: Veronica Rodgers?

RESP: Yes. She was in with her. And I, I said well, "Do I have to make my mind up now?" and she said, "No, no no no, there's no need to make your mind up now, you've got," you know, "You've got time." So she then gave me, she said, "Oh it'll be April the 30th that you come in." (17) (18)

INT: Right. Which was how, how long after that?

RESP: Erm, think it was the Tuesday after Easter so about a fortnight, that was all, two weeks, yeah. Yes because we was going to London on the Friday. So it was the weekend of the marathon, yeah. Erm, so that was, that was right. It was a Tuesday after Easter, whatever date that would be and I went, it was only literally a fortnight, I wouldn't have thought it was any more. (19)

INT: Right, OK.

RESP: Before I was due to go in. So we then, she says, "Have you got any questions?" Well I sort of... (12)

INT: Yeah.

RESP: I just couldn't think of anything.

INT: No, it's a bit difficult, isn't it?

RESP: And my daughter said to her, well, well then she said about having, "You may have to have chemotherapy, you may have to have radiotherapy." And Karen was a bit concerned with the radiotherapy, with the Warfarin but they mix OK. And she said, "Yes, that's fine." And she sought of asked, sort of one or two questions because she'd gone through a similar thing really because she'd got abnormal cells and had to have a hysterectomy. (13)

INT: Right.

RESP: When she was thirty-seven. So I think she was more geared for questions, as I say, I just blank, I couldn't think of anything.

INT: Yeah, it's a huge shock, isn't it? A huge shock.

RESP: Of course it wasn't what I was expecting to hear, not really, I most admit. (23)

INT: No, yeah. Um, so when you're actually in the room with Miss Wheheadner, there was yourself and your daughter, Veronica?

RESP: Veronica.

INT: And Miss Wheheadner, was anybody else there, do you remember?

RESP: I've got a feeling there could have been a nurse as well.

INT: A clinic nurse?

RESP: Yeah.

INT: In a sort of uniform then?

RESP: Trying to think. Yeah, I think there were possibly one of the erm, nurses. Apart from the one that actually, you know, called me in.

INT: Right, OK.

RESP: To go and see her. Yes, I feel sure there was. But Veronica was making notes while Dr Wheheadner was talking and that, you know.

INT: Yeah.

RESP: And the she said, well, "If you do think of anything, I'm here all morning," you know, "And I will see you again," you know, "But go with Veronica now and.." So we, we then went with Veronica to the other room. (7)

INT: The quiet room?

RESP: The quiet room.

INT: With seats and sofas and stuff?

RESP: Hmm. And she says, "Well first of all make yourselves a cup of coffee, just, you know, make yourselves a drink and I'll be back in one minute." And she came back and she sort, she was marvellous really because she just sat and went through it all again with me soes it literally started to sink. (9) (21) (12) (13)

INT: Yeah.

RESP: In a bit then.

INT: Yeah, a bit of repetition.

RESP: That's right, yeah. So, erm, but she was, she was brilliant and I've seen her one, two, I've seen Veronica twice and I saw Karen when I went back to Mr Sibering's clinic, Karen was there and I think I saw Jill, I think it was Jill when I went to see Dr [? 14.00] the oncologist.

INT: Right, OK.

RESP: I think I've done my rounds of them, I don't know!

INT: You've seen nearly all of them, I think there's four of them there.

RESP: Well Veronica, I saw Veronica at the clinic but she was busy with somebody else when I went back to see Mr Sibering erm, I didn't see any, I didn't see any of them while I as in, not in hospital but Mr Sibering came most days. His favourite saying was, "How, how high will that arm go, how high?"

6
8

INT: Arm, yeah.

RESP: You know.

*Q3. AND WHAT HAPPENED WHILE YOU WERE TALKING ABOUT WHAT TREATMENT YOU COULD HAVE?

INT: Erm, when Miss Wheheadner was actually talking about the treatment options you could have, you said she had a piece of paper, did she draw a diagram?

RESP: Yes, she drew diagrams, yeah

INT: Did she show you any, any mammograms or any pictures or anything like that?

RESP: Not mammograms she didn't, no.

INT: No, just the diagram?

took 7 words.

