Evaluation of Consumer Research Panels in cancer research networks

Final Report

Annexes

This document forms part of the report:
Surrey, West Sussex & Hampshire
Cancer Research Network

Partnership Cancer Research Panel

26th January 2005
Beacon Service

18.45 Welcome and introductions (Angela Rayner & Karen Poole)

19.00 Background to the Research Panel Initiative (Karen Poole)

19.10 User Involvement in the Surrey, West Sussex & Hampshire Network (Angela Rayner & Hilary Blackburn)

19.15 So what do we mean by Cancer Research? How can users be involved? (Professor Hilary Thomas)

19.30 Group Work
4 groups, each led by a facilitator
Each group member to introduce themselves

2 Groups to consider
“What do you think are the benefits of involving users and carers in cancer research?”

2 Groups to consider
“What do you think are the challenges of involving users and carers in cancer research?”

20.00 Break for refreshments

20.20 Feedback from Groups

20.30 Open Forum – questions
Completion of evaluation / contact form for future meetings

Future Meeting dates:
Monday 21st February 18.00 /18.30
or
Tuesday 8th February 18.00 /18.30
Surrey, West Sussex & Hampshire Cancer Research Network

Partnership Research Panel

1st March 2005 18.00 – 20.00
Beacon Service

- Welcome and feedback from launch
  Karen Poole
  Research Network Manager

- Introductions
  All

- The National Perspective
  Dr Tony Stevens
  Consumer Liaison Worker

- What next?
  - Terms of Reference for Panel
  - Role of the Panel Chair
  - Guidance for User Involvement
  - Role of the Secretary
  - Facilitator

- Signposting the future
  - Preferred location and time
  - Frequency of meetings
  - Deciding upon a programme of work
  - Provision of training and support

- Expenses
  Angela Rayner
  User Partnership Facilitator

- Independent Evaluation of Panel
  - Focus Group 23rd March 18.30 – 19.45 or 20.00 – 21.15

- AOB

- Date of next meeting

Annex A
Example agendas for introductory meeting and training event
### Activity 3: Terms used to search the National Research Register

<table>
<thead>
<tr>
<th>Central South Coast</th>
<th>Humber and Yorkshire Coast</th>
<th>Surrey, West Sussex and Hampshire</th>
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<tbody>
<tr>
<td>Southampton + cancer:sy 2003</td>
<td>Hull + cancer</td>
<td>Royal Surrey + cancer</td>
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<td>Southampton + cancer</td>
<td>Castle Hill Hospital + cancer</td>
<td>Royal Surrey County Hospital + cancer</td>
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<td>Royal South Hants Hospital + cancer</td>
<td>The Princess Royal Hospital + cancer</td>
<td>Surrey + Sussex + cancer</td>
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<td>Princess Anne Hospital + cancer</td>
<td>Scarborough + cancer</td>
<td>Crawley Hospital + cancer</td>
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<td>Countess Mountbatten House + cancer</td>
<td>Bridlington + cancer</td>
<td>East Surrey Hospital + cancer</td>
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<td>The Manor House + cancer</td>
<td>Malton Community Hospital</td>
<td>Frimley Park + cancer</td>
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<td>Portsmouth + cancer</td>
<td>Hull and East Riding + cancer</td>
<td>Frimley + cancer</td>
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<td>Royal Hasler hospital + cancer</td>
<td>East Riding + cancer</td>
<td>Ashford + cancer</td>
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<td>Queen Alexandra hospital + cancer</td>
<td>Alfred Bean Hospital</td>
<td>St Peter’s + cancer</td>
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<td>St Mary's Hospital + cancer</td>
<td>Bridlington and District Hospital</td>
<td>Peter’s + cancer / St Peter’s / St Peter’s Hospital</td>
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<td>St Mary's Healthcare Trust + cancer</td>
<td>Goole and District Hospital</td>
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<td>Isle of Wight + cancer</td>
<td>Hornsea Cottage Hospital</td>
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<td>Salisbury + cancer</td>
<td>Westwood Hospital</td>
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<td>Royal Hampshire County Hospital + cancer</td>
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<td>Winchester and Eastleigh + cancer</td>
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<td>RHCH + cancer</td>
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<td>Andover War Memorial</td>
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<td>Hampshire + cancer</td>
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<td>Alton Community Hospital</td>
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<td>Royal West Sussex + cancer</td>
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<td>St Richard’s Hospital + cancer</td>
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<td>Chichester + cancer</td>
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<td>Bognor War Memorial</td>
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<td>Bognor War Memorial</td>
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<td>King Edward Hospital</td>
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<td>Midhurst Community Hospital</td>
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<td>Princess Elizabeth Hospital</td>
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<td>Guernsey</td>
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<tr>
<td>St Helier + cancer</td>
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<td>Jersey</td>
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Evaluating Consumer Involvement in Cancer Research Network Activity

This questionnaire is designed to be completed electronically. Use of the TAB key on your keyboard will take you from one question to the next. Please type only in boxes shaded grey.

PLEASE RETURN THE COMPLETED QUESTIONNAIRE USING ‘SAVE’, RETURNING TO THE E-MAIL, AND CLICKING ‘FORWARD TO’ kate.kelley@wash.nhs.uk TO ENSURE YOUR RESPONSES ARE RETAINED IN THE ATTACHMENT.

DEFINITIONS OF TERMS USED IN THIS QUESTIONNAIRE

For the purposes of this scoping exercise we use the following definitions:

**Consumers**\(^1\): patients (previous or current), carers, or any member of the public who could be a potential user of the health system

**Consumer involvement**\(^2\): by involvement we mean that consumers are active partners in the research process rather than ‘subjects’ of research … Many people describe public involvement in research as doing research with or by the public, rather than to, about or for the public”

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\(^2\) INVOLVE (2004) Involving the public in NHS, public health, and social care research: Briefing notes for researchers. Eastleigh: INVOLVE.
1. Title of project/trial

2. How many professional researchers were involved in your project/trial? 

3. How many consumers were involved in your project/trial? 

If you have answered 0 consumers to this question please go onto question 4. For answers of 1 service user or more go straight to question 5.

4. On reflection can you think of the main reason why consumers were not involved in your project/trial

Thank- you for your participation you have now finished.

The following questions are about the involvement consumers had in your project/trial.

5. What role did consumers have in setting up the research project/trial?

Please tick the appropriate box

a. There was no consumer involvement
b. Consumers were consulted in the setting up of the research project
c. Consumers were democratically involved in the setting up of the research project
d. The setting up of the project was consumer-led
e. I don’t know
6. What role did consumers have in seeking funding for the project/trial?

a. There was no consumer involvement
b. Consumers were consulted on seeking funding for the research project
c. Consumers were democratically involved in seeking funding for the research project
d. The seeking of funding was consumer-led
e. I don’t know

7. What role did consumers have in designing the project/trial materials? i.e. questionnaires

a. There was no consumer involvement
b. Consumers were consulted on the design of the project materials
c. Consumers were democratically involved in designing the research materials
d. The design of the research materials was consumer-led
e. I don’t know

8. What role did consumers have in designing the project/trial information? i.e. patient information leaflets

a. There was no consumer involvement
b. Consumers were consulted on the design of the project information
c. Consumers were democratically involved in the design of the project information
d. The design of the project information was consumer-led
e. I don’t know
9. What role did consumers have in managing the research project/trial?

a. There was no consumer involvement
b. Consumers were consulted on the management of the research project
c. Consumers were democratically involved in managing the research project
d. Project management was service user-led
e. I don’t know

10. What role did consumers have in collecting data?

a. There was no consumer involvement
b. Data collection carried out primarily by professional researchers
c. Data collection carried out equally by consumers and professional researchers
d. Data collection carried out primarily by consumers
e. I don’t know

11. What role did consumers have in analysing data?

a. There was no consumer involvement
b. Data analyses was carried out primarily by professional researchers
c. Data analyses was carried out equally by consumers and professional researchers
d. Data analyses was carried out primarily by consumers
e. I don’t know
12. What role did consumers have in the interpretation of data?

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<thead>
<tr>
<th>Option</th>
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<tbody>
<tr>
<td>a. There was no consumer involvement</td>
<td></td>
</tr>
<tr>
<td>b. Consumers were consulted on the interpretation of the data</td>
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<tr>
<td>c. Consumers were democratically involved in the interpretation of the data</td>
<td></td>
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<tr>
<td>d. The interpretation of the data was consumer-led</td>
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<tr>
<td>e. I don't know</td>
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</tbody>
</table>

13. What role did consumers have in planning and carrying out the dissemination of the research findings?

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<thead>
<tr>
<th>Option</th>
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<tbody>
<tr>
<td>a. There was no consumer involvement</td>
<td></td>
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<tr>
<td>b. Consumers were consulted on the dissemination of findings</td>
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<tr>
<td>c. Consumers were democratically involved in the dissemination of findings</td>
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<tr>
<td>d. Dissemination of findings was consumer-led</td>
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<tr>
<td>e. I don't know</td>
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</tbody>
</table>
The following questions refer to particular aspects of service user involvement

<table>
<thead>
<tr>
<th>14. The consumer’s role</th>
<th>Please tick the appropriate box</th>
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<tbody>
<tr>
<td>a. The roles of consumers were documented.</td>
<td>n/a</td>
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<tr>
<td>b. The process by which these roles were agreed was documented</td>
<td>n/a</td>
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<tr>
<td>c. Consumers had honorary contracts if necessary.</td>
<td>n/a</td>
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</table>

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<th>15. Finance</th>
<th>Please tick the appropriate box</th>
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<tbody>
<tr>
<td>a. Costs of consumer involvement were included in the funding application and/or the project budget.</td>
<td>n/a</td>
</tr>
<tr>
<td>b. Consumers were offered payment for their involvement, at an appropriate rate.</td>
<td>n/a</td>
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<tr>
<td>c. Consumers were reimbursed for their travel and subsistence expenses.</td>
<td>n/a</td>
</tr>
<tr>
<td>d. Consumers were reimbursed for other expenses, such as childcare or carer expenses.</td>
<td>n/a</td>
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</table>
### 16. Accessibility

- a. An inclusive recruitment strategy was in place and pursued.
- b. Meetings were timed and planned for the convenience of consumers.
- c. Venues were used that have good physical access for all, and are convenient for researchers/advisors.
- d. Information was made available in alternative and appropriate format.

