

**WE ARE  
MACMILLAN.  
CANCER SUPPORT**

## **Full report**

**A Macmillan Cancer Support report**

**The research priorities of people  
affected by cancer**

**Macmillan Listening Study  
Macmillan Research Unit  
University of Southampton**

The image features two silhouettes of people sitting on chairs and facing each other in conversation. The person on the left is a woman with a handbag on the floor next to her. The person on the right is a man holding a pair of glasses. The entire scene is rendered in a solid blue color.

**WE  
LISTEN TO  
PATIENTS**

**Cancer  
Experiences  
Collaborative**

**school of nursing  
and midwifery n+m**

## **Peer review**

To ensure that the findings from the research in this report are of sufficiently high scientific quality for publication the draft report was subjected to independent external peer review with six expert reviewers and three people affected by cancer. The authors amended the draft report in response to the comments made by the reviewers to the satisfaction of Macmillan Cancer Support.

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## **Macmillan Cancer Support's research programme**

This report is an output from Macmillan Cancer Support's research programme delivered by the Macmillan Research Unit at the University of Southampton. The University of Southampton is the administrative base for the NCRI Supportive and Palliative Care Research Collaborative entitled *Cancer Experience: Supportive and Palliative Needs, Problems and Solutions* (CECo). For more information about Macmillan's research programme please contact Dr Jim Elliott, Head of Research, Macmillan Cancer Support, 89 Albert Embankment, London SE1 7UQ, tel: 020 091 2020, email: [jelliott@macmillan.org.uk](mailto:jelliott@macmillan.org.uk)

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<sup>1</sup> The patient and carer co-researchers were consulted on how they wished to be named in reports, papers and other material related to the study. Their wish was to be acknowledged rather than listed as co-authors unless they had a particularly active involvement in the writing process. For the purposes of this report, members of the co-researcher team were involved in a reviewing capacity.

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# Lay Summary

**'It's not just about the actual tumour or the after effects of your operation, it's more, it's how you feel, whether or not you get depression, whether or not you're worried if it's going to go onto your family, all of that needs to be researched.'**

(quote from a participant)



**‘Living with cancer. Waiting for it to come back. Waiting for it to make you feel poorly. Waiting for it to make you feel poorly enough to no longer be able to live at home. And waiting for it to make you die... So, just a small study would be of enormous interest, I think, to the people who plan and deliver our care. It would help because it would start to deliver information that could apply pressure to the institutions and the organisations that deal with us in some way to change, or to work to a certain standard. Or to at least be aware that there are issues around how we all live with cancer.’** (quote from a participant)





## Patient priorities for research:

The research priorities of people affected by cancer as identified in the Macmillan Listening Study.

### Key findings

- Cancer patients identified the theme 'Impact of Cancer' as being the most important area for research from 15 other research priorities.
- The theme 'Impact of cancer' related to many concerns, including the psychological effects of cancer on patients and other people affected by cancer; the impact of cancer on everyday life and daily activities, and employment and financial issues.
- Other areas of interest included research into the risk factors and causes of cancer, and more research into the early detection and prevention of cancer.
- Patients are generally supportive of cancer research and are happy to take part in research, usually because they want to help others people affected by cancer.
- Patients typically thought of research in terms of lab-based studies and had little or no knowledge of other types of research.
- Some patients were critical of cancer research, feeling they had not been adequately informed about the process of research or study findings, that certain types of cancer, such as breast cancer, dominated research.
- Patients typically accessed information about cancer research through the media (newspapers, television, radio). Several were critical of media 'hype' and the impact this had on patients.

- Patients wanted better signposting to reliable and accurate information about cancer research.
- Patients and carers, with adequate support and training, can become valuable collaborators in the research process.

### Recommendations

- The National Cancer Research Institute should develop a formal strategy to access and respond to the views of people affected by cancer
- research information must be disseminated effectively to health professionals and members of the public
- a review of the current research evidence related to each of the research priority areas identified by patients is needed before specific areas of study are commissioned
- research into aspects of the impact of cancer on everyday life that has not been adequately researched to date should be supported
- the involvement of people affected by cancer in research activities should be encouraged and supported
- greater awareness of involving patients and carers in the research process to be promoted in academic institutions and research related organisations, such as Research Ethics Committees and Research and Development organisations.

**'That's the thing about research. We can participate just by being asked questions but do we know what happens to that information afterwards? Do we know how it is pulled together? Do we see it at the end? Do we know who it is going to? Do we know whether it does anything?'** (quote from a participant)

## Background and introduction

Macmillan Cancer Support commissioned and funded the Macmillan Listening Study to find out the research priorities of people affected by cancer. Data collection for the study began in August 2004. This report outlines the key findings from the study.

Patients and other service users are increasingly getting involved in developing and monitoring health services and in the conduct of health research. People affected by cancer are becoming more involved in the cancer research process through initiatives such as Consumer Research Panels and the NCRI Consumer Liaison Group.

However, involving people affected by cancer in setting the research agenda has remained poorly developed. This is significant as priorities identified by patients and others can enhance both public confidence and the relevance of research. Studies have also shown that the research priorities of patients may differ from those of clinicians. Furthermore, as cancer patients are the main focus for cancer research activity, they are one of the most important constituents for cancer research funding bodies.

## Research aims and objectives

### Aim

To undertake a national exercise exploring the views people affected by cancer have about cancer research and their research priorities

### Objectives

- To explore the perceptions people affected by cancer have about cancer research.
- To identify the cancer research priorities of people affected by cancer.
- To identify potential gaps in current knowledge about cancer, its treatment and care from the perspective of people affected by cancer.
- To provide a mechanism by which people affected by cancer can draw upon their experiences to comment on the direction of cancer research.

### Research methods

The study adopted a participatory approach. Cancer patients and carers were involved at all stages of the research process, from commenting on the overall design of the study to actively undertaking data collection and analysis with an experienced research team at the Macmillan Research Unit.

Data were collected through consultation groups held at 10 venues across all four UK nations. Sites included seven cancer centres, two hospice day care settings and a South Asian cancer support group. Consultation groups combined a focus group approach with a nominal group technique. The focus group approach allowed patients to



**‘My daughter died of a brain tumour nine years ago when she was 10 years of age and shortly after she died, I remember hearing a radio programme and it said we are celebrating 70 years of cancer research and I got so angry, I thought, “What do you mean celebrating 70 years and they haven’t come up with anything, they haven’t been able to save my daughter, where’s all these millions of pounds going?”, you know and it was just when I contracted the disease myself that I realised that there have been advances, you know, within the last nine years that probably that if she had been diagnosed today, she might have stood a better chance.’** (quote from a participant)

share their experiences of research and talk about their feelings and knowledge about research. The nominal group technique enabled patients to raise and prioritise research ideas.

Overall, 105 patients participated in 17 consultation groups. Twelve consultation groups were held with patients from a mixed background in terms of gender, disease type and stage of treatment, and five consultation groups were held with patients from under-researched groups (patients from South Asian backgrounds, patients receiving palliative care services and patients aged over 75 years).

## Knowledge and attitudes towards cancer research

Most participants had limited knowledge of cancer research. When asked what types of research they thought cancer researchers undertook, many participants referred to images of laboratory based research. Hence there was little awareness of other types of research, such as prevention or supporting people living with cancer.

Most patients obtained information about cancer research through the media (newspapers, television, radio or magazines). Patients also used the internet to retrieve information about cancer research or cancer in general. Several patients criticised what they saw as media ‘hype’ and the subsequent impact this had on people affected by cancer, particularly concerning stories about breakthroughs in treatment.

Participants were typically happy to participate in studies. The main reason for this was a sense of altruism - wanting to feel part of something that could benefit others in the future. Several patients

also felt that by participating in research, they would get a better overall standard of care.

Whilst most patients were supportive of cancer research, several had alternative views, questioning whether cancer research had really progressed very far or feeling pessimistic over the likelihood that there would be a cure for cancer. Participants who had been involved in research sometimes felt that they did not have any or adequate information concerning the details or results of the study or the research process. There were also criticisms of a perceived bias in cancer research towards more common types of cancer, such as a breast cancer, whilst other cancer types were somewhat neglected. Several participants were also critical of drug-company research, commenting on potentially conflicting interests and what they perceived to be an inappropriate profiting from cancer.

## The research priorities

Patients generated many research ideas and arranged them into 15 broad areas (Table 1). Patients voted on the areas they felt to be the most important and of these, ‘Impact on life, how to live with cancer and related support issues’, ‘Risk factors and causes’, and ‘Early detection and prevention’ were the highest priorities.

## Impact on life

The Impact on life was the top theme and relates to the impact cancer and treatment has on everyday life. This theme is very broad and encompasses nine areas including:

- psychological consequences (how cancer affects patients and those close to them psychologically, how to manage psychological problems, the influence of mental attitude on recovery)

**'It's not just about the actual tumour or the after effects of your operation, it's more, it's how you feel, whether or not you get depression, whether or not you're worried if it's going to go onto your family, all of that needs to be researched.'** (quote from a participant)

**'I think the money theme has to be there because, at the end of the day, we can't exist without finances and it is bad enough having cancer but there is probably only one thing worse than having cancer and that is having cancer with no money.'** (quote from a participant)

- support groups (evidence of their effectiveness and how to access them)
- aftercare (the need for improved aftercare as well as outcomes of care)
- the impact cancer has on daily activities (such as driving and travelling) and how these can be supported
- employment and financial issues (difficulty for patients gaining employment, re-entering the workplace or continuing work, the financial cost of cancer in terms of treatment, insurance and benefits)
- the impact of cancer on family members and friends
- pain management (and its impact on quality of life)
- diet in managing cancer (what is the evidence that healthy eating helps patients to live longer, what should cancer patients be eating?)
- general lifestyle issues in managing cancer (eg what impact does exercise or living in a family have on a patient?).

### Risk factors and causes

Risk factors and causes were voted the second most important area for research by patients. The interest with risk factors and causes related to four main concerns: the environment, genetics, diet and stress. Environmental concerns related to general concerns (eg air pollution, electricity pylons and nuclear power stations) and daily exposure to hazards (eg mobile phones, TVs and microwave ovens).

Rank	Key theme	Number of consultation groups in which topic received at least one vote [N=17]
1	Impact on life, how to live with cancer and related support issues	13
2	Risk factors and causes	12
3	Early detection and prevention	9
4	Research into general information needs (on cancer, treatment, research and access to)	11
5	Use and effectiveness of complementary and alternative therapies	7
6	General education of public about cancer	5
7	Research into different cancer and patient types	7
7	Research on treatment (curative treatment, treatment types and improvements)	5
7	Experiences and management of side effects	7
8	Organisation and funding of health and social care services	6
9	Coordination, impact and funding of research	4
10	Research into recurrence	3
11	General communication issues involving all parties	3
12	Accessing patients' views about cancer, services and research	2
13	Health and safety in the hospital	1

**'The hereditary thing is something that worries me and I think if that can be investigated ... the thing I find difficult sometimes to cope with is when my children or my daughter in law, I have three grandchildren and I have been questioned, 'Is this hereditary?' You know, I can't answer that question.** (quote from a participant)

**'A cure could be very expensive, lots of medical resources, but prevention, if you can nip a thing before it even starts, nip it in the bud, it's much better than having to go into hospital and maybe having major surgery and all the follow-up treatment that you need.'**

(quote from a participant)

## Early detection and prevention

Research into early detection and prevention was voted the third most important area for research. The role of primary care (especially general practitioners) in detecting cancer early was raised as a particular area of concern. The role of diet as a means to prevent cancer was also discussed. Patients discussed beliefs that certain food types may help to prevent cancer and patients wanted research to examine these claims.

## Other research areas

Other areas of cancer research included the following:

- research into information needs (relating to cancer, treatment, research and access to information)
- complementary and alternative therapies (their use and evidence of effectiveness)
- public education (how to educate the general public about cancer and early symptoms, and to correct the popular negative image of what it means to have cancer)
- research into different types of cancer (such as prostate cancer, rarer cancers) and different patient types (such as children)
- research into treatments (including more research into finding cures and improvements to current treatments)
- experiences and management of side effects
- research into how health and social care services are organised
- the organisation and funding of cancer research (eg the centralisation of research activity and whether more research should go into prevention or cure)

- recurrence (how to prevent it)
- communication issues (how to improve health professionals breaking bad news to patients, improving communication between health professionals and other health professionals, and how patients can communicate their diagnosis or prognosis to their families)
- how to engage with patients more effectively in the organisation and delivery of health services and research
- research into health and safety (eg MRSA).

## Conclusion

People affected by cancer have clear views about how and what research should be conducted. Even though patients may benefit from cancer research, it cannot be assumed that their views necessarily agree with those of the scientific community. Patients participating in the *Macmillan Listening Study* identified a broad range of research studies and have recommended potentially new and important areas of study. This study demonstrates that consulting with people affected by cancer is vital in ensuring that research addresses their needs and concerns.



# Executive Summary

## Aim

To undertake a national exercise exploring the views people affected by cancer have about cancer research and their research priorities.

## Objectives

1. To explore the perceptions people affected by cancer have about cancer research.
2. To identify the cancer research priorities of people affected by cancer.
3. To identify potential gaps in current knowledge about cancer, its treatment and care from the perspective of people affected by cancer.
4. To provide a mechanism by which patients can draw upon their experiences to comment on the direction of cancer research.

## Study purpose and context

Patient engagement in health research and shaping health services is recognised as an important and necessary activity both within the UK and internationally (Hanley *et al.*, 2004; Department of Health, 2006). Within cancer research, there have been moves to involve patients and carers in the research process, with initiatives including consumer research panels and the formation of the NCRI Consumer Liaison Group. However, the involvement of people affected by cancer in research prioritisation remains under-developed (Corner and Wright, 2004). This is significant given patient derived priorities can enhance public confidence and increase the relevance of research (Glass, 2001; Hanley *et al.*, 2004). In light of this, Macmillan Cancer Support commissioned and funded a UK wide public consultation exercise about the research views and priorities of people affected by

cancer, with the support of the NCRI.

This report presents the findings from the consultation exercise.

## Methods

An exploratory qualitative research design was used and consultation groups were the main method of data collection, combining a focus group approach with a nominal group technique (Krueger, 1994; Murphy *et al.*, 1998). The study adopted principles of participatory research and as such patients and carers were involved in the design and conduct of the study. Volunteers became patient and carer co-researchers and received training and support to co-moderate consultation groups with researchers from the Macmillan Research Unit and assist with the analysis.

Consultation group participants were identified from cancer clinics in seven cancer centres across all four UK nations, two hospice day care settings and one South Asian cancer support group. There were 105 participants who participated in 17 consultation groups across the UK. There were 12 consultation groups that were held with patients from a mixed background in terms of gender, disease type and stage of treatment, and five consultation groups were held with patients from under-researched groups (patients from South Asian backgrounds, patients receiving palliative care services and patients aged over 75 years).

## Key Findings

In consultation groups, participants were asked to talk about cancer research before identifying priority issues. In discussion many participants made reference to laboratory based research. Research into causes of

cancer and its treatment was typically cited as the focus of current research.

Many patients had been involved in research as participants. Although participants were generally supportive of cancer research and were happy to take part, often for altruistic reasons, some were critical of it, particularly when they had participated in research but had not been informed of progress or findings.

Participants had often accessed information about cancer and research through the media (newspapers, television, radio). However, they were critical of media 'hype' and the impact this had on patients. Participants were also critical of drug companies that appeared to inappropriately profit from cancer.

When asked for their research ideas, participants expressed clear views about their own priorities for cancer research.

## 1 The research priorities

The ranked lists of research themes identified in the consultation groups were combined, taking into account the ranked scores each theme received. The consultation exercise generated 15 broad research themes. Of the 15 themes, three accounted for most of the 'votes' cast and were therefore identified as the highest priority. These are 'impact on life, how to live with cancer and related support issues', 'risk factors and causes', and 'early detection and prevention'.

The top theme 'Impact on life' relates to the impact cancer and treatment has on everyday life. This theme is broad, encompassing nine areas identified as important for research, including: psychological consequences (the impact on the patient or others, the influence of mental attitude on recovery); support groups (evidence of their effectiveness) and after-care (the need for improved after care as well as outcomes of care). Other topics within

**Table 1: Research areas in order of priority**

Rank	Key theme	Number of consultation groups in which topic received at least one vote [N=17]
1	Impact on life, how to live with cancer and related support issues	13
2	Risk factors and causes	12
3	Early detection and prevention	9
4	Research into general information needs (on cancer, treatment, research and access to)	11
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11	General communication issues involving all parties	3
12	Accessing patients' views about cancer, services and research	2
13	Health and safety in the hospital	1



this theme include the impact cancer has on daily activities (such as driving and travelling), and employment and financial issues (difficulty for patients gaining employment, re-entering the workplace or continuing work, the financial cost of cancer in terms of treatment, insurance and benefits). Participants also felt there is a need for research into the impact of cancer on family members and friends. Symptom management was rarely discussed, although pain management was raised in several consultation groups.

'Risk factors and causes' is the second ranked priority area for research, incorporating four main areas of concern: the environment, genetics, diet and stress. Environmental concerns relate both to general concerns, such as air pollution, electricity pylons and nuclear power stations and daily exposure to hazards, such as mobile phones, TVs and microwave ovens. Common issues raised were the need for family members to be tested after a diagnosis of cancer and whether a cancer diagnosis was related to previous cancers in the family.

Research into 'Early detection and prevention' is the third highest priority theme. A particular area of concern includes the role of primary care (especially general practitioners) in detecting cancer early. Research into diet as a means of cancer prevention was also identified. Participants discussed beliefs that certain food types may prevent cancer and patients wanted research to examine these claims.

Other research priorities include: information needs (into cancer, treatment, research and access to information); complementary and alternative therapies (use and effectiveness); Public education (to educate the general public about early symptoms and to correct the popular negative image of what it means to have cancer); research into different types of cancer (such as prostate cancer) and different patient types (such as children); research into treatment (including more research into finding cures and improvements to current treatments); experiences and management of side effects and research

into the organisation and funding of health and social care services. Participants were also interested in the coordination and funding of research, discussing issues such as the centralisation of research activity and relative benefits of research into prevention or cure. Remaining areas of interest include: research into how to prevent recurrence; communication issues (involving patients communicating with their families as well as health professionals communicating with patients); how to engage patients in health services and research; and finally research into health and safety, with particular interest in MRSA.

## **2 Consultation groups with participants under-represented in research**

Priorities identified in the consultation groups with participants from the South Asian communities did not differ significantly from the priorities of the general consultation groups. However, the qualitative data about experiences and involvement in research did yield issues of note in relation to this particular ethnic group. In general, participants reported low levels of involvement in research, particularly clinical trials. Participants generally were confused about the term 'research' and had difficulty in identifying and recalling their involvement in studies. The effects of ethnic and cultural difference on the research priorities were most apparent in the priority given to herbal and Ayurvedic medicine and to food. Research into the importance of support groups and emotional support were also identified, although this needs to be seen in the context that the participants were recruited through a South Asian cancer support group.

The two consultation groups conducted with people receiving palliative care services also revealed that people at the end of life had similar research views and priorities to the general consultation groups. In one group, early detection and prevention was voted the highest research priority, while in the other, issues about research (eg. its impact, whether research should be focused more on prevention or cure) received the most votes.

Analysis of the qualitative data did reveal certain issues. For example, the impact of pain on quality of life and pain management were discussed, as was the importance of public education of the nature of hospice care, although these were not reflected in the final prioritised lists.

The consultation group with participants aged over 75 also yielded similar issues, including communication issues and the identification of the causes of cancer. The qualitative data also generated similar results as participants discussed a range of issues including causes of cancer (environmental and dietary), the role of self help groups, diet in the management of cancer and the psychological impact of cancer. It was notable that concerns for more research into prostate cancer were also raised.

## Implications and recommendations

Cancer patients participating in this study have clear views about what should be researched in the future. The views of participants in this study do not accord with the current proportion of spend on cancer research in the UK. Consequently, cancer research funding bodies should consider the perspective of people affected by cancer when developing future strategies for cancer research. There are some important recommendations for the conduct of cancer research. On the basis of these findings, we make the following recommendations:

- 1. The NCRI should develop a formal strategy to access and respond to the views of people affected by cancer** – The study reveals that cancer patients can make an important contribution to discussions about the research agenda. This study also indicates that patient priorities may not be adequately supported in UK, as indicated by the current proportion of NCRI funding. The NCRI should thus ensure that people affected by cancer are involved in decision-making about the future research agenda. The UK research portfolio should be diversified if it becomes transparent that the research priorities of people affected by cancer are unmet. The findings from the *Macmillan Listening Study* suggest that research into the Impact on life, how to live with cancer and related support issues, may be examples of these unmet areas. These areas have been identified by the NCRI as requiring development.
- 2. Research information should be disseminated effectively to health professionals and members of the public** – Researchers, academic centres and funding bodies should develop effective dissemination strategies to ensure that participants, clinicians and other interested parties have access to research information and that research findings are implemented through service delivery where appropriate. This can be done through newsletters, websites or public launches of findings. It should be understood, however, that not all participants wish to receive findings from studies, and thus information should be provided in accordance with their needs and wishes. Research commissioners and providers should ensure that, as far as possible, accurate, reliable and appropriate information is provided to the media. A UK-wide public dissemination strategy for cancer research may be of value.
- 3. A comprehensive appraisal of the current research evidence related to each of the research priority areas identified by patients is required before specific areas of study are commissioned** – This is necessary to assess the extent to which priorities identified by participants are under-researched (thus requiring targeted funding in the future), or are supported in the literature (thus requiring more effective dissemination and implementation in practice). Macmillan Cancer Support has already commissioned a comprehensive review of the top priority area (the Impact on life).
- 4. More research needs to be conducted into the top priority research area, the 'Impact of cancer'** – Efforts should be made to support more research into the top priority area, the Impact of Cancer. Research is particularly important for

aspects of this theme that have received little academic attention to date.

5. **Involvement of people affected by cancer in research activities should be encouraged and supported** – Active consideration should be given to supporting effective and appropriate involvement of people affected by cancer in cancer research. This involvement, however, places many demands on the research process. For example, sufficient financial resources need to be provided to enable effective training and support of co-researchers. Guidelines need to be developed to inform research organisations of best practice in user involvement. In order to support these guidelines, evaluations of user involvement activities and assessments of the ‘added value’ of involving people affected by cancer in the research process should be undertaken.
6. **User involvement in research requires facilitating in practice** – Involving people affected by cancer in research will generate procedural challenges. Ethics committees need to assess the impact involvement in research has on patients and carers who are involved as advisers and co-researchers. R & D organisations need to consider the implications of user involvement in research, such as the honorary contract status of patient and carer co-researchers. In addition, the NCRN research portfolio needs to be developed to reflect user involvement studies and related methodologies. The current system of data accrual does not reflect the demands placed upon research nurses and clinical staff in recruiting into qualitative studies. Qualitative studies typically require smaller numbers of participants than large scale clinical trials and may take longer to recruit participants into.

## Conclusion

People affected by cancer have clear views about how and what research should be conducted and can be engaged effectively in setting research agendas. Even though patients are the beneficiaries of cancer science, it cannot be assumed that their views are concordant with those of the scientific community. Thus consultation with people affected by cancer is vital to ensure that research addresses their needs and concerns. Participants in this study clearly want to see a broad range of research studies undertaken in the UK and have recommended potentially novel and important areas of academic inquiry.

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# The *Macmillan Listening Study*: Listening to the views of people affected by cancer about cancer research

## 1 Aim, objectives and introduction

### Aim

The aim of the study was to undertake a national exercise exploring the views people affected by cancer have about cancer research and their research priorities

### Objectives

The objectives of the study were to:

- 1 explore the perceptions people affected by cancer have about cancer research
- 2 identify the cancer research priorities of people affected by cancer
- 3 identify potential gaps in current knowledge about cancer, its treatment and care from the perspective of people affected by cancer
- 4 provide a mechanism by which patients can draw upon their experiences to comment on the direction of cancer research.

### Introduction

Decisions about where cancer research funds should be allocated are typically made by the scientific community (Corner and Wright, 2004). A comprehensive literature review

found no published examples of cancer patients having a role in deciding where funds should be directed for cancer research, ie identifying priorities for cancer research (Corner and Wright, 2004). We believe this is the first UK-wide study to attempt to listen to the views of people living with cancer about cancer research priorities. With the support of the National Cancer Research Institute (NCRI) the *Macmillan Listening Study* was commissioned and funded by Macmillan Cancer Support to explore the views patients have about research and identify their research priorities. An innovative participatory approach was adopted to identify the research experiences and priorities of people affected by cancer across the UK whereby patients and carers worked in partnership with the Macmillan Research Unit in Southampton at every stage of the research process. The priorities raised by the participants are documented in this report and these should be considered alongside those previously identified by academics and clinicians when developing the future UK cancer research agenda.