RESP: Just she drew sort of, she put err, 'mastect...', 'mass' then she drew the, the, like the wide local excision, what they'd do and how they'd take it from the lymph nodes.

INT: Hmm-hm.

RESP: Erm. I don't think there was, I don't think she drew any more. She went in, you know, quite in detail of the options so, you know, so, erm, so it just concerned me because I didn't know whether I'd got to give her an answer there and then.

12 17

INT: Yeah, of course.

RESP: Which I couldn't do anyway, so erm.

INT: Did the idea that you had a choice of treatment, did that surprise you or shock you in anyway?

6

RESP: Well it surprised me really, I thought you'd be told, "Right, we're going to do this or we're going to do that." Of course they've said since, gone are those days that they can do that now.

18

INT: Yeah.

19

19 13

16:10

RESP: You know, they've got to sort of give this preference. I mean we did talk about it when I came home, not particularly that day but the day that I went for pre, I think it was. They talked about it

more then and Karen says well, she went with me that day as well and she said, "The thing is, what you've got to think, Mum, before is, are you going to have that done now or are you going, if it had not got it all are you going to want to have more surgery following it?"

INT: Is that what they told you, is that what..?

16) RESP: Well that's what, as I said, if it came back erm, when they'd done the wide local, if it came back that there were more cells there, they would then have to go on and probably do a full mastectomy. SO it was knowing, right, do I go ahead and have the full one and be done with it.

INT: Right yeah.

RESP: Or do you take a chance in, virtually, isn't it?

INT: Yeah. That it might possibly recur again.

RESP: That's right. But, err.

INT: How do you feel you got on with Miss Wheheadner.

RESP: She was alright, yeah, she was... 8)

INT: Do you think she listened to your needs and your concerns and..?

RESP: I think so, I think, you know, if I could have come out with more questions she would have been there for me.

INT: Yeah.

RESP: Erm, and she would have answered them and I think with the same, you know, "If you do think of anything, please come back because I'm here all morning, please come back and I'll try and answer any more questions that you've got." So I mean, she did give me the time and, you know. But as I say, I just, I must admit I just couldn't take it in at the time so. 12) 13) 12) 10)

INT: And while she was telling you about your diagnosis and your treatment options, how much did you understand about what you were being told?

RESP: I think I understood most of it, I mean, I understood, yes, right it was cancer. Erm, and I understood that I'd, I'd got the two choices that err, erm, yeah, I think I took, you know I, understood the majority of it. I did take that in, I mean, admitted as I said, I'd got, it'd got no questions because none was forth coming at that time. 15)

INT: Hmm, no. Is there any information you think you didn't understand at all, or found confusing later on or..?

RESP: No, I don't think so because I've got that many booklets somewhere as well.

INT: They give you a big pack, don't they?

RESP: I've got a wallet full in there, first of erm, I mean Veronica gave me two, well she gave me the wallet. The wallet's been very good because it came, you know, it, you can keep everything and sort of, keep everything in it and err, and I've collected more along the line since then of course.

INT: Is this what the breast care nurses gave you?

RESP: This is, not that, err, this is basically, physio, yeah they gave me the support group and gave me the breast unit treatment diary which has got your exercises and everything and a guide to cancer services in Derby. Erm, which I've sat and read through, you know.

INT: I was going to ask you, did you, did you find any of that information particularly useful?

RESP: Yes I, I did find quite a lot of it because I thought, erm, in the treatment book I mean, you've got, you know, if you'd had forgotten what the physio had told you I mean, you could look up your exercises and what have you and erm, it explained to you about, you know, the difference between the wide local and the mastectomy which I did sit and, I mean I must admit I've sat and read them.

INT: Yeah.

RESP: And it does explain, you know, what to expect after the operation and everything so I did find them all, you know, sort of very useful erm. Let me see, oh yeah, that was, that's bit more of it, the radiology bit. But err yeah, so, I mean, I came away with that and I mean, Veronica gave me her card, if I felt I should need to talk to her and she has rung me, she rang me on Friday to see how I was going on and...

INT: Right.

RESP: Erm, make sure I was all right, you know. Which I thought, I thought was very caring.

INT: Hmm, absolutely.