### 17. Training and support – researchers

- a. The research team had access to expertise in working with consumers
- b. Academic/clinical researchers ensured that their own training needs in relation to working with consumers in research were identified and met

### 18. Training and support – consumers

- a. Consumers were given the opportunity to identify their training and personal support needs and to review these as the project progresses.
- b. Consumers had access to training and learning opportunities to facilitate their involvement in the research.
- c. Arrangements were in place to provide ongoing research support to consumers (e.g. research supporter, mentor, explicit part of another researcher’s role).
- d. Consumers had access to information resources (e.g. access to the internet, a library, research papers, key documents).
- e. Consumers had equal access to project communications.
f. Consumers had access to personal support (e.g. advocate, key worker, mentor).

19. Recognition
   a. The nature and extent of consumer involvement was clearly documented in project documents, including the protocol
   b. Details of consumers’ involvement were documented in project outputs (e.g. reports, publications, presentations)
   c. Individual consumers were acknowledged in project outputs

20. Accessibility of findings
   a. Consumers gave their advice on the choice of methods used to distribute the research findings
   b. Research findings were disseminated to study participants in appropriate formats and easily understandable language
   c. Research findings were disseminated to relevant broader groups and organisations in appropriate formats and easily understandable language

21. Reflection
   a. A separate, independent reflective process took place, and reflections were documented and disseminated

21. Please make any comments you would like to make here.
For any queries contact:

Dr. Kate Kelley, Patient and Public Involvement Unit, Worthing Hospital, Lyndhurst Road,
Worthing, West Sussex, BN11 2DH.
01903 205111 ext. 4198, Kate.Kelley@wash.nhs.uk

PLEASE “SAVE” THE QUESTIONNAIRE, RETURN TO THE INITIAL EMAIL AND “FORWARD” TO Kate.Kelley@wash.nhs.uk

Thank you
PARTICIPANT INFORMATION SHEET

Study title: An Evaluative Review of ‘Consumer Research Panels’

Names of Researchers: Vivienne Brown, John Sitzia, Phil Cotterell and Alison Richardson

You are invited to take part in this research study. The study is an evaluation of the development of a collaborative model of ‘Consumer Research Panels’ within cancer research networks. A research team from Worthing and Southlands Hospitals NHS Trust and King’s College London is carrying out the study.

Before you decide whether to take part it is important for you to understand why this research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If there is anything that is not clear or if you would like more information please refer to the person whose contact details are at the end of this leaflet. Take time to decide whether or not you wish to take part.

Thank you for taking the time to read this information.

What is the purpose of the study?

Involvement in cancer services is concerned with enabling people who are users of cancer services to contribute their unique knowledge and experience in order to inform and influence the perspectives of professionals and policy makers. More recently there has also been a focus upon encouraging the involvement of cancer service users in cancer research. Research in health and social care is often focused on care and treatment issues but it has usually been the professional, the researcher, who decides what research to conduct, how to tackle the research, and to decide what aspects of the research findings are important.

The development of Consumer Research Panels is a two-year initiative, funded by the National Cancer Research Network and Macmillan Cancer Relief, that aims to advance consumer involvement in NHS cancer research, through the
establishment and support of Consumer Research Panels in three pilot site cancer networks. The panels are to be made up of consumers who in some way have experience of cancer services.

The intention is that these panels will be involved in identifying and prioritising research areas that are important to consumers. Panel members will be enabled to comment at early stages of protocol development and to offer their own ideas about research outcome measurement. It is also intended that consumer panel members will be encouraged to work with researchers on projects and to collaborate at all stages of the research process including analysis and dissemination of research results.

The purpose of this evaluation study is to explore and document the work of Consumer Research Panels and to look at issues around consumer involvement in NHS cancer research more widely. The evaluation will focus upon the ‘difference’ being made to NHS cancer research, in terms of consumers actually being involved in decision-making around the planning, implementation and dissemination of local cancer research.

The overall aim of this evaluation is to provide information about the value of Consumer Research Panels as a mechanism for effective and meaningful user involvement in cancer research networks, and to establish how consumer involvement in research is undertaken in the other cancer research networks in England.

The study has nine stages:

**Stage 1: Literature review** - We will review relevant documents that have been published by organisations such as the Department of Health, and the National Cancer Research Network, in order to provide a background to the evaluation.

**Stage 2: Examination of Consumer Research Panel documentation** - We will collect records documenting the functioning and process of the three Consumer Research Panels (e.g. meeting agendas and minutes).

**Stage 3: Examining the Cancer Research Network’s research activity** - We will use national databases of research activity, such as the National Research Register and National Cancer Research Network database, to identify research projects being carried out within each of the 3 pilot site networks. We will do this before the Consumer Research Panel has been established and again 12 months later in order to examine whether research activity has changed in this period.

**Stage 4: Examining the level of consumer involvement within the Cancer Research Network research activity** - We will examine the nature, extent, and quality of consumer involvement in cancer network research activity on two occasions, before the Consumer Research Panel has been established and again 12 months later in order to examine whether consumer involvement in research activity has
changed in this period. This will be done by contacting the Lead Investigators for a sample of research projects being carried out within each pilot site research network and asking them to answer some questions by telephone or e-mail.

Stage 5: Focus groups with Consumer Research Panel members - We will hold focus groups with approximately eight consumer members of each Consumer Research Panel in order to gather their views. The same members will be asked to take part in focus groups on two occasions, once in the early stages of the panel’s development, and again when the panel has been established for twelve months.

Stage 6: Focus groups (or interviews) with researchers involved with the Consumer Research Panel - We will hold a focus group (or interviews where it is not possible to set up a focus group) with approximately eight researchers who are involved with the Consumer Research Panel in order to gather their views. The same researchers will be asked to take part in focus groups on two occasions, once in the early stages of the panel’s development, and again when the panel has been established for twelve months.

Stage 7: Interviews with network researchers not involved with the Consumer Research Panel - We will conduct telephone interviews with approximately 5 researchers in each network who are not involved with the Consumer Research Panel in order to gather a variety of views regarding consumer involvement in research within each pilot site research network.

Stage 8: Interviews with key informants - We will hold face to face or telephone interviews with a number of key informants in each network before the CRP is set up and again when the CRP has been established for 12 months. Key informants will include network leads and managers.

Stage 9: Survey of consumer involvement in research in other Cancer Research Networks – We will carry out a questionnaire survey to establish the extent of, and process of, involving consumers in research throughout the remaining 31 cancer networks. The survey will be undertaken at two time points 12 months apart in order to explore the development of consumer involvement initiatives.

The study will be carried out between June 2004 and May 2006.

Why have I been chosen?

You have been asked to participate in this study because you are consumer member of a Consumer Research Panel. In total the study will gather the views of approximately 42 individuals within each cancer research network, 8 of these will be consumer members of the panels.
Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. The decision to withdraw at any time, or a decision not to take part will not affect the standard of care you may receive or your involvement in the panel.

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

You are invited to take part in Stage 5 of the study – focus groups with Consumer Research Panel members. You will be asked to take part in two focus groups. The first group will take place shortly, in the early stages of the establishment of the Consumer Research Panel; the second will take place in 12 months time.

The focus group will consist of yourself and approximately 7 other consumer members of your panel. You will be asked to discuss your views and experiences of being a member of the panel. Phil Cotterell who is a member of the research team will facilitate the group. The group will last about an hour and will be held on a mutually convenient date and time, at a central location. The research team will reimburse any travel expenses you incur.

The discussion will be tape recorded and transcribed. The research team will pick out and document the key themes from the discussions. You will be sent a summary of the key themes from the groups you have participated in and will be asked to say whether or not you feel that the themes identified reflect your experience. Extracts of the discussion may be used in reporting the findings of the study, however at no time will you be identified in the reporting of results.

What do I have to do?

If you agree to participate in this study please pass your contact details to the Chair of the Consumer Research Panel. With your permission, they will pass on your details to the research team. A member of the research team will then contact you to confirm your agreement and then a consent form will be sent to you for you to sign.

After your agreement has been gained we will arrange a date, time and venue for the focus group. We will also send you the topic list of questions we wish to ask the group.

Agreeing to participate does not stop you from pulling out of the study at any point without giving a reason. We will ask you then if we can use the information you have given to date rather than lose it, but you will be free to refuse this.
What are the possible disadvantages and risks of taking part?