## 2 Background

Cancer represents a major burden on the population, patients and the National Health Service. Significant resources are spent each year on research into the causes, treatment and care of people with cancer. The NCRI, which brings together 19 of the largest cancer research funding bodies in the UK, has a collective spend in excess of £300 million per year (NCRI, 2004). This spend varies across areas of cancer research where cancer biology receives 43% of the annual funding allocation in contrast to only 3% of funds being spent on prevention (NCRI, 2004). The spend also varies by cancer type where research into lung cancer (affecting 14% of all cancer cases and with a high mortality rate) receives less than 4% of the collective spend compared with breast cancer (affecting 15% of all cancers and a relatively low mortality rate) receives over 17% of the total spend each year (NCRI, 2004; Cancer Research UK Information Resource Centre<sup>1</sup>; Cancer Research UK Information Resource Centre<sup>2</sup>).

Given the extent of cancer burden and the substantial investment in cancer research, it is important to assess the degree to which areas receiving funding reflect the breadth of experiences of people affected by cancer, particularly when a great deal of the investment in cancer research derives from charitable donations from members of the public.

### User involvement in cancer research

In recent decades, there has been growing awareness of the importance of involving service users both in the organisation and delivery of health services and in the conduct of health research (Tritter, *et al.*, 2003; Gattelleri, *et al.*, 2001; Evans *et al.*, 2003; Gott *et al.*, 2002; Boote *et al.*, 2002). The UK governments' commitment to user involvement is evident in recent whitepapers, such as *Choosing health* (Department of Health, 2004)

and *Our health, our care, our say* (Department of Health, 2006), both of which have resulted from extensive public consultation.

The trend towards greater user involvement has impacted on the conduct of research. The need for collaboration between patients, health professionals and academics in the conduct of health research has been highlighted by the Department of Health (Department of Health, 2000a). The Research Governance framework, for example, suggests that user involvement is central to good research practice and states that: 'Relevant service users and carers or their representative groups should be involved wherever possible in the design, conduct, analysis and reporting of research' (Department of Health, 2005: 8).

In 2004, INVOLVE published a guidance document illustrating the potential for service user involvement at all stages of the research process from identifying research priority areas to dissemination (Hanley, *et al.*, 2004). Numerous benefits have been identified in involving service users in research. These include: identifying research issues relevant to service users that may not be identified by asking academics or clinicians alone (Tallon *et al.*, 2000); assisting with the recruitment of participants into studies, particularly in providing access to participants from diverse ethnic minority groups (Katbamna, 1997); assisting in the dissemination of research findings (Hanley *et al.*, 2004). User involvement can also generate particular challenges, ranging from the financial cost and time required to support training and other activities, concerns with confidentiality where users have access to study data, the physical and emotional demands of involvement, and the provision of payment in such a way that does not have any tax or benefit implications (Wright *et al.*, 2006; Hanley *et al.*, 2004). These challenges require

effective management and appropriate training to ensure the quality of the research and welfare of the users involved in the study are not affected.

Despite the noted benefits of user involvement, such activity has remained under-developed until recently. A survey of clinical trial centres revealed that only 23 of 62 involved users in the design of studies (Hanley *et al.*, 2001) and only 42% of NHS providers receiving R & D Support Funding involved patients in their research activities (Buckland and Gorin, 2001). Funding organisations and medical research charities in particular fare better where 62% of those surveyed involved users (O'Donnell and Entwistle, 2002).

User involvement strategies in UK cancer research organisations have also been somewhat limited. This is in contrast to organisations outside the UK that have been successful in involving people affected by cancer in research and more specifically in setting research priorities. The US National Cancer Institute, for example, has involved advocacy groups in advising national research agendas through their representation on 'Progress review groups'. Similarly, the National Breast Cancer Foundation of Australia has undertaken a national cancer research prioritisation strategy through consultation with patients, members of the medical and scientific community and policy makers.

It is interesting to note that a study conducted by the US National Cancer Institute found that while patients and members of the public supported cancer research, many felt they had little access to research information and were critical of how research priorities were determined by scientists (Jenks, 1997). In 2001, the NCRI recognised the need to improve the public image of cancer in the UK and suggested that a greater involvement of users in setting the research agenda would accomplish this (Glass, 2001). In 2002, the Macmillan Research Unit at the University of Southampton undertook a telephone / online survey of the then 15 NCRI member organisations and 20 non-cancer specific medical research bodies (Corner and Wright,

2004). The survey examined how priorities for funding cancer research were determined and identified whether users were involved in this.

Only five NCRI members consulted with service users in setting research priorities. Those that did access users' views employed a range of strategies. The Scottish Executive Health Department, for example, consulted with patient representatives to develop their research strategy through 'Portfolio steering groups'. In contrast, several of the non-cancer funding bodies had developed sophisticated means of user involvement. The Alzheimer's Society, for example, established the Quality Research in Dementia Advisory Network, divided into 13 regions in England, Wales, Scotland and Northern Ireland, each involving a co-ordinator and a maximum of 15 participants (Corner and Wright, 2004).

Recently, there have been advances in user involvement in cancer research with initiatives such as the Consumer Liaison Group of the National Cancer Research Network (NCRN) and the development of Consumer Research Panels by the NCRN and Macmillan Cancer Support. Similarly, the Supportive Care and Psycho-oncology Research Group based within the North Trent Cancer Research Network provides an excellent example of how users can be involved in the research process (Stevens *et al.* 2003). In this network, open consumer conferences, representation of consumers on project steering groups and the establishment of a Consumer Panel for Research enabled a greater awareness of and involvement in research.

### **Priority setting in health research**

Health research priority setting exercises have typically involved health professionals to the exclusion of service users (Tierney, 1998). It has been suggested that economic constraints in the UK have resulted in a preference for cost-benefit analyses above patient-derived prioritisation methods (Stewart, 1995; Liberati, 1997). However, the priorities of users have been shown to differ from those of professionals (Bartlett, 1999; Fisher, 2002; Tallon *et al.*, 2000). For example, Tallon *et al.*

(2000) found a mismatch between health professional and user priorities in osteoarthritis where GPs prioritised surgical success rate research in contrast to patients who prioritised physiotherapy and complementary medicine. Consequently, as Tierney suggests, priorities 'need to respond to the professionals' agenda but they also need to be congruent with priorities for healthcare research in general, which, in turn, must respond to the needs of healthcare systems and the populations served' (Tierney, 1998: 18).

INVOLVE have cited many reasons why it is important to involve service users in research priority setting and research more generally, commenting that service users may offer different perspectives from those of professionals, that service-user derived priorities are more likely to be of importance to the general public and therefore to healthcare, public health and social care services as a whole, and that public involvement can help to ensure that resources are focused on research that is of relevance (Hanley *et al.*, 2004).

Traditionally, priorities for investment in cancer research in the UK have been determined by individual funding bodies, often involving the scientific community. In 2001, the National Cancer Research Institute (NCRI) was established and brought together the major research funding bodies to agree a collective strategy for cancer research in the UK. However, questions about the nature and breadth of the research portfolio have been raised, as well questions about how patients can be involved in setting the strategic direction for research.

Our review, completed in 2004, found no peer reviewed published accounts of priority setting exercises for cancer research involving patients, although there was an extensive literature on priorities set by professionals (Corner and Wright, 2004). Common strategies for prioritisation included the use of Delphi techniques (a group process that involves written responses to a series of questionnaires) (Cawley and Webber 1995; Hinds *et al.*, 1990; Funkhouser and Grant, 1989) and individually

completed questionnaires (Bakker and Fitch, 1998; Ropka *et al.*, 2002). Priorities resulting from such studies are varied and include the following areas:

- outpatient and home care research (Fochtman *et al.*, 2000)
- physiological responses to cancer treatment, especially chemotherapy (Oberst, 1978)
- the measurement of quality of life and late effects of treatment in long-term survivors of childhood cancer (Hinds *et al.*, 1994)
- strategies to allow nurses' time to provide emotional support to cancer patients and carers (Barrett *et al.*, 2001)
- the early detection of cancer (Ropka *et al.*, 2002)
- symptom management (Bakker and Fitch, 1998)
- quality of life issues (Mooney *et al.*, 1991)
- risk reduction / screening (Stetz *et al.*, 1995).

Kreiger *et al.* (1999) used statistical information related to cancer to inform research priorities while Weinstein (1983) determined research priorities through cost-effectiveness analysis. It is evident from this literature, therefore, that while much is known about health professional research priorities, the research agenda of service users remains under-developed.

## **Involving patients in health research priority setting**

The involvement of patients in determining research priorities in areas other than cancer has become more common in recent years (Oliver *et al.*, 2004). Researchers have used a variety of techniques to elicit the views of patients. Johanson *et al.* (2002), for example, used a consensus conference to identify the research priorities of patients and health professional groups. The National Centre for the Coordination of Health Technology Assessment identified the research priorities of users through a series of meetings in which ideas were voted upon by attendees (Oliver *et al.*, 2001). Research charities and patient advocacy groups have also involved patients in setting research priorities. The Multiple

Sclerosis Society and the Alzheimer's Society have successfully involved their members in setting research priorities through the distribution of questionnaires. The Alzheimer's Society distributed questionnaires listing research questions to members through a newsletter. Members then score their priorities and a Delphi approach is used to finalise the priorities (Corner and Wright, 2004).

O'Donnell and Entwistle (2002) reported that of the research funding organisations that involved service users (62% in total), 67% of them consulted with patients to identify priorities/topics for research. Increasing activism within user groups, particularly in the US, has ensured that the priorities of patients are being heard. Organisations such as the National Breast Cancer Coalition are now effective in directing and commissioning research (National Breast Cancer Coalition website).

Several commentators have suggested there are difficulties associated with the involvement of service users in prioritisation exercises. Dicker and Armstrong (1995), for example, suggest that service users do not wish to set priorities and believe that priority setting should be left to health professionals. Graham *et al.* (2000), however, indicate that this reticence may be the result of a failure to develop a rapport with patients.

It has also been suggested that service user groups are too diverse in terms of values and experiences to enable the forging of a consensus view of priorities (Gaminde, 1999). Ignoring these differences can lead to the prioritisation of the views and preferences of dominant groups above marginalised sections of society, such as older people and ethnic minorities (Dolan *et al.*, 1999; Holm, 1998; Barnes and Bennett, 1998). Challenges may also occur as a result of service users not having enough technical expertise to assess healthcare priorities (Tebensel, 2002). Consequently, many organisations offer training for service users/ patients to assist them in considering health research ideas (Oliver *et al.* 2001). Oliver *et al.* (2004) suggest that any exercise that attempts to involve service users in setting a health

research agenda needs time and resources, as well as appropriate skills and working practices through which priorities are set. As the involvement of users in setting research priorities is an emerging field of study, any work that seeks to do this inevitably contributes to the growing literature documenting effective ways of supporting such activity (Oliver *et al.*, 2004).

### **Participatory research: research in collaboration**

Participatory Research is a truly collaborative approach that seeks joint ownership of research and the involvement of the participants at every stage of the research process from formulating questions and designing a research plan to collecting and analysing data (Beamish and Bryer, 1999b; Higgs *et al.*, 2001; Chappell, 2000; Lindsay and McGuinness, 1998).

Participatory research is seated in many different philosophical traditions but has at its core the principle of research as a democratic process in which participants occupy an active citizenship status within the study (Reason and Bradbury, 2001). Here, there is a blurring of the roles of the researcher as an unobtrusive and 'objective' observer not influencing the behaviour of the research subject and the participant being involved in the study only through the invitation of the researcher (Beamish and Bryer, 1999). Participatory research has often been used in research with marginalised communities due to its emphasis on giving voice to those often excluded from the research process.

Given the interest in the views and priorities of people affected by cancer, it was felt appropriate to involve cancer patients and carers in the design and conduct of the study. More than this, it was felt important to adopt a model of co-ownership with cancer patients and carers. In this regard, it was hoped that the data collected in the study would be richer and more resonant with the views of participants given that teams of professional researchers did not moderate the discussions alone. In line with many participatory research

studies, a participatory research group was established to guide and inform the research process. Numerous models of Research Groups exist, and it was decided to form a 'user reference group' comprising cancer patients and carers recruited primarily through the patient forums of UK Cancer Networks (as discussed in the next section) (Wright *et al.*, 2006).

While Participatory research shares many of the advantages that involving users brings (eg ensuring that the research is relevant to participants and increasing participation rates), a number of difficulties have been noted. Participatory research is a costly venture both in time and money, and funding bodies are more likely to fund conventional methodologies (Winter *et al.*, 2001). Ethical problems can also exist, particularly where participants, who felt supported by the study, can feel abandoned once the research is completed (Northway, 2000). Consequently, participatory research requires careful planning and sustained effort if it is to be effective and if those involved are to feel confident and supported in influencing the direction of research.



## 3 Methods

### Study organisation

Three groups were established to assist with the running of the study:

#### The steering committee

The steering committee consisted of Macmillan Research Unit researchers, representatives from the NCRI member organisations and chairs of community organisations.

Organisations were selected to offer a broad range of perspectives in terms of cancer types, research areas and user involvement expertise. These included representatives from the NCRI, Cancer Research UK, Breakthrough Breast Cancer, the National Cancer Research Network, South Asian Palliative Care Awareness, Breast Cancer Care, CancerBacup, The Prostate Cancer Charity, the Patient Involvement Unit – NICE, and Macmillan Cancer Support. Two patient and carer representatives involved in other groups in the study were also involved (MS and MG). MS was selected as a carer representative and had extensive experience of user involvement and had been involved in data collection and analysis. MG was selected as a patient representative and also had extensive experience of user involvement and had been an adviser for the study through the user reference and co-researchers groups. The committee ensured that the project was designed appropriately and effectively and met regularly to advise on the design and progress of the study, the interpretation of results and the dissemination strategy of the findings.

#### The methodology review group

The methodology review group was established to provide peer-review of the study. The committee was composed of three members, one with international recognition of expertise in research methods and two with expertise in user involvement. The group advised on the

original study proposal and helped to ensure the rigour of the data and the effectiveness of the user involvement strategy.

#### The user reference group

In line with participatory research, the 'user reference group' was established to advise on the study design. A two-phase process was used to recruit members into the user reference group. First, all patient forums in each of the then 40 cancer networks in the UK were contacted requesting volunteers to take part in the research (the Cancer Network in Northern Ireland was not established at this time). Twenty-five people took part in the meeting, of whom 11 were male and 14 were female. While the majority of representatives were patients, three were involved in a caring capacity. The user reference group members also represented a range of cancer types, rather than predominantly coming from similar backgrounds, eg breast cancer.

At the meeting, however, it was evident that certain population characteristics were not represented in the user reference group. There were no representatives from minority ethnic backgrounds or from people in the palliative stage of their illness. Thus three additional members were approached directly: one representative from a minority ethnic group was contact through a national cancer organisation and two patients receiving palliative care services were identified through one of the participating hospices, identified and approached in collaboration with the clinical team.

The user reference group meeting was coordinated by the project researchers and members were given an outline of the proposed study design, patient information sheets and a proposed list of consultation group questions. This provided user reference

group members with sufficient material to allow them to understand and comment on aspects of the research design before it was finalised and submitted to the Multi Centre Research Ethics Committee.

### The patient and carer co-researcher group

Volunteers were requested from the user reference group to establish a patient and carer co-researcher group. Ten patients and carers volunteered and subsequently this increased to 15 co-researchers to include previously unrepresented groups (eg those from minority ethnic backgrounds and those in the palliative stages of cancer). Of the 15 co-researchers, two were receiving palliative care services, two were from minority ethnic backgrounds and one was a carer. Patient and carer co-researchers were involved from across the UK, including the South of England, the North of England, Wales and Scotland.

The patient and carer co-researchers received training and support to undertake data collection and analysis with the Research Unit team. The patient and carer co-researchers met over the course of the study to continue training, to share experiences of data

collection and to reflect on findings from the data (Wright *et al.*, 2006). Table 1 illustrates the involvement of each of the patient and carer co-researchers in the study.

### The research design

An exploratory qualitative research design was adopted for the research priority setting exercise. The exploratory nature of the study was significant given that no other studies have examined the views and priorities of patients and carers in this way. Consultation groups were the main method of data collection, which combined a focus group approach with an amended nominal group technique (Krueger, 1994; Kitinger, 1995). A focus group approach informed part of the consultation group design as it can: allow participants to generate their own ideas rather than responding to those set by others; enable researchers to follow up, clarify and elaborate on topics raised by the participants; and encourage participants to develop research ideas by exchanging thoughts/opinions and experiences in a group setting. Extensive training of the patient and carer co-researchers was necessary to ensure that the moderator avoided asking 'leading questions', would encourage reticent participants and ensure that the views of more confident participants would not dominate the discussion (Wright *et al.*, 2006).

An amended nominal group technique (NGT) was also adopted in an effort to achieve consensus over research priorities. NGTs were developed by Delbecq and Van de Ven in 1971 to aid community decision-making and are particularly helpful in generating ideas in situations involving individuals with diverse views (Delbecq and Van de Ven, 1971; Murphy *et al.*, 1998). These techniques also allow participants to raise views and opinions in a manner protected from the direct rejection of other participants (Wellings *et al.*, 2000).

NGTs have been successfully applied to various areas of health research (Telford *et al.*, 2004; Campbell and Cantrill, 2001) and are usually conducted in the following manner:

Co-researcher	Study Tasks		
	Advise on study	Data collection	Data analysis
EP	•	•	•
FW	•	•	
GS	•	•	
HB	•	•	
JB	•	•	
JF	•	•	
JS	•	•	•
JW	•	•	•
MG	•		
MM	•	•	
MS	•	•	•
NF	•	•	•
NM	•	•	
SJ	•	•	
VF	•		•

- 1 Each participant records his or her ideas independently and in private.
- 2 Ideas are shared and listed where one idea is collected from each individual and then listed in front of the group by the facilitator.
- 3 The process is repeated until all ideas have been listed.
- 4 Each idea is discussed by the group.
- 5 Individuals record their judgements or vote on the ideas independently.
- 6 Further discussion and voting may take place.

Typically participants are asked to identify issues before attending the NGT session. It has been suggested, however, that it is inappropriate to undertake such a preliminary exercise with participants who may share potentially sensitive information (Aspinal *et al.*, 2006). Hence it was decided to modify the process due to the particular circumstances of study participants.

## Participants

Potential participants were identified for most consultation groups across a range of radiotherapy, chemotherapy, general and cancer site specific clinics. Where possible, participants recruited through the hospital trusts were approached by NCRN research nurses. Where this was not possible, other members of the clinical team identified and approached potential participants. Participants receiving palliative services were recruited into two consultation groups from hospice day care settings where the initial approach was made by a member of the day care professional team. It was anticipated that participants from diverse ethnic backgrounds would be recruited from hospital trusts for a series of consultation groups. However, the research nurses at those sites concerned felt unable to recruit sufficient numbers. A common reason given was that they felt they saw too few patients from these backgrounds in their clinics. Consequently, participants had to be recruited through one South Asian cancer support group and invited to participate by an employee of the organisation.

Patients were excluded from the study if they were: under the age of 18, or deemed by the research nurse or other member of the clinical team to be too unwell, have complicating health factors (eg severe mental illness) or liable to be distressed by study participation.<sup>2</sup> All other potential participants over 18 years were invited to participate. A maximum of twelve participants were recruited into each consultation group. The research nurses and clinical team members were given a sampling matrix based on gender, disease type and stage of treatment (in treatment and one to three years post-treatment) to guide recruitment. It was made clear that previous involvement in research was neither a prerequisite or a barrier to participation and that nurses must approach all potential participants meeting our broad inclusion criteria.

Patients stating an interest in participating in the study were given an information sheet and a 'consent to approach' form. This form gave members of the Macmillan Research Unit permission to contact the potential participant at home for their final decision about participating. Serial 'consent to participate' was obtained at the consultation group. The study was approved by the South East Multi-Centre Research Ethics Committee and complied with all R & D requirements at participating sites.

## Consultation groups

Two types of consultation groups were held: those with participants from mixed backgrounds in terms of gender, cancer types and stage of treatment and those with participants from under-represented backgrounds, such as South Asian participants, people receiving palliative care services and patients aged over 75 years. The purpose of these groups was to increase the representativeness of the findings rather than provide the basis for comparative analyses. Each consultation group was co-

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<sup>2</sup> Attempts were made to hold consultation groups with participants aged between 13 and 19. However, it proved difficult to recruit participants into the groups. This was for various reasons, including the site from which potential participants were approached served a large catchment area and thus the distance to the groups discouraged patients.

facilitated by a member of the Macmillan Research Unit and by a patient/ carer co-researcher. Another patient/ carer co-researcher acted as an observer at most consultation groups, detailing such issues as observations on the quality of the group discussion (eg dominant or reticent participants), and highlighting key issues emerging from the discussion. The question schedule was developed in full consultation with the user reference group, steering committee and the patient/ carer co-researchers and was piloted by the co-researchers (Appendix II).

Careful consideration was given to support participants in generating potential areas of research in the consultation groups. It was recognised that this could be a challenging task for many participants given their variable levels of prior involvement in research and relatively limited knowledge of cancer research. The structure of the consultation groups was influenced by Krueger's model of focus group questioning (1994). The groups began with introductory questions, asking participants to discuss previous involvement in research and how they accessed research information. This allowed an accessible and non-challenging introduction to discussions about research. During this process, if participants had a particularly biomedical view of research, they were encouraged to think about other areas of research that were currently being undertaken. Transition questions were then asked where participants were encouraged to discuss their general understanding, knowledge and perceptions of cancer research. This enabled participants to focus their thinking about cancer research.

Key questions and tasks related to the nominal group technique section of the discussion and involved participants writing research topics they felt to be important on 'post-it' notes. These were read to the group, and participants were asked why they felt these ideas were important for research. Other participants then read out similar ideas or questions, thus grouping the post-its into different research areas. These research areas were then assembled onto boards and each participant was given three votes with which

to identify independently the research area they felt to be most important. They were allowed to use all their votes for one research area, two votes for one area and one for another, or one vote for three separate research areas. Voting therefore served as an indication of the relative importance of research ideas. Hence a research area not receiving any votes in a consultation group did not mean it was unimportant to participants, but rather that they thought other research areas required greater attention.

Closing questions were then asked where priorities identified through the voting process were fed back to the group and discussed. This provided an effective summary of the discussion and also allowed additional views not covered in the consultation group to be raised. A short questionnaire was given to all participants at the end of the consultation group discussions in which experiences of taking part in the group and further ideas arising after the group could be documented. Each consultation group was audio-recorded and transcribed verbatim. All names were replaced with pseudonyms and identifiable details removed. Two data sets were collected: the consultation group transcript and a ranked list of written research ideas and priorities resulting from each group.

### **The analytic process**

Both data sets were subjected to thematic analysis (Strauss, 1987). For the tables of research priorities, this involved grouping and 'naming' all the ranked clusters of research topics generated in the consultation groups. The lead researcher (DW) analysed all 17 tables of ranked priority areas in this manner and collectively all the tables were then independently assessed by two other members of the research team (CF and IO) and tables of priorities were given to five patient / carer co-researchers for independent analysis (four involved in data collection and one not) (EP, MS, JS, JW, VF). Where research ideas were unclear, transcripts of the consultation group discussions were referenced for clarification. Appendix III provides an example of thematic analysis conducted on one consultation group

priority table. With few exceptions, there was close agreement between the independent analyses. Substantive differences were resolved by referring to the full consultation group transcript, meeting with the independent analyst and mutually agreeing on an appropriate name for the cluster.

The ranked lists of research themes for the 17 consultation groups were combined using the ranked scores of each theme per group. The ranked scores within each consultation group have a possible range from one (for the research theme receiving the fewest votes) to six (for the research theme receiving the most votes). Six was the maximum number of research themes identified by the vote casting exercise in any consultation group). Therefore, the highest score possible from this exercise across all 17 groups is 102 for any given theme (six points x 17 consultation groups = 102).

The lead researcher analysed all consultation group transcripts and six were independently analysed by two researchers (YG and IO). A process of progressive focusing occurred whereby topics identified through a reading of the interview transcripts were clustered into a set of emerging themes (Hammersley and Atkinson, 1989). After this, the range of responses relating to individual themes was identified and then organised into sub-themes and written up. The analyses were compared and again, with few exceptions, there was close agreement. Sample transcripts were also made available to co-researchers. Data were managed and retrieved using the NUD\*IST 6 software.

## 4 Findings I: Participant characteristics and attitudes, knowledge and experience of research

### Participant characteristics

A total of 17 consultation groups were held across the UK. Twelve consultation groups were held with people from mixed backgrounds. Five consultation groups were held with patients from often under-represented backgrounds; two consultation groups with participants from South Asian backgrounds conducted in English, Hindi and Gujarati; two consultation groups with people with advanced cancer; and one consultation group with people aged over 75 years.

In total, 105 participants took part in the study with a median of six (range three-11) participants in each consultation group (Table 2). One fifth of eligible patients approached ultimately participated in one of the groups. Reasons for refusal included non-availability and not wishing to share views in a group. Men were more likely to decline, often citing a reluctance to discuss issues in a group setting. A third of participants were male (n=33, 31.4%) and participants had a range of cancer types and sites and ages. Twelve participants were from Black African, Black Caribbean and South Asian ethnic groups. A total of 14 participants took part in the study from the two hospices, although patients in the palliative stage of illness also took part in other groups. Nearly a quarter of the participants were on active treatment while three quarters were off active treatment (including patients in the palliative stage of their illness).