RESP: I really did, you know, because I didn't expect that, I thought, "Well I shall probably see her when I eventually have to go back to clinic for another appointment."

INT: Yeah.

RESP: But erm, no, she says, "I'll ring you, I'll ring you again in a few weeks when you've started your treatment." You know, so, I just found them all very caring and very eager to help, is the word.

INT: Yeah, hmm-hm.

RESP: So.

INT: When you were speaking to Miss Wheheadner about the treatment you were going to get, you were going to have the wide local or mastectomy...

RESP: Hmm.

INT: Erm, did you get, at any time did you get the impression that there might be erm, she might have a preference for one kind of treatment or one treatment was better than the other?

RESP: Not really, no, no.

INT: That's good.

RESP: No, there was no sort of persuasion there and the same as when I saw Mr Sibering on the Friday morning, there was no, "ell I think, you know, it might be better if you have this done or it might be better if you have that done." I mean they basically said, "We can't make your mind up for you."

UNBIASED/UNDIRECTED

INT: Hmm-hm.

RESP: Which I suppose they can't because people will soon say, "Ooh, well, I needn't have had that done."

INT: Yeah, course.

RESP: You know.

INT: And when you saw Veronica afterwards, you know, after you'd been to see Miss Wheheadner...

RESP: Yeah.

INT: What sort of things did you talk about then?

RESP: Well she sort of started from scratch again and went through it all with me, erm, and she sort of said, you know, that the preferences that you've got erm, and said basically, she explained it all to me again which by then it started to sink in a bit.

INT: Hmm.

RESP: At that point. We were quite a little while and as I say, Karen asked her more questions and then we sort of talked in general, so she was putting you at your ease, you know, before you started again and, so, I felt, you know, that it was a help because by then I was beginning, as I say, beginning to take it in.

INT: Yeah.

RESP: So err, I think that talk definitely helped with that and you were sort of away from the clinical bit as well in that room, you know.

INT: Yeah, bit more pleasant isn't it really.

RESP: It is really, yeah.

INT: Yes.

RESP: Yeah.

INT: It's not someone sitting behind a desk or something.

Build up
info on
background
of
Mrs
(12) (9)

(9)

(21)

(15)

less clinical environment
+ relaxed time
+ pace + being put
+ relaxation
+ added feeling of m.

RESP: Yeah, that's right.

INT: Erm, let me see, where are we? We've been talking that much!

RESP: Yeah, sorry.

INT: When do you think, no, no, it's fine. Through out the consultation err, who, with Miss Wheheadner, who did you think asked most of the questions and who did most of the talking?

RESP: My daughter.

INT: With the questions?

RESP: Asked the questions.

INT: And Miss Wheheadner did...

RESP: She answered her, yes, she answered her erm, because I told her it was my daughter anyway. Erm, and she answered, oh yes, she answered her and what have you.

INT: And you said about a week later you went in for your, ^{op} two weeks later.

RESP: Two weeks I went, I went for pre-clark [?] in, erm, oh, we talked about stopping my Warfarin on the Monday, I had the last doe on the Monday because I was having the operation on the Friday so I went for pre-clark in, on the Wednesday. And the first thing the nurse said to me, "Have you stopped your Warfarin." I said, "Yes. I had my last dose on Monday." "Oh well, I think you'll have to come in today." I says, "Pardon?" This was twelve o'clock, lunchtime.

INT: What, to have the operation?

RESP: No, they wanted me to go in that day soes they could get me heparin converted [?].

INT: Oh right, OK.

RESP: And she said, "We want you here for four o'clock." But that just hit me like a bomb, I think it hit me worse than knowing what it was.

INT: Yeah.

RESP: And, anyway, she carried on, she did some blood tests and what have you. The I had to go, she said, "Well, would you like to go and sit tin the waiting room because the physio will come and fetch you in a minute and then you've got to see the breast care nurse again." And erm, so I went out to the waiting room and Karen was sat there and she says, "Whatever's the matter, Mum?" I says, "I've got to come in today." She says, "Pardon?" she says, "And you're not having your op til Friday, that's ridiculous." So, we sat there, anyway and, and then we went with the breast care nurse, err, physio, and we went up to the quiet room and she was going over one or two things and then all of a sudden it just hit me what this nurse had said. I just broke down. And she said, "Whatever's the matter, Brenda?" And Karen said, "That's the first time I've seen my mum cry." And she said, "It's because they've told her she's got to come in today."