The research is not looking at areas of personal care or treatment, and we will not ask any questions about these. However the nature of interviews and of more informal ways of researching people’s experiences and views can, potentially, lead into areas that are personal or sensitive for the person concerned. In talking to someone about the group you are involved with you may find yourself getting upset. For example, you might tell us about some disagreement you have had in your panel, which was distressing for you. Therefore it is very important that you and we know that participation can stop at any time if you become uncomfortable. Feeling tired is also a potential problem as talking for any period of time can be exhausting, perhaps especially for some of you who have/have had a cancer diagnosis.

If an aspect of the research should upset anyone then there will be someone available to support you. Some people will already have people they can talk to, whether it is family or friends, General Practitioner (GP), or other healthcare staff like specialist nurses and this may well be your preferred person. In any case, a member of the research team will be in touch with you after any research related contact to see how you are, and can help with putting you in contact with an appropriate person for support if needed.

What are the possible benefits of taking part?

This study is not intended to offer medical benefits. Some people, however, do like being involved in research that, whilst not directly helping them, may be of benefit to others. Others like to have a say and describe what they feel about their involvement and how it has affected them. Consumer’s unique knowledge of their condition, needs and services available is beneficial for the development of cancer research locally and nationally.

What happens when the research study stops?

In terms of your participation, the study will ‘stop’ once the second focus group is over and you have had the opportunity to comment on the discussion themes from that group. Our plans for sharing the results are described below.

What if something goes wrong?

If there are any areas of concern to you or a complaint about any aspect of the research, then in the first instance we would ask you to discuss the concern either with a member of the research team or your panel facilitator. If the problem cannot be resolved in this way, then you can register a formal complaint with the Lead Organization, Worthing & Southlands Hospitals NHS Trust. This complaint will be processed using the formal NHS complaints system. You should write to:
Will my taking part in this study be kept confidential?

All information collected from you during the course of the research will be kept in strict confidence. The information will be stored in a locked cabinet and/or password-protected computer files in the Research Department at Worthing & Southlands Hospitals NHS Trust. The Trust has systems in place to make sure that the information is kept in compliance with the Data Protection Act and other legal and government requirements.

The information will not be passed on to any party outside the research team: specifically, the information will not be passed on to either your Panel facilitator or The National Cancer Research Network or Macmillan Cancer Relief, who will be presented only with the final report. Any information that is given by you and used in the research report will be strictly anonymous and no facts will enable comments to be associated with you.

What will happen to the results of the research study?

When the whole study is finished, the research team will write a report for the study commissioners, The National Cancer Research Network and Macmillan Cancer Relief. The commissioners can be approached for a copy of this report. Also, we will write a short summary of the report and the study results, and this summary will be sent to every individual who has participated in the study and the Cancer Research Networks. We will publish the results in service newsletters, user group’s newsletters and academic journals. Finally, the study results will be presented and discussed at national and local meetings. You will not be identifiable in anything written or published.

Who is organizing and funding the research?

The National Cancer Research Network and Macmillan Cancer Relief are funding the evaluation jointly. Worthing & Southlands Hospitals NHS Trust is the ‘Sponsor’ of the study, which means that it takes responsibility for the overall good management of the research and for its overall quality.

Who has reviewed the study?

A Multi-Center Research Ethics Committee has approved the research. The host organisation, Worthing and Southlands Hospitals NHS Trust, and each NHS organization within the cancer research network have also approved the research. The study is monitored and shaped by Reference Group made up of service users, researchers and representatives from the funders.
What do I do now?

If you agree to participate in this study please inform the Chair of the Consumer Research Panel. You may have some questions and you are welcome to contact a member of the research team, via the contact below, who will be happy to answer any queries.

If you do not want to take part for any reason you need do nothing.

Contact for further information

Phil Cotterell

Patient and Public Involvement Research Unit,

Research and Development,

Worthing Hospital, Lyndhurst Road, Worthing, BN11 2DH.

Tel: 01903 285222 ext 4188

Fax: 01903-285217

E-mail: phil.cotterell@wash.nhs.uk

I would like to thank you very much for taking the time to read this information sheet and thank you in advance if you feel able to participate in the study.

If you decide to participate you will be given a copy of this patient information sheet and consent form to keep for your records.
Lay Summary

Project title: An Evaluative Review of ‘Consumer Research Panels’

Researchers: Vivienne Brown, John Sitzia, Phil Cotterell and Alison Richardson

Background information

This project is about involving people who have cancer, or have cared for people with cancer, in decisions about what cancer research should be done, and how it should be carried out.

The development of Consumer Research Panels is a two-year initiative, funded by the National Cancer Research Network and Macmillan Cancer Relief, that aims to advance consumer involvement in NHS cancer research, by setting up and supporting Consumer Research Panels in three cancer research networks.

The panels are to be made up of people who in some way have experience of cancer services. These panels will be involved in identifying and prioritising research areas that are important to consumers. Panel members will be able to comment at the early stages of planning of research projects. They will also be encouraged to work with researchers on projects and to collaborate at all stages of the research process including analysis and dissemination of research results.

The problem

Involving consumers in this way has not been evaluated to date. We do not really know if this initiative will actually make a difference to NHS cancer research. Many questions need to be explored, for example: who has the opportunity to get involved in consumer research panels? Are the views and experiences of consumers taken on board by researchers? What is it like to be involved in these panels? What is it like for researchers to work with the panels? What do other cancer network staff and researchers think of this initiative? What helps people to participate and collaborate in this initiative, and what hinders their participation? What are other cancer networks, which do not have Consumer Research Panels, achieving in terms of consumer involvement in research?

Description of the evaluation project

The purpose of this evaluation project is to see if the Consumer Research Panels are ‘making a difference’, to local NHS cancer research and for the people involved in the panels, and also to explore some issues around consumers in NHS cancer research more broadly.
In order to find out whether or not the collaborative model of working via Consumer Research Panels influences cancer research in networks, we need to ask the people who are involved, including: consumers, researchers, health professionals and Cancer Research Network Managers.

Individuals’ personal views and experiences of Consumer Research Panels will be gained in different ways including: telephone interviews, face-to-face interviews, questionnaires, or focus groups. Focus groups will consist of small groups of individuals who will discuss their experiences in a group forum.

The evaluation will collect information in nine stages:

**Stage 1: Literature review**
We will review relevant documents that have been published by organisations such as the Department of Health, and the National Cancer Research Network, in order to provide a background to the evaluation.

**Stage 2: Examination of Consumer Research Panel documentation**
We will collect records that show how the three Consumer Research Panels have worked (e.g. meeting agendas and minutes).

**Stage 3: Examining the Cancer Research Network’s research activity**
We will use national databases of research activity, such as the National Research Register and National Cancer Research Network database, to identify research projects being carried out within each of the 3 pilot site networks. We will do this before the Consumer Research Panel has been established and again 12 months later in order to examine whether research activity has changed in this period.

**Stage 4: Examining the level of consumer involvement within the Cancer Research Network research activity**
We will examine the nature, extent, and quality of consumer involvement in cancer network research activity on two occasions, before the Consumer Research Panel has been established and again 12 months later in order to examine whether consumer involvement in research activity has changed in this period. This will be done by contacting the Lead Investigators for a sample of research projects being carried out within each pilot site research network and asking them to answer some questions by telephone or e-mail.

**Stage 5: Focus groups with Consumer Research Panel members**
We will hold focus groups with approximately eight consumer members of each Consumer Research Panel in order to gather their views. The same members will be asked to take part in focus groups on two occasions, once in the early stages of the panel’s development, and again when the panel has been established for twelve months.

**Stage 6: Focus groups (or interviews) with researchers involved with the Consumer Research Panel.**
We will hold a focus group (or interviews where it is not possible to set up a focus group) with approximately eight researchers who are involved with the Consumer Research Panel in order to gather their views. The same researchers will be asked to take part in focus groups on two occasions, once in the early stages of the panel’s development, and again when the panel has been established for twelve months.

**Stage 7: Interviews with network researchers not involved with the Consumer Research Panel**
We will conduct telephone interviews with approximately 5 researchers in each network who are not involved with the Consumer Research Panel in order to gather a variety of views regarding consumer involvement in research within each pilot site research network.

**Stage 8: Interviews with key informants**
We will hold face to face or telephone interviews with a number of key informants in each network before the CRP is set up and again when the CRP has been established for 12 months. Key informants will include network staff such as: the Lead Manager for Patient and Public Involvement, the Chair of the Network Cancer Partnership Group, the Network Lead Clinician, the Network Lead Clinician for Research, the Network Research Manager, the CRP Facilitator.

**Stage 9: Survey of consumer involvement in research in other Cancer Research Networks**
We will carry out a questionnaire survey to establish the extent of, and process of, involving consumers in research throughout the remaining 31 cancer networks. The survey will be undertaken in two stages 12 months apart in order to explore the development of consumer involvement initiatives.

**What will happen to the information gathered?**
As we collect information we will analyse it to look for issues or ‘themes’ that come up. We will also try to describe consumer activity in research going on around the country, for example what sort of involvement is occurring, what enables consumer involvement in research, what barriers to this exist and what difference, if any, it has made to local NHS cancer research.