### Attitudes, knowledge and experience of research

#### Involvement in research

Forty-six participants (43.8%) self-reported that they had been involved in research before taking part in the *Macmillan Listening Study*. Almost all of these had been involved in clinical drug trials, although some participants were involved in other types of research such as other trials (involving surgery, care and vitamin supplements), genetic research, a lifestyle impact survey, a side effect management study, an information needs study, and a screening study. While most participants who were involved in research were able to discuss the nature of the studies in detail, it was evident that for a minority, there was uncertainty as to the purpose of the research they were taking part in:

'The trial, I think well it's taken out of doctor's hands more or less to say what treatment or what the operation would involve then, you know... I'm not sure where I came in that, but I remember something about the trial and I remember signing something.' (Yvonne, CG1)

For most people, the predominant reason for taking part in research was to help others in the future, as explored later. Occasionally, however, patients gave alternative motivations for participating. Zoe, for example, took part in a drug trial because it gave her access to treatment otherwise unavailable. As an ovarian cancer patient receiving palliative treatment, she agreed to participate as she wanted to take anything that could potentially benefit her:

<b>Table 2: Participant data</b>		
Gender:	Male	N = 33 (31.4%)
	Female	N = 72 (68.6%)
Age:	30-39	N = 4 (3.8%)
	40-49	N = 10 (9.5%)
	50-59	N = 25 (23.8%)
	60-69	N = 28 (26.7%)
	70+	N = 23 (21.9%)
	Missing*	N = 15 (14.3%)
Tumour site:	Breast	N = 22 (21.0%)
	Gynae	N = 23 (21.9%)
	GI	N = 19 (18.1%)
	Prostate	N = 4 (3.8%)
	Haematological malignancies	N = 8 (7.6%)
	Lung	N = 9 (8.6%)
	Other	N = 6 (5.7%)
	Missing*	N = 14 (13.3%)
Treatment information:	Number on treatment	N = 17 (16.2%)
	Number off treatment	N = 58 (55.2%)
	Missing*	N = 16 (15.2%)
	Palliative (hospice)	N = 14 (13.3%)
Number approached:	An audit of recruitment was undertaken in six participating centres. Across these sites, 379 patients were approached of which 155 (40.9%) declined to participate at the first approach, 144 (38.0%) consented at the first approach but later declined or did not attend, and 80 (21.1%) participated in the consultation groups.	
<p>*Missing data is a result of a range of factors including: data not being held at the participating site (such as the support group) or because participating sites were unable to provide the data. Much of the data is missing as a result of the consultation groups with participants from diverse minority ethnic backgrounds ultimately having to be recruited outside hospital trust settings. As we did not have ethics clearance to collect this data from participants directly and the South Asian cancer support group did not hold this information, this data had to be reported as missing.</p>		



'All you think about is living really... I was told that it was terminal, there was a mass and literally they gave me weeks or months to live... So, when I had an operation and they offered me chemo, you're just grabbing. Because, with the trials, you are a bit, "Should I or shouldn't I"... so you think, well "nothing ventured, nothing gained", so grab at anything.' (Zoe, CG17).

Several participants had to withdraw from studies or were unable to participate in research. In most cases, this was due to adverse side effects in clinical drug trials, although one participant could not take part in a study, much to her frustration, as she was aged over 60. Nigel, however, withdrew from a trial as he was 'fed up with tablets', had 'misgivings about [cancer research] charities', and was concerned about the medication he was taking – Thalidomide (CG12). However, Sita declined to take part due to a fear of taking other medication:

'They were going to change the drug, you know, if I can have that drug. For my breast but I didn't want to have that... Because I was just scared you know. I just wanted to stay on the Tamoxifen.' (Sita, CG15)

Most participants were happy with the studies they were involved in, although some were critical of specific aspects of the research. One participant commented on her surprise at the length of time it takes for research to be completed while two participants, both taking part in separate lifestyle impact questionnaires, were critical of the nature of the questions asked:

'The thing that bothered me was in the last week, it used to say "Have you been able to walk, such and such, in the last week?". Now the previous two weeks I had probably been flat on my back in bed but in the last week I was fine, so that is a false report really isn't it?' (Audrey, CG17)

## Knowledge of research

Many participants had limited knowledge of cancer research. When asked what types of research they thought cancer researchers' undertook, many participants referred to images of laboratory based research. Kevin's response was typical of many:

**Facilitator** Think back about research and first of all, if I ask you to think about what you think cancer researchers do, what sort of image does it conjure up in your mind?...

Kevin An Einstein sitting in a lab and a chemical lab adding that to that. Looking at genetics... That would be mine. A little Einstein, you know. Doing all these tests and coming to the Eureka moment. (CG17)

Most participants cited biomedical types of research, particularly research into causes and treatment. In relation to causes, different examples of causative research were given including environmental, dietary and hereditary causes:

'I think... that [research is] going into the actual cancer to find out what the actual cancer is so that it can be researched and treated. Then after, obviously after it's been found what the cancer is or what type of disease it is, then to find a treatment which is good enough to treat it promptly'. (Michael, CG1)

Research into cancer treatment was also commonly cited as an area of research activity, particularly curative research: 'I'd imagine that the majority of the research goes into new drugs and maybe a smaller part into the causes of different cancers' (Ann, CG1). Other examples of ongoing research were less frequently cited and included research into screening and early diagnosis, prevention, complementary and alternative therapies and supporting people living with cancer:

'Well, I understand that Macmillan, the charity, Macmillan one deals quite a lot with the ongoing care of cancer patients.' (Susan, CG8)

'Places like Bristol Cancer Health Centre do that... They do lots and lots of research about the way natural complementary therapies work and do help.' (Audrey, CG17)

### **Access to research information**

Most participants accessed information about cancer research through the media (newspapers, television, radio or magazines). Much of this information concerned stories about health scares, such as food additives (eg Sudan 1) or environmental pollution, articles about breakthroughs in treatment or recommendations for cancer prevention. Elsie gave an account of the type of information she accessed through the radio:

'I heard on Classic FM, the radio, yesterday that they have discovered something else to do with skin cancer and the way they put it was, it puts the cancer cells into a coma and prevents the tumours from growing and this could happen with other kinds of cancers.' (Elsie, CG11)

In addition to the media, several participants accessed the internet to obtain information about cancer research or cancer more generally. Internet use did not appear to be related to the age of the participant and across many of the groups, patients had accessed information in this manner. Linda discussed the types of information she accessed from the internet:

'I'm one of these people that likes to have a lot of information. I'm on the internet all the time. Just looking for information about the experiences of other people who are having the same treatment as I have had... And, kind of academic information as well. It's that balance. Not that I am terrifically academic but I do like to read. Cut to the chase. I read the summary that says "It works" or "might work".' (Linda, CG17)

Other sources of information about research included books or leaflets, but these were less frequently used. For those participants who did access information about cancer, treatment and research from the media, several were

critical of the style of reporting or the content of the information. Participants were critical of media 'hype', particularly concerning stories about breakthroughs in treatment, and the subsequent impact this had on people affected by the disease:

'It was on the television the other week and in the sensational newspapers as well, a brilliant new breakthrough in the treatment of cancer and then you read the small print and it's really nothing and then it comes to nothing... It's not nice for the people who've got cancer who, I use the word mental state, the way you're thinking, it's no good for lasses like that. I mean I get through life and it doesn't bother me but there are individuals who, when they read about things in the newspapers and their hearts lift a bit and they say, "Oh great!", and then nothing comes of it and they feel let down again.' (Nigel, CG12)

Barbara was also critical of the accuracy of the information provided in the media: 'You read the papers about this is good for you then sort of six months later you get somebody else saying you shouldn't eat that, the newspapers particularly seem to give some information and then the opposite comes out some time later, which to the readers is confusing.' (Barbara, CG2).

Other participants were critical of 'information overload': 'I went on the net to see what was happening with my particular research in America, but I got to the stage where it was information overload, I'd had enough.' (Colin: CG10). Several participants were also critical of a tendency to present the 'worst case scenario':

'Those leaflets and everything we read on the internet and everything we read in the newspapers, a lot of them are worst case scenarios and I can remember one of the Breast Care Support nurses saying, "Oh, my God, don't read anything. Don't read any books. Don't read any of that stuff on the Internet"... because what you are reading is going to scare you to death. Because it is all worst case scenarios and I did go out and I got all the books in the universe about women

who had had breast cancer and in the end they all died and I thought, "Yeah, I am sure you are right. Worst case scenario is not a good thing to know about".' (Linda, CG17)

### Attitudes to research

Most participants said they would be happy or were happy to take part in research. Several reasons were given for this. First, there was a realisation by some that the treatment they were now receiving had been supported by research: 'We wouldn't be here today if someone else hadn't done it before us' (Gemma, CG2). Second, there was a sense in which by taking part in research, they could experience the benefits of participating in studies that were informed by the latest thinking: 'I just wanted anything that may help my situation and obviously focus with the hope that the treatment would perhaps kick it into touch or help in some ways.' (Ingrid, CG8). Third, and most usually, participants wanted to take part for altruistic reasons as they wanted to feel part of something that could benefit others in the future: 'I thought I would like to do it to try and aid in the future for somebody to get help as well.' (Margaret, CG12)

Several participants expressed the belief that by participating in research, they would get a better overall standard of care and a more frequent monitoring of their disease than they would otherwise receive. Zoe and Kevin supported this view when Zoe fed back her experiences of being involved in research:

Zoe What I find is that the trials, is that, with them being a company, I think what you tend to do is get a better follow up. You get scans. You know. You need a scan. It's done like that. Where, in ordinary on the ground chemotherapy, you can wait six to eight weeks for a scan and that. With trials, not that I want attention, but you sort of...

Kevin There seems to be a raised level of service when you are on a trial.

Zoe That's it, yeah.

Kevin Because somebody else is picking that up for them on the NHS. (CG17)

Participants were generally supportive of cancer research, and often cited improvements in the understanding, testing and treatment of cancer as being examples of the importance of cancer research. Research was seen to be 'an integral part of making progress' (Pat, CG10). Lorna reflected on previous experiences of cancer in her family to consider the impact that research had had:

'When I had my cancer diagnosed, they had monthly medicine, well, my dad had exactly the same thing and they didn't have that, so I know that 14 years is a long time, but you think obviously if they'd had that when my dad was here, but at least that was something positive.' (Lorna, CG14)

Some participants, however, gave alternative views of cancer research, questioning whether cancer research had really progressed very far or feeling pessimistic over the likelihood that there would be a cure for cancer. Cate, for example, had mixed views about cancer research:

'My daughter died of a brain tumour nine years ago when she was ten years of age and shortly after she died, I remember hearing a radio programme and it said we are celebrating seventy years of Cancer research and I got so angry, I thought, "What do you mean celebrating 70 years and they haven't come up with anything, they haven't been able to save my daughter, where's all these millions of pounds going?", you know and it was just when I contracted the disease myself that I realised that there have been advances, you know, within the last nine years that probably that if she had been diagnosed today, she might have stood a better chance.' (Cate, CG11)

Participants who had been involved in research sometimes felt that they did not have any or adequate information concerning the details or results of the study. Barbara, for example, was unhappy that she had not heard

any results from the research study she was involved in:

'The form of cancer that I had is a genetic form of it that's passed through my father's side of the family so I've been under the genetics department in the hospital where they've attempted tracing back the family tree cause there's a lot of cancer on my dad's side of the family. They've taken blood from myself and my dad and allegedly that went off to Amsterdam for some research that they were doing into the genes, but as of yet we've heard nothing, I mean that's a good five or six years ago and we haven't heard anything since then.' (Barbara, CG3)

Linda discussed this further and criticised the lack of information relating to the process of research or the implications of findings:

'That's the thing about research. We can participate just by being asked questions but do we know what happens to that information afterwards? Do we know how it is pulled together? Do we see it at the end? Do we know who it is going to? Do we know whether it does anything?' (Linda, CG17)

Participants were also critical of the coordination of research. Several commented on what they saw as a bias in cancer research towards more common types of cancer, such as a breast cancer, while other cancer types, such as prostate cancer, were somewhat neglected. There was a sense that, while there was a need to recognise different levels of incidents of cancer in the UK, cancer research should support a wider spectrum of disease:

'Research into cancer seems to be focused, almost a tunnel focus on one thing and you hear it all the time. My daughter gets notices about it, it's about time she had her scan and all that sort of thing, you see, concentrating on breast cancer and three out of five men over 50, 60 are going to get prostate cancer. You get nothing like the emphasis on the research into prostate cancer, that you do into the ladies' breast cancer.' (William, CG4)

One recurrent theme across several consultation groups was a sceptical view of the nature of cancer research and the conflicting interests certain funders of cancer research had. In particular, there was a sense of injustice with drug companies who were seen to be making profits out of cancer. Hence there was a view from some that it was in the interest of drug companies not to find a cure:

'I think personally speaking that drug corporations should not be allowed to make a profit. I think in a perfect world, those companies should be funded by government to do the research and to produce the drugs at the minimum cost to make sure that everybody who needs those drugs can have those drugs. I think it's actually obscene that chemical companies make money out of people suffering and I also think it's obscene if it's true... they do actually know how to stop cancer now and yet it is not cost effective for them to put that out, because they're making so much money out of these drugs like Tamoxifen and such that they would rather let us get cancer and treat us than stop us from getting cancer.' (Anita, CG7)

Susan felt the interests of drug companies actually affected the types of research that were undertaken in the UK:

'I may be a bit cynical here, but I get the feeling that current research is very much driven by perhaps funding from the drug companies, who are concentrating very much on the chemotherapy approach, whereas there are many other things. I wouldn't say that I'm into alternative medicine, but I do see a complementary practitioner who talks quite a lot about these things and he says how money driven conventional research is and that a lot of other areas are being neglected because of this.' (Susan, CG8)

## 5 Findings II: The research priorities

Most participants found it easy to share their research ideas and experiences in a group setting. However, there were certain challenges. In those groups where there was noticeably little knowledge or experience of cancer research or access to research information, such as with the South Asian consultation groups, significant support was required from the moderator to allow research ideas to be generated.

In terms of writing down research ideas onto post-its, many found this exercise unproblematic. There were a few exceptions, however. In those few instances where participants were unable to write their ideas due to blindness or language/literacy problems, a member of the research team or support staff supported the participant in the exercise.

In the main, there was little difficulty for participants in identifying similar research ideas from their post-it notes, and thus by reading out their suggestions, areas of research interest emerged automatically. However, there were instances where participants had difficulty in separating particular areas of potential research. For example, some participants did not separate prevention from the identification of causes as there was a belief that in order to prevent cancer you had to identify what caused it in the first place. Several participants also discussed prevention and early detection together as there was a belief that detecting cancer early prevented cancer from developing to a more advanced stage. Public education was also linked by some to early detection as it was felt that public awareness was a key factor in encouraging early presentation to the GP. Communication was also linked to information as several participants felt that breaking bad news was related to how information was conveyed.

Voting was also unproblematic for most participants. This was undertaken individually and not as a group exercise and most had no difficulty in using their three votes to indicate priority areas. Concern was expressed, however, that all research ideas should be listed in the report and not just those receiving the highest priorities. Not all participants had free access to the board on which priority areas were voted upon, and again support was required to facilitate this process. This was particularly the case with the hospice day care consultation groups where the research team and support staff were instructed by some of the participants to place votes on priority areas on their behalf.

In the main, there was a high degree of consensus among participants over the research priorities. Often, there was a clear 'winner' for the top priority and participants usually agreed why it was important. However, there were occasions where there was a lack of consensus. In one consultation group, for example, it was evident that the top priority, 'How close are we to a cure?', did not meet with universal agreement as one participant felt that it was not a type of question that could readily be translated into a research project:

*'I feel that "How close are we really to a cure?" is not an important question. I can't imagine that there is a cure. I can't condone that question... Actually I'd said I don't think it's an important question, I meant I think it's kind of an irrelevant question, it's not a possible question.'* (Sarah, CG14)

However, these differences were rare and there was a general agreement over the research priorities.

The questions and ideas generated by participants in the consultation groups related to 15 broad research themes (refer back to section 3 for explanation of how themes were

derived). The three themes with the highest combined ranking for all 17 consultation groups were 'Impact on life, how to live with cancer and related support issues', 'Risk factors and causes', and 'Early detection and prevention' (Table 3). Table 4 illustrates the research questions and ideas related to each theme. Where research ideas were unclear, their meaning was verified through reading the corresponding transcript. This helped to ensure that the research ideas were categorised correctly.

It was evident from this that there were three ways in which participants raised issues that were important to them: research questions, statements of need and descriptions of personal experiences. These issues were not mutually exclusive and provided rich supportive data justifying research priorities given. Hence statements of need or descriptions of experiences provided important indicators for research areas. Appendix IV illustrates all the ideas relating to each priority area. In this section, the top five priorities will be discussed. Appendix V documents the remaining priority areas.

**Table 3: Research themes and ranked scores of research themes identified in consultation groups**

Rank	Key theme	Total rank score [Possible Range: 1-102]	Number of consultation groups in which topic received at least one vote [N=17]
1	Impact on life, how to live with cancer and related support issues	68	13
2	Risk factors and causes	58	12
3	Early detection and prevention	48	9
4	Research into general information needs (on cancer, treatment, research and access to)	34	11
5	Use and effectiveness of complementary and alternative therapies	30	7
6	General education of public about cancer	24	5
7	Research into different cancer and patient types	23	7
7	Research on treatment (curative treatment, treatment types and improvements)	23	5
7	Experiences and management of side effects	23	7
8	Organisation and funding of health and social care services	21	6
9	Coordination, impact and funding of research	19	4
10	Research into recurrence	11	3
11	General communication issues involving all parties	10	3
12	Accessing patients' views about cancer, services and research	9	2
13	Health and safety in the hospital	1	1



**Table 4: Research themes and sample questions in the consultation groups**

Research priority	Subtheme	Sub-subtheme
Impact on life, how to live with cancer and related support issues	Psychological consequences	Impact on patient and others
		Role of mental attitude in recovery
		Support mechanisms
	Self-help groups and peer support	Impact of support groups
		How to establish or access groups
	Follow-up and after care	Impact of after care
		General
	Impact on social functioning	
	Work and other financial impacts	Employment issues
		Financial consequences
	Pain management	
	Impact on family and others	
	Diet in managing cancer	
General lifestyle issues in managing cancer		



### Sample research ideas generated in consultation groups

- How do you cope with the initial shock?
- What is the psychological impact for family and friends?
- Does stress play a part in recovery after diagnosis?
- Is there any evidence that a positive mental / psychological attitude can help a patient heal?
- Could hospitals have mental health personnel on board to call round when you are waiting for your scan or treatment and offer to talk to you?
- Is it possible to strengthen the support mechanism following the diagnosis of cancer?
- Do support groups help?
- How do you contact others going along the same journey?
- Research into establishing help groups for particular cancers.
- Does the support you receive after surgery for cancer impact on you, eg from GP, Cancer nurse, etc?
- Research into aftercare – living with cancer day to day.
- Research into the impact on: Quality of life / Giving up regular activities / Driving and travelling / Loss of independence / Attitudes to disability.
- For younger cancer sufferers: help with finding work – cancer sufferers might be viewed negatively workwise.
- Research into return to work schemes.
- What are the financial experiences of cancer patients, eg benefits?
- Money issues, eg state benefits and prescription charges.
- Need for research into pain, pain control and its impact on quality of life.
- Can there be some research into the effect on the family of a member being diagnosed with cancer?
- Research into effects on children of cancer patients.
- Support for partner and children.
- What difference does diet make in having bowel cancer?
- Food – What to eat, what not to eat? What reaction / side effects?
- Does living in a family make a difference, eg husband and children, to your recovery?
- What are the lifestyles of longer survivors?

**Table 4: Research themes and sample questions in the consultation groups (continued)**

Research priority	Subtheme	Sub-subtheme
Risk factors and causes	Environmental	
	Genetic	
	Diet	
	Stress	
	Other	
Early detection and prevention	Early diagnosis, detection and prevention.	Prevention
		Early diagnosis
		Symptoms

### Sample research ideas generated in consultation groups

- What environmental factors contribute to causing cancers and what can be done to eliminate/control these?
- How is Sellafield nuclear power station contributing to the high incidence of cancer in the east of Ireland?
- Is there any link between electricity and cancer?
- Microwave use with cancer. Mobiles. Radiation from TVs and computers.
- Radiation from TVs and computers.

- Is it genetic?
- I have had cancer. Will my children inherit it? Will it be possible for my children to get tested? At what age?
- Is there any work being done into identifying possible occurrence patterns about from 'genes'?
- Family history to promote early detection.

- Does diet have a part to play in why we develop cancer?

- Has cancer become very common because there is too much chemicals in the food?
- What are the dietary factors implicated in causing certain cancers and what can be done to control / eliminate them?

- Research into causes of cancer: life history, effects of stress and general 'dissatisfaction' with life.
- Lifestyle, stress or anxiety?

- What are the causes of cancer?
- Why do people get cancer when they are vegetarian and don't drink or smoke?
- What causes changes in the body for rogue cells to develop?
- What causes mesothelioma in people who have not had above normal exposure to asbestos?
- What are the risk factors of ovarian cancer?
- Is smoking a cause or just an unhelpful factor, ie is it will it just not help or is it a cause?
- Is cancer linked to trauma such as major operation external effect car crash?

- Prevention – more financially useful than cure. Can you prevent cancer – causes – what is cancer? – types.
- More research into preventative medicine.

- Diagnostic screening most worthy objective of research. Is it possible, or will cancer remain not susceptible to this approach?
- Should family be tested after you have been diagnosed?
- Medical check ups at certain ages, ie teens, 20s, 30s, etc.
- Would a blood test annually be a diagnostic help?
- How can cancer diagnosis be made more efficient / effective?

- What are the early symptoms of cancer?

**Table 4: Research themes and sample questions in the consultation groups (continued)**

Research priority	Subtheme	Sub-subtheme
Early detection and prevention (continued)	GP awareness, knowledge and training, and related issues.	GP knowledge and training
		GP support and funding
	Diet as a prevention	
	Lifestyle	
Research into general information needs (on cancer, treatment, research and access to)	Cancer	
	Treatment	
	Research	
	Access	
	General	
Use and effectiveness of complementary and alternative therapies	Research into effectiveness	
	General ideas	
General education of public about cancer		

### Sample research ideas generated in consultation groups

- Do GPs know what symptoms relate to all kinds of cancer?
  - How can GPs be kept more up to date on research?
  - How can we better train GPs to diagnose disease?
- Can GPs have support in earlier diagnosis with cancers that can be camouflaged by other symptoms?
  - Perception is that GPs can be inhibited from referring patients for scans, biopsies and the like for financial reasons.
- Is diet important as a preventative measure?
  - Do any specific foods help prevent / restrict growth of cancers – (generally and in specific cancers)?
- If we improve lifestyle, do we stand a better chance of avoiding cancer?
- My first reaction on being diagnosed as suffering with prostate cancer was the almost total lack of information about the condition.
  - More information on the different types of cancer, and general helpful knowledge of own cancer.
- Are patients given specific information about drugs and effects on the body?
- How do I participate in trials?
- Where can you easily access information on your specific cancer?
  - Where do I get more information if I am not on the internet?
  - Where can you investigate easily research into the drugs you are being prescribed?
- How to give easily understandable information to people who may not take in what is said.
  - Why is there such disparate information concerning dietary requirement following treatment for pancreatic cancer?
- Are vitamins, minerals and supplements helpful?
  - Can researchers look at the beneficial effects of complementary therapies in the treatment of cancer patients?
  - Do any of the complementary therapies, ie reflexology, meditation, visualisation, reduce tumours in cancer patients?
- How can we incorporate alternative / complementary to run alongside conventional medicine?
  - Could a qualified homeopath be included in the cancer care team?
- If in some way the general fear of cancer could be lessened it might encourage people to seek help earlier.
  - How can we educate / make aware the symptoms of ovarian cancer?

**Table 4: Research themes and sample questions in the consultation groups (continued)**

Research priority	Subtheme	Sub-subtheme
Research into different cancer and patient types		
Research on treatment (curative treatment, treatment types and improvements)		
Experiences and management of side effects		
Organisation and funding of health and social care services		
Coordination, impact and funding of research		
Research into recurrence		
General communication issues involving all parties		
Accessing patients' views about cancer, services and research		
Health and safety in the hospital		

### Sample research ideas generated in consultation groups

- Research into younger people overall, eg prostate, breast cancer.
- There is a need for more research into the treatment of prostate cancer and the origins of this disease.

- Which drugs are best for different cancers? How much research is done into every cancer?
- How do you know which treatment is suitable for you? More beneficial?
- Why can't I be treated with gene modified T CELLS to cure mesothelioma?
- I have heard that a tumour will 'die' if its blood supply is cut off. Has any research been done in applying this to ovarian cancer?

- Does chemotherapy cause many patients to develop diabetes?
- Is there any research into the side effects of chemotherapy and counteracting these to avoid permanent damage or short term discomfort?
- Why can't more be done to help women who have breast cancer and have to cope with severe menopause symptoms caused by drugs?
- Could research be done into the side effects of post-operative drug treatment?