INT: Hmm-hm.

RESP: She said, "Today?" And anyway, she went out and she saw Veronica and Veronica then got on to Mr Sibering and he said, "That is ridiculous," he said, "It would do more harm than good to put her on heparin today because she would bruise to high heaven."

INT: Right.

RESP: He says, "Tomorrow, yes, but not today." I went in Thursday, afternoon actually.

INT: Oh so you didn't.

RESP: So I didn't go in on the Wednesday no.

INT: OK, right.

RESP: So then I saw...

INT: You must be relieved.

RESP: Oh! Then Veronica came and as I say, she'd got on to Mr Sibering and erm, "No, my word, we don't want her in today. No, that's stupid." So she said, "Tomorrow, but," she said, "You'll have to ring up to find out what time they want you." So erm, anyway, I rang about twelve o'clock, I think I had to be there between two and three, something like that.

INT: Right.

*Q4. SO, PLEASE TELL ME WHAT OPERATION(S) YOU HAD FOR YOUR BREAST CANCER?

RESP: But then Veronica, the physio went and Veronica came in again and she made the form out, similar to this one, put in that I was going to have the wide local excision but she said, "You haven't signed anything yet so," she said...

INT: You can change your mind.

2) RESP: I can change your mind, you can change your mind. So she sat basically and went through things again with us and erm, she said, "You've no need to make your mind up til the last minute." But I had to go, so of course it was a bit of a rush Friday morning then. Erm, but veronica, she went through, you know, everything again with us. So then I went in Thursday and, as I say, I said to the sister, I said, "I just don't know, I just cannot make my mind up." "Don't worry, I'll get Mr Sibering to come and have a word with you." And he came at eight o'clock on the Friday morning. 13

INT: On the Friday morning, so you went in, did you go in on the night time?

RESP: I went in Thursday afternoon. 18

INT: Yeah.

RESP: They gave an injection Thursday night and then of course out the Ted socks [?] on, then I had to go, he came at eight o'clock, I was the second one in theatre that morning. Erm, as he sat on the bed talking to me, quite a little while, then I signed the consent form. Erm, he went out the curtains, the anaesthetist came in to talk to me.



INT: They'll be a queue!

RESP: Outside the curtains there was a nurse from the breast care unit to take me up there but I'd got to have this needle put in and I still hadn't had a wash by then and I thought, "This is ridiculous." So then went charging of up to the breast care nit in a wheelchair and then they did, I was up there quite a while as well and they did all sorts of scans and then they gave me a local anaesthetic and then they put this needle in you see.

INT: To help guide them.

RESP: 'X' marks the spot I think it said on the end of it! Erm, so we're coming back down from there and I sort of having to hold my arm like this because I daren't put it down because this needle was sticking.

INT: Oh yeah, right.

RESP: It was padded round it.

INT: Yeah.

RESP: But the radiologist that did it he says, "Do not let anybody move that needle," he says, "because it's vital it stops where it is."

INT: Hmm.

RESP: So I'm sort of coming down the corridor like this and the porter's saying to me, "Can you put your arm down, love, we've got to get through this door." I says, "I can't." And he looked at me. Anyway, when I went to theatre and Jo, the sister was there, she says, "Are you alright, Brenda?" I says, "Yeah," I says, "But I can't put me arm..." So she had to come and help me put the gown on for theatre.

INT: Oh yeah.

RESP: Erm, and then of course they took me to theatre in a wheelchair and we're going through the doors and I'm, we were like this, it was funny really when I think about it, it didn't feel funny at the time.

INT: No, but looking back.

RESP: When I look back, and the porter's saying, and Jo says to him, "You'll have to open both doors to get her through, because she can not put her arm down." "Oh," he says, "Oh." Then we got to theatre and they put me on this trolley and I'm still having to keep me arm up here and this chap's trying to put things on me. I says, "I can't put me arm down." He says, "It's alright love, I realise you, you've got a needle in there." Your know, so, all trying to put the ECG things on me back, you know, and

what have you. Oh dear, as I say, it didn't seem funny at the time but, it was when I think about it afterwards.