When all the results have become clear, we will write a report that will be used by the National Cancer Research Network and Macmillan Cancer Relief to guide the future plans for Consumer Research Panels. We will also present the results at regional meetings of consumers and, using existing networks, we will try to make sure the results are also raised and talked about at local group level. Anyone who participates will automatically be informed of the results directly, and we will be happy to share the results with anyone else who asks.

**The research team**
The National Cancer Research Network and Macmillan Cancer Relief have commissioned an external research team to carry out the evaluation. This is a joint team from Worthing & Southlands Hospitals NHS Trust and King’s College London, part of the University of
London. Phil Cotterell, a specialist researcher in cancer care who is also a palliative care nurse, will carry out most of the interview work.

We have set up a group to steer the project and to provide advice and support to the researchers. This ‘Reference Group’ has a number of consumers on it, and these consumers will participate at all stages of the research. Their unique experience and knowledge as users of cancer services will be very important in shaping the research.

**Timescale**
The evaluation is due to begin in June 2004 and will last for twenty-four months.

**Further information**
We are more than happy to provide more information about the evaluation project or to answer any questions you might have.

Please contact:

**Phil Cotterell,**
Patient & Public Involvement Research Unit,
Worthing Hospital,
Lyndhurst Road,
Worthing,
West Sussex,
BN11 2DH.
Tel: 01903 285222 ext. 4188,
Fax: 01903 285217,
E-mail: phil.cotterell@wash.nhs.uk.
Study title: An Evaluative Review of ‘Consumer Research Panels’

Names of Researchers: Vivienne Brown, John Sitzia, Phil Cotterell and Alison Richardson

**Guidelines for an Effective Focus Group**

The focus group will consist of between 8-12 people from your Consumer Research Panel (CRP). We will have a guided discussion on a range of aspects to do with the CRP.

When conducting a focus group in a research project it is wise to all agree certain points at the outset. This avoids any misunderstandings and will, hopefully, offer reassurance to participants on a number of issues. When we meet to conduct the focus group we will spend the first few minutes discussing these points but they are given to you in advance so that you can consider them and then raise any queries you may have.

All those present in the focus group need to agree that we will observe the following principles:

- Confidentiality will be agreed and respected.
- There will be respect for each person’s opinion and point of view.
- We will be non-judgemental and sensitive to each other’s experiences and thoughts.
- One person will speak at a time and be offered the respect of being listened to.
- If clarification is required then this will be provided at any stage. Before, during, or after the focus group. This is not a problem.
CONSENT FORM

Project title: An Evaluative Review of ‘Consumer Research Panels’

Names of Researchers: Vivienne Brown, John Sitzia, Phil Cotterell and Alison Richardson

Please initial each box

1. I confirm that I have read and understand the information sheet dated 30-09-04 for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I agree to my interview/focus group being audiotaped.

4. I agree that anonymous written extracts of research data obtained from me may be used in any future article or written work.

5. I agree to take part in the above study.

_______________________ ________________            ____________________
Name of Participant Date Signature

_________________________ ________________            ____________________
Researcher Date Signature

1 for participant; 1 for researcher

Participant Identification Number:

Consent for consumer participants (Stage 5)
Topic guide for focus groups with consumer members of Consumer Research Panels (Activity 5)

Background questions to be completed individually following consent
Demographic questions such as age, gender, ethnicity, experience of cancer and voluntary and/or consumer groups, previous experience of involvement as a consumer in research, reasons for joining the CRP.

Baseline Focus Group questions

<table>
<thead>
<tr>
<th>Topic areas</th>
<th>Prompts</th>
</tr>
</thead>
</table>
| Expectations      | - What is your understanding of the aims and role of the CRP?  
                   | - What do you think the CRP will achieve?  
                   | - Who do you think will benefit from the work of the CRP?  
                   | - What do you expect from the CRP as a member?  |
| Recruitment       | - How were you recruited to the CRP?  
                   | - Could this process be improved at all?  |
| Induction and training | - What are your thoughts about the induction process?  
                          | - Could this process be improved at all?  
                          | - Have you received enough preliminary support and training?  
                          | - Could this be improved at all?  |
| Outcomes          | - How would you define a successful outcome for the CRP?  |
| Role              | - What do you anticipate your role will be in the CRP?  |
| Attributes        | - As consumers, what attributes are you bringing to the CRP?  |
| Research community| - How do you think the CRP will work with the research community?  
                          | - Do you anticipate any barriers?  |
| Decision-making   | - So far, what has been the process for deciding what the CRP does?  
                          | - So far, who is it that decides what the CRP does?  |
| Payment           | - What do you feel about the level of payment you receive for your involvement in the CRP?  |
| Open topic        | - Is there anything else you would like to add?  |
## 12 month Focus Group questions

<table>
<thead>
<tr>
<th>Topic areas</th>
<th>Prompts</th>
</tr>
</thead>
</table>
| CRP set up         | - Was the setting of the CRP as expected / according to plan?  
                      - Begin with reminder of the group’s aims as recorded in the baseline focus group.  
                      - Does the group feel it has achieved these aims – or not?  
                      - Does the group feel as though it has been worthwhile?  
                      - From the experience of the past 12 months, would members be involved in this sort of initiative again?  
                      - Would members do anything differently or change anything in light of this experience? |
| Expectations – met?| - On reflection, which recruitment strategy worked well – and which didn’t?  
                      - Has membership been maintained – or decreased – or increased?  
                      - If people have left the panel, why?  
                      - Was there a ‘rolling programme’ of recruitment? What did it consist of? |
| Recruitment        | - On reflection, how did the initial induction and training go?  
                      - Did it prepare you for your work as a group?  
                      - Has there been any subsequent or ongoing training?  
                      - What has been useful and what has not? |
| Induction and training | - On reflection, how did the initial induction and training go?  
                        - Did it prepare you for your work as a group?  
                        - Has there been any subsequent or ongoing training?  
                        - What has been useful and what has not? |
| Support for panel  | - Where has support / help for the panel come from?  
                      - Facilitator?  
                      - Any other admin staff?  
                      - NCRN co-ordinating centre / User Involvement lead?  
                      - Local (host) cancer research network?  
                      - Local cancer network user / partnership group?  
                      - Other CRPs?  
                      - Payments: have members been paid or offered payment for their work? Accepted? Appropriate rate? Expenses? Any other issues of remuneration?  
                      - Facilities open to CRP / resources? e.g. access to local health specialist library? |
| Role               | - On reflection, what do you now see as an ongoing role for the CRP? |
| Activity           | - What have been the CRP’s main activities?  
                      - Where does the ‘work’ come from?  
                      - How do you prioritise the work?  
                      - What exactly does the panel do for each work activity?  
                      - Who decided on the panel’s ‘role’ in these activities? |
| Impact             | - Which activities have ‘made a difference’ / had the most ‘impact’?  
                      - How does the group gauge ‘impact’?  
                      - What have been the personal ‘impacts’ upon members? |
### Internal relationships
- Does the group feel it has changed the local ‘research culture’ at all? Any examples?
- How would you say, overall, that you ‘work’ together as a group?
- How are decisions made? Inside meetings or outside meetings? By consensus usually?
- What has worked well in terms of group working? Where have problems arisen?

### External relationships
- Have you met researchers / research-active professionals?
- Have you worked with any?
- Has it felt ‘collaborative’ or not?
- Does the panel have any links with the CN user group? Describe. Any benefits?

### Next steps
- Where does the panel go from here?
- What can others – NCRN, Macmillan – do to help you?
- What (in the CRP) might be changed for the better?
- What is the potential for the CRP format? Nationally?
- Is there a long-term sustainable role?

### Open topic
- Is there anything else you would like to add?
## Topic guide for interviews with researchers involved with a Consumer Research Panels (Activity 6)

### Background questions to be completed individually following consent

The participant’s age, gender, ethnicity, experience of cancer and/or voluntary groups.

### Baseline Focus Group/Interview Questions

<table>
<thead>
<tr>
<th>Topic</th>
<th>Questions</th>
</tr>
</thead>
</table>
| Researcher background      | 1. How long have you been a researcher?  
2. Please describe your current post. (Academic/clinical)  
3. What are your main research activities within the CRN?  
4. Can you describe how your activities fit into the CRN’s research portfolio of studies?                                                                                                                                                                                                                   |
| Consumer involvement      | 5. What experience of consumer involvement in research do you have? (Specific example)  
6. Was this experience positive or negative? (If not covered in 5 above)  
7. Have you received any training on consumer involvement in research? Please explain.                                                                                                                                                                       |
| Expectations               | 8. What is your understanding of the role of the CRP and what it aims to achieve?  
9. What do you feel the CRP can achieve?  
10. Do you have plans to involve the CRP with your research? Please explain.  
11. What do you feel the CRP could offer your research project/s?  
12. What might be the limits of consumer involvement in research? (Specific ideas)                                                                                                                                            |
| Recruitment/engagement     | 13. How have you found out about the CRP and got involved with it?                                                                                                                                                                                                                                                                       |
| Outcomes                  | 14. How would you define a successful outcome for the CRP? (Specifically to your own project and broadly for the CRP)                                                                                                                                                                                                                   |
| CRP                       | 15. How do you think you will work with the CRP?  
16. Do you foresee any potential challenges or issues in working with the CRP? Please explain.                                                                                                                                                                               |
| Decision-making           | 17. Who do you think will make decisions about the functioning and work of the Panel?                                                                                                                                                                                                                                                |
| Open topic                | 18. Is there anything else you would like to add?                                                                                                                                                                                                                                                                                    |
### 12-month interview questions