- How can the process of receiving chemotherapy be more streamlined?
- Would it be helpful to give more funding to oncology nurses in order to help them speed up clinics, ie chemotherapy to relieve stress for them and patients?
- Scalp – cooling. Why can the hats not fit better so that the whole head is in contact with it to prevent hair loss in patches?

- Is there a need to rationalise the number of cancer charities? Pool resources?
- Why is there no national integration of research?
- Should research and hence funds be concentrated on prevention or cure?
- Should research and hence funds be concentrated on the more common cancers?

- Does diet help to prevent recurrence of cancer, particularly say, breast cancer?
- Having a prophylactic mastectomy on right side as well – by how much will this reduce the possibility of a cancer returning or what is the likelihood of cancer in the other breast.

- Communication between patient and GP.
- Communication between consultant and GP.
- How to tell others about my illness?

- Need to check patient's suspicion of possible causative lifestyle habits, ie smoking, aerosol use, etc.
- How can patient concerns be best understood and responded to?
- How can patients' experience and knowledge from the research trial (to which they have been subject) be gained by the medical staff?

- Research into infection.



## Impact on life, how to live with cancer and related support issues

The highest priority area for future research identified by consultation group participants was research into the 'Impact on life, how to live with cancer and related support issues'. While participants were aware of biomedical research currently being undertaken in the UK, they wanted to see more research into the issues that they faced living with cancer on a day-to-day basis and how these could be managed and supported. Several participants explained that research into the ongoing support, management and experiences of cancer patients was important to them as they could utilise the findings from such studies in their own management of cancer.

Linda, in one consultation group gave such a comprehensive account of research issues relating to this area and reasons why they are important that it is quoted in full here:

'Living with cancer. Waiting for it to come back or waiting for it to metastasise. Waiting for it to make you feel poorly. Waiting for it to make you feel poorly enough to no longer be able to live at home. And waiting for it to make you die, you know. It's the negative cancer journey isn't it? I try not to do that, overmuch, but it is the reality for us. We have all experienced that in different ways. I know from the 35 of us who have breast cancer, secondary breast cancer, so we are all in the same boat really but our experiences are so different because of the way our bodies respond to it or have it or whatever. And, I would love to know, I would love for somebody to come and talk to the 35 of us and find out how we are all coping and the reasons why we are coping. What are the reasons why we are not coping? Could it be that we are having bad experiences in hospital? Yes, one of the group has had a terrible experience in hospital. Could it be that we are having difficulties at home because our partners can't cope and, you know, are taking it out on us in some way? Yeah, one of the girls has that experience. Could it be that we are coping because we are having so much CoQ10 we feel perfect, or so much foot massage that we feel fab?.. And so, just that

small study would be of enormous interest, I think, to the people who plan and deliver our care including, and I am not just talking about the Onco teams at the hospital, it includes our GPs, the district nurses attached to the GPs or hospices, the Macmillan nurses attached to our hospices and the national organisations set up to support and 'do things' about cancer and various different types of cancer organisations. It would help because it would start to deliver the information that could apply pressure to the institutions and the organisations that deal with us in some way to change, or to work to a certain standard. Or to at least be aware that there are issues around how we all go on.' (Linda, CG17)

The issue of 'Impact on life' was very broad, encompassing nine areas including psychological consequences, self help groups and peer support, follow up and after care, impact on social functioning, work and other financial impacts, pain management, impact on family and others, diet in managing cancer and general lifestyle issues in managing cancer. While these nine areas highlight broad avenues for research, they were collated within the theme 'Impact of life', participants viewed these as different aspects of the problems and issues of living with cancer on a day to day basis. Hence pain management was included within this theme as participants discussed this issue in terms of its impact on quality of life.

Each of the nine areas will now be explored.

### Psychological consequences

Participants wanted research to be conducted into the psychological consequences of cancer. This related to three areas including the emotional and psychological impact that cancer had on patients and others, the role that mental attitude had in recovery, and research into the provision of appropriate support mechanisms.

### The impact of cancer on the patient and others

Participants felt that their experiences of cancer were more than the purely physical aspects of

their illness, and thus wanted research conducted into the emotional and psychological impact cancer had on their lives. As one participant put it, 'the emotional side of a cancer patient is as important as the chemotherapy side' (Audrey, CG17). These 'non-physical' issues were seen to be key areas for future research:

'It's not just about getting a stethoscope or dissecting things and looking at it, it's about things like, for example, in the centre I go to, I had aromatherapy and in the healthy living centre, now we have a palliative care aromatherapy and counselling for people with progressive or terminal illnesses. So it's not just about the actual tumour or the after effects of your operation, it's more, it's how you feel, whether or not you get depression, whether or not you're worried if it's going to go onto your family, all of that needs to be researched.' (Liz, FG9)

Particular areas of interest included identifying the ways in which a cancer diagnosis or living with cancer impacts on the emotional and psychological well being of patients and others. This research was felt to be particularly important given the range of detrimental experiences that participants had. Participants used terms such as feeling they were 'under sentence' (Neil, CG12), that they were automatically 'going to die' (Sally, CG9), or as Alan put it, 'Bye bye, you're finished.' (CG9).

Not all participants shared these experiences of psychological difficulties, however. Liz, for example commented on the benefits that a cancer diagnosis had:

'I was diagnosed with colon cancer, ... and I'm having a ball, I really am, I learnt a lesson that there's more to life than just sitting watching paint peel...I know it sounds a terrible thing to say, but do you know there's a good side to cancer as well, it gives you a wake-up call, it really does.' (Liz, CG9)

Consequently, although the main rationale for prioritising research into the psychological consequences of cancer was the distressing impact the cancer diagnosis had on

participants' lives, the potential for research to address other psychological responses is also indicated.

### **The role of mental attitude in recovery**

Participants were not interested solely in the psychological issues caused by having cancer, but conversely, they wanted to see research undertaken on whether psychological attitude had an impact on the probability and speed of recovery. For many participants, there was a firm belief that positive thinking makes a difference to cancer survival. One participant cited research to back up her opinion: 'I think one of the things that research has shown is that those who are positive are more likely to come out the other side than if you're negative' (Liz, CG9). For most participants, however, the importance of 'positive thinking' in recovery was something they either believed or were aware that others around them believed, and hence they wanted research specifically to assess the validity of these assumptions.

Participants often gave examples from their own experiences of living with cancer to support their belief in the importance of positive thinking: 'People are telling me a year down the road now that they thought I'd be dead. The only person that didn't believe that was me and I never doubted it. Now personally in my case, I think that's got as much importance as the medical side of it' (Michael, CG1).

Other examples of the importance of mental attitude included the impact of setting life goals, and again, here specific research was recommended:

Linda It would be interesting how that setting goals actually affects your survival. You, know, does it affect your survival that you have got that taskoriented goals to reach this certain amount, this certain point in time and I have wondered for myself, you know, in my taskoriented goal, would be to reach my next birthday, and be 53 instead of 52 and does your strength of feeling about your goal lend

itself in any way? How does that affect what you cannot control in your body?

Audrey That's something they can research, isn't it. If you're a positive person, does that help? (CG17)

As a consequence of these beliefs and 'positive attitude' behaviours, research into the impact of positive thinking and mental attitude was given a high priority:

'I think what I've noticed about this group is that people seem to have a very strong, positive mental attitude and I'm wondering is there any evidence to suggest that positive mental or psychological attitude can help a patient?' (Cate, CG11)

### Support mechanisms

As many participants were psychologically affected by the diagnosis of cancer and also believed that positive thinking was important in recovery, it was felt necessary to provide effective psychological and emotional support for those distressed by their cancer experiences. Ideas generated by participants usually focused on statements of need rather than specific research questions, but are worth considering as they do highlight the need to assess the quality and coordination of psychological support for people affected by cancer. Participants had mixed experiences of psychological support services. Colin, for example, gave a critical account of support services and used this to justify the need for research to explore ways in which psychological support after diagnosis could be improved:

'Is it possible to strengthen the support mechanism for the diagnosis of cancer?... One of the things that was suggested to me was that I should go and receive counselling, it took about six months to arrange... That's fine, that worked with me, I'd gone in with [a positive] attitude anyway, but can you imagine somebody else that was at the very pits who didn't know which way to turn, you know, there's no support, it's an absolute negative.' (Colin, CG10)

It was also suggested that particular types of patients were particularly vulnerable and should be targeted for support. These included those who had responsibilities for looking after young families, those who were alone and older people.

### Self help groups and peer support

Participants wanted research to be conducted on support groups and other forms of peer support. In particular, they suggested that research should examine the extent to which support groups benefited people living with cancer. This issue was important to participants because many who had accessed both formal and informal support groups had found the experience to be positive: "Do support groups help?"... because I found out an awful lot... I think that when people have had a similar experience, you talk to people on a different level about it.' (Janet, CG13).

Although the majority of participants did not use support groups and were unaware of their existence, a few shared experiences of establishing their own informal networks, either forming a 'buddy system' (Beryl, CG7), or a 'virtual' peer support group through email or via the telephone:

'We sort of formed our own [support group] when we were in hospital. There was sort of three, four, five of us that were all with the same breast cancer were all going on to the same chemo we're all here at the same time and we just all phone each other up you know, three days after your chemo you ring up and you say, "How do you feel?" and they say, "How does just hit by a truck sound?". And you think, "Oh good, well it's not just me then" so we sort of done our own.' (Clare, CG1)

Participants also drew attention to the difficulties of establishing effective peer support for certain sections of society. In particular, peer support for men with cancer was discussed as, 'it seems to be a macho thing, they don't want to talk to anybody' (Alan, CG9). In addition, it is interesting to note the specific value given to support groups within different ethnic groups where cultural

variations in the open discussion of cancer can leave some patients and carers isolated (CancerBACUP, 2004). In this regard one of the South Asian consultation groups drew particular attention to the need to share experiences of cancer and commented on the challenges of doing so within their particular cultural background. Similarly, the challenges of sharing experiences with patients from a South Asian background were discussed:

**Komal** All the leaders when they get together they should talk to each other and share their experience and then we feel so much better. We feel so light. People, if you come in the group and you don't share your experiences, you feel really "Oh, it is just me only I am suffering"... But passing the information and your experiences, you are aware of so many other things and you learn a lot from each other.

**Hema** You know, in our culture, we don't share. These people. When I had the skin cancer I talk about my family and friends. They were surprised. "How did you tell everybody?" They were very shocked, you know. (CG15)

Given the benefits that many participants shared with support groups and the challenges in establishing this for certain sections of society, it was felt important to research support groups and to explore evidence of their effectiveness.

### **Follow-up and after care**

Participants wanted more research to go into follow-up and aftercare. In particular, they wanted researchers to explore the extent to which follow up services meet the needs of those affected by cancer. This was important to participants as there was a general sense that after care services could be improved: 'It just seems to be, "Right, you've had your operation, you're fine... cheerio now, we'll see you in six months time", and you're out the door and that's it, get on with your life again.' (Alan, CG9)

One participant felt there was need for an effective 'management plan' for cancer and that research should examine the 'planned maintenance' of the disease: 'If one [machine] breaks down, then that machine would be put under a specific plan of maintenance. If you are broken down, then they should be looking at how to stop you breaking down again'. (Kevin, CG17) Thus Kevin wanted research to identify how patients can best be supported to manage the 'in-between' phase, between the points 'when you break down', in an effort to improve recovery and minimise the risk of recurrence. (Kevin, CG17)

This 'in between' management was closely related to a consideration of how patients can best care for themselves, and was therefore linked to the theme of self-managing activities (such as diet and exercise). Research into the effectiveness and provision of after care was therefore of particular interest as it allowed patients themselves to take an active part in their own management of their cancer.

### **Impact on social functioning**

For many participants, cancer had a significant impact on their day-to-day activities. Consequently, research into the impact of cancer on social functioning and how these can be supported was important to many participants. Participants justified reasons for this being a priority area by sharing experiences of how cancer had impacted on their lives, preventing them from sleeping, travelling, driving, shopping, taking part in recreational activities, etc. For example, the impact that cancer had on social functioning was raised in one of the hospice day care consultation groups where the loss of independence and a sense of isolation were listed as major concerns:

**Brian** There's also travel, that was a big part of my life, travelling, I loved to travel and I can't get travel insurance. I can, but it costs more than the holiday, you know and this is something else that I don't want to have to give up, but I'm having to accept it and I can't drive either because my eyesight's affected. So, I feel very much cut off, I can't work, I

can't drive, I can't travel. Life has had to take a completely different turn and it's very hard to keep cheerful.'

**Tim** Yes, I'd go along with that, exactly, you are limited, your driving, isolates you, shopping, everything and you're dependent on other people. (CG5)

Related to this lack of independence was concern at the way people's treatment of the cancer patient changed. Participants spoke of 'losing power', of not 'being in control', of being made to feel 'abnormal', as if they 'didn't exist', and of being treated 'like a nine-year-old'.

As cancer had such implications for the day-to-day experiences of patients, it was considered to be an important area for research. However, the relative importance of these 'social' concerns in relation to other 'medical' issues, did not meet with universal agreement:

**Philip** So what is the purpose of research? You could say, is it important to look at insurance and deprive people of their foreign holidays or should it all go into finding new cures or extending people's life spans? Should we just forget the lifestyle side and focus on the hard sort of stuff, curing life, extending life?

...

**Facilitator** What's your answer to the question, Philip?

**Philip** Well, in terms of where the research money should go, I think we should be fairly hard nosed and say it should go on medical research primarily, because it's more important to extend life. I mean I think especially when you look at younger people who are affected by cancer, that seems to me to be a priority over having foreign holidays.

**Facilitator** Does anybody else hold a different view...?

**Mandy** I don't think that life should be the only thing that you look at, because

sometimes life may not be worth living as it is...the quality of life needs to be improved if possible to make life bearable and it's no good living for another 50 years if you're really unhappy. (CG6)

## Work and other financial impacts

### Employment issues

Participants felt that it was important to examine the impact cancer had on the employment status of patients, experiences in the workplace and ways in which people with cancer can be supported in their employment activities. Most of the ideas generated were focused around statements of need or descriptions of experience, but they are nevertheless important to consider as they suggest that employment issues are of concern to patients and thus warrant further enquiry.

Participants shared a range of experiences relating to the impact cancer had on their own employment. For some, cancer had resulted in the necessity to change the nature of tasks performed at work, to reduce the number of hours worked or take early retirement:

We'd done a year [in business] and you just sort of get on your feet in the first year and the second year we had all these plans. But, of course, me being diagnosed with cancer... it hit us for six because I couldn't do anything, I can't lift anything heavy and it meant obviously we had to employ more staff to cover me. (Clare, CG1)

This inevitably affected an individual's personal finances and several participants commented on the difficulties resulting in the delay to sick pay after leaving work. Employment was also important in maintaining social contact and a sense of independence and social worth.

Participants also described discrimination they experienced at work from their colleagues, either through work place gossip or through attempts to make the patient redundant. Barbara, for example, recounted her experiences of returning to work: 'When I went



back to work to see the force doctor, because I'm a police officer he threatened to sack me because he said, 'Because you've got a high risk of getting cancer again, I don't think you'll be effective as a police officer.' (CG3).

Given the range of experiences related to employment issues, participants felt this was an important area for research.

### Financial consequences

Participants wanted researchers to explore the financial difficulties faced by people affected by cancer, and many drew upon their own experiences to justify this as an important area of research:

'I think the money one has to be there because, at the end of the day, we can't exist without finances and it is bad enough having cancer but there is probably only one thing worse than having cancer and that is having cancer with no money.' (Kevin, CG17)

The financial difficulties shared by participants either related to problems with benefits or insurance, or directly with the cost of cancer itself. The following interchange from one of the hospice day care consultation groups illustrates the varied experiences and concerns that surfaced about insurance and benefits:

Philip You pay more for your travel insurance than you do for your holiday.

Mia Yes, and you can't get away with not telling them, can you?

Tim No.

Mia I mean I can understand that if you've got a tumour, you can't drive, but I mean car insurance is certainly depriving of probably something that means a lot to you and the family.

Nicola And why is it that if you're not insured, it goes up for your spouse?

...

Elizabeth Well, it's discrimination again, isn't it?

Mia Well, somebody needs to look into what kind of insurance we can get and the travel, be it for health or whatever.

...

Philip Is the extra cost of insurance proportionate to the risk of someone with cancer having, needing medical treatment when they're abroad. It seems disproportionate, that they're using it as an opportunity to make money. Is it proportionate? Is it equitable? (CG6)

In addition to insurance and benefits difficulties, patients also shared experiences of the cost of the cancer itself. This was related to the cost of chemotherapy, complementary medicines and expenses associated with the general impact of cancer on their lives. Peggy described the various costs of cancer she experienced:

'It cost me a lot only because I live on my own and I've got a dog and I was in the hospital back and forward five times... so each time the dog had to go into kennels. I had to pay somebody to feed the cat. I was very weak, very ill. I had to pay people to do my shopping, gardening, cleaning, I couldn't do anything at all... It cost me a lot of other things as well because I had to buy new clothes and things because I lost so much weight.' (Peggy, CG3)

It was of interest therefore to participants to find out more about the experiences of other patients and how these might be supported.

### Pain management

There was very little discussion of symptoms, although pain management was raised in several consultation groups and in some detail in one of the hospice day care consultation groups. Rather than provide specific research questions, participants stated the need for pain management as a broad area for research:

Facilitator Do you think pain is something that should be researched?

Debbie Definitely.

Anne Oh yes. You can fight cancer if you are not in pain. I don't think you can fight anything when you are in pain and I think, for me, when people say cancer research, that is what I would want. I would want the research how best they can help, not just me, but everyone to make a better life... To me, quality of life is important. (CG5)

Pain was mentioned by several participants and accounts of the impact this had on quality of life were discussed. Pain was not the only symptom that was raised, the impact of blindness on quality of life and experiences of weight loss were also discussed, although these were not put forward as research areas.

### Impact on family and others

Many participants were not solely concerned about the impact that cancer had on the lives of patients, but were concerned about the impact that cancer had on partners, family and friends. Participants were aware of the emotional and other demands made on those close to them and were concerned that they were unsupported. As a result of this, participants wanted to see research undertaken to identify the psychological and other effects cancer had on others and the ways in which these issues can be supported.

Again, personal experiences and observations by participants were given to justify this as an important area for research. For example, Anita said that although she was able to cope with cancer, she was concerned with those around her:

'I can deal with breast cancer, because it's happening to me, but the rest of my family can't deal with it, because they feel so totally incapable of helping me and anything that I can do to be as normal as possible is so important also for them and I think they get lost in this, because we tend to be the centre of attention and they get very lost in the whole

thing and they're not supported in the way that we're supported. (Anita, CG7)

Concern was expressed in particular for the welfare of children. Several participants noted changes in the behaviour of their children, which they attributed to the effects of cancer. Therefore, participants thought it important for support to be provided for their families.

### Diet in managing cancer

Diet was of significant interest to participants in many consultation groups. Participants were particularly interested in evidence for the role of diet in the cause, prevention and management of cancer. In terms of dietary management, participants wanted to know whether a healthier diet was going to impact on their survival. Participants had accessed certain dietary recommendations from the media, from health professionals and via other means and wanted research to provide the evidence for claims about the importance of healthy eating.

Many participants held the belief that a healthy diet can improve and prolong life. Janine, for example, had observed this behaviour in others:

'It must be very psychological. My next door neighbour was a boozier, she was a drinker, she loved life, she's a lovely lady, she found she had cancer, she went onto all this healthy food and I just wonder why you suddenly change your diet, it is all psychological, isn't it, you think, "Right, let's change our diets, this is going to cure me."' (Janine, CG14)

Dietary management was also of interest to participants as a research area as it was seen as something that the participant could use to help them manage cancer themselves. Different examples of diets were shared in the consultation groups, including the Hay diet (not combining 'a carbohydrate with a protein at the same meal') and a diet suggested in Prof Jane Plant's book. Given the concern participants had about dietary management, there was felt to be a need to assess how dietary advice and support can be provided:



Tim Well, I wondered how much cooperation between nutritionists, because I've found when I go to hospital, they don't want to know, they're only interested in like operations and chemotherapy and radiotherapy, they're not really interested in the other side of it.

Facilitator And you would like them to be?

Tim Mmm.

Mandy You could do with a centre maybe for nutrition, couldn't you, you could do with a separate building almost for dietary needs. (CG5)

Consequently, participants wanted to see research conducted into what diets would be helpful in managing their cancer, the evidence for improvements in outcomes and also how best to provide information on dietary advice:

'I would like more research done into [diet], just sensible suggestions, maybe unproven scientifically, no doctors will accept that it has any part, especially with ovarian cancer, but the information I'm picking up, increasingly I think it will become one of the major ways of preventing as well as controlling cancer and maybe, I'd like Macmillan to go into giving, producing a booklet to say that would encourage people to go away and eat healthily.' (Ingrid, CG8)

### **General lifestyle issues in managing cancer**

In addition to dietary management, participants also wanted research to explore whether certain lifestyle factors, such as living with a partner or family or the amount of exercise taken, has any affect in improving or prolonging survival. Many participants held a belief about the relationship between a healthy lifestyle and cancer survival: 'You have got to keep your body in its optimum state so it will not then revert to producing more cancers.' (Audrey, CG17).

Numerous examples of lifestyle issues were cited in the consultation groups, including living with a family or partner, relaxation,

exercise and smoking. Peter, for example, was interested in the evidence for benefits of exercise in preventing recurrence:

'Every time, they say, the fitter you are, you are less likely to get sickness and flu's and colds and all the rest. Does it also influence anything in cancers and that? ... The fitter you are, is it more likely to come back or less likely to come back if you keep yourself fitter than what you were before?' (Peter, CG13)

There was recognition by some participants, however, that certain lifestyle changes, such as giving up smoking, were difficult to make and that, as with diet, they had to be appropriate so as not to undermine a patients' quality of life.

### **Risk factors and causes**

Participants voted for research into risk factors and causes of cancer as the second priority area. Few participants referred to causes of cancer in the way that many health professionals would, focusing on areas such as environmental, genetic, diet, stress or other factors rather than causes at a more molecular, cellular level. One possible reason for this was that participants did not have the technical knowledge to discuss basic science questions and were more inclined to focus on other issues: 'I would think that biomedical people should decide [on biomedical research] because they have got all the knowledge.' (Kevin, CG17).

Nevertheless, the broad theme of identifying the causes of cancer was seen to be a priority area by many participants for preventative reasons. In this regard, many participants had difficulty in separating cause and prevention and thus voted on these areas together. From their perspective, it was necessary to identify the cause of cancer so that it could be prevented. Some participants were interested in the causes of cancer at the cellular level, asking questions such as 'What causes changes in the body for the rogue cells to develop?' (Joanne, CG10). However, in the main, participants discussed causes in terms such as environmental and genetic factors.

### **Environmental factors**

Participants wanted research to identify the environmental causes of cancer, both in terms of potential broad geographical causes (such as 'cancer clusters') and research into the possible causes they face on a day-to-day basis (such as mobile phones and electricity pylons). There were two principal reasons why participants were interested in environmental causes of cancer: first, to identify whether these factors could have caused their own cancer, and second, because they felt that such research could help to ensure that such cancers could be prevented in the future.

Many participants justified their prioritising of environmental factors by reflecting on their own histories. Examples of geographical factors and possible causes of 'clusters' of cancer populations were varied and included air pollution (road traffic, power stations), the location of electric pylons and polluted rivers. Jim's account of possible environmental factors is typical of many participants:

'There must be ongoing research into you know these electricity pylons. If you live in close proximity because I know a particular pylon where I used to live and loads of people, a young lad 12 years of age contracted cancer. A friend of mine who moved from there, he's got prostate cancer; a lady who bought his house from him near that pylon died from cancer. Just up the road from where I used to live, the next house up the husband and the wife in their early 50s both had non Hodgkin's. Somebody else in that road had cancer, I live 60 yards down the road, I've had cancer. What's in the ground, is there a stream with something running through I don't know?' (Jim, CG1)

Discussion about day-to-day environmental causes provided equally varied suggestions including the use of aerosols, microwave ovens, fridges, freezers, TVs, bedside radios, mobile phones, general 'ambient' electricity, and air conditioning systems. Participants also discussed their concern about the level of environmental exposure at work, citing examples of traffic fumes, asbestos and radiation as possible causes. This was of such

interest that in one of the South Asian consultation groups, they suggested this as a specific area of research interest: 'They should do the research where the person used to work, which job'. (CG15)

### **Genetic factors**

Participants felt it was important to research hereditary and genetic risk factors associated with cancer. Specific areas of genetic research that participants were interested in included gene therapy, stem cell research, family histories and hereditary links. Participants wanted to see research in this area for several reasons. First, as with environmental risk factors, patients were interested in finding out possible causes of their own cancer and would look to previous occurrences in the family. Second, patients wanted researchers to investigate genetic causes of cancer as there was a belief that identifying genetic causes would provide an effective means for preventing cancer through early detection. This was of particular interest for those with families who were therefore worried whether it could be passed onto their children and therefore required some form of testing in the future:

'The hereditary thing is something that worries me and I think if that can be investigated ... the thing I find difficult sometimes to cope with is when my children or my daughter in law, I have three grandchildren and I have been questioned, "Is this hereditary?" You know, I can't answer that question. (Stephanie, CG1)

### **Dietary risk factors**

Many participants wanted cancer researchers to investigate whether certain food types and the use of additives and chemicals in the manufacture of foods could cause cancer. This was felt to be an important area for research as eliminating dietary causes was seen to be central in the prevention of cancer. Participants voiced numerous concerns about diet and cancer. Concern was particularly expressed for younger generations who were not being educated to eat properly:

'I've got diet... is there any research being done... on diet... I'm a qualified home economist and you know I'm working my heart out to try and get young people to eat properly now you don't know the consequences. I mean the junk food that they're eating now what is this, I mean it's too early for us to say but what are, we know there are heart problems and diabetic problems but are there going to be any other problems?' (CG2)

The growth of convenience foods and the use of additives in products, like margarine, were also of concern. There was concern with the preparation of convenience foods, particularly with the use of microwave ovens and cling film. There was felt to be little knowledge of what went into processed foods: 'I know more about what goes into dog's stomachs, than I do what goes into mine'. (Janice, CG4) Many participants had a firm belief that ingesting these chemicals could result in the development of cancers:

'When we are thinking about what to eat and what not to eat, every food has chemical spray on it. So when we are taking in the body, these can come out making the cancer inside of our bodies. (Hema, CG15)

For Vikas, there was a belief that the use of chemicals was contributing to an increase in cancer:

'The cause of cancer spreading I think is mainly caused by the food we are eating, whether it is grain, potatoes – any item growing in the farm has got chemicals in order to prepare the land. Ten years back, you had 10 tons of grain now we are getting 20 tons from same land because chemicals have been put on it – that is the main cause of spreading cancer.' (Vikas, CG16)

Consequently, diet was a priority for participants who wanted greater evidence of the link between poor diet, the use of chemicals in food and cancer. Such evidence was seen as a means of educating people to eat more healthily.