INT: In-between seeing Miss Wheheadner and going in for your operation, did you talk to anybody else about erm, your diagnosis and what treatments you might have? Discuss with your family or friends?

RESP: Well we talked, Norman and I talked about it.

INT: Hmm.

RESP: And as I say, ^{daughter} Karen did come and, the day we came, on the Wednesday about, "Well nobody can make your mind up, only you, Mum, but if needs be are you going to want to have to lots of surgery." And I said, "I don't know Karen." So basically I think, I talked about it with Karen and my son, of course although my son's away. We talked about it and, erm. I went, I say, we went to London the weekend of the London marathon because he was running in the marathon so that took it off me a bit but I was able to talk to my daughter-in-law. We sat and talked one night. Erm, because she was a staff nurse on intensive care.

INT: Right.

RESP: And with her own mum going through it as well.

INT: So what was her, what was her take on things?

RESP: Well she said, she said, "Well, my mum had the wide local, but," she says, "There again mum, I can't tell you what to do." But she said, you know, "You're a bit old which, you'll be led which way to go." Sort of thing, you know. As I say, I, I, it just seemed like a burden on me for a day or two before, because I kept thinking I've got this decision to make and I can't do it.

INT: Hmm.

RESP: You know. Erm, but we did, and we did it and we made the right decision.

INT: Yeah. So, erm, you been, you've been, you've had your operation, what happened after your operation when you came round, were you, were you OK, were you alright?

RESP: Yes, I was fine. Well they, they were, they were, Norman and my daughter were laughing when they came because Norman had rang up in the morning to see what roughly what time I was going down.

INT: Yeah.

RESP: And Jo had told him I was the second one on the list so she said, "Well I should..." Norman, what time did she tell you rind back?

RESP2: Err, nine, err, two o'clock.

RESP: Two o'clock. Erm, but at about half past one, quarter to two, she actually came and rang him, she went and rang him and said, "She's back." I think she'd waited til I'd come round a bit and then

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she says, I can only remember her saying, "I must go and ring your husband." And she dashed off and she just said to him, "She's round, she's come back, she's round, she's OK, you can visit when you like." And he says, "Well, we'll leave her a little while before we come." And I think they came, what time did you come love? About four?

RESP2: I don't know, after four.

RESP: Yeah, and both of them were amazed to see me sat up in bed, or propped up in bed, where I'd got two slices of toast on a plate because I was absolutely starving.

INT: You'd had nothing from the previous night, had you?

RESP: Well, when you have your meal and whatever, six o'clock.

INT: Yeah, it's a long way to go, it's like twenty-four hours almost.

RESP: And then one of the health care assistants came and said, [whispers] "Would you like some toast?" I says, "Ooh, I would please." And yeah, I think I only ate a slice of it but it was something.

INT: Yeah.

RESP: And then they brought me a drink, a hot drink, because I'd been having water. Erm, I was so thirsty, I've never drunk so much water. Erm, and I didn't drink that, I went to sleep again and Karen and Norman just sat there, you know. I came round and then, I sort of felt fine, really, afterwards, no problem.

INT: Hmm. Did you see Mr Sibling at any point, did he come round afterwards?

RESP: Not that night. No, I saw him Saturday morning.

INT: Right.

RESP: he, he had a habit of, I used to say, I've got a mouthful of breakfast and he'd come, any time after eight o'clock and you'd probably just put some breakfast in your mouth and he's come and, you know, he just. He came Saturday morning and he just said, "Everything's gone fine, I just want you to keep moving that arm for me." He looked at the drains, erm, he says, "Just be careful when you move that you've got two drains." Well they told me that on the Friday after dinner because they'd come and give you one of these little gift bags now to put your bottles in.

INT: They put them in Christmas bags at Christmas.

RESP: Yeah. Yeah. He asked me if I wanted it back when I came home, I said, "No thank you! You can have it!" I don't really want to see one again, you know.

INT: No.

RESP: Erm, and he sat and talked to me and he said, "Just, just please keep moving that arm." And he sort of patter, he's got such a nice...