<table>
<thead>
<tr>
<th>Topic</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Involvement with CRP</td>
<td>1. Can you describe what your involvement with the CRP has been?</td>
</tr>
<tr>
<td></td>
<td>• What was the level of involvement? Project? Examples?</td>
</tr>
<tr>
<td></td>
<td>• Nature, frequency, length.</td>
</tr>
<tr>
<td></td>
<td>• What factors influenced the level of involvement? i.e. funding, ethics, stage of project?</td>
</tr>
<tr>
<td></td>
<td>2. How was contact made with the CRP?</td>
</tr>
<tr>
<td></td>
<td>• How did you originally hear of the CRP?</td>
</tr>
<tr>
<td></td>
<td>• Who initiated contact?</td>
</tr>
<tr>
<td>Impact of involvement with CRP?</td>
<td>3. What were you hoping to achieve?</td>
</tr>
<tr>
<td></td>
<td>• What did you achieve?</td>
</tr>
<tr>
<td></td>
<td>4. Do you think the panel’s involvement made a difference to your research? Examples? Why?</td>
</tr>
<tr>
<td></td>
<td>5. Has the panel made any difference to local cancer research culture generally?</td>
</tr>
<tr>
<td></td>
<td>• How?</td>
</tr>
<tr>
<td></td>
<td>• Why not (organisational barriers-time)?</td>
</tr>
<tr>
<td></td>
<td>6. What are your reflections on your involvement?</td>
</tr>
<tr>
<td></td>
<td>• Has being involved with the CRP changed your ideas about working with consumers?</td>
</tr>
<tr>
<td></td>
<td>• Did the panel have an understanding of research/your research/what you wanted from them?</td>
</tr>
<tr>
<td></td>
<td>• Do you anticipate any further involvement with the CRP in your projects?</td>
</tr>
<tr>
<td>CRP impact generally</td>
<td>7. What do you think the achievements of the CRP have been?</td>
</tr>
<tr>
<td>Next steps</td>
<td>8. What do you think are the next steps for the CRP?</td>
</tr>
<tr>
<td>Support for CRP</td>
<td>9. Can you think of anything that is needed to support the CRP’s work and involvement in research projects?</td>
</tr>
<tr>
<td>Open topic</td>
<td>10. Is there anything else you would like to add?</td>
</tr>
</tbody>
</table>
**Topic guide for interviews with researchers not involved with a Consumer Research Panels (Activity 7)**

**Background questions to be completed individually following consent**
The participant's age, gender, ethnicity, experience of cancer and/or voluntary groups.

**12-month interview questions**

<table>
<thead>
<tr>
<th>Topic</th>
<th>Questions</th>
</tr>
</thead>
</table>
| Researcher background      | 1. Please describe your current post. (Academic/clinical?)  
2. What are your main research interests / activities?  
3. Do you have links with your local CRN?                                                                                                                                                                                   |
| Consumer involvement       | 4. Do you have any experience of consumer involvement in research? In any of your own research?  
  - If yes, was this positive or negative?  
  - If yes, how did you access the consumers?  
  - If no, what would change your mind about involving consumers in research? (Incentives?)  
5. Is consumer involvement in research relevant to your area of work?  
6. *If interviewee has experience of user involvement* - Have you received any training on consumer involvement in research?                                                                                           |
| CRP                        | 7. Have you heard of the CRP?  
  - How did you hear of the CRP?  
  - Do you know what the CRP’s role is?  
8. Have you any thoughts on working with the CRP in the future?  
  - How might you work with the CRP?  
  - What benefits / challenges do you envisage?  
  - What model of user involvement would work best for them?                                                                                                                                                        |
| Open topic                 | 9. Is there anything else you would like to add?                                                                                                                                                            |
# Topic guide for interviews with cancer network / research network key informants
(Activity 8)

## Baseline Interview Questions

<table>
<thead>
<tr>
<th>Topic</th>
<th>Questions</th>
</tr>
</thead>
</table>
| **Cancer Research Network (CRN) activity and agenda** | 1. What is the CRN’s main research activity?  
2. What is the CRN’s research agenda/targets?  
3. How is the agenda arrived at?  
4. What is the CRN’s position on consumer involvement in research?  
5. To date, how has the CRN involved consumers in research activity? Please give examples. |
| **Key Informant background**               | 6. What is your current role within the CRN? (Manager/researcher/clinician/lay person)  
7. How long have you been involved in the CRN?  
8. Where do your research interests lie? (If any) |
| **Consumer involvement**                  | 9. What experience of consumer involvement in research do you have, if any? (Specific example)  
10. Was this experience positive or negative? (If not covered in 9 above)  
11. Have you received any training on consumer involvement in research? Please explain.  
12. Do you feel consumer involvement in research can bring any benefits to your research network/research portfolio?  
13. Do you feel consumer involvement can offer anything to individual research projects? Please explain.  
14. Other than the CRP, are you aware of alternative ways/models of engaging with consumers in research? |
| **Expectations**                           | 15. What is your understanding of the role of the CRP and what it aims to achieve?  
16. What do you think the CRP can achieve?  
17. What might be the potential challenges or issues of working with the CRP? Please explain.  
18. What might be the potential benefits of working with the CRP? Please explain.  
19. What might be the limitations of the CRP?  
20. Are there links between the CRP and the Cancer Partnership Group (CPG)? Please explain.  
21. Are there any potential benefits or problems in having the link between the CRP and the CPG? Please explain. |
| **Outcomes**                               | 22. What would be successful outcomes of the CRP? |
| **Decision-making**                        | 23. Who do you think will make decisions about the functioning and work of the Panel? |
| **Open topic**                             | 24. Is there anything else you would like to add? |
### 12 month Interview Questions

<table>
<thead>
<tr>
<th>Topic</th>
<th>Questions</th>
</tr>
</thead>
</table>
| Involvement with CRP         | 1. The CRP has now been going for 12 months. What has been your role in the CRP, if any?  
  • **Ask CRP facilitators only** what have been the most difficult aspects of their CRP role. |
| Links / work flow            | 2. Are there links between the CRP and the CPG? Describe. Benefits?  
  3. Are ideas from service side/CPG feeding into the CRP? Vice versa?  
  4. Who (else) is ‘feeding into’/using the CRP?  
  • Research groups?  
  • University?  
  • National groups?  
  • What are the links? |
| CRP impact / outcomes        | 5. What do you think the role of the CRP has been?  
  6. What have they been doing? Main achievements?  
  7. What impact has their work had SO FAR?  
  • Impact on services/clinical culture/CRN  
  • Impact on research agenda/recruitment  
  • Impact at study level  
  • Impact on research culture generally  
  • Impact on attitudes about CIR?  
  • Any other success indicators other than impact and above points? |
| Support for CRP              | 8. How has the CRN supported the CRP? (Funding, admin, staff, philosophically)  
  9. What are plans for supporting it in the future?  
  10. Do you think it’s a good use of money? Who should fund it? |
| Future                       | 11. Do you think CRP model is working? Sustainable?  
  12. Do you have any alternative suggestions/models for consumer involvement in cancer research? |
| Open topic                   | 13. Is there anything else you would like to add? |
Scoping Consumer Involvement in Cancer Research Networks

Questionnaire for Cancer Research Network Managers (April 2005)

This questionnaire is designed to be completed electronically. Use of the TAB key on your keyboard will take you from one question to the next. Please type only in boxes shaded grey. Should you have any difficulties or queries in completing the questionnaire, please contact Viv Brown (Lead Researcher) on 01903 285076 or vivienne.brown@wash.nhs.uk.

PLEASE RETURN THE COMPLETED QUESTIONNAIRE USING ‘SAVE’, RETURNING TO THE E-MAIL, AND CLICKING ‘FORWARD TO’ vivienne.brown@wash.nhs.uk TO ENSURE YOUR RESPONSES ARE RETAINED IN THE ATTACHMENT.

DEFINITIONS OF TERMS USED IN THIS QUESTIONNAIRE

For the purposes of this scoping exercise we use the following definitions:

**Consumers**: patients (previous or current), carers, or any member of the public who could be a potential user of the health system

**Consumer involvement**: by involvement we mean that consumers are active partners in the research process rather than ‘subjects’ of research … Many people describe public involvement in research as doing research with or by the public, rather than to, about or for the public

**Consumer Research Panel (CRP)**: A Consumer Research Panel consists of a group of consumers who are interested in being involved in aspects of research carried out by a cancer research network; the panel may also have members from the local research community. Cancer Research Panels are a new initiative set up by the National Cancer Research Network and Macmillan Cancer Relief.