### **Stress risk factors**

Participants thought that research should identify whether stress or emotional state could cause cancer and whether there were methods for managing stress to minimise the risk of developing cancer. As with other risk factors, identifying stress as a potential cause of cancer was believed to be an important means of preventing cancer in the future. Many participants looked back at their own experiences of cancer and attributed their cancer to periods of significant stress. There was a belief that stress and anxiety could reduce the effectiveness of the immune system resulting in greater susceptibility to diseases such as cancer:

'When your immune system is perhaps compromised by something else, you're fighting something else, that is possibly when the cancer gets going. It's known that stress weakens your immune system and therefore you're more subject to cancer.' (Susan, CG8)

In the consultation groups, participants often associated their cancer with periods of stress:

'When I first got ovarian cancer, I'd had quite a stressful year at work. I used to be a lecturer in further education and I had to deal with some quite yobbish people at times and teaching is a stressful occupation full stop and when you had to change to a new department and had a particularly difficult group, it didn't help and I think I was absolutely worn out and I think that possibly may have contributed.' (Susan, CG8)

Participants therefore wanted research to provide evidence for commonly held assumptions about the link between stress and cancer.

### **Other risk factors**

In addition to environmental, genetic, dietary and stress risk factors, participants wanted research to examine whether other possible contributory factors could cause cancer. Participants, for example, were interested in whether it was possible for cancer to be caused by a physical trauma. Several

participants shared experiences of possible links with physical trauma:

Anita Is cancer linked to trauma such as major operations, external effects?

Fran Yes, I've heard of people who have a nasty trauma, accident or something like that and then cancer sometimes comes after the accident.

Sophie My aunty had a bad car accident with her neck years ago, when there weren't any seatbelts and she developed throat cancer, so you often wonder whether, trauma.

Tricia When I was diagnosed with Hodgkin's, the specialist said to me, "have you been involved in an accident?" and I said that I broke my wrist a couple of months before and he raised his eyes as if to say, "oh, that follows", but I never did know his reaction, why he was like that, but I did wonder.' (CG7)

As with all risk factors discussed in this section, the interest in identifying a definitive cause of the cancer was important both in terms of responding to a personal interest and finding out what participants could have done differently, and also in terms of preventing cancer from developing in the first place.

### Early detection and prevention

The issue of the need for early detection was ranked the third highest research priority. Participants were keen to reflect on how they were diagnosed and whether it would have been possible to be diagnosed sooner. This generated many ideas about early detection and prevention ranging from specific research questions to statements of need. Accounts of delayed and mis-diagnoses were common and many participants felt that the role of the GP was pivotal in achieving earlier diagnosis. Detecting cancer early was seen to be a key factor in preventing the spread of the disease, and it was for this reason that many participants felt this issue to be such an important one for research. Cancer prevention was not seen solely in terms of an avoidance of risk factors (as discussed above) but was

also discussed in terms of preventing cancer from advancing to a more aggressive state or detecting the cancer early enough to identify it at a precancerous stage.

### Early diagnosis, detection and prevention

#### Prevention

Just as participants wanted research to identify risk factors that caused cancer, they also wanted research to explore what activities and measures can be taken to prevent cancer from occurring in the first place. Many participants felt that preventative research took precedence over other types of research as 'prevention is better than cure'. Research into cancer prevention was seen as important as it would avoid difficulties caused to the patient and would resolve resource implications surrounding the treatment of cancer:

'A cure could be very expensive, lots of medical resources, but prevention, if you can nip a thing before it even starts, nip it in the bud, it's much better than having to go into hospital and maybe having major surgery and all the follow-up treatment that you need.' (Stella, CG10)

Participants wanted research to identify the ways in which cancer can be prevented: 'You don't go straight from your bath into the garden without drying yourself off, otherwise you'll catch a cold and there may be certain things in our lives that we do that will be more protective.' (Cecil, CG4). In particular, participants wanted to see research into various strategies for preventing cancer and the recurrence of cancer. Exercise and especially diet were raised as fruitful areas of research into cancer prevention:

'Well, I would also add that we could have more research into diet, because we read, if you eat 4lbs of beetroot every day, then it stops this, that and the other. A lot of it's rubbish, but is there any sort of research into diet that could be beneficial?' (Elizabeth, CG6)

## Early diagnosis

Participants suggested that research should identify and develop measures and techniques to identify particular cancers easily and effectively. Research into early detection was believed to be important as it was believed to be central in the prevention of more aggressive forms of cancer, thus resulting in cancers that could be treated more effectively and with a higher potential for cure: 'I think the biggest cure is finding it early... and I think you can cure more people if they get there early'. (Fred, CG3)

There was a recognition, however, that certain cancers, such as breast cancer, lent themselves more to screening techniques, whereas others were more difficult to detect. The development of screening for a range of cancer types was therefore seen to be an important area of research. Peggy, for example, explained why she felt researchers should identify a diagnostic test for ovarian cancer:

'If you go to your GP now and you've got certain symptoms he'll think, "Well this patient may be diabetic", two minutes, test done. "This lady may have osteoporosis", again two seconds, test done, somebody may be suffering from high blood pressure test done, you know it's quick, but with cancer it seems to be very hit and miss the diagnosis... I know they do breast screening now and other screens...if there was some quick way in which people could be eliminated from it [cancer] as much as possible.' (Peggy, CG3)

Many participants shared their experiences of how their cancer was detected and expressed their dissatisfaction either with being misdiagnosed, with the length of time it took for the diagnosis to occur or for a lack of recognition of the importance of early symptoms. The role of the GP in detecting the early symptoms of cancer and referring their patients for further examination was seen to be central in the speedy diagnosis of cancer and recommendations for improvements to GP services were made, as explored later. Several participants compared the current attitudes towards early detection in the UK with those in America and have suggested

that a different approach to diagnosis and testing would be preferable:

Ingrid What has made me feel very angry is that I feel prevention is not a remit of the average British doctor, they haven't time for prevention, they just sit and wait and it's reaction and that is typical throughout the medical profession, I feel... I think prevention is one way they could go more and if you look on the net in America, I've got some leaflets off the net, it's constantly coming up, what puts you at risk of certain diseases...

Erica In America, there is a move that people have a blood test every year, because most Americans tend to have an annual medical. And the men, most of them have PSA tests and they're saying that now women should be having the CA125 test to show any movement before particularly ovarian cancer, because I mean they call it the 'hidden cancer,' don't they, because it's often quite large by the time you even discover it and I know a friend who emailed me when we told them the news and said, "Were you having blood tests?" No, I was not. So, that kind of research, is it effective? (CG8)

It is thus evident that participants wanted research undertaken specifically on the development of effective diagnostic tests. Detecting cancer early was seen to be central to improving the chances of survival, increasing the effectiveness of treatment and minimising the impact of cancer on day-to-day life.

## Symptoms

Participants wanted research to identify the early symptoms of different types of cancer and for the findings from this research to be disseminated to health professionals and the general public alike. The early recognition of cancer symptoms was seen by many participants to be an important factor in ensuring early detection. For example, Tracy had ovarian cancer and looking back on her experiences, she was aware of her early symptoms and felt these were important to research and share with the general public and the medical profession:



'I've had ovarian cancer and the man who did my operation said, "It's the silent killer, there are no symptoms", and I don't think that is quite true because looking back I did have symptoms and I didn't have the knowledge to know what they were. I seem to remember years ago in a hairdressers reading a woman's magazine about ovarian cancer and it said how you start to eat your food and after a few mouthfuls you don't want anymore and you put on excessive weight around the middle and that didn't sort of sink in. And I went to the doctor, I must have been going backwards and forwards for months, with what I thought was bladder trouble and I even went to see somebody because they thought I had a hernia...and I think education, GPs as well, but for women to know that if you do suddenly get terribly fat round the waist it's not just, "Oh, God", you know, "I'm getting fat", it means something.' (Tracy, CG3)

### **GP awareness, knowledge and training, and related issues**

As discussed in the previous section, participants felt that it was important for primary care services to be improved and supported to promote early detection and more rapid referral. Many of these ideas related to statements of need rather than specific research questions, but they do indicate that research designed to evaluate and improve primary care services would be important, particularly as many participants saw the GP role as pivotal in assisting early detection and diagnosis. There was a sense from participants that GPs did not have the requisite experience and expertise in recognising the early symptoms of cancer, resulting in late referral or misdiagnosis. Participants wanted GPs to be better educated both in terms of recognising the early symptoms of cancer, the management of cancer and in the referral of their patients for further investigation:

'I think there's a definite issue with GP education. I mean my particular issue with my GP is that I started the symptoms in February, but I wasn't referred to a consultant until the end of May. I don't know if those months were

particularly crucial, but it does seem quite a long period... I think the GPs need educating more about cancer referrals. (Philip, CG6)

In contrast, several participants commented on the responsibility of patients to approach their GP in the first place and discussed general reticence and procrastination in seeking medical opinion, particularly among male patients. There was also a recognition that the role of the GP was particularly demanding and that their work as 'generalists' made the early detection of cancer difficult. This 'generalist' approach was seen in stark contrast to the 'specialist' system in America, a model that was thought more effective in detecting serious health problems like cancer. Hence, participants also recognised the necessity of providing the infrastructure and resources to allow GPs to facilitate an earlier detection of cancer:

Dorothy [Reading out a research idea]  
Training for GPs to enable them to diagnose quicker and pass on to ...

Steven But that could also encompass giving them aids to diagnosis. In other words doing a diagnosis which they might otherwise, to send people..., I mean if a GP can all right, take stool samples or take blood samples. (CG12)

### **Research into general information needs**

The fourth priority area identified by consultation group participants concerned general information needs. Most ideas centred around statements of need: participants felt they needed more information on cancer, treatment, research and how to access information. The fact that more information was voted the fourth priority, however, does illustrate the need both for more information and for more effective means of dissemination.

#### **Information about cancer**

Participants expressed the need to receive more information on their cancer, particularly for those with rarer cancers who found it difficult to access information on their cancer type. It was suggested that most people would

wish to receive information about their cancer and that this was an important part of maintaining control and coping with the illness. Information on cancer and the progression of the disease emerged as an important issue in one of the hospice day consultation groups. One of the participants explained why it was important for her to be kept informed of her disease progression: 'I still like to be informed. I can cope with what I know. I cannot cope with the unknown. That's what frightens me.' (Erica, CG5). It was evident therefore that for some participants, being informed was a necessary part of planning and coping with their cancer.

### **Information about treatment**

Understandably, for many participants, the treatment regimes they were undertaking were a significant part of their experiences of cancer. In this regard, many participants discussed their need to receive more information about the treatments they were taking. Participants wanted to be advised about how to take medication and the possible side effects. Olga, for example, wished she had more information about the side effects of her treatment before consenting to any treatment plan:

'I've learnt more afterwards because of the effects the ongoing effects that are causing me problems now. At the time I couldn't ask questions 'cause I wasn't in a state to ask questions... so I didn't know enough about the after effects of everything... I can honestly say that if I had known everything that I know about radiotherapy now I would have trusted to the operation.' (Olga, CG2)

Hence information about treatment, as with information about cancer, was seen by participants to be important in terms of their own decisionmaking and management of their cancer.

### **Information about research**

Several participants stated that they wanted more information about research. As explored earlier, participants tended to access research

information through the media and this was often seen to be sensationalist and inaccurate. Hence there was a feeling from some participants that they wanted more accessible information on research. This was linked to the reporting of cancer research in the press and the need for simple, understandable information to be provided to those affected by cancer:

'I am involved in a group of women who email one another with secondary breast cancer... I did ask about the opinions of the rest of the group about research. One of the things that came through time and again from the responses I got was that huge need for information. One of the things that one of the women said I thought was very, very interesting and important. It is about, when there are trials and when there is news, when something does happen, those of us who are sort of most immediately affected by trials or by breakthroughs or cures or treatments, there should be some way that we have that sent to us so that we don't get absolutely hysterical by seeing something in the press.' (Linda, CG17)

Other participants wanted the research information to be provided in 'lay person's language', and for full details to be given about the research in question, such as the source of funding for ongoing research and the outcomes of research.

### **Access to research information**

Due to the need for information into various aspects of cancer and its treatment, several consultation group participants wanted to identify the most effective means of identifying sources of information. As Colin discussed:

'I just wondered if there was any way of signposting, a system could be set up which simplifies the whole thing. I know there's a whole lot of publications, but sometimes it's information overload and I think if the whole thing was simplified and there was very concise and very short signposting system, it takes a lot of pressure off people.' (Colin, CG10)



Several avenues of information signposting were discussed. The internet was an obvious source, but was not freely available to all people and many felt there was a tendency on these sites to portray the 'worst case scenarios'. Other suggestions included leaflets provided at surgeries.

### **General information**

Participants discussed their need for information on a range of other issues relating to cancer. Several participants felt the need for more information concerning the management of their cancer, particularly in relation to diet. Information was also requested in such areas as prevention, financial and benefits advice, and, for one participant attending hospice day care, about hospice services because, 'hospices are not only a place where you go to die.' (Erica, CG5)

### **Complementary and alternative therapies (CAT)**

Participants wanted to see more research into CAT. In particular, participants wanted research to explore the types of CAT cancer patients used and evidence for their effectiveness in treating cancer or in helping people to live with cancer. Participants were interested in this as an area of research as many had used CAT and felt it to be beneficial. All participants interested in this issue felt that such therapies should be complementary to existing treatment regimes and not used instead of them: 'I don't think it should replace your surgery and your chemotherapy. I think it should run alongside it.' (Audrey, CG17)

Participants referred to a wide range of CAT they had used, including the use of minerals and supplements, herbal remedies, reflexology, acupuncture, reiki, homeopathy and aromatherapy. Faith and spiritualism were also cited and the importance of prayer and 'faith healing' was also discussed. They described various benefits they or people they knew had from CAT use, including a reduction in tumour size, relaxation and a sense of

greater control in their own disease management:

'I used Arnica and Hypericum when I had surgery and, although I wouldn't mention it to the doctors, the sister that came to check my scar, the healing of the operation, suddenly looked up and said "are you taking something?" and I said, "Yes, I'm taking Arnica and Hypericum". She said "I thought you were because you are healing so well". Things like that. Why isn't that passed on to other patients who have had major surgery?' (Audrey, CG17)

In one of the South Asian consultation groups, the use of Ayurvedic medicine was raised as potential area for research:

'Ayurvedic medicine – We heard that there was the treatment or cure for cancer in that. In olden days the herbal doctor used to tell the formula to their students only no one else and some of them did not tell anybody and passed away with the formula, so what I will say that researchers should take out the medicine from that, and there is no side effects in the herbal medicines.' (CG16)

Given the extent of CAT use and the generally positive experiences many patients had, participants were interested in any evidence that demonstrated that CATs benefit patients. For those who were certain of the benefits of CAT, it was felt important to disseminate the advantages of complementary remedies to the general public and health professionals alike as well as incorporating CAT support in the current oncology team.

# 6 Findings III: Research views and priorities from under-researched consultation groups

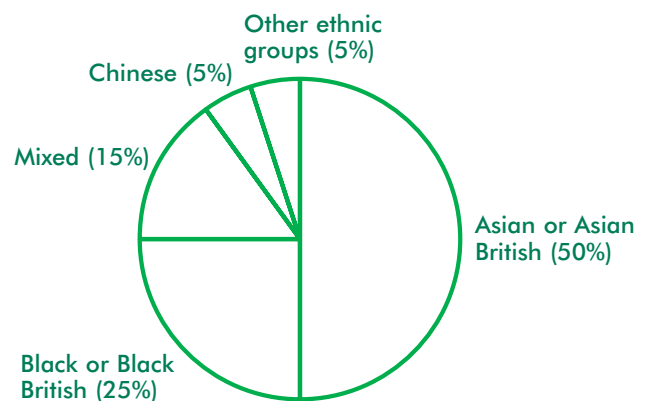
## South Asian consultation groups

### Background and context

Two consultation groups were held with participants from South Asian backgrounds. As noted previously, the priorities identified by these groups were not significantly different from the priorities identified in the general consultation groups. However, the content of the discussions did at times reflect social and cultural difference and experiences of wider social inequalities. The impact of inequalities on the research should also be borne in mind with regard to the difficulties the study experienced in recruiting participants from a range of different ethnic and cultural backgrounds. Although the inclusion of participants from South Asian groups is important for the research, these groups are not representative of minority ethnic groups in the UK. The lack of representation of participants from a diversity of ethnic groups is a cause of concern and is a matter that requires further attention to ensure that the views and experiences of those who are socially marginalised are both valued and reflected in research.

Interest in ethnicity and cancer has increased over the past 10 years and has been given added impetus by the collection of census data on ethnicity in 1991 and 2001. According to the 2001 census (ONS, 2001), one person in 12 in Great Britain is from a 'minority ethnic' group. The size of the different population groups are shown below (see Figure 1):

Figure 1: Ethnic minority populations in the UK (source, Office of National Statistics)



Research has highlighted ethnic variations in the incidence of cancer (Aspinall and Jacobson, 2004) and inequalities of access to cancer information and cancer services (National Cancer Alliance, 2002; Raja-Jones, 1999). In comparison to the general population of England and Wales, cancer incidence for Scottish, Irish, 'West Indian' and South Asian migrants in England and Wales is lower, as is cancer mortality, calculated through standardised mortality ratios (Harding and Rosato, 1999). Despite the lower incidence of cancer within minority ethnic populations, emerging data suggest an 'epidemiological transition' in which ageing and lifestyle changes are leading to a rising incidence of cancer in different ethnic groups (Aspinall and Jacobson, 2004). Some studies suggest that cancer incidence rates among migrants will rise to rates similar to that of the receiving population within one or two generations (Harding and Rosato, 1999; Zeigel *et al*, 1993). The need to understand how ethnicity, culture and faith can affect

experiences of cancer, service provision and care are being recognised in research (Randhawa and Owens, 2004), service provision (CancerBACUP, 2004) and policy guidance (Department of Health, 2000b).

### Consultation groups

Consultation group discussions were held with South Asian participants because those from South Asian backgrounds constitute the largest proportion of minority ethnic groups in the UK. Little is known about experiences of cancer among these groups (National Cancer Alliance, 2002). However, there have been particular concerns that limited information about cancer that meets the linguistic needs of the different South Asian communities is leading to inequalities in access to information and care (Randhawa and Owens, 2004, Chattoo *et al*, 2002). Research has also found that South Asian patients can be excluded from clinical trials due to the cost and time associated with language provision and due to cultural stereotyping from health care professionals (Hussain-Gambles *et al*, 2004).

Participants for the two consultation groups were recruited through a cancer support group. Decisions about recruitment and language provision were made in consultation and collaboration with the lead support group worker. On the advice of the worker, it was also decided that the groups should be single sex in order to minimise inhibition and promote open discussion (see also Patel *et al*, 2005). The groups consisted of: Hindi-speaking Gujaratis and Punjabis from India, the Indian Punjab and from Pakistan. The study information sheets and consent forms were made available to participants in English, Gujarati and Hindi. The groups were facilitated by a co-researcher who was fluent in English, Hindi, Gujarati and Kachi.

### Experience and involvement in research

In general, participants in both groups reported low levels of participation in research, particularly clinical trials. However, several participants had been taken part in

qualitative research that appeared to have been specifically concerned with involving those from diverse ethnic groups. It is of particular relevance, that in both groups there was confusion about the term 'research' and participants had difficulties in identifying and recalling their participation in research. For example, when asked about whether she has been involved in research Hema's response was: 'No, I have just been to the cancer health centre in Bristol'. In the male group, Mehul's response to a similar question from the facilitator was: 'I do not remember anything'. Later in the discussion when the group was asked about whether they had heard about cancer research in the media, Mehul replied: 'I don't think that anybody is doing any research except Macmillan. There is nobody else'.

The difficulties and confusion about the meaning of the term 'research' were in marked contrast to the wider study groups and should be considered in relation to the specific health care experiences of those who do not speak English. It is significant that research has identified an under-representation of South Asian participants in UK-based cancer clinical trials and it has been suggested that South Asian patients may be excluded from trials due to the increased cost and time associated with language provision to facilitate their involvement (Hussain-Gambles *et al*, 2004). There was no evidence from the group discussions that participants did not want to be involved in clinical research and one participant stated that he would be 'happy' to be involved in clinical research 'because of the service to mankind'. The difficulty that participants had in identifying and recalling their involvement in research may also be related to the lack of information and feedback about the outcomes of research to participants, which participants were critical of. The following extract is a discussion from the men's group regarding dietary research that some participants had taken part in:

Facilitator Can you remember anything about that research?

Rahul Yeah we did discuss a lot.

Facilitator What was the outcome of the research?

Rahul We do not know. We did not get the feedback, we discussed it and they [the researchers] went away. (CG16)

### Research ideas and cultural difference

The effects of ethnic and cultural difference upon the research priorities identified in the two groups were most visible in the priority given to herbal and Ayurvedic medicine and to food. The discussion surrounding Ayurvedic medicine in the men's group was related to beliefs that a cure for cancer had been found in Ayurvedic medicine, but had not been preserved or shared with the lay public. It is interesting to note that the discussion elicited stories of those close to participants whose cancer was reported as being cured by Ayurvedic practices:

'There was a barber, when my sister-in-law had cancer, he took it out...he took the knife and cut the wound open and cleaned it. After that he...put the medicine on it and he made the paste of clay and wrapped it around the wound...I asked about the barber when I went to the Punjab. I came to know that he passed away and he has not given the formula to anybody...we should get the formula because people died with it.' (CG16)

The same participant highlighted the need for medical research to work 'hand in hand' with Ayurvedic medicine. Ayurvedic medicine was also seen as important in managing the side effects of cancer treatments, with discussion in both of the groups emphasising that herbal and Ayurvedic medicine had no sideeffects.

In the women's group the issue of 'How medicines affect different cultures differently' was connected to herbal medicine, with Hema clarifying the rationale for her choice of research topic with: 'I heard details where they research into herbal, homeopathic. Like we have so many herbal medicines' (CG15).

The topics of food and diet were discussed in both of the groups in relation to the prevention

of cancer, the relationships between 'chemicals' in food and cancer and what foods are suitable for patients undergoing treatment. Talk about food was a recurring theme in the women's group and was also used as a marker of ethnic and cultural difference, 'I think that Indian people should stay with the Indian diet'. Issues of cultural difference were more ambiguous in other topics. For example in the group with women participants, nurse training was identified by one participant as a priority for research. The participant felt that nurses involved in her care had been 'rude' and negligent.

### Emotional support and support groups

Research into the importance of support groups and emotional support were identified by both groups. The prioritisation given to these issues needs to be seen in the context that the participants were recruited through a South Asian cancer support group where emotional support and the sharing of experience were central features of the group. However, the prioritisation of research into emotional support and the sharing of experience could also be a reflection of the value given to culturally responsive support. Two participants in the women's groups pointed to the importance of being able to communicate through shared language with others in a group, while the importance of talking about cancer was framed in relation to varying cultural contexts:

Komal People share their experiences and you learn a lot from others "Oh it is not only me who is suffering, there is so many other people like me" And maybe by talking to other people you feel so light.

Hema You know in our culture, we don't share....When I had skin cancer I talked to my family and friends. They were surprised 'How did you tell everybody?'. They were very shocked you know.