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INT: Bedside manner.

RESP: Bedside manner. He sort of touches you on your shoulder and said, "Good girl," you know, "You're doing OK." I mean erm, as they came most mornings, even the Bank Holiday Monday I think he came and err, then on the Wednesday I was moved off Ward Two up to Ward Sixteen because they were waiting for surgical beds and they said, you know, one's sort of self nursing ones, they were very sorry that they'd got to move us. Must admit it was quieter up there because there was only three of us in the bay and it was a six-bedded bay. So I did get some sleep then.

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INT: And then how soon after that did you, how long were you in hospital?

RESP: Eight days.

INT: Eight days, then you went home?

RESP: I came home.

INT: And when did you next go back for a consultation?

RESP: Erm, came home on the Friday, the following Friday to my operation and then I went back on the Thursday.

INT: Hmm.

RESP: The 13th of May I went back.

INT: To get your results?

RESP: Erm, and I went because I had to go to physio first so we did like a u-turn round the whole of the hospital because physio's up there and surgical thing's way up the other side of the hospital.

INT: Hmm, I know.

RESP: So I felt a bit. And I'd got myself churned up anyway.

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INT: Yeah.

RESP: Not knowing.

INT: Because you'd been getting the results from what they'd took from your cancer.

RESP: From Mr Sibling, yeah.

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INT: Of course.

RESP: And err, but Norman went in with me to see him and we went in the examination room first because he didn't do stitches on the outside he did steristrips.

INT: Hmm.

RESP: And erm, I didn't have my last drain out until the Friday I came home because they daren't take that out because, until my Warfarin had levelled. And we went in and he came through, as I say, Karen, the breast care nurse, was with him. And he's got a very junior doctor with him but he said, "Do you mind?" and I said, "No." Erm, and he, he just, he said, "Let's have these steristrips off now, I'll be very gentle," he said. But I didn't know that he was actually so gentle I didn't realise he's pulled them off and there was just a couple of lose ends of stitches sticking out and Karen just trimmed those off. He says, right, "Get dressed and then come through and we'll have a little chat."

INT: Hmm. And what did he say when you went through.

RESP: So we went through and err, he said, well of course we get the paper out again and we have more drawings and he said right, he said, "Let me tell you one thing to start with." So I said, "Right." He said, "The surgery you've had is it, there won't be any more surgery."

INT: Hmm.

RESP: And I just went [sigh].

INT: Hmm.

RESP: I looked at Norman and he looked at me and then he gets his bit of paper and he says, "Right, this is what we've done, they've taken that away, this is a good area and that is fine." And he draws four little round things, "They're your lymph nodes and there's a bit in one of them."

INT: Ahh.

RESP: "But," he says, "We're not worried about that little bit," he said, "Because you're radiotherapy will blast that." And he said, "You'll go on from me to see Dr Otymia [?]."

INT: The oncologist.

RESP: The oncologist.

INT: Hmm.

RESP: "And he will discuss options with you about chem..." he said, "There'll probably be some medication, tablet wise, but it will be him to decide and also chemo or radiotherapy or both."

INT: Oh right.

RESP: Erm, then he said to me, "Have you got any questions?" As said, "I haven't," I says, "All I want to say is thank you and you've given me the answers what I wanted."

INT: Yeah.

RESP: I say, "You've told me there's no more round that outside." And you know, he says, "Well," he says, "You will see me," he says, "I shall see you every three months to start with and then it will gradually get to six months and you'll have another mammogram in twelve months." And so, we'd more or less, well, we came out with Karen, Karen came out with us and she said, "Do you want to go away again and discuss things." I said, "Not this time, Karen," I says, "He's given me the answers."

INT: Hmm.

RESP: I says, "The one thing I was dreading he's answered." Which to me, you know, is, I didn't need to know anymore really.

INT: Yeah.

RESP: And I went the, I think I went the following week, I think I be, either there or the DRI, I went to the DRI the following week, yes, to see Dr Otymia, the consultancy with him. As I say, Jill was there for that one.

INT: Hmm.

RESP: And erm, he says, "Right, decision time again," he says. Not more!

INT: Never made so many decisions in your life then!