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<table>
<thead>
<tr>
<th>Section 1: An overview of consumer involvement in your Research Network</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. How much of a strategic priority is consumer involvement in research for your Research Network? Please rate on a scale of 1 to 10, where 1 = ‘not at a priority at all’ and 10 = ‘highest priority’</td>
</tr>
<tr>
<td>5. Can you identify any ‘drivers’ of any kind which would raise this level of priority in your Research Network?</td>
</tr>
<tr>
<td>6. Has your Research Network taken any steps so far to take forward local consumer involvement in research? (e.g. background reading, consultation with experts and advisory groups, discussions with local consumer groups, involvement-related training, conference attendances)</td>
</tr>
<tr>
<td>7. Has the Cancer (service) Network consumer group been involved in these activities, and if so how?</td>
</tr>
<tr>
<td>8. Please give an overview of the ways in which consumers are involved in research in your network at the present time, and provide examples of key initiatives</td>
</tr>
<tr>
<td>9. Are consumers involved in any Research Network committees or groups? If so, please describe the consumers’ role</td>
</tr>
<tr>
<td>10. In which areas, or topics, or activities, has consumer involvement in research been most successful? Please describe</td>
</tr>
<tr>
<td>11. In which areas, or topics, or activities, has consumer involvement in research been least successful? Please describe</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Section 2: Consumer involvement in individual projects / trials</th>
</tr>
</thead>
<tbody>
<tr>
<td>12. Please estimate the proportion (%) of all projects / trials in your Research Network’s portfolio that, to the best of your knowledge, actively involve local consumers</td>
</tr>
<tr>
<td>13. It would be helpful to have a picture of consumer involvement at project/trial level. Please could you complete the matrix below to indicate (a) at which stages of the research process consumers have been involved, and (b) the level of involvement in projects/trials in your portfolio. The TAB key will take you from cell to cell – please click on the tick boxes to indicate involvement at that stage/level.</td>
</tr>
</tbody>
</table>
### Section 3: Recruitment of consumers

15. How many consumers approximately have been actively involved in research in your network?

16. How were consumers recruited?

17. Please identify any recruitment strategies that have been particularly successful – or unsuccessful

18. Have any of these strategies specifically addressed issues of inclusivity, diversity and representativeness?

### Section 4: Resource requirements

19. Is there a Network member of staff who has a specific responsibility for consumer involvement in research? If so, please give details of the post, including the proportion of time (as a Whole Time Equivalent figure) committed to consumer involvement in research.
What are the approximate recurrent annual costs to the network to support consumer involvement in research? Please give an approximate cost for each item

A. Staff salary costs
B. Payments to consumers
C. Reimbursement of consumers' expenses
D. Training for consumers / consumers' conference costs
E. Room hire / catering costs for meetings
F. Other (please specify)

Section 5: Support and barriers

Which are the key factors that have advanced consumer involvement in research in your Research Network?

And which are the key factors that have hindered consumer involvement in research in the Network?

What practical support would be useful to the Network (e.g. a national website with advice, training provision, shared learning events)

Section 6: The 'Consumer Research Panel' model

How much do you know about the Consumer Research Panel model for involvement in cancer research networks? Please rate on a scale of 1 to 10, where 1 = ‘nothing at all’ and 10 = ‘everything’

In your view, how useful would the Consumer Research Panel model be to your network in advancing consumer involvement in research? Please rate on a scale of 1 to 10, where 1 = ‘not at all useful’ and 10 = ‘extremely useful’

Please can you elucidate your response to Q25 above

Does your research network currently have any specific plans to introduce a Consumer Research Panel?

Thank you very much for completing this questionnaire.

PLEASE RETURN THE COMPLETED QUESTIONNAIRE USING ‘SAVE’, RETURNING TO THE E-MAIL, AND CLICKING ‘FORWARD TO’ vivienne.brown@wash.nhs.uk TO ENSURE YOUR RESPONSES ARE RETAINED IN THE ATTACHMENT.
This questionnaire is designed to be completed electronically. Use of the TAB key on your keyboard will take you from one question to the next. Please type only in boxes shaded grey. Should you have any difficulties or queries in completing the questionnaire, please contact Viv Brown (Lead Researcher) on 01903 285076 or vivienne.brown@wash.nhs.uk.

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### DEFINITIONS OF TERMS USED IN THIS QUESTIONNAIRE

For the purposes of this scoping exercise we use the following definitions:

**Consumers**: patients (previous or current), carers, or any member of the public who could be a potential user of the health system

**Consumer involvement**: by involvement we mean that consumers are active partners in the research process rather than ‘subjects’ of research … Many people describe public involvement in research as doing research with or by the public, rather than to, about or for the public”

**Consumer Research Panel (CRP)**: A Consumer Research Panel consists of a group of consumers who are interested in being involved in aspects of research carried out by a cancer research network; the panel may also have members from the local research community. Cancer Research Panels are a new initiative set up by the National Cancer Research Network and Macmillan Cancer Relief.

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Section 1: An overview of consumer involvement in your Research Network

4. How much of a strategic priority is consumer involvement in research for your Research Network?
   Please rate on a scale of 1 to 10, where 1 = ‘not at a priority at all’ and 10 = ‘highest priority’

5. Can you identify any ‘drivers’ of any kind that would raise this level of priority in your Research Network?

6. Over the last year has your Research Network taken any steps to take forward local consumer involvement in research?
   (e.g. background reading, consultation with experts and advisory groups, discussions with local consumer groups, involvement-related training, conference attendances)

7. Please give an overview of the ways in which consumers are involved in research in your network at the present time, and provide examples of key initiatives implemented over the last year

8. Has the Cancer (service) Network consumer group been involved in these activities/initiatives, and if so how?

9. In which areas, or topics, or activities, has consumer involvement in research been most successful? Please describe

10. In which areas, or topics, or activities, has consumer involvement in research been least successful? Please describe

Section 2: Consumer involvement in individual studies

11. How many locally led studies are there in your Network Portfolio?

12. Are you aware of any consumer involvement in these studies? Yes ☐ No ☐
    If yes please describe how consumers were involved in these studies
### Section 3: Recruitment of consumers

13. In the last year, approximately how many consumers have been actively involved in research in your network?

14. How were consumers recruited?

15. Please identify any recruitment strategies that have been particularly successful – or unsuccessful

16. Have any of these strategies specifically addressed issues of inclusivity, diversity and representativeness?

### Section 4: Resource requirements

17. Is there a Network member of staff who has a specific responsibility for consumer involvement in research? If so, please give details of the post, including the proportion of time (as a Whole Time Equivalent figure) committed to consumer involvement in research.

18. What are the approximate recurrent annual costs to the network to support consumer involvement in research? Please give an approximate cost for each item

<table>
<thead>
<tr>
<th>Item</th>
<th>Cost</th>
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</table>

### Section 5: Support and barriers

19. Which are the key factors that have *advanced* consumer involvement in research in your Research Network?

20. And which are the key factors that have *hindered* consumer involvement in research in the Network?

21. What practical support would be useful to the Network (e.g. a national website with advice, training provision, shared learning events)
**Section 6: The ‘Consumer Research Panel’ model**

22. How much do you know about the Consumer Research Panel model for involvement in cancer research networks?
   - Please rate on a scale of 1 to 10, where 1 = ‘nothing at all’ and 10 = ‘everything’

23. In your view, how useful would the Consumer Research Panel model be to your network in advancing consumer involvement in research?
   - Please rate on a scale of 1 to 10, where 1 = ‘not at all useful’ and 10 = ‘extremely useful’

Any further comments

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Thank you very much for completing this questionnaire.

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Evaluation Reference Group

Description of Role/Terms of Reference

<table>
<thead>
<tr>
<th>Post</th>
<th>Consumer Member of Evaluation Reference Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duration</td>
<td>June 2004 to May 2006</td>
</tr>
<tr>
<td>Payment</td>
<td>Payment will be made for attendance at Reference Group meetings to the sum of £88.95 per meeting. Reasonable travel expenses will also be paid.</td>
</tr>
<tr>
<td>Training</td>
<td>The NCRN will provide training for Reference Group members.</td>
</tr>
</tbody>
</table>

Composition of the group
The group will consist of the Research Team (5), consumer members (6-8) and funder’s representatives (2).
Consumer members will be drawn from a range of forums that may include Cancer Network Patient Forum groups, Cancer Partnership Groups, National Cancer Research Network Consumer Liaison Group, and CancerVoices.

The working definition of consumer used for this project is that used by the Steering Group of the project ‘Development and Evaluation of a Collaborative Model for Consumer Research Panels in Cancer Research Networks’:

“…patients (previous or current), carers, or any member of the public who could be a potential user of the health system”

Purpose of the group
All members of the group will bring their own individual expertise as consumers, researchers, or funders. Consumer members will use their knowledge and experience to assist the research team in ensuring that the research remains in tune with consumers' concerns and needs.
This group is not a support group, pressure group or a representative body for consumers but rather group members act in an advisory capacity with regard the research project.

The consumer members are required to take a broad view of a variety of topic areas and research methods and have the confidence and experience to take an active part in the Reference Group meetings.

The main duties will involve having time and confidence to read documentation about the research and being prepared to reflect the views of consumers at the Reference Group meetings without representing a particular constituent group above others.

Attendance at the five planned Reference Group meetings is desired. Communication between meetings will take place by phone, e-mail or post.

The Reference Group will act as a mechanism to ensure the acceptable progress of the research. An essential role of the Group shall be to act as a forum for discussion and decision-making about the project design and methodology including: the selection of a typology of involvement to guide data collection and analysis, the selection of interview questions, methodological decisions such as the size and nature of interview samples, analysis, data interpretation and reporting, and the production of a strategy for dissemination.

### Principal Responsibilities

1. **To attend the planned research training session/s for consumer members**
   
   It will help prepare you for your work as a consumer member.