Meeta They are scared to tell, everybody. I had my neighbour, she had cancer and she is too scared to tell me that she had it...I keep

asking her 'Sheila, what is wrong with you?'. She couldn't say anything... (CG15)

Talk about the prioritisation of research into emotional support was also related to the need for holistic approaches to cancer, where medical, social, emotional, financial and spiritual support was identified as important. One participant advocated research into the effects of emotional support on drug dosage and pain relief. Other participants in the men's group were critical of what they perceived as the greater attention and funding given to medical research. One participant commented: 'I mean everybody is spending so much money on medicine... so many new things are coming out, good things are coming out... and I am sure somebody... may be forgetting this side (the emotional side) of it'.

### **Consultation groups with participants receiving palliative care services**

Two consultation groups were conducted in a hospice day care setting with participants receiving palliative care services. One hospice was situated on the south coast while the other was situated in the north. Both groups involved seven participants each and were mixed in terms of gender, age and cancer type. Of the 14 patients participating in the palliative care consultation groups, 13 were white and one was of black African-Caribbean ethnic background.

One consultation group involved two patient co-researchers identified from the participating hospice, while the other involved patient co-researchers who were involved in the general consultation groups.

### **Experience and involvement in research**

As with the general consultation groups, the minority of participants had taken part in previous studies. Examples of previous participation in research included taking part in a randomised drug trial, a lifestyle impact questionnaire and health services research, 'Someone was asking what I thought about the Hospice and Day Care and how I

responded to whatever was going on.' (Sarah, CG5)

Knowledge of cancer research was typically limited with participants finding it hard to give examples of different types of cancer research. Like the general groups, many participants accessed information about cancer and research through mainstream media, including TV and the press. Concern was expressed with the lag time associated with the reporting of information in the press and clinical applications:

'I keep reading snippets that journalists have put in and they apparently read medical papers and they just pick on something and yet one knows that the actual outcome of the research is going to be five, 10, 20 years hence and I think that's misleading for people who have that particular form of cancer.' (Eileen, CG6)

In addition to concerns about the reporting of research information in the press, participants also raised concerns about advertising for cancer research. One participant, for example, commented on the impact such advertising had on her family: 'The advert where the little boy looks in the mirror and sees his mum behind affected my daughter immensely. She asked for a magic mirror when I go.' (Anne, CG5). For Mandy, concerns were raised about the sensitivity and representativeness of TV advertising:

'I've only seen the advertisements that have been on the television where they're all very worried and then they come back saying, 'I've got the all clear', which in my case is a little bit strange because I've got terminal cancer and I find it a bit hurtful.' (Mandy, CG6).

### **Research priorities**

Participants in the hospice day care consultation groups had similar research ideas and priorities to the general groups. Areas of concern included: research into early detection and prevention, communication issues (eg between health professionals and patients), information, impact on life (eg psychological



consequences for family and friends), causes of cancer, and issues about the nature and coordination of research itself.

In one consultation group, research into early detection and prevention was voted the highest priority. Reasons for the importance of early detection and prevention included reducing the financial costs for cancer services and preventing the physical and psychological consequences of cancer from occurring in the first place:

'Early diagnosis to us, it makes everything else underneath go down, if you've got early diagnosis, then you won't have to worry about so much money for either machines, more people in panic – it all goes down a level once you find that.' (Anne, CG5)

In the second consultation group, however, participants were more interested in the nature of research itself. The concern of cancer research related to several areas, such as the extent to which research funds should be concentrated on biomedical research (eg curative treatment) or social research (eg impact on life); and the evidence for the effectiveness of research:

Daniel Has any research ever been done on how effective research is in terms of years saved?

Facilitator When you say years saved, do you mean survival?

Daniel Yes, the fundamental purpose of the research is to cure or to give extra years, surely. (CG6)

For both consultation groups, the issue of the emotional impact of cancer and family and friends was voted the second priority. Particular attention was given to the psychological demands a terminal diagnosis of cancer has on family members and the need to support this. Sarah, for example, shared her experiences:

'When I had my mastectomy, my husband took it very badly and I wondered if some sort of information my husband could have with

how to cope with it. I know that was a big problem.' (Sarah, CG5)

Similarly, in both groups, participants shared negative experiences of being informed about cancer by their GP or other health professional and the impact cancer had on everyday life. The financial costs of cancer were highlighted where, for one participant for example, the cost of travel insurance was more expensive than the cost of the holiday itself.

Comparing the palliative care consultation groups with the general groups revealed several distinct research issues. Whereas for most consultations, concerns with symptoms and symptom management were not raised, the experiences of pain and pain control were voted joint fourth priority in one of the palliative care groups. The experience of pain was linked by one participant to quality of life:

'You can fight cancer if you are not in pain. I don't think you can fight anything when you are in pain and I think, for me, when people say cancer research, that is what I would want. I would want research to consider how best they can help, not just me, but everyone to make a better life so that you have still got quality of life.' (Anne, CG5)

The other notable issue arising from the palliative care consultation groups centred around the need for more information concerning hospice services. There was a view that the popular image of a hospice as a 'place you go to to die' was incorrect and resulted in patients being put off from accessing an important and beneficial service:

Anne [I want] research into patients knowing what is available to them and where they can actually look for help. Sometimes people don't know about the hospices and they don't know what's readily available to them... Where can you look for help like hospices?

...

Mandy Yes, but people... they're frightened. That's the last place they're going to look, at the hospice.

Anne That's because the information isn't readily made available.

Mandy That's right.

Anne Hospices are not only a place where you go to die.

Mandy Exactly, palliative care.

Anne It's a lack of information. (CG5)

### Consultation group with participants aged over 75

One consultation group was held with five cancer patients aged over 75. Participants were recruited through one of the participating cancer centres. Four of the participants were male and one was female. The consultation group represented a mix of cancer types.

### Experience and involvement in research

No participant in the consultation group had been involved in research prior to the *Macmillan Listening Study*. One participant had been approached to take part in a drug trial but was unable to participate because he was recovering so well: '[The consultant said] "As far as the research is to take place, we can't accept you because the bone scan gives you a clearance."' (William, CG4)

The local and national press was the main source of information about cancer and research, and participants discussed at length news stories about environmental causes of cancer, often in derogatory terms: 'Well, there were periodic scares about it [pylons], which if they haven't got anything better to do, they put in the newspapers.' (Janice, CG4) One participant accessed information about cancer and research through the internet.

As with the general groups, participants were supportive of cancer research and cited improvement in the treatment and testing of cancer as examples of evidence of the impact that such research has made. Participants were

happy to take part in research and again, as with the general groups, cited a desire to help other people as a motivating factor. One participant was critical of cancer research as he thought it too dominated by certain cancer types, such as breast cancer, while he argued for more research into other cancers, such as prostate cancer.

### Research priorities

The research issues identified and prioritised by consultation group participants were similar to those of the general and other under-researched groups. The top priority areas from this consultation group were developing and accessing support groups to allow views and concerns to be shared and as a source of information, and research into environmental and potential lifestyle causes of cancer. In terms of the latter issue, specific attention was given to the need to identify possible causes through consultation with the patient:

'I'd prefer to see cancer research that involves the patient, starting at the point when you come in first of all. You sit with a nurse and they ask you very personal questions about some of your life habits that you, the patient, may suspect. It might be completely potty, you may say, 'Does gooseberry jam give you this?'... In my case, my suspicion of aerosols... If the question's asked often enough, it may re-concentrate the mind on that as a possible cause, because this cancer business, I'm sure it is very insidious... I'm sure for the most part, cancers are of slow origin, something somewhere goes momentarily wrong and it can be in that low state of activity for quite a long time before it erupts and shows itself to be a real problem to you. I think that question about your lifestyle is an important query.' (Cecil, CG4)

Other areas of research interest included more research into prostate cancer, information issues (again with a particular focus on prostate cancer), research into developing new treatments, developing health care services, and identifying potential risk factors from food additives.



In contrast with other consultation groups, there were no distinct differences. It is notable that issues about prostate cancer (its treatment, cause and information concerning the disease) was discussed at length by the group and was listed in two of the eight research ideas that were generated by the discussion. Similarly, it is interesting to note that research into 'Impact on Life' was not discussed as extensively as in other consultation groups. This may be due to a general positive attitude to cancer by participants: 'The fact that I was a cancer sufferer seemed not to traumatise me and my philosophy had been to "live for the now."'

## 7 Discussion

### Patient awareness and knowledge of cancer

Almost a decade ago, the US NCI found that patients had a limited understanding of cancer research, wanted more information about cancer research and were critical of how research priorities were determined by scientists (Jenks, 1997). It is interesting that although participants involved in the *Macmillan Listening Study* generated a broad range of topics for research, their own experience and knowledge of current research was largely limited to biomedical research. It was particularly noticeable that knowledge of cancer research was poor in the South Asian groups, related in part to the limited access they have to research information in their first language. It is also significant that many participants wanted to receive more information about cancer research as well as cancer and its treatment. This was particularly the case for those who had been involved in research and had not been informed of the results. This suggests that the translation of research findings to participants in research as well as the general public remains poor.

Furthermore, the study shows that most people rely on the media or the internet as a source of information about cancer, including research. However, concerns were raised about the accuracy and sensationalism of much of this information as well as a tendency to portray 'worst case scenarios'. This suggests that there is a need for research funding bodies to disseminate their research activities more effectively to those affected by cancer. There is also a need to enhance and ensure the quality of information that is currently accessed by patients and others via various means. For participants in research studies, there is a need to offer findings to patients, although as MacNeil and Fernandez (2006) comment, such dissemination of results needs to be done appropriately.

The need for greater clarity in the dissemination of research and the findings from studies is particularly important given the often sceptical views some participants had over the motives for research, particularly those of drug companies. There are clear parallels here with AIDS activism where the boundaries of science and motivations of the medical and scientific communities have been challenged by patients (Epstein, 1996; Epstein, 1997). As in the case of AIDS, this study raises questions as to who should be consulted when determining decisions about investment in cancer research. It also suggests that cancer research should become more democratic and accessible to the communities it seeks to serve (Porter, 1980; Martin, 1996).

The consultation groups held with South Asian participants also suggest the need to improve the dissemination of information to patients from diverse ethnic backgrounds. A recurring theme in the men's South Asian group related to participants' feeling that healthcare professionals were not keeping patients informed about their illness, drug regimens and support services. An overarching experience across both of the South Asian groups was a lack of knowledge about and participation in clinical research. The emphasis given by South Asian participants to communication and information should be considered with regard to wider inequalities and to the ways in which not speaking English can affect access to information. For instance, the third of the national surveys of NHS patients (Airey *et al*, 2002) found that amongst cancer patients, 32% of South Asian patients did not completely understand their diagnosis, compared to 25% of black patients and 19% of all patients.

## Patient priorities and current research activities

This is the first time that cancer patients across the UK have been consulted about priorities for cancer research. At the outset, concerns were expressed by the scientific community and healthcare professionals over the feasibility of consulting patients as the assumption was that discussion of priorities for cancer research would be too complex. These concerns were not unique to this study and have often been voiced in relation to user involvement studies (Hanley *et al.*, 2004). Our study, however, challenges these preconceptions as individuals were able to discuss a wide range of issues relating to science, medicine, health and social care, the nature and value of cancer research, as well as identify and agree on research priorities.

It was interesting to note that, although differences in priorities were identified across consultation groups, the areas of highest priority did not differ markedly between the general groups and those groups that targeted older patients, patients from South Asian backgrounds or patients with advanced cancer.

When contrasting the research priorities of patients with those of health professionals, it is interesting to note that there are both similarities and differences. Quality of life issues have also been raised by health professionals as an area of research priority (Ropka *et al.*, 2002; Bakker and Fitch, 1998; Stetz *et al.*, 1995; Mooney *et al.*, 1991). Oncology nurses have placed early detection as a high research priority (Ropka *et al.*, 2002) as well as research into risk reduction (Stetz *et al.*, 1995), while the Department of Health (1999) reported early and accurate referral to be a priority area.

Despite these similarities, there are areas of difference. For example, symptom management, particularly in the area of pain, has been prioritised by health professionals in several studies (Bakker and Fitch, 1998; Mooney *et al.*, 1991; Stetz *et al.*, 1995). This did not feature strongly as a priority area for participants in the *Macmillan Listening Study*.

While communication issues have been raised as a priority area by health professionals (Bakker and Fitch, 1998), the issue of how patients can communicate their cancer to others appears to be a new priority.

There were certain priority areas identified by participants that do not appear to reflect those commonly raised by health professionals. In particular, research into complementary and alternative therapies, what patients can do for themselves to manage their cancer (such as diet) and the specific ways in which cancer impacts on day to day activity are not commonly cited by health professionals as areas of high priority.

The priorities identified by participants do not reflect the current proportion of spend in cancer research in the UK. For example, the highest priority area for research identified by participants was the 'Impact on life, how to live with cancer and related support issues'. However, the NICE guidelines on 'Improving supportive and palliative care' (2004) have suggested there is a paucity of research evidence in this area and hence have recommended that further research is conducted. Furthermore, research into supportive and palliative care accounts for only 4% of current UK cancer research funding. Similarly, the third research priority, early detection and prevention, accounts for only 12% of UK cancer research funding (NCRI, 2004).

The second priority, *risk factors and causes*, does accord with the greatest area of NCRI research activity, cancer biology, which currently accounts for 43% of cancer research funding. However, the participants' interest in this area differed from that commonly held by the scientific community in that they focused on broad concerns such as environmental and familial causes rather than causes at a cellular level. It was also notable that research into cancer treatment was ranked equal seventh with research into the management of side effects and research into different cancer types.

The findings from this study suggest that, while participants felt that research into the causes

of cancer and other biomedical concerns were important, they wanted a more diverse portfolio of research activity than is currently ongoing in the UK. The NCRI have already identified areas such as supportive and palliative care and early detection and prevention as requiring strategic development and initiatives are underway to increase research activity in these areas. The views of cancer patients reported in the *Macmillan Listening Study* therefore support these strategic developments, and also indicate specific areas of potentially fruitful research activity within them.

### **Comparing priorities from the *Macmillan Listening Study* with current research knowledge and activity**

While comprehensive reviews of the literature are needed, a brief scoping of literature was conducted to assess recent research activity. This exercise involved searching for literature reviews for the top research priorities and revealed areas where there is little evidence (suggesting potential scope for further research) and areas where some research has been conducted (indicating the need for more effective dissemination). With the top research priority, the 'Impact on Life', for example, some of the related issues have been explored to some extent. Literature reviews exist on the psychological impact of cancer on patients and some research has been conducted that has evaluated psychological interventions for patients (Edwards *et al* 2004; Solà *et al* 2004). Some research has also been conducted in the following areas: the impact of support groups on cancer patients (Edwards *et al* 2004), patients' satisfaction with after care and strategies to improve follow-up services (Jeffery *et al* 2002), and the emotional and psychological impact on family and others (Visser *et al*, 2004; Scott *et al* 2003). This literature therefore illustrates the need to disseminate existing research findings more effectively to people affected by cancer, providing evidence is robust.

There are areas, however, where a great deal more research is necessary. Even for those

issues where research has been undertaken, gaps in research evidence exist. For example, research into employment and financial issues has been predominantly undertaken from a US perspective and thus the experiences and needs of patients in the UK remains under-researched (Wilson and Amir, 2005). Similarly, research into the emotional and psychological effects on children have tended to focus on the impact of breast cancer, highlighting the need for more research into the impact of other cancers, particularly the impact on children of fathers diagnosed with cancer (Visser *et al* 2004).

According to the literature reviews found, little research has been conducted on the effect cancer has on social functioning and the impact this has on the patient. Quality of life surveys have addressed these concerns to some extent, although little is known about the effect of cancer on day-to-day activities, such as shopping and driving (Rogers 1998; Pourel *et al* 2002; Roos *et al* 2004). Similarly, little research has been done on the role of exercise in the management of cancer (Humpel and Iverson 2005). Humpel and Iverson have suggested that little is currently known about what exercise would be most beneficial for which cancers, at which stage of disease or treatment and thus conclude that there is a need to develop evidence-based guidelines on exercise (Humpel and Iverson, 2005).

The second priority, risk factors and causes, also suggests areas where research has been done and where there are gaps in the evidence. For example, there has been research on chemical carcinogenesis from a biological perspective (Wogan *et al* 2004), and epidemiological studies of mobile phone use and cancer do exist (Kundi 2004; Moulder *et al* 2005). Research has been conducted on the role of genetics and cancer, such as the human genome project and the discovery of genetic determinants of susceptibility for some cancers (Taramelli and Acquati 2004). Research has also been conducted on diet and food additives as a causal factor of cancer, although much of this research is now dated (Boyland 1963; Boscott 1970; Shubik 1980; Fairweather and Swann 1981).

However, it appears that there is little research on emotional stress as a risk factor for cancer.

In assessing the third priority area, early detection and prevention, some research has been undertaken on screening, for example in colorectal cancer (Towler, 1998) and breast cancer (Olsen and Gøtzsche, 2001). Similarly, the role of diet and lifestyle in preventing cancer has been studied to some extent, although one review paper suggests that despite extensive research during the last 30 years, few specific dietary determinants of cancer risk have been established (Key *et al.*, 2002). In terms of the other priorities, the desire for more information about cancer and its treatment reflects findings from other studies (Gaston and Mitchell, 2005). With regards to complementary and alternative therapies, while some research has attempted to examine their effectiveness, well designed studies are required that have larger sample sizes, reliable blinding, and specific and clinically relevant outcome measures (Pan *et al.*, 2000).

Finally, it is interesting to note that while research has been conducted on health professionals' communication skills (eg Arora 2003), no research was identified on communication issues faced by patients in discussing their cancer with family members and others. Consequently, a brief scoping of the literature does indicate the need for more effective dissemination where the research evidence exists and potentially new areas of study. In order to develop the study's findings further, a more systematic appraisal of the literature to identify the current evidence base for the top priorities identified by participants is needed.

### **The involvement of co-researchers**

The involvement of patients and carers in health research has often been criticised on the basis of three main concerns: patients become 'professionalised' through their involvement in research; patients are difficult to identify and involve; it is difficult to ensure that patients are representative; (Hanley *et al.*, 2004). However, findings from the *Macmillan Listening Study* reject these views and suggest

they are unfounded. While patient and carer co-researchers gained skills and became 'professionalised' through the course of the study, this in no way negated their patient or carer status (Wright *et al.*, 2006). The identification of participants to establish the user reference and co-researcher groups proved relatively straightforward and it was possible to ensure a broad range of views were represented through careful involvement strategies.

The involvement of patients and carers in the user reference group was successful in that they readily comprehended and responded to complex research issues. On the basis of their recommendations, changes were made to the research design, the recruitment process, the consultation group question schedule and related material, such as the patient information sheet. Their input was as follows:

- The user reference group approved of the overall design of the study and the use of consultation groups. However, they commented on the need to capture individual responses, such as with the use of follow-up questionnaires.
- The user reference group clarified the 'post-treatment' category of participants to be approached in the study.
- The user reference group agreed with the recruitment strategy, but emphasised the need to ensure that all participants are approached and not just those perceived to be research positive or experienced.
- The user reference group recommended changes to the Patient Information Sheet, rewording sections to make it more accessible and changing the font to make it more legible.
- The user reference group examined the proposed questions for use in the consultation group and rephrased some of these to make them clearer.

The involvement of patient and carer co-researchers in the data collection resulted in successful consultation groups for the following reasons:

- The patient and carer co-researchers, with the Macmillan Research Unit, used their experience to remain aware of the needs

of participants (eg if a participant becomes fatigued), thus enhancing the ethical nature of the study.

- The co-researchers continued to assist in ensuring the appropriateness of patient information sheets and research questions asked.
- Involving patients and carers as co-researchers did challenge the researcher/researched divide. It was apparent in some consultation groups that participants were more at ease when they realised that the groups were led by patients or carers.
- Patient and carer co-researchers used their experience and knowledge of cancer to encourage participants to develop and follow up issues.
- Patient and carer co-researchers were involved in the hope that participants felt able to discuss a range of research interests rather than focusing on what they thought were the interests of 'experts'.

The establishment of the user reference and patient and carer co-researcher groups did generate particular challenges. Activities of both groups required significant resources in time and money, and the logistics of organising meetings with patients and carers located across the UK were considerable. Consultation groups are a particularly challenging means of collecting data and require skills from the researcher to ensure that relevant discussion is supported and remains focused around the topics of interest and that all ideas are generated from the group rather than being led by the moderator. Furthermore, the ability to run successful consultation groups is very much a 'craft skill', where competence is gained through experience. In this regard, it is unrealistic to expect novice researchers to conduct the consultation groups without support, which is why the collaborative approach of co-moderation with experienced researchers from the Macmillan Research Unit worked well. Similarly, thorough training and support provided by the Macmillan Research Unit was central in ensuring that rigorous and meaningful data were collected from the consultation groups. These experiences support conclusions made by Oliver *et al* (2004) that effective involvement of lay

representatives in setting research priorities requires appropriate skills, time, resources and working practices.

Other challenges of involving co-researchers related to how they were perceived and related to by participants. While many user reference group members and patient and carer co-researchers were novices, others had extensive experience of user involvement and several had been involved in research before. In this regard, while they were all patients or carers, they were not always seen as true peers to study participants. Thus, it was important in the training to discuss appearance and how co-researchers raised issues in order to promote successful discussion. This was of concern in the South Asian consultation groups where it was noted that differences in degrees of education and, particularly in one of the groups, differences in age and gender between the participants and the co-researchers made discussion more complicated.

Furthermore, there were challenges for the patient and carer co-researchers in conducting consultation groups in different settings. For example, it was potentially challenging for some co-researchers to moderate consultation groups with patients in the palliative stage of their treatment when they were not themselves receiving palliative care. In this case, again the role of co-moderation with an experienced researcher and thorough training was of paramount importance.

As the involvement of patient and carer co-researchers was extensive, it was felt important to reimburse their time. However, this required lengthy investigations and consultation between the University of Southampton and Macmillan Cancer Support.

It was evident that there was a lack of awareness of user involvement and related methodologies from some ethics committees and related organisations. At no point were ethical issues asked concerning the welfare of patients and carers as co-researchers. Principles of research ethics were nonetheless followed in the study. For example, co-



researchers signed terms of reference indicating that they would keep information from the consultation group confidential, and were able to leave the study at any time without having to give a reason. Clinical supervision was also provided for all co-researchers.

Difficulties arose with research governance, especially with some sites requiring patient and carer co-researchers to have honorary contracts to undertake consultation groups with participants. This was a particular challenge as the honorary contract process at some sites necessitated occupational health and other forms of clearance.

Despite these challenges, with training and support, it has been possible to ensure that effective collaboration is maintained with patient and carer co-researchers in the design and conduct of the study.

## Limitations

The study has limitations. Given that this is the first study of its kind, it was necessary to adopt an exploratory qualitative approach. This inevitably meant that the number of participants was relatively low in relation to other study designs, although to hold as many as 17 consultation groups on a single issue is unusual (Maxwell, Rosell and Forest, 2003). However, it does indicate that the results of this study should be used to provide a baseline for further research.

While the intention was to include a broad range of individuals representative of the UK cancer population and this was achieved, 20 per cent of patients approached, and fewer men than women participated in the consultation. Nearly 44% of participants said they had been involved in research before the *Macmillan Listening Study*, which is higher than the UK average. It is possible that the views of those with research experience could differ from those who had not been involved in research and hence there is a possibility that this over-representation could influence the findings. Similarly, while attempts were made to ensure representation from diverse

minority ethnic groups, predominantly South Asian patients took part due to challenges of recruitment. This group is clearly not representative of other ethnic communities, such as Black African, Black Caribbean and Chinese patients. Furthermore, the representativeness of the study is further limited as all participants were patients whose views and priorities may differ from those of carers and the general public. In addition, it is possible that the views of participants in the *Macmillan Listening Study* are not representative of patients located in more rural locations.

Discussions of the topics identified by the South Asian groups suggest the impact of cultural difference and experiences of inequality in the identification of research priorities. Because of the relatively small numbers of participants involved in the two groups and because the wider study failed to recruit participants from a diversity of ethnic and cultural backgrounds, it is not possible to draw any firm conclusions about the effects of ethnic and cultural difference on the priorities identified for research. In view of growing concerns about ethnic disparities in health, this is an area that needs further examination.

There were cases when the appropriateness of a consultation group was questioned. The hospice day care setting was unlike other consultation groups in that the participants were likely to see other participants again after the group was held. Many participants were part of the same day group and hence there were issues about sharing information with other participants that they may wish to conceal.

It was evident in the study that a collaborative approach to research is effective in that patient and carer co-researchers can learn from working with experienced researchers, and that researchers can benefit from the experiences of the co-researchers. However, supporting such collaboration in research required significant time and financial resources. In particular, training and support are needed to enable the collection of useful and meaningful data from service users.



## 8 Conclusion

The *Macmillan Listening Study* has demonstrated the need to consult with people affected by cancer over the identification of strategic priorities for research. In addition, the study has illustrated certain advantages that the involvement of people affected by cancer in the research process has to research priority setting exercises.

Even though patients are the beneficiaries of cancer science it cannot be assumed that their views will be concordant with those of the scientific community. This study demonstrates that patients with cancer have clear views as to what the most important priorities for research investment are. Where research has been undertaken in priority areas, a need for more effective dissemination of research findings is suggested. Where priorities are not supported by research evidence, such as aspects of the impact cancer has on the lives of people affected by cancer, potential areas for further enquiry are identified.