RESP: I haven't! not just off the cuff like that. And he said, "Well," he said, "We can offer you the chemotherapy," and he said, "We have to offer it you now," he said, "Because some ladies want everything." I said, well then he went on to tell me, explained it all to me, the process of chemotherapy and ending up with radiotherapy but he said that, "The difference that it will make to you will be five per cent."

INT: If you have the chemo?

RESP: If I had chemo.

INT: Right, say five per cent of extra cover, if you like, preventing it coming back.

RESP: Hmm. He said, "You have to weigh that five per cent up against the side-effects."

INT: Yeah, and were they going to be quite severe? OK.

RESP: He says, "Of course it's a six month course in different cycles and they do so many days and then you have a break and then so many more days and then you've still got your six weeks radiotherapy at the end of it."

INT: Right.

RESP: So, he said, "Of course," he said, "One of the side-effects as you probably know is losing your hair," he says, "But don't worry about that," he says, "Because we give you a chip ² a week, you go somewhere in town and go and get one." I says, "Oh, thank you." He says, "But then of course it does grow back," he says, "It might grow back a different colour."

INT: OK.

RESP: "Could be red," he says, "Could be red." I says, "Oh thank you." And it's this colour and anyway we smiled about it and I said...

Chemo
SE is
benefit

to give you a wig

INT: It grows back stronger and curlier.

RESP: Yeah. I know there was a lady in there that had had, she'd had actually breast cancer, a year, err, nine years before. She'd had a lump nine years before and they'd given her some chemo before she went in to have, and then she had a full mastectomy and erm, she, she said when she came in hospital it was first time she'd been anywhere without a wig and hers was really, I mean, I wouldn't have thought it, I would have thought she'd just had it cut short, but it really was quite nice. And I said, "You're never going back to wearing a wig again are you?" So she said, "No, not now." So I said, "Well, if it's only going to give me that benefit, I think my answer is no. I will stick with the radiotherapy."

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INT: Yeah.

RESP: So he says, "Well I'm going to put you on some medication as well," but I can't have the, I can't think what it is, the normal one, tamaz, tom...

INT: Tamoxifen.

RESP: Tamoxifen. Can't have that because that doesn't like the Warfarin.

INT: Right.

RESP: But he gave me irrimidet [?].

INT: Right.

RESP: That's just one a day for the next five years.

INT: And have you started your radiotherapy now then?

RESP: No.

INT: No, when's that start?

RESP: Your guess is as good as mine!

INT: Oh. Right.

RESP: I've had the planning done so, I had to go back, I saw him one week, I went back on the Monday and had the first bit done where I was all nicely marked up with purple and bits of microcord and, "Will you try and not lose those until you come again." So then I had to go back on the Friday and they did the, the rest of the measuring up and put the, what they call the tattoos, where they put the die in and scratch your skin.

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INT: Yeah.

RESP: The permanent one. So err, from then which is, will be err, fortnight on Friday since I had that done but, I mean you've got conflicting erm, conflicting reports about how long you're going to be. I mean one told me it could be three weeks, the one last week, oh, on the Friday, I said to her, "Oh," she said, "Well all these x-rays we've taken go to Dr Otymia now. He decides on the treatment and then

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they go to the planning people." She says, "I could ring you up next Friday and say you've got to come," you know, sort of "on the Monday." Well that didn't happen but then when Veronica rang me last week she said it's usually about four weeks.

INT: Right.

RESP: After the planning. But I don't know. But then there's been conflicting reports that they are behind.

INT: Ah right, OK.

RESP: Apparently there was quite a piece in the Telegraph, in the local paper. I don't, we don't have it so I don't know but that was up to six weeks.

INT: Oh, you must be sick.

RESP: So, you know, we were going, it's a bit, you don't know what to do really because we were going to try and have a few days away in-between before I start the radiotherapy because, I thought, well once you start that it's every day.

INT: Yeah course.

RESP: For six weeks.

INT: And you've got to keep it going really and...

RESP: Apart from Saturday and Sunday of course.