2. **To attend Reference Group meetings**
   
   Five Reference Group meetings are planned, the first meeting will be in June, and the timing of subsequent meetings will be negotiated. It is anticipated that the meetings will be held at a venue in London. Reference Group meetings are an opportunity to meet your fellow Reference Group Members and update yourself with current developments. We understand that people may be unable to attend all these meetings.

3. **To deal with the associated paperwork of the group**
   
   You may be asked to read certain paperwork before meetings. You may also be asked to give your opinion on documents between meetings.

4. **At group meetings**
   
   You will be asked to contribute to the discussion to ensure that consumer priorities, rather than individual or purely researcher priorities, are reflected,
and to ensure that the final decisions take into account issues of concern to consumers overall.

5. **Research role**
   It may be appropriate for you to draw upon your own experiences and knowledge to consider the responses gained from research participants and offer views about the relevance of accounts received and/or gaps in accounts obtained.

6. **Research input**
   You may like to discuss your own understandings and thoughts about the information gained by this research project. Your interpretations of this information are important and will be taken on board in the final analysis.

7. **Presentation of results**
   You can become involved in formal or informal teaching opportunities about the research if you feel comfortable doing so.

### Person Specification: Consumer Member of Evaluation Reference Group

<table>
<thead>
<tr>
<th>Factor</th>
<th>Essential attributes</th>
<th>Desirable attributes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Qualifications</strong></td>
<td>None</td>
<td></td>
</tr>
<tr>
<td><strong>Experience</strong></td>
<td>Direct or indirect experience of cancer services.</td>
<td>Committee/Group working experience. Links with consumer networks, associations, or groups.</td>
</tr>
<tr>
<td><strong>Special Skills</strong></td>
<td>Willingness to familiarise yourself with medical and research language.</td>
<td>To keep up to date with current research issues in this project.</td>
</tr>
<tr>
<td><strong>Specialist knowledge</strong></td>
<td>Knowledge of consumer perspectives.</td>
<td>To have an understanding of research.</td>
</tr>
<tr>
<td><strong>Personal qualities</strong></td>
<td>Good communicator. Ability to listen to others and express own views about consumer concerns in discussions.</td>
<td>Self confidence in a mixed group of professionals and consumers. Able to respond to challenging tasks. Experience of receiving fairly complex agenda papers and preparing for meetings.</td>
</tr>
</tbody>
</table>
Guidelines for working together

All members bring their own individual expertise and will work in active partnership with each other with mutual respect for their colleagues.

In all meetings there will be agreement that all those present will observe the following principles.

- Confidentiality will be agreed and respected.
- There will be respect for each person’s opinion and point of view.
- We will be non-judgemental and sensitive to each other’s experiences.
- All experience will be valued.
- One person will speak at a time and be offered the respect of being listened to.
- Everyone will be given the opportunity to participate.
- We will support and be honest with each other.
- If clarification is required it should be requested and provided.
- It is acceptable to disagree but should be done so within the above parameters.
Titles of local research studies (taken from National Research Register)

Studies identified with this symbol - $ - are listed NCRN portfolio studies

Studies identified in baseline period

Central South Coast
1. A randomised controlled trial to assess the cost-effectiveness of intensive versus no scheduled follow-up in patients who have undergone resection for colorectal cancer with curative intent (The FACS Trial)$
2. Gene expression profiles of acute leukaemia, plasma cell dyscrasia and MDS
3. The effects of Dexamethasone on the behaviour of young children with acute lymphoblastic leukaemia (ALL)
4. A study of Lymph Node Sampling in Colorectal Carcinoma Resection Specimens
5. Living with von Hippel Lindau disease (VHL): an exploration of this inherited condition utilising a grounded theory approach
6. Respect for patient autonomy: The anxieties surrounding disclosure and informed consent in the treatment of childhood cancer
7. The misdiagnosis of actinic keratosis as a squamous cell or basal cell carcinoma, comparing the clinical diagnosis with the histological findings
8. To determine the expression of Epstein-Barr virus related antigens in large B-cell lymphomas and relate this to their immunophenotype and morphology
9. A multicentre dose escalation study of irinotecan and carboplatin in chemotherapy naïve patients with extensive small cell lung cancer
10. An internal five arm randomised trial of carboplatin and paclitaxel versus triplet or sequential doublet combinations in patients with epithelial ovarian or primary peritoneal carcinoma
11. A phase III, randomized, multicentre, dose escalation, efficacy and safety study examining the effects of treatment with peginterferon alfa-2a in patients with Child's A or B cirrhosis in chronic hepatitis C virus infection
12. A study of the experience of living with secondary breast cancer$
13. A parallel double blind RCT to investigate the efficacy of an oral nutritional supplementation (Prosure) to prevent or delay the development of cachexia in patients with incurable solid tumour cancer
14. A quantitative survey to establish ward nurses’ understanding of the prevention and treatment of lymphoedema in patients who have breast cancer
15. Immunohistochemical expression of MLH1/MSH2 in right and left sided colon cancer
16. Expression of dystroglycan and dystrobrevin in head and neck cancer

Humber and Yorkshire Coast
1. Do nurses perceive cancer related fatigue as an important issue, and are they providing best support to these patients receiving palliative chemotherapy?
2. A prospective study measuring the hepatic vein transit times of patients undergoing treatment for metastatic colorectal cancer
3. A study to examine whether lymphoedema developed as a consequence of breast cancer treatment adversely affects quality of life
4. Investigation of IL-10 and IL-12 levels in patients with head and neck cancer compared with healthy subjects; relationship to disease stage
5. The Breathing Clinic study
6. The role of carbonic anhydrase IX in malignant melanoma
7. The effect of enhanced pre-operative information on patient recovery following colorectal surgery: a randomised controlled trial (Phase 1)
8. Genetic markers for recurrence in early breast cancer

Surrey, West Sussex and Hampshire
1. Evaluation of nurse-led follow-up service for women with gynaecological cancer
2. Exfoliated colonocytes in colorectal cancer screening and diagnosis
3. Scintigraphic, anatomical and physiological aspects that influence sentinel node detection by nuclear medicine imaging techniques
4. The role of the insulin-like growth factor (IGF) axis in prostate disease
5. Use of microarray technology to assess response of ovarian patients to chemotherapy involving existing standard and new cancer therapies
6. Quality of life assessment following cryosurgery of the prostate

Studies identified in follow-up period

Central South Coast
1. An audit of the management of sex cord - stromal testicular tumours in Wessex
2. Proteomic analysis in breast screening study. (A study to develop blood tests for use in breast screening programmes)
3. What factors influence illness behaviour prior to a diagnosis of lung cancer? A study to explore the experience of developing chest problems
4. The relationship between social support/isolation and colorectal cancer and the mediating role of biomarkers
5. A thematic analysis of semi-structured interviews using a phenomenological approach into palliative care patients experiences of 'fatigue' following treatment with methylphenidate - an exploratory study
6. A study to explore the information needs of patients when newly diagnosed with inoperable lung cancer
7. A study of the effectiveness of the "Macmillan Approach to Weight loss and Eating difficulties" (MAWE) in helping people live with advanced cancer
8. Assessment of aldehyde dehydrogenase in viable cells compared with viable CD34 7AAD cells in PBSC
9. A phase I/II trial of DNA vaccine with a PSMA27/pDom fusion gene given by intramuscular injection in HLA A2+ patients with prostate carcinomas with or without electroporation
10. A phase I/II trial of anti-CEA DNA vaccine (ACVA) with a CEA/pDOM fusion gene given by intramuscular injection in patients with carcinomas expressing CEA
11. Analysis of cell specific chimaerism following reduced intensity conditioning allogeneic stem cell transplantation for haematological malignancy
12. Cardio-protection against the toxic effects of anthracyclines given to children with cancer: A systematic review

Surrey, West Sussex and Hampshire
1. Genetic profiling of molecular alterations suitable to targeted therapies in metastatic squamous cell carcinoma of the head and neck
2. PGSNPS - Pharmacogenomics of Early Breast Cancer Chemotherapy
3. The role of Diet and Lifestyle in Survival after Breast Cancer
The North Trent Cancer Research Network
Consumer Research Panel

THE WORK OF THE CRP

The purpose of the CRP is to engage consumers, both cancer patients and carers, in the process of research into the causes, treatment and palliation of cancer illnesses.

Members of the CRP have helped with many aspects of cancer research. They sit on local and national committees which oversee the work of cancer researchers, are members of the steering groups for research protocols and clinical trials, offer advice on the day to day running of cancer units and the work of the professionals involved, and help produce better information and care for patients based on their own experiences. Most remarkably, some of our members are actively involved in the process of research from the planning of research, through the application for ethical approval, the data gathering and data analysis, to the authorship of articles in the research literature, and the translation of the research into clinical practice.

We are currently embarking on the ultimate step which would be for consumer research ideas to be fully worked up into clinical trials. We would hope that in the near future, some of the research ideas which have come from our members will be fully investigated and result in positive help and support for the dedicated staff and deserving patients in the health service.

David Ardron, CRP vice chairperson.
Central South Coast Cancer Network
Consumer Research Panel
Interim Terms of Reference

Purpose

To improve the way research is prioritised, commissioned, undertaken, disseminated and used by the theoretical and practical involvement of consumers with experience of cancer

Definition: Consumers are defined as Patients, Advocates, Carers, Campaigners and all those who use the Health services

Aims

The key aims of the panel are:

• To be the consumer voice in the development, monitoring and evaluation of cancer research projects both local and national
• To act as a consumer advisory body to professionals wishing to produce research proposals for areas of cancer research
• To act as a consumer advisory body to cancer, supportive and palliative care clinicians/researchers seeking to educate service users and the general public about cancer care issues.