In addition, it is clear that many patients are supportive of cancer research but have limited knowledge about current research or have a particular biomedical view of research. Furthermore, patients would like to receive more information about their cancer, its treatment and cancer research, and feel that current resources through the media or internet are often misleading or inaccurate. This generates particular challenges for the cancer research funding bodies and the scientific community.

Participants in this study clearly want to see a broad range of research studies undertaken in the UK. The study thus indicates that patient identified priorities should be considered when developing the UK strategy for research. Macmillan Cancer Support with other members of the NCRI should consider how to respond to the priority areas highlighted in this report.

# 9 Recommendations

Cancer patients participating in this study have clear views about what should be researched in the future. Participants also highlighted several ways in which the conduct of cancer research can be improved, such as providing more effective means of disseminating research findings. On the basis of the study findings, we make the following recommendations:

- 1 The NCRI should develop a formal strategy to access and respond to the views of people affected by cancer –**  
The study reveals that cancer patients can make an important contribution to discussions about the research agenda. This study also indicates that patient priorities may not be adequately supported in UK, as indicated by the current proportion of NCRI funding. The NCRI should thus ensure that people affected by cancer are involved in decision-making about the future research agenda. The UK research portfolio should be diversified if it becomes transparent that the research priorities of people affected by cancer are unmet. The findings from the *Macmillan Listening Study* suggest that research into the Impact on life, how to live with cancer and related support issues may be examples of these unmet areas. These areas have been identified by the NCRI as requiring development.
- 2 Research information should be disseminated effectively to health professionals and members of the public –**  
Researchers, academic centres and funding bodies should develop effective dissemination strategies to ensure that participants, clinicians and other interested parties have access to research information and that research findings are implemented through service delivery where appropriate. This can be done through newsletters, websites or public launches of findings. It should be understood, however, that not all participants wish to receive findings from studies, and thus information should be provided in accordance with their needs and wishes. Research commissioners and providers should ensure that, as far as possible, accurate, reliable and appropriate information is provided to the media. A UK-wide public dissemination strategy for cancer research may be of value.
- 3 A comprehensive appraisal of the current research evidence related to each of the research priority areas identified by patients is required before specific areas of study are commissioned –**  
This is necessary to assess the extent to which priorities identified by participants are under-researched (thus requiring targeted funding in the future), or are supported in the literature (thus requiring more effective dissemination and implementation in practice). Macmillan Cancer Support has already commissioned a comprehensive review of the top priority area (the 'Impact on life').
- 4 More research needs to be conducted into the top priority research area, the 'Impact of cancer' –**  
Efforts should be made to support more research into the top priority area, the Impact of Cancer. Research is particularly important for aspects of this theme that have received little academic attention to date.
- 5 Involvement of people affected by cancer in research activities should be encouraged and supported –**  
Active consideration should be given to supporting effective and appropriate involvement of people affected by cancer in cancer research. This involvement, however, places many demands on the research process.

For example, sufficient financial resources need to be provided to enable effective training and support of co-researchers. Guidelines need to be developed to inform research organisations of best practice in user involvement. In order to support these guidelines, evaluations of user involvement activities and assessments of the 'added value' of involving people affected by cancer in the research process should be undertaken.

- 6 User involvement in research requires facilitating in practice** – Involving people affected by cancer in research will generate procedural challenges. Ethics committees need to assess the impact involvement in research has on patients and carers who are involved as advisers and co-researchers. R&D organisations need to consider the implications of user involvement in research, such as the honorary contract status of patient and carer co-researchers. In addition, the NCRN research portfolio needs to be developed to reflect user involvement studies and related methodologies. The current system of data accrual does not reflect the demands placed upon research nurses and clinical staff in recruiting into qualitative studies. Qualitative studies typically require smaller numbers of participants than large-scale clinical trials and may take longer to recruit participants into.

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# Appendix I: Glossary

**Ayurvedic** – Ayurveda is a holistic system of medicine originating from India. It provides guidance in relation to diet and lifestyle to enable people to live healthier lives and to improve the health of those who are ill. It is founded on the principle that the mind is closely connected to the body and that there are energetic forces called 'Tridoshas' that affect people and nature.

**CA125** – Cancer Antigen 125 is a substance that is widely used as a tumour marker. CA125 is found in women and is associated with cancer of the uterus, fallopian tubes and ovaries, and also of the breast, lung, pancreas and colon.

**CAT** – Complementary and alternative therapies (often defined as CAM – Complementary and alternative medicines) are practices often viewed by clinicians as being unconventional or non-standard. These include meditation, reflexology, massage, reiki, aromatherapy, homeopathy, acupuncture, dietary supplements, large-dose vitamins and spiritual healing. These practices can either be used alongside more traditional therapies (complementary) or be used in their place (alternative).

**CG** – Consultation groups were the main method in the study and combined a focus group approach with an amended nominal group technique. This permitted an open discussion of research issues and consensus of research priorities to be achieved.

**CoQ10** – Coenzyme Q10 is a substance found in many foods and in most body tissues. The body uses CoQ10 as an antioxidant and to produce energy for cells. It is being used in the treatment of cancer and in managing side effects of some cancer treatments.

**NCI** – The National Cancer Institute (NCI) is part of the National Institutes of Health (NIH), which is one of the eight agencies that make

up the Public Health Service in the US Department of Health and Human Services. The NCI coordinates the National Cancer Program, which supports and conducts research, training, dissemination, and other programs related to various aspects of cancer.

**NCRI** – The National Cancer Research Institute was established in 2001 and comprises the major UK organisations that fund cancer research. The purpose of the Institute is to help members develop common plans for cancer research and avoid duplication of effort. There are 19 charity and government partners that collectively fund more than £330 million per year of cancer research in the UK.

**NCRN** – The National Cancer Research Network was established by the UK Department of Health in 2001 and provides the NHS with the infrastructure to support cancer clinical trials in England. The Network aims to improve the speed, quality and integration of research and hence ultimately to improve patient care.

**NGT** – Nominal group techniques were developed by Delbecq and Van de Ven in 1971 as an aid to community decision-making and are particularly helpful in generating ideas in situations involving individuals with diverse views. NGTs usually involve participants recording their ideas independently and in private, sharing and listing ideas, discussing each idea in the group, and recording judgements or voting on ideas independently.

**PSA** – Prostate specific antigen is an enzyme that is produced in men by the prostate gland. A PSA test measures the level of the enzyme in the blood and can help identify disease in the prostate gland. It is usually done to screen for prostate cancer in older men.

**Sudan 1** – Sudan 1 is a red dye that is used for colouring products such as waxes, oils and shoe polish. It is not permitted to add Sudan 1 to food in the UK or in the rest of the EU although inadvertent contamination of some food products has been found. The UK Food Standards Agency state that Sudan 1 can contribute to an increased risk of cancer but at the levels of Sudan 1 found in food in the UK, the risk is small.

**Users** – The definition of ‘user’ is complicated as there is no single definition. It is also contentious, with people often preferring the titles ‘patients’, ‘patients and carers’, ‘people affected by cancer’ or ‘consumers’. The term ‘user’ does not solely include patients and their carers but may also include members of the general public, potential patients and public, community and voluntary organisations and health professionals. This report uses the term ‘user’ to denote people affected by cancer broadly.

# Appendix II:

## Consultation group question schedule

### General Welcome

- Remind participants to complete first part of consent form.
- General housekeeping (what happens in the event of fire?).
- What is the study about?
- How were the participants selected?
- What is going to happen (group discussion and tape recording)?
- Establishing ground rules (not talking at once, respecting peoples' views).

### Opening question

- 1 Could we go round and say briefly who we are? (Keep this section as brief as possible. Perhaps begin by saying our names and a brief background.)

### Introductory questions

- 2 Has anyone been involved in any research?
  - 2a If yes, in what way?
  - 2b What did it feel like?
  - 2c What was it for?
  - 2d What sort of research was it – drug trial, qualitative?
  - 2f Do you think the research was important?
- 3 For those who haven't been involved in research, have you heard anything about cancer research before, for example within the cancer centre or in the newspapers?

### Transition questions

- 4 What sort of things do you think cancer researchers research?  
cue: Biomedical research, cancer prevention, service delivery and organisation, etc. If people only mention biological research, ask something like:

- 4a We have discussed lab-based, biomedical research, but what sort of things do you think researchers research other than this?

If the discussion does not discuss a broad range of research areas, the facilitator will briefly define the breadth of possible types of research. It is important to make sure participants are presented with a range of issues rather than one issue as this may skew the research ideas discussed later. During this discussion, the observer notes the range of themes discussed.

- 5 Do you think that cancer research makes a difference to people?
  - 5a If yes / no, why?

### Key questions

#### Task

The observer passes the list of issues discussed in part 4 to the facilitator. The facilitator uses this to summarise the discussion. Ensure that all issues are discussed. If you emphasise non-biomedical research, this could bias the results of the study. The summary should lead onto the first task as follows:

- 6 If I could summarise our discussion so far, we have discussed a range of issues that you think cancer researchers research. These issues included [present issues]. What we want you to do now is to develop this further. We want you to think about your experiences of cancer and to use this to think about what you would like to see researched. We would like you to write down your research ideas on post-its. There is no right or wrong answer, we are interested in your views. Write down a separate research idea on each post-it

and use as many post-its as you like. Ideas can be a word, a phrase or a question.

cue: What issues about your cancer, care or treatment do you think are most important to know?

- 7 What I want to do now is to go round the group and each in turn read out one of your research ideas. After reading it out, my colleague will put your research idea up on the board. If anyone thinks they have a similar research idea, I would then like these to then be placed on the board.

- ie Participant 1 reads out one idea. The co-facilitator places this on a board. The facilitator then asks the rest of the group for similar ideas. These ideas are then read out and placed on the board. The facilitator then asks:

7a Is there one particular idea that the group thinks reflects this whole topic?

- The co-facilitator places the idea at the top of the board. This process is repeated until no post-its are left.

- 8 Are there any themes that stand out as being of particular importance?  
cue – Ask participants why certain themes are important. Dissenting voices must be encouraged and their reasons for not agreeing explored.

- 9 You are now being given three stars. What I want you to do is each in turn vote for what you feel are the most important research themes. You can place one star on three themes, two stars on one theme and one on another, or three stars on one theme.

- The co-facilitator hands out the stars. Participants are to place the stars next to the theme written by the co-facilitator at the top of the board. The co-facilitator adds up the number of stars and the facilitator reads out the themes in order of the priorities given.

- 10 What do people feel about these priorities?

CUE – Again, ask participants why certain themes are prioritised. Encourage dissenting voices and explore reasons for not agreeing.

### Ending questions

- Facilitator provides a summary of the discussion and priorities
- 11 Does this summary reflect what we have been discussing?
- 12 Are there any issues we haven't covered that you think are important to raise?

### Close

Facilitator thanks the people attending and explains what will happen next.

Ask the participants to complete the consent form and remind them about completing the questionnaire.

## Appendix III: Sample table of research topics and initial thematic analysis for one consultation group

Consultation group 14			
Rank	Research topics	Number of votes	Themes identified in analysis
1	<ul style="list-style-type: none"> <li>• How close are we really to a cure?</li> </ul>	8	Proximity to cure
2	<ul style="list-style-type: none"> <li>• Does a holistic approach to cancer treatment improve long-term outcomes?</li> <li>• Do cancer patients treated holistically fare better than those treated 'in bits'?</li> </ul>	3	Impact of holistic approach
2	<ul style="list-style-type: none"> <li>• To continue to look into other issues – location/lifestyle.</li> </ul>		
	<ul style="list-style-type: none"> <li>• Research into chemical and cancer. Immune system. Farming community and cancer.</li> <li>• What environmental factors contribute to causing cancers and what can be done to eliminate/control these?</li> </ul>	3	Risk factors causing cancer
2	<ul style="list-style-type: none"> <li>• Why can't I be treated with gene modified T CELLS to cure mesothelioma?</li> </ul>	3	Access to curative treatment
3	<ul style="list-style-type: none"> <li>• Complementary therapies.</li> <li>• Do any of the complementary therapies, ie reflexology, aromatherapy, meditation, visualisation, reduce tumours in cancer patients?</li> </ul>	2	Effectiveness of complementary therapies
3	<ul style="list-style-type: none"> <li>• More research into less high profile cancers.</li> <li>• Get the government to invest more money in minor cancers, etc.</li> </ul>	2	Research into rarer cancers
3	<ul style="list-style-type: none"> <li>• Is price a factor into cancer treatment?</li> </ul>	2	Economics of cancer treatment
3	<ul style="list-style-type: none"> <li>• There are screening programmes for breast and cervical cancers. Can screening be developed for a greater range of cancers?</li> <li>• To improve early diagnosis/ causes into cancers.</li> <li>• Medical check ups at certain ages, ie teens, 20s, 30s, etc.</li> <li>• How can cancer diagnosis be made more efficient / effective?</li> </ul>	2	Detecting cancer early

<b>Consultation Group 14 (continued)</b>			
<b>Rank</b>	<b>Research topics</b>	<b>Number of votes</b>	<b>Themes identified in analysis</b>
3	<ul style="list-style-type: none"> <li>• How can patient concerns be best understood and responded to?</li> </ul>	2	Accessing patients' views
4	<ul style="list-style-type: none"> <li>• Why treatments effective for some but not ineffective for others?</li> <li>• Are cancer drugs given to patients with the consideration if they are suitable for them?</li> <li>• Genetic research. If there are more of a certain cancer in one family.</li> </ul>	1	Effectiveness and suitability of treatment  Genetic risk factors
4	<ul style="list-style-type: none"> <li>• How can patient experience and knowledge from the research trial (to which they have been subject) be gained by the medical staff?</li> </ul>	1	Access the views of research participants
4	<ul style="list-style-type: none"> <li>• Consultants should inform patient of all research that is taking place in respect of their personal condition – to reassure.</li> </ul>	1	Access to research information about cancer
4	<ul style="list-style-type: none"> <li>• The suggestion that eating certain types of food might prevent cancer. Has the above been researched?</li> <li>• Do any specific foods help prevent / restrict growth of cancers – (generally and in specific cancers)?</li> <li>• What are the dietary factors implicated in causing certain cancers and what can be done to control / eliminate them?</li> </ul>	1	Diet as a cause and preventative measure
5	<ul style="list-style-type: none"> <li>• What causes mesothelioma in people who have not had above normal exposure to asbestos?</li> </ul>		Causes of cancer
5	<ul style="list-style-type: none"> <li>• Do patients when they get treatment have food reactions?</li> </ul>		Side-effects of treatment
5	<ul style="list-style-type: none"> <li>• Worldwide. If all the cancer research groups got together, would there be better results?</li> </ul>		International coordination of research
5	<ul style="list-style-type: none"> <li>• Asbestos was known about in 1931 – but used until 1984 in factories.</li> </ul>		Access to information on risks
5	<ul style="list-style-type: none"> <li>• percentage research into cure versus percentage research into more effective treatments, eg prolonging life.</li> </ul>		Consultation of cancer research: cure or prolonging life



# Appendix IV: Full findings table

Research idea receiving at least one vote (dark green)

Research idea receiving no votes (light green)

Research priority	Subtheme	Research idea
Impact on life, how to live with cancer and related support issues	Psychological impact	<p>As a result of the disease, you realise that there is a difference between important and urgent.</p> <p>Personally, I must say that the fact that I was a cancer sufferer seemed not to traumatise and my philosophy has been to 'live for the now'.</p> <p>Psychological elements on family and friends.</p> <p>Mental attitude.</p> <p>Does stress play a part in recovery after diagnosis?</p> <p>Stress weakening the immune system. Stress hindering a cure?</p> <p>Could hospitals not have mental health personnel on board to maybe call round when you are waiting for your scan or treatment and just offer to talk to you?</p> <p>Is the mental attitude a bonus?</p> <p>Is it possible to strengthen the support mechanism following the diagnosis of cancer?</p> <p>Is it good to be reflective?</p> <p>Is there any evidence that a positive mental / psychological attitude can help a patient heal?</p> <p>Research into emotional support available.</p> <p>Mental.</p> <p>Ongoing emotional support.</p> <p>Feel good about yourself.</p> <p>Help us to cope with uncertainties.</p> <p>Improving positive mind set – visualisation, meditation.</p> <p>How to keep people positive and motivated with treatment.</p> <p>When to put the lid on it and take it off again.</p> <p>I found the unknown very frightening.</p> <p>How to cope with the initial shock?</p>
	Self help groups and peer support	<p>Self help group after treatment finished re: diet, exercise, etc.</p> <p>Support groups. Someone to vent feelings / worry / other than family because you worry and protect them.</p> <p>Leaflets to give patients a clearer idea of the type of cancer they have and encourage them to talk about it either in groups or with family.</p>

Research priority	Subtheme	Research idea
		<p>Good to listen to other people's views and complaints regarding their illness.</p> <p>General discussions on individual problems observed by doctors needed to explain problems.</p> <p>Men. Recovery – daily every day living. Help to talk face-to-face with people.</p> <p>To talk to someone in same situation.</p> <p>More help groups for particular cancers.</p> <p>Being able to talk to someone about cancer.</p> <p>How do you contact others going along the same journey?</p> <p>Communication in the groups to share your experiences.</p> <p>Talking about your treatment and side effects.</p> <p>Do support groups help?</p>
	Follow-up and after care	<p>GPs are follow-up but are not always in full knowledge of what has been done or what is going on.</p> <p>Aftercare.</p> <p>Aftercare – living with cancer day to day.</p> <p>After care before the treatment and after treatment.</p> <p>Back up. After care.</p> <p>Follow up general monitoring/ information.</p> <p>Does the support you receive after surgery for cancer impact on you, eg from GP? Cancer nurse, etc? Friends?</p> <p>Nursing care and after care.</p>
	Impact on social functioning	<p>'I could no longer win races with my grandson every time.'</p> <p>'People started treating me as an invalid. Family are the worst.'</p> <p>Quality of life.</p> <p>Giving up regular activities.</p> <p>Social life.</p> <p>Driving and travelling.</p> <p>Loss of independence.</p> <p>Attitudes to disability.</p>
	Work and other financial impacts	<p>For younger cancer sufferers: help with finding work – cancer sufferers might be viewed negatively workwise.</p> <p>Difficulties with insurance – availability.</p> <p>Employer's attitude.</p> <p>Social services.</p> <p>Return to work schemes.</p> <p>The financial experiences of cancer (benefits).</p> <p>Money issues, eg state benefits and prescription charges.</p>

Research priority	Subtheme	Research idea
	Pain management	Pain management. Pain/ pain control – quality of life.
	Impact on family and others	Family counselling – written information. Psychological elements on family and friends. Support for partner and children. Carers needs (break). Family support. Benefit of family support and holistic support. Can there be some research into the effect on the family of a member being diagnosed with cancer? Worry about the family. Research into effects on children.
	Diet in managing cancer	Diet and nutrition. What difference does diet make in having bowel cancer? Food – what to eat, what not to eat? What reaction/ side effects?
	General lifestyle issues in managing cancer	Does living in a family make a difference, eg husband and children, to your recovery? Exercise and fitness as to getting cancer and after treatment. What are the lifestyles of longer survivors?
Risk factors and causes	Environmental	Mobile telephones? Damaging. Microwave use with cancer. Mobiles. Radiation from TVs and computers. Environmental exposure to chemical agents, ie house insulation, excessive dust. Electro-magnetic forces as a cause and as a cure? How is Sellafield nuclear power station contributing to the high incidence of cancer in the east of Ireland? The environment! Is there any link between electricity and cancer? Atmosphere (Car fumes?) (Mobile phones?) (Toxins?) To continue to look into other issues – location/ lifestyle. What environmental factors contribute to causing cancers and what can be done to eliminate/ control these? Dwellings should not be built near to electrical installations or suspicious areas where perhaps people have suffered from cancer. The air we breathe in very pollution. Radiation.
	Genetic	Research into family genes. Genetic research. Is it genetic?

Research priority	Subtheme	Research idea
		<p>Research into the hereditary nature of breast cancer in particular.            'I have had cancer. Will my children inherit it? Will it be possible for my children to get tested? At what age?'</p> <p>Seeing more into cancer being in family genes.</p> <p>Study in genes.</p> <p>Cancer onto children, ie genes.</p> <p>Is there any work being done into identifying possible occurrence patterns about from 'genes'?</p> <p>Genetic research. If there are more of a certain cancer in one family.</p> <p>Family history to promote early detection.</p>
	Diet	<p>Diet – research available?</p> <p>Diet.</p> <p>Diet: can research into diet be extended?</p> <p>Does diet have a part to play in why we develop cancer?</p> <p>Diet – as a cause and to help with a cure?</p> <p>Food additives</p> <p>Greater study of food and food sources.</p> <p>More checks before foods go on sale to general public.</p> <p>What are the dietary factors implicated in causing certain cancers and what can be done to control / eliminate them?</p> <p>I think diet issue must be important.</p> <p>More food are preservative. It is not fresh.</p> <p>Did cancer has become very common because there is too much chemicals in the food?</p> <p>Chemicals of food consumed – side effects these have.</p> <p>Investigation into food, ie margarine and like products. Foods from animals fed poor and/ or unsuitable materials.</p> <p>Chemical in food.</p>
	Stress	<p>Research into causes of cancer: life history, effects of stress and general 'dissatisfaction' with life.</p> <p>Lifestyle, stress or anxiety.</p> <p>Stress related.</p> <p>Stress on cancer.</p> <p>What effects stress has to cancer.</p>
	Other	<p>Causes.</p> <p>Research.</p> <p>There is a need for more research into the treatment of prostate cancer and the origins of this disease.</p> <p>Can you prevent cancer – causes – what is cancer? – types.</p> <p>What are the risk factors of ovarian cancer?</p>

Research priority	Subtheme	Research idea
		<p>General research into all causes so that some cancers can be prevented. All cancer patients should fill in detailed lifestyle and occupational questionnaires.</p> <p>Our neighbours in the eastern world do not have as extensive cancer patients as in the West.</p> <p>Contraceptive pill.</p> <p>Establish vulnerable persons.</p> <p>Exercise and fitness as to getting cancer and after treatment.</p> <p>Research into chemical and cancer. Immune system. Farming community and cancer.</p> <p>What are the causes of cancer?</p> <p>Why do people get cancer when they are vegetarian and don't drink or smoke?</p> <p>What is the causes of cancer?</p> <p>Causes – why?</p> <p>Why is cancer spreading?</p> <p>Increase of cancer</p> <p>Is smoking a cause or just an unhelpful factor, ie is it will it just not help or is it a cause?</p> <p>Is cancer linked to trauma such as major operation external effect car crash?</p> <p>What causes changes in the body for rogue cells to develop?</p> <p>What causes mesothelioma in people who have not had above normal exposure to asbestos?</p> <p>What's the main cause of cancer? What are the symptoms?</p>
Early detection and prevention	Preventative Screening	<p>Preventative Screening.</p> <p>Diagnosis – simple screening.</p> <p>Diagnostic screening most worthy objective of research. Is it possible, or will cancer remain not susceptible to this approach?</p> <p>Firm having own employees checked.</p> <p>If cancers 'run' in families, is very early screening being done? If not, why not?</p> <p>Should family be tested after you have been diagnosed?</p> <p>To get a general MOT on reaching the age of 50.</p> <p>There are screening programmes for breast and cervical cancers. Can screening be developed for a greater ranger of cancers?</p> <p>Medical check ups at certain ages, ie teens, 20s, 30s, etc.</p> <p>Would a blood test annually be a diagnostic help?</p>
	GP awareness, knowledge and training, and related issues.	<p>Making GPs aware of early symptoms in some forms of cancer.</p> <p>Cancer research: Step up diagnosis – before cancer gets a grip.</p> <p>GPs should be made aware of symptoms of cancer and facilities to give a quick if not certain diagnosis.</p> <p>GP/ medical professionals' education!</p>

Research priority	Subtheme	Research idea
		<p>Doctors need more knowledge and training especially GPs – at beginning.</p> <p>Can GPs have support in earlier diagnosis with cancers which can be camouflaged by other symptoms?</p> <p>Training for GPs to enable them to diagnosis quicker or pass on to expert.</p> <p>I think my own GP should have more say in having you seen by a consultant much sooner than I experienced. I was waiting almost a year before I seen anybody.</p> <p>All GPs to be encouraged (even if in doubt) to refer patients for immediate investigation, ie X-rays, etc.</p> <p>Diagnostic aids should be more readily available to GPs.</p> <p>More research into cysts – early seriousness should not ignore it. GPs.</p> <p>GPs should eliminate cancerous symptoms more quickly.</p> <p>Do doctors (GPs) know what symptoms relate to all kinds of cancer?</p> <p>How can we better train GPs to diagnose disease?</p> <p>GPs more aware of symptoms.</p> <p>How can GPs be kept more up to date on research?</p> <p>Research into how to get people to actually go to the doctor.</p> <p>Perception is that GPs can be inhibited from referring patients for scans, biopsies ad the like for financial reasons.</p> <p>Research into why it is taking so long to pick up on cancer – by the GP.</p>
	Early detection	<p>Prognosis</p> <p>Prevention/ treatment/ cure – which is most important?</p> <p>Early diagnosis.</p> <p>Prevention – more financially useful than cure. Can you prevent cancer? – causes – what is cancer? – types.</p> <p>More research into preventative medicine.</p> <p>What research for early diagnosis of prostate cancer?</p> <p>What are the early symptoms of cancer?</p> <p>Fast early detection and treatment.</p> <p>Early diagnosis.</p> <p>To improve early diagnosis / causes into cancers.</p> <p>How can cancer diagnosis be made more efficient / effective?</p> <p>Skin cancer back of my head. Early diagnosis should be done.</p> <p>Early diagnosis. Communication. Prevention.</p> <p>Diagnosis of ovarian cancer quicker – symptoms.</p> <p>How to quicken biopsy results.</p>
	Diet	<p>What food stuffs are beneficial to prevent cancer? Proof.</p> <p>Is diet important as a preventative measure?</p>