INT: Give them a call, give them a call and just say, well, you're thinking of having a few days away, is it alright you know. (25)

RESP: I'm going down, I'm going on Monday, I've got to have my iron ore checked for my Warfarin so I thought, it's only just down the corridor, junction eleven at the DRI, I might just have a walk down and see if there's somebody, you know, I could have a word with and erm, you know, say, well, we think, you know, I'm not pushing for it or anything, I just...

INT: No, not all.

RESP: Wanted to book, you know, a few days away.

INT: Absolutely. I'm sure they'll understand. I'm sure they'll be fine.

RESP: Yeah.

INT: Um, let me see. In-between sort of erm, the consultation with Miss Wheheadner to the point when you had your operation, did you look for any information about breast cancer and treatments erm, in magazines, books, videos, TV programmes, did you call the support group at all?

RESP: No, I haven't called it.

INT: OK, right.

RESP: No.

INT: Erm, seems a strange question, but do you feel you had the amount of choice that you wanted?

RESP: I think so, yes. I think I had more than. I think it's nice that you do have the choice. Well, probably not nice is the right word but, I think it's nice, better than somebody just saying to you, "Right, we're going to do this," or "We're going to do that."

INT: Hmm.

RESP: Erm, I mean with something, I mean the only other major operation I've had is gall stones, the gall bladder out but, I mean that, that is something you don't have to make a decision about, you know. But I do think you were given enough preference and enough information quite honestly.

INT: Do you feel you had enough information to make your choice?

RESP: I think so.

INT: Hmm-hm.

RESP: I mean it's a very personal decision, isn't it, really?

INT: Yeah, absolutely. And, what do you think was the most important thing that you were told or read or heard that helped you make your decision what treatment to have?

RESP: I think it was when Mr Sibling said on the Friday that it, there was a very good erm, of what's the word for it? Sort of, feedback that it was very successful what I was having done, the wide local. You know, they'd had very successful...

INT: Results.

RESP: Results from having it done that way.

INT: That kind of thing, yeah.

RESP: Erm, and as I say, he didn't, didn't push me at all it was just with him saying that I think that made me make the decision, yes, that that's what we'd go, go along with.

INT: Right, OK. Looking back from when you were first diagnosed until now, how do you feel about the care you've received?

RESP: I feel as though I've had great care taken of me. Everybody's been very caring, from the staff on the ward upwards. I must admit and I don't think you could have had anybody better, with a better bedside manner than Mr Sibling and the breast care nurses have been there for you.

INT: And has your care met your expectations do you think?

RESP: I think in some ways it's gone above.

INT: Right.

RESP: And that phone call from Veronica last week made a great difference, it really did.

INT: Yeah.

RESP: Because I didn't expect it.

INT: No.

RESP: I thought, you know, I shall see her again when I go to clinic probably, erm. I think, you think you come out of hospital and that's, you know, apart from what other treatment you've got to receive, erm, and your appointments are made for you and everything, I mean, that is the thing, I mean, at each time I've gone the appointments have been given you. Before I'd even had the operation I'd got my appointment for when I saw him afterwards, you know. Veronica gave it me, erm, I think it must have been on the Wednesday when I went for me pre-clarking [?]. She says, "And this is your appointment to see Mr Sibering afterwards."

INT: Hmm-hm.

RESP: You know, I though, forward planning, you know! No I think, I have had brilliant care.

INT: If you were told you had the power and money to change one thing about the service, the breast service at Derby City General, what do you think it would be?

RESP: Ooh, dear, that's a hard one. I don't know, I honestly don't know the answer to that one. As I say I just couldn't find anything really that I would want to change because, as I say, everybody was just so caring.

*Q5. NOW THAT YOU HAVE BEEN THROUGH THIS EXPERIENCE, WHAT DO YOU THINK ARE THE MOST IMPORTANT THINGS SOMEONE WITH BREAST CANCER NEEDS TO KNOW?

INT: Hmm. That's OK. Um, now you've been through this experience what do you think are the most important things someone with breast cancer needs to know about first of all, their diagnosis?

RESP: As it was explained to me I think that was important.

INT: Hmm.

RESP: That it's explained to them and people have the time to sit and spend with them.

INT: Yeah, hmm.

RESP: Because if you're not expecting it.

INT: Yeah.

RESP: I mean, if I'd had a lump...