Structure

The Panel will consist of 12 – 15 members at a maximum, and will meet monthly for the first six months and then review the frequency of the meetings.

Responsibilities

The key responsibilities of the Consumer Research Panel members will be:

• To participate in meetings, contributing to discussions, questioning professional representatives and contributing to decision-making debates
• To represent the consumer voice on research project design and planning committees
• To participate in training and mentoring new panel members and to actively promote the panel in study day and conference education programmes for professionals and consumer groups, both locally and on the national stage.

Formal decision-making will only be possible when there is a quorum of the panel. That quorum will be two-thirds attendance (this will not include the Secretary – a professional officer of the Committee).

New members will have a period of training and induction prior to formally participating in the activities of the Panel.

Officers of the Committee will be the Chair and Vice-Chair. The Chair and Vice-chair posts will be elected by the Committee, for a period of 2 years, with the option of a further term (2 years) if it is the wish of the Committee in quorate. Apologies will be required from Panel members who are unable to attend.

Key responsibilities of the Chair will be:
• To manage the agenda of panel meetings giving priority and timings to matters for discussion
• To lead the panel discussions and to facilitate decision-making, ensuring that appropriate levels of agreement are determined and recorded
• To represent the views and decisions of the panel in other forums, in particular at the Central South Coast Cancer Research Network Steering Group.

Secretarial and organisational support for the panel will be through the cancer Network user Involvement facilitator and the Lead Nurse for the Cancer Research for the Cancer Research Network. The Secretary will be responsible for the minutes of meetings and their dissemination in a timely fashion. In addition, the Secretary will circulate any documentation or presentational matter pertinent to meetings.

January 2005

For Review after 6 months
Humber & Yorkshire Coast Cancer Research Network (H&YCCRN)
CONSUMER RESEARCH PANEL (CRP)

HUMBER & YORKSHIRE COAST CANCER RESEARCH NETWORK
(H&YCCRN)

Dorothy Fagge    Jane Ash
Chair      Research Assistant
33, Main Street    Centre for MRI
Saxby All Saints    Hull Royal Infirmary
Brigg     Anlaby Road
DN20 0QF       Hull HU3 2JZ

Tel: 01652 618615    Tel: 01482 674076
Email: Dfagge@aol.com Email: Jane.Ash@hey.nhs.uk

Consumer Research Panel (CRP)

Terms of Reference

Purpose

To work in partnership to improve the way research is prioritised, commissioned, undertaken, disseminated and used by the theoretical and practical involvement of consumers with experience of cancer.

Who is a consumer?

A consumer is someone who uses health services.
Humber & Yorkshire Coast Cancer Research Network (H&YCCRN)
CONSUMER RESEARCH PANEL (CRP)

Aims

The key aims of the panel are:

- To save lives.
- To be the consumer voice in the development, monitoring and evaluation of cancer research projects both local and national.
- To act as the consumer advisory body to those wishing to produce research proposals for areas of cancer research.
- To act as a consumer advisory body to cancer, supportive and palliative care clinicians/researchers seeking to educate service users and the general public about cancer issues.

Structure

The panel will consist of a maximum of 12 members with an additional list of interested parties.

Responsibilities

The key responsibilities of the Consumer Research Panel members will be:

- To participate in meetings, contributing to discussions, questioning professional representatives and contributing to decision-making debates.
- To represent the consumer voice on research project design and planning committees.
- To participate in training and mentoring new panel members and to actively promote the panel in study day and conference education programmes for professionals and consumer groups, both locally and on the national stage.

Formal decision-making will only be possible when there is a quorum of the panel. That quorum will be a minimum of 5 persons of the group. (This will not include any professional officer of the Committee).

New members will have a period of training and induction prior to formally participating in the activities of the panel.

Officers of the committee will be the Chair and Vice-Chair. The Chair and Vice-Chair posts will be elected by the committee, for a period of two years, with the
Humber & Yorkshire Coast Cancer Research Network (H&YCCRN)
CONSUMER RESEARCH PANEL (CRP)

option of a further term (two years) if it is the wish of the committee in quorate. Apologies will be required from panel members who are unable to attend.

**Key responsibilities of the Chair will be:**

- To manage the agenda of the panel meetings giving priority and timings to matters of discussion.
- To lead the panel discussions and to facilitate decision making, ensuring that appropriate levels of agreement are determined and recorded.
- To represent the views and decisions of the panel in other forums, in particular at the Humber & Yorkshire Coast Research Steering Group.
Surrey, West Sussex & Hampshire Cancer Research Network

Partnership Research Panel

Terms of Reference

THIS DOCUMENT IS FOR GUIDANCE PURPOSES ONLY

Purpose

To improve the way research is prioritised, commissioned, undertaken and disseminated and used by the theoretical and practical involvement of consumers with experience of cancer.

Aims

The key aims of the panel within the Surrey, West Sussex and Hampshire Cancer Network are to:

• To be the consumer voice in the prioritising, development, monitoring and evaluation of cancer research projects both local and national

• To work with professionals participating in the basic and clinical research cycle for areas of cancer research

• To act as an advisory body to cancer, supportive and palliative care clinicians/researchers seeking to educate service users and the general public about cancer care issues

1. Structure

1.1 The Panel will consist of consumers affected by cancer, health professionals and researchers. The Panel will be comprised of no less than 50% consumers, and will have maximum of 35 members. Panel members will meet, initially, on a monthly basis. We hold a database of consumers who are registered to receive information about the panel, and will be invited to contribute at their preferred level of involvement. The Panel will serve for two years.

1.2 New members will have a period of training and induction prior to formally participating in the activities of the Panel. We aim to provide additional training based on individual needs for the Panel duration.

1.3 The key responsibilities of a Panel member will be:

  • to participate in meetings, and contribute to discussions, to question professional representatives and contributing to decision-making debates
  • to represent the consumer voice on research project design and planning committees
to participate in training, to mentor new panel members, to actively promote the panel in study day and conference education programmes for professionals and consumer groups, both locally and on the national stage.

1.4 Formal decision-making will only be possible when there is a quorum of the Panel. That quorum will be the eight Panel members (specifically 5 consumers) in addition to the Chair or Vice-Chair. Notification of meetings should be no less than 6 weeks, and allow non-attendees the opportunity to vote by proxy if required.

1.5 Officers of the Committee will be the Chair, Vice-Chair and Secretary. The key responsibilities of the Chair and Vice-Chair positions are as set out in the applicable role definitions approved by the Panel.

1.6 The Chair and Vice-chair posts will be consumers and elected by the Panel for a year.

1.7 The secretary will be a panel member and appointment will be approved by the Panel.

1.8 Two members of the Panel will attend the Network User Partnership Group that meets bi-monthly to share information and integrate with the wider network.

1.9 An Annual General meeting will be held to review the Terms of Reference, appointment of the Chair, and review progress.

2. Meetings and Secretariat

Meetings will be held at the Beacon Service, Gill Avenue, Surrey, GU2 7XX, unless otherwise stated on the agenda. Other venues may be required if the Panel are meeting cancer site-specific multidisciplinary teams, or other patient groups.

3. Financial Management

Consumer Panel Members will be paid at £7.00 per hour, £25 for half day or £50 for full day, in addition to travel expenses and parking. Any other pre-approved travel and subsistence expenses will also be reimbursed. The Panel will have no direct responsibility for the funds allocated to its functioning as a project. However, a financial statement should be offered by the Secretary bi-annually.

4. Code of Conduct

As a group
- we share our published Aims and Objectives;
- we run the group according to our members’ needs, in a clear and accountable manner;
- we welcome everyone equally, and we take steps to make the group open and accessible;
- we support and train our members;
- we make sure that everyone within the group understands and respects confidentiality and that individuals take responsibility for identifying information that must be kept within the group;
- we ensure everyone’s right to speak;
- we respect the opinions of others without criticism;
we listen to each other and respond with sensitivity;
we provide accurate and practical information;
we ensure when asked to give a view on behalf of the group, that it is truly the view of the
  group and not a personal view;
carers and professionals work in mutual co-operation and agree to respect any information
  shared to enable an open and safe environment;
we support each other.

5. Milestones

- To agree a strategy for the Consumer Research Panel by June 2005.
- To identify training needs of Panel Members and have a training programme in place by
  June 2005
- Annual General Meeting to be held in February 2006

6. Definition of Consumer

Usage of the term 'consumers' can result in some confusion. It has proven difficult to find a
name for people who become involved. Some labels come into fashion and are then rejected;
for example, early definitions often focused on what people were not –

  - 'lay people' were considered to be those who possessed no professional expertise
  - The term 'citizen' has also fallen out of favour, because it is considered by some to focus
    more upon legal rights than about individual perspectives
  - Usage of the terms 'customer' or 'client' have decreased because they do not seem to
    include any sense of partnership or collaboration.
  - The terms 'user', 'service user' or 'patient' are also unpopular with some people because
    they seem to imply dependency and sickness.

The term 'consumer' has become, by default, the most commonly used term and following this
general trend (as it encompasses current and past patients, carers, users, customers, clients
and supporters), the NCRI and the NCRN have adopted this terminology.