Research priority	Subtheme	Research idea
		<p>The suggestion that eating certain types of food might prevent cancer. Has the above been researched?</p> <p>Do any specific foods help prevent/ restrict growth of cancers – (generally and in specific cancers)?</p> <p>More research on diets eg Asian food. How to prevent cancer by diet.</p>
	Lifestyle	If we improve lifestyle, do we stand a better chance of avoiding cancer?
Research into general information needs (on cancer, treatment, research and access to)	Cancer	<p>Leaflets to give patients a clearer idea of the type of cancer they have and encourage them to talk about it either in groups or with family.</p> <p>My first reaction on being diagnosed as suffering with prostate cancer was the almost total lack of information about the condition.</p> <p>Information about condition and prognosis.</p> <p>A lot more awareness in to all cancers.</p> <p>What is the likelihood (%) that I will die from this cancer given my age, amount of nodes affected, etc?</p> <p>More information on the different types of cancer, and general helpful knowledge of own cancer.</p>
	Treatment	<p>More information about consequences of radiotherapy, eg possible ongoing problems.</p> <p>Are patients given specific information about drugs and effects on the body?</p> <p>Information about side effects to be readily available.</p> <p>Information on treatment programme.</p> <p>More information about the drugs.</p> <p>New drugs [info and lack of]</p>
	Research	<p>How do I participate in trials?</p> <p>Consultants should inform patient of all research that is taking place in respect of their personal condition – to reassure.</p>
	Access	<p>Access to information.</p> <p>Where can you easily access information on your specific cancer?</p> <p>Where do I get more information if I am not on the internet?</p> <p>Where can you investigate easily research into the drugs you are being prescribed?</p> <p>At the moment individuals have to contact their own search for further information. Is there any way this can be signposted?</p>
	General	<p>Help with financial advice.</p> <p>Financial help.</p> <p>Easy information (plain English).</p>

Research priority	Subtheme	Research idea
		<p>How to give easily understandable information to people who may not take in what is said.</p> <p>Easily accessible information about diet.</p> <p>Doctors' sensitivity – keeping patients informed.</p> <p>Knowledge to patients – drugs and hospices, etc – nurses / financial and other services.</p> <p>Why is there such disparate information concerning dietary requirement following treatment for pancreatic cancer?</p> <p>What about MOABs, etc?</p> <p>Too blunt – not too much information as requested.</p> <p>I want more and clearer info about my situation, treatment effectiveness and prognosis.</p> <p>Asbestos was known about in 1931 – but used until 1984 in factories.</p>
Use and effectiveness of complementary and alternative therapies	Effectiveness	<p>Are vitamins, minerals and supplements helpful?</p> <p>Reflexology – good or bad for cancer?</p> <p>Can researchers look at the beneficial effects on complementary therapies in the treatment of cancer patients?</p> <p>Do any of the complementary therapies, ie reflexology, meditation, visualisation, reduce tumours in cancer patients?</p> <p>Research into herbal and homeopathic medicine and their benefits.</p>
	General	<p>Research into alternative therapy as well as mainstream medication.</p> <p>Vitamins and minerals with cancer.</p> <p>Relaxation and alterative therapy.</p> <p>Homeopathy.</p> <p>How can we better advise patients on diet that may help control cancer?</p> <p>How can we incorporate alternative / complementary to run alongside conventional medicine?</p> <p>Post diagnosis. Would it help to have dieticians and alternative medicine on hand?</p> <p>Could a qualified homeopath be included in the cancer care team?</p> <p>Complementary therapies.</p> <p>'Emotional'. Emotional side. Alternative medical "ayurvedic".</p> <p>'Faith'. Research into power of faith in healing.</p> <p>Complementary support.</p> <p>Can you take any herbal medicine given by your doctor? Because there is no side effect with herbal.</p> <p>Non drug treatments (spiritual).</p> <p>Using Ayurvedic medicine to look at treating side effects.</p>
General education of public about cancer		<p>Research into education to make people more aware of the dangers as well as the cost. It will never happen to me! (If it does, I'm dead.) Both are untrue.</p>

Research priority	Subtheme	Research idea
		<p>Research should be given or integrated into education so people can make informed choices. It's vital that everyone gets involved.</p> <p>More research as to why breast cancer occurrence has moved from one in 11 five years ago to one in nine now.</p> <p>Psychological: need to move public perception forward to reflect current levels of success in treatment.</p> <p>If in some way the general fear of cancer could be lessened it might encourage people to seek help earlier.</p> <p>More information to general public about early symptoms.</p> <p>More advertising on TV for awareness.</p> <p>How can we educate / make aware the symptoms of ovarian cancer?</p> <p>What about picking a person or persons to go round factories or groups and talk about their cancer and their treatment?</p> <p>I wonder if there should be more education in schools and for young mums about the damage that too much processed food can do and how it might be responsible for colon cancers?</p> <p>Is there a way in which siblings of cancer sufferers can be more than encouraged to have themselves checked?</p> <p>Educating public about positive approach to cancer. Not the big C.</p> <p>More Asian people should be aware of bone marrow and the effect. (What is awareness of bone marrow donation in Asian Communities.)</p>
Research into different cancer and patient types		<p>Research into younger people overall, eg prostate, breast cancer.</p> <p>Important that you research people types in relation to how they deal with the disease.</p> <p>Research into prostate cancer in general and new drugs available for treatments.</p> <p>There is a need for more research into the treatment of prostate cancer and the origins of this disease.</p> <p>Cancer in children.</p> <p>More research into less high profile cancers.</p> <p>Get the government to invest more money in minor cancers, etc.</p> <p>Less known about more 'unusual' cancers, eg lobular breast cancer.</p> <p>Lymph node research.</p> <p>More research on young children get skin cancer, leukaemia.</p> <p>Why are even little kids get leukaemia?</p>
Research on treatment (curative treatment, treatment types and improvements)		<p>Which drugs are best for different cancers? How much research is done into every cancer?</p> <p>Better targeting of unpleasant chemicals so they only home in on the cancer cells.</p> <p>How do you know which treatment is suitable for you? More beneficial?</p> <p>Is there much research being done into non-oestrogen receptor tumours – breast cancer?</p> <p>How close are we really to a cure?</p>

Research priority	Subtheme	Research idea
		<p>Does a holistic approach to cancer treatment improve long-term outcomes?</p> <p>Do cancer patients treated holistically fare better than those treated "in bits"?</p> <p>Why can't I be treated with gene modified T cells to cure mesothelioma?</p> <p>Is price a factor in cancer treatment?</p> <p>Why treatments effective for some not effective for others.</p> <p>Are cancer drugs given to patients with the consideration if they are suitable for them?</p> <p>Effective treatment of cancer. At the moment lots of research is being done for treatment of cancer, eg Herceptin is very effective for treatment.</p> <p>Research into surgery for cancer (surgery and treatment).</p> <p>What has happened to magic cures?</p> <p>I have heard that a tumour will 'die' if its blood supply is cut off. Has any research been done in applying this to ovarian cancer?</p> <p>Looking more into radiotherapy which has taken a back seat as more drug company driven chemo takes over.</p> <p>Postcode.</p> <p>New drugs [info and lack of]</p> <p>How medicines affect different cultures differently.</p>
<p>Organisation and funding of health and social care services</p>		<p>Facilities available for operations to cancer areas in hospitals in UK.</p> <p>More money – machines / drugs.</p> <p>How can the process of receiving chemotherapy be more streamlined?</p> <p>Would it be helpful to give more funding to oncology nurses to help them speed up clinics, ie chemotherapy to relieve stress for them and patients?</p> <p>'I would prefer to see the same doctor on each consultation.'</p> <p>Who is responsible for ensuring that current results are available at consultation with specialist, ie scans and blood?</p> <p>I think patients should be allowed to feel and look at what is getting fitted after what body part is removed.</p> <p>Cancer care [training for nurses]</p> <p>Pre-emptive treatment.</p> <p>Planning.</p> <p>Preventing reoccurrence (supplements, diet, etc.)</p> <p>Role of GP: Start, end and during.</p> <p>Lead nurse [A point of contact]</p> <p>Separate department in DHSS for dealing with cancer patients.</p> <p>Scalp-cooling. Why can the hats not fit better so that the whole head is in contact with it to prevent hair loss in patches?</p>

Research priority	Subtheme	Research idea
		<p>Is there any chance that research could be done into opening some of the local hospitals which have been closed being reopened for post operative cancer recovery units?</p> <p>'Can I see the same consultant or even a group or two or three?'</p> <p>If the family have to travel a long distance to the hospital, where do they stay, etc?</p> <p>Time results [waiting]</p>
Coordination, impact and funding of research		<p>Get more financial assistance from the government via tax deduction on charities so as more research can be done.</p> <p>The growth in 'charity shops' show the great need for funding in these areas.</p> <p>How effective in extending life?</p> <p>Does research have other purposes?</p> <p>Is medical research most important? (c.f. with social research)</p> <p>Blue skies research for new cures.</p> <p>Is there a need to rationalise the number of cancer charities?</p> <p>Pool resources?</p> <p>Why is there no national integration of research?</p> <p>All research lbs (private) to be responsible to one national research lab and information collated for the good of all sufferers.</p> <p>Should research and hence funds be concentrated on prevention or cure?</p> <p>Should research and hence funds be concentrated on the more common cancers?</p> <p>What problems raised in cancer research by animal liberationists?</p> <p>Research should be centralised instead of money being dispensed among various establishments.</p> <p>Worldwide. If all the cancer research groups got together, would there be better results?</p> <p>Percentage research into cure versus percentage research into more effective treatments, eg prolonging life.</p>
Experiences and management of side effects		<p>Research into after effects with regards to treatments such as radiation, nausea, etc.</p> <p>Side effects of treatments.</p> <p>Drugs and side – effects – how do drugs work? – cure or palliative?</p> <p>Does chemotherapy cause many patients to develop diabetes?</p> <p>Is there any research into the side effects of chemotherapy and counteracting these to avoid permanent damage or short term discomfort?</p> <p>Research into neuropathy following chemotherapy.</p> <p>Why can't more be done to help women who have breast cancer and have to cope with severe menopause symptoms caused by drugs?</p> <p>Could research be done into the side effects of post-operative drug treatment?</p>

Research priority	Subtheme	Research idea
		<p>Side effect of the medication.</p> <p>What could be done fore the side effects after chemotherapy for eg overweight, body pains, etc?</p> <p>Research into the side effects and how it can be cured.</p> <p>Research of treatment of side effects while in hospital. Benefit support.</p> <p>Research into smell of chemo and sickness.</p> <p>Do patients when they get treatment have food reactions?</p> <p>Side Effects – external – body. Why treatment effect on skin?</p>
Research into recurrence		<p>Does diet help to prevent recurrence of cancer, particularly say, breast cancer?</p> <p>Guidelines for reoccurrence more than check ups.</p> <p>Patients worried about cancer coming back.</p> <p>Having a prophylactic mastectomy on right side as well – by how much will this reduce the possibility of a cancer returning or what is the likelihood of cancer in the other breast.</p>
General communication issues involving all parties		<p>Communication. Method of being informed that I had cancer – rather casual.</p> <p>Communication between patient and GP.</p> <p>Communication between consultant and GP.</p> <p>Communication between other hospital staff, eg junior doctors.</p> <p>Nurses good communicators.</p> <p>Access to notes in hospital.</p> <p>GP awareness and training.</p> <p>How to tell others about my illness?</p> <p>Bad news (communication).</p> <p>Bad news.</p>
Accessing patients' views about cancer, services and research		<p>Need to check patient's suspicion of possible causative lifestyle habits, ie smoking, aerosol use, etc.</p> <p>Drs need to view patients as experts on themselves.</p> <p>How can patient concerns be best understood and responded to?</p> <p>How can patients' experience and knowledge from the research trial (to which they have been subject) be gained by the medical staff?</p>
Health and Safety in the hospital		<p>Research into infection.</p>



# Appendix V:

## Supportive qualitative data for remaining consultation groups priorities

### Remaining research priority areas

#### General education of public about cancer

Participants wanted researchers to assess ways in which public awareness of cancer could be promoted. This was viewed to be important because public education was seen to be central in detecting cancer early through the recognition of early symptoms and also in preventing cancer by informing people of potential causes of cancer. Educating the general public was also linked with information as participants discussed various means by which people could be educated.

Participants typically justified their view of the importance of public education through statement of need. One participant, for example, felt that there was a need for education in schools while another called for greater awareness of early symptoms:

*'Ovarian cancer is supposed to be without any symptoms, but it isn't and I think if you asked a hundred people who have had ovarian cancer, "What exactly did you feel like, and what happened to you?", and they'd say about the weight increase and you might get some idea of what the symptoms are. I don't believe it's without symptoms I know it isn't and I think it's only education and publicity that will do this.'* (Tracy, CG3)

Educating the public about the need to present early to the GP with suspected symptoms was also discussed:

*'When I discovered a lump, I was two of three weeks and I thought, is it a lump, it's not a lump, is it a lump and I got to the stage where*

*I thought I really have to go to the doctor, but there's a lot of people that don't go until it's too late.'* (Kirsty, CG12)

Participants discussed barriers to public education and it was suggested that public fear of cancer and its treatment was a factor. Hence, removing the public fear of cancer was seen as a way of facilitating early detection. Different strategies for public education were discussed including education in schools, TV advertising and leaflets, but it was felt that research into effective means of public education was important.

#### Research into different cancer and patient types

Several participants wanted to see more research into specific cancer types or more patient types. Research into the causes and treatment of children with cancer was raised as a priority in relation to other patient types. Adrian explains why: 'I feel sorry for children with cancer... I think they haven't had a life as such so if research could be put into children.' (CG13). Other participants wish to see more research into the causes and treatment of specific cancer types that they saw as being less well researched, such as prostate cancer. This often related to a broader discussion of the relative merits of research into common or rarer cancers.

#### Research on treatment (curative treatment, treatment types and improvements)

Research into various aspects of treatment was voted the joint seventh research priority with research into different cancer and different cancer types. Participants were

interested in various research issues relating to treatment including research into curative treatment, more research into the specific aspects of cancer treatment (such as radiotherapy), and improvements to existing treatment regimes. For example, Philip, a participant in one of the hospice day care consultation groups, felt that research into curative treatment was an important area of study:

'I hate to use the cliché, but something like looking out for new cures, sort of blue sky research. I think that's important...but it may be that there's plants in the rainforest, while it's still there, that we should be testing.' (Philip, CG6)

Barry, a patient diagnosed with mesothelioma, was interested in the possibility of curative treatment for his disease:

'Why can't I be treated with modified T cells to cure mesothelioma, because it is the only known cure?... It's in the experimental stage at the moment... a clinical trial has been going on [in America] for some five years, I believe, and they've been trying it out on breast cancers first off, then they... went on to breast cancer and the prostate cancer... but they are really experimenting down those two lines and they dropped the lung cancer for some unknown reason.' (Barry, CG14)

Other participants were interested in improvements to existing treatments, such as better targeting of cancer cells by drugs. Several participants discussed specific treatments such as more research into non-oestrogen receptor treatment, lymph node research (why 'should it be necessary to remove the whole lot?' (Kirsty, CG12)), and radiotherapy: 'I've got looking more into radiotherapy, which has taken a back seat as more drug company driven chemo takes over.' (Susan, CG8)

Participants were also interested in reasons why the same treatments would result in different responses in different cancer patients. This was of interest to two participants from minority ethnic backgrounds who raised issues

about the effect of treatment on different cultural backgrounds: 'How does medicine affect different cultures?' (Hema, CG14). Finally, the availability of treatments was also discussed. In particular, the issue of 'postcodes' and the accessibility of certain medications were raised in several consultation groups.

### **Experiences and management of side effects**

Participants wished to see more research undertaken on investigating the side effects patients experienced with their cancer treatment and how these may be alleviated. This was viewed as an important area of study as many participants experienced severe side effects resulting from chemotherapy, radiotherapy and surgical interventions. Common side effects included hair loss, fatigue, pain, nausea, peripheral neuropathy. Each side effect impacted on the patients' quality of life. Hair loss was a commonly experienced side effect, 'It is part of the uniform for cancer victims!' (Tony, CG13), and was important to many as it affected their confidence in public.

Side effects as a research issue was important to many participants because they felt it was difficult to deal with such problems while living with cancer. Furthermore, as Tracy explained, the side effects could be long term and impact on day-to-day life:

'Well I had something that causes me a great deal of stress much more when it started and that was that for my treatment I was given Taxol and Carboplatin... and it has left me with peripheral neuropathy which has really affected my life. I can walk, which is fortunate, but my feet are permanently painful and well my fingers are not so bad but I have trouble with earrings and doing buttons up and things like that.' (Tracy, CG3)

Several participants discussed more specific side effects relating to treatment for their specific cancer including reactive asthma, hyperactivity and early onset of menopausal symptoms. Consequently, participants wanted

more research on counteracting and minimising the side effects of various treatments, and hence improving a patients' quality of life:

'When they're making these tablets in research, are they also trying to find something that will counteract it and will take away that nastiness for people? I mean it's bad enough having an illness.' (Penelope, CG2)

### **Organisation and funding of health and social care services**

While the majority of participants were satisfied with the standard of services they received, there were those who felt they received less than satisfactory care. Furthermore, many participants reflected on their experiences and felt there were aspects of their care that could have been improved. Hence, they felt that research should go on efforts to improve the organisation and delivery of both health and social care services. Most ideas generated were more statements of need, but they do indicate potential areas of research aimed at evaluating current service provision and examining means of optimising cancer services.

Participants generated many recommendations for service improvement. Some of these can be viewed as broad service level changes while others focused on specific aspects of their care. Broad service improvement suggestions included such issues as improving the continuity of care, the provision of more specialist cancer centres, permitting some procedures to be undertaken at local hospitals or health centres (such as blood tests) and the provision of greater resources for machinery and drugs. Other examples include greater awareness of the dietary needs of South Asian patients in the hospital and the need for a 'key worker' to serve as an informed point of contact within the hospital for patients who have queries about their cancer and treatment.

More specific suggestions for service improvement included more effective scalp cooling techniques to prevent uneven hair loss and the opportunity for patients to examine prostheses before they are inserted.

One significant area of concern was with waiting times and it is here that many participants felt research should look at ways of quickening the speed of referrals and test results. Participants commented on the stress associated with waiting. Dorothy described the delays she experienced and how she resolved them:

'I was recommended from the hospital doctors to be seen and I still had months to wait and they kept putting it off and putting it off and it was, "It'll be next month, it'll be next month", and in the end I went up to the emergency and I sat there and I said, "I'm not moving until I get an appointment", and I got an appointment and it was within weeks I was getting chemo and radiotherapy.' (Dorothy, CG12)

### **The coordination, impact and funding of research**

Participants were reflective about the nature of cancer research and asked questions relating to its organisation and impact. For example, several participants suggested a national coordination of research funding bodies both within the UK and internationally and no participant was aware of the National Cancer Research Institute or their efforts at providing such coordination. Colin's view was typical of those who suggested such coordination:

'There's such a plethora of research bodies – why isn't there a national integration? It's like anything else, they're all vying for one thing... why cannot we draw the line together and have some sort of national co-ordinating body that directs research where it should take place and get an equitable playing field?' (Colin, CG10)

Steven, however, was concerned about the potential consequences of such coordination:

'I think you've got to be careful to centralise. If you pool resources, then the trouble is you don't necessarily get the diversity of ideas that are being put forward. If you start to centralise things too much, then lateral thinking can go out the window, because one research centre will pursue one line and another one will pursue another. Now one might be no good, but if they're all doing the same thing and it was the wrong idea, you know.' (Steven, CG12)

Participants also asked whether research should be more focused on prevention or cure (the consultation groups' response to this was that it should be concentrated on prevention), and whether research should concentrate more on biomedical or social issues. Other questions about the nature of research were concerned with whether research should target common cancers more than rarer cancer, whether animals should be tested and what the evidence is for the impact of cancer research on the lives of people affected by cancer: 'Has any research ever been done on how effective research is in terms of years saved?' (Philip, CG6).

### Research into recurrence

For several participants, after successfully receiving their cancer diagnosis, there is a fear of the cancer spreading or recurring. This often manifested itself in a thought that any pain was the sign of a new or returning cancer. As Komal put it:

'The doctors, they operated me and everything and said, "It is fine now and because we have found everything, it is fine now" and at the same time I was threatened so much that the doctors told me, "This was the first attack, now if you get a second attack, we can't do anything" and all the time, that fear is all the time in my mind even if I sleep I have got a little bit of pain I say "I am dying now!"' (Komal, CG15)

Consequently, participants wanted researchers to identify the causes of recurrence, identify the early symptoms of recurrence, disseminate guidelines to health professionals and patients

alike informing what to look for in recurring cancer, and how to manage their own health so as to prevent recurrence:

'Maybe research [should go] into why you get a reoccurrence... why does it reoccur, maybe 20 years later or 15 years later?' (Kirsty, CG12)

### General communication issues involving all parties

Participants wanted researchers to assess how health professionals communicate information about cancer to patients and others. Communication related both to breaking bad news and to discussing details of treatment regimes to the patient and others. This was important to patients as many participants had poor experiences of bad communication skills and discussed how this affected them:

'This late afternoon, Friday night, my husband had come from work to visit me and [the doctor] come along and draw the curtains with the sister and he said, "Well, I'm awfully sorry, I have got bad news. We found a mass". "A mass of what?" He said "A cancer. There is a mass and we just don't know where it is coming from". So my husband said, "Well, what are you talking about?"... He said, "Weeks, maybe months left," he said to the sister "She can go home for the weekend".'

 (Zoe, CG17)

People commented on the manner in which they received their cancer diagnosis and recommended being told in person rather than over the telephone. Interestingly, participants wanted researchers to also examine and make recommendations on how cancer patients could communicate information about their cancer to those around them. Several participants shared their experiences of finding it difficult to communicate their cancer to others, such as partners and particularly children and suggested that this would be an important area of study:

Sally Well, I was diagnosed, my youngest child was three years of age and I just thought I was going to die...

Jo That's you're first instinct.

Sally ... and I couldn't talk to my husband, I wanted to talk to him about what kind of funeral I wanted, but I couldn't and I went home and I cleaned all my cupboards out, so my family wouldn't have to do it...

Alan Well,... I couldn't talk to my wife, I don't know just what it was. I think it was maybe the fact that you try to cut them out in case...

Sally Well you think they're under enough stress.

Alan ...enough stress, because me being the main bread earner, I was there to work, you know, and I just couldn't. And to this day, I still feel that she resents me not talking to her about it, you know. The day I found [the lump], I couldn't even talk to her that day, she knew there was something the matter. (CG9)

### **Accessing patients' views about cancer, services and research**

This theme related more to statements of need than specific research questions. It was felt important by several participants for health professionals to view patients as experts in their own right. There was a sense that the treatment and management of cancer and the quality of research itself would be improved if the views of patients themselves were accessed. As Toni put it:

'I work with children, we're social workers working with children and I mean we view the parent as the professional, you know, you're in a case conference, they're the professional parent, because they are the parent of the child. I think I'm the professional patient here, I'm the only one who knows me.' (Toni, CG11)

However, the experience of some participants is that their views or experiences were rarely asked by health professionals. Cecil expressed

what he thought the patient could bring to discussions about the management of cancer:

'Every cancer patient must look over his shoulder and think, "I wonder if it's something I've done in the past. I wonder if there's a reason for this, why have I got problems with my water works or my lungs", you know, we all know about smoking and I think that's a well proven case. But there are other things... when you come to the hospital here, I am just a little surprised ... as to why there's not a questionnaire or a 20 minute discussion with a nurse, when they're going through your history to say, "Are there any events or any activities or any habits in your life which, in your mind, you suspect might have contributed to your current condition?"' (Cecil, CG4)

### **Health and safety in the hospital**

Several participants shared their experiences of adverse incidents and what they perceived to be breaches in health and safety guidelines. Stephanie shared her observations while she was in hospital:

'There was an elderly lady walking round that didn't get washed because she didn't want to get washed, but the smell of her was making me feel sick. She had a wound and what did they do? They went and put her in a bath, well all that mess from her bowels and whatever surely was in that water going into her wound as well, things like that you it know worries me terribly.' (Stephanie, CG1)

Hence more research was suggested on assessing how hospital infections, such as MRSA, could be reduced, and educating and improving health and safety in hospitals for health professionals and the patients alike.











